Perceived causes of initial development and relapses in anorexia nervosa: A comparison to theoretical models of aetiology.

A thesis
submitted in fulfilment
of the requirements for the degree
of
Masters of Social Sciences
at
The University of Waikato
by
GABRIELLE KATINKA MAY BATENBURG

2015
ABSTRACT

Anorexia nervosa is a disorder which causes significant impairment, both acute and chronic, for those who experience it. Anorexia nervosa is associated with a long-term course and high rates of relapse. The purpose of this research was to investigate the perspectives of those with anorexia nervosa on aetiology and their views on causes of relapse. The aim was to gain a better understanding of how those with anorexia nervosa conceptualise it; compare it to theoretical models and considered how these perceptions may relate to treatment. Sixteen semi-structured interviews were conducted with eight participants, consisting of eight initial interviews, then eight follow-up interviews to reflect on preliminary findings.

Findings related to three main domains: definitions of anorexia nervosa, causes of initial development, and causes of subsequent episodes (relapses). Individual and collective definitions of anorexia nervosa were markedly different from diagnostic definitions, mainly due to the increased detail but there was also contention around how diagnostic definitions focus on body image and resistance to recovery. Causes of anorexia nervosa in this study matched other in-depth research of accounts, but varied with respect to aetiological models. A key difference uncovered in this study was the emphasis placed by participants on different aspects of anorexia, which fell outside of weight and body image concerns, and notable that these aspects became a part of the reasoning for anorexia.

Perspectives on the causes of relapse indicated three main categories: those which were present during initial development, those which were present during the initial development but only became significant after experiencing anorexia, and those which were unique to relapse. Due to the limited research in this area it was challenging to compare these findings to other studies; however, they do represent an important aspect of treatment and research, which could be enhanced. A model of aetiology of anorexia nervosa was developed integrating current findings with established theoretical models and research; key influences contributing to relapse were also modelled. Relevant recommendations for diagnosis, treatment, and relapse prevention are presented throughout the discussion.
ACKNOWLEDGEMENTS

First and foremost I would like to acknowledge the women who took part in this study. I could not have done it without you and I appreciate your willingness to share this part of your life with me; thank you for your candour, kindness, and patience. I hope it lives up to your expectations.

I would like to acknowledge my friends and family who have supported me through this period of my life. In particular, this piece of work would not be the same without the help of my mother, Cari. I have appreciated all your suggestions and comments but more importantly your faith in me. Thank you for the time and effort you put into helping me with this; I love you. I would also like to mention my friends who have been completing their theses alongside me – thank you for the support and companionship.

I need to acknowledge the work and support of my supervisors. Jo, you have been a wonderful support when I needed you and your assertions that I would complete this in time were invaluable; thank you for caring. Josh, your input at the beginning and end of this project was so needed and I cannot thank you enough for this feedback. I appreciate your willingness to review this even when stressed and busy. Carrie, although you were only part of this for a brief time I do thank you for temporarily assuming the role as my supervisor and your contributions despite not having a lot of knowledge about the project. And finally, to all the people not mentioned who helped me with this project, even fleetingly, thank you.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>i</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>ii</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>iii</td>
</tr>
<tr>
<td>List of figures</td>
<td>vi</td>
</tr>
<tr>
<td>List of tables</td>
<td>vii</td>
</tr>
<tr>
<td>Chapter One</td>
<td>1</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Anorexia nervosa as a mental disorder</td>
<td>3</td>
</tr>
<tr>
<td>Chapter Two: Literature Review</td>
<td>6</td>
</tr>
<tr>
<td>Aetiology of anorexia nervosa</td>
<td>6</td>
</tr>
<tr>
<td>Biological models</td>
<td>6</td>
</tr>
<tr>
<td>Cognitive behavioural models</td>
<td>10</td>
</tr>
<tr>
<td>Psychosocial models</td>
<td>17</td>
</tr>
<tr>
<td>Sociocultural Influences and models</td>
<td>24</td>
</tr>
<tr>
<td>Risk factor research</td>
<td>27</td>
</tr>
<tr>
<td>Summary</td>
<td>32</td>
</tr>
<tr>
<td>Personal experiences and perspectives</td>
<td>32</td>
</tr>
<tr>
<td>Perceptions of experiencing anorexia nervosa</td>
<td>33</td>
</tr>
<tr>
<td>Perceptions of cause</td>
<td>33</td>
</tr>
<tr>
<td>Perceptions of relapse</td>
<td>40</td>
</tr>
<tr>
<td>Rationale for present research</td>
<td>41</td>
</tr>
<tr>
<td>Chapter Three: Method</td>
<td>43</td>
</tr>
<tr>
<td>Qualitative research design</td>
<td>43</td>
</tr>
<tr>
<td>Participants</td>
<td>44</td>
</tr>
<tr>
<td>Recruitment</td>
<td>44</td>
</tr>
<tr>
<td>Participant characteristics</td>
<td>45</td>
</tr>
<tr>
<td>Data collection measures</td>
<td>46</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

Figure 1. Neurobiological model based on stress and dysregulation of the HPA axis (Connan et al., 2003, fig. 2). ................................................................. 7

Figure 2. Compulsive exercise maintenance model within the context of other cognitive, personality, and behavioural traits for EDs (Meyer et al., 2011, fig. 1). 9

Figure 3. Integrated cognitive behavioural model focused on body, weight, and shape concerns in describing the aetiology of eating disorders (Williamson et al., 2004, fig. 1). .......................................................................................................... 11

Figure 4. Cognitive behavioural maintenance model of AN based on extreme drive for self-control and coexisting low self-esteem (Fairburn, Shafran, et al., 1999, fig. 1). ........................................................................................................... 14

Figure 5. ‘Transdiagnostic’ theory of the maintenance of eating disorders. ‘Life’ is shorthand for interpersonal life (Fairburn et al., 2003, fig. 4)........................... 16

Figure 6. Model indicating deficits in a range of areas and subsequent lack of self-esteem and control, causing AN (Blank & Latzer, 2004, fig. 2) ....................... 18

Figure 7. Adapted open systems model of the anorectic family (Minuchin et al., 1978). ........................................................................................................ 23

Figure 8. Combined tripartite model indicating the relationship between sociocultural factors and ED’s. Dashed lines indicate pathways only endorsed by one study (Keery et al., 2004, fig. 7; Shroff & Thompson, 2006, fig. 2; van den Berg et al., 2002, fig. 5). ....................................................................................... 26

Figure 9. Developmental model of pertinent risk factors indicated in Table 2 and associated potency for AN (Jacobi et al., 2004, fig. 2). OCPD: Obsessive-compulsive personality disorder; BDD: Body dysmorphic disorder; OCD: Obsessive-compulsive disorder................................................................. 30

Figure 10. General model describing the causal factors contributing to the development of an ED (Nicholls, 2007, fig. 5.1) ....................................................... 31

Figure 11. Interaction of distinguishing features of anorexia .................... 62

Figure 12. Consolidated model of aetiology ............................................. 190
Figure 13. Influences of relapse on aetiology of AN. Bolded text indicates factors relating to relapse. ................................................................. 192

LIST OF TABLES

Table 1. Fixed and variable markers, retrospective correlates and correlates for AN, and variable risk factors for EDs (adapted from Jacobi et al., 2004; Pike et al., 2008). .......................................................... 28

Table 2. Endorsed causes for AN from those diagnosed across three studies (Nevonen & Broberg, 2000; Nilsson, et al., 2007; Tozzi et al., 2003). ................. 35

Table 3. Participants’ demographics ................................................................. 45

Table 4. Major themes and associated sub-themes for initial causes.............. 91

Table 5. Endorsed causes of relapse which paralleled initial development. .... 125

Table 6. Endorsed causes of relapse which became more significant following initial episode. ................................................................. 138

Table 7. Endorsed causes of relapse unique compared to the initial episode. ... 148
CHAPTER ONE

Introduction

Anorexia nervosa is a significant mental disorder within New Zealand, and worldwide. It is associated with high mortality, often being described as the mental disorder with the highest mortality rate (Birmingham, Su, Hlynshy, Goldner, & Gao, 2005; Striegel-Moore & Bulik, 2007). Estimated mortality rates for anorexia nervosa range from slight increases in expected mortality rate (1.38), to almost 18 times more likely to result in death than would be expected for that individual (Birmingham et al., 2005; Seinhausen, 2002). Death in anorexia nervosa is often caused by suicide (Birmingham et al., 2005) and medical complications (Fairburn & Harrison, 2003). In New Zealand, people with an eating disorder have one of the highest rates of suicidal ideation (22.9%), suicidal plan (10.1%), and suicidal attempts (9%), in comparison to those reporting anxiety, mood, and substance use disorders (Oakley Browne, Wells, & Scott, 2006).

The average lifetime prevalence of anorexia nervosa is less than 1% of the population and estimates of young females in the United States and Western Europe yield a prevalence rate of approximately 0.3% per year (Hoek & van Hoeken, 2003). In New Zealand, the prevalence over a year has been reported as 0.1% and lifetime prevalence estimated to be about 0.6%, although low rates of incidence are likely to underestimate these rates due to small sample sizes used to predict prevalence (Oakley Browne et al., 2006). Māori may be at greater risk of developing anorexia nervosa, as they are proportionally more likely to develop an eating disorder compared to non-Māori (Oakley Browne et al., 2006).

A consistent theme across research is that anorexia nervosa takes a significant toll on many facets of a person’s life, impacting those closest, especially on family members, and has significant medical and psychological consequences that can persevere throughout the person’s life (Bulik, Reba, Siega-Riz, & Reichborn-Kjennerud, 2005). Lifetime prevalence of major depression, other mood disorders, obsessive-compulsive disorder, anxiety disorders, and substance use disorders are significantly increased in comparison to non-psychiatric controls (Bulik, Sullivan, Fear, & Pickering, 2000; Sullivan, Bulik,
Fear, & Pickering, 1998). Anorexia nervosa often disrupts both social and biological development, especially if onset is during or prior to adolescence (Bulik et al., 2005). The disorder is one of the ten leading causes of disability in young women (Zerwas et al., 2013). A recent review suggests that less than a half of those with anorexia nervosa (46%) fully recover from it, while a third only partially improve with residual features (Seinhausen, 2002). Approximately a fifth (20%) can be expected to be chronically ill over the long term. However, when less stringent criteria for recovery are considered, recovery rates for core symptoms of weight restoration, normalization of both menstruation and eating behaviour occur in approximately half of those with anorexia nervosa (Seinhausen, 2002).

Anorexia nervosa is a disorder which has been described as very ego-syntonic, whereby the goals and progression of the disorder are typically in agreement with the person’s sense of themselves and values, and this differentiates it from many other psychological disorders (Vitousek, Watson, & Wilson, 1998). In this respect, symptoms of anorexia may not cause the individual as significant distress when compared to other mental disorders; however, significant impact or distress may by more prominent for others associated with the person with anorexia, such as family members (Vitousek et al., 1998). Resistance to treatment or change can be high and one of the ego-syntonic nature of anorexia can be contributory (Vitousek et al., 1998).

Understanding the aetiology of anorexia nervosa is particularly important in the process of assessment, treatment, and prevention (Stice, 2002). Furthermore, understanding aetiological factors can inform maintenance processes which are also important for guiding treatment (Stice, 2002). This study attempts to contribute to our understanding of the perspectives of those who have experienced anorexia nervosa in New Zealand. Specifically, the research aims to explore perceptions of the cause of anorexia nervosa in people who have experienced it, as well as causes contributing to relapse. In addition, these qualitative accounts will be compared with theoretical and quantitative approaches to predicting aetiology. The aim of this study is to elucidate discrepancies which may contribute to high treatment resistance and drop-out observed with anorexia nervosa (Vitousek et al., 1998).
Anorexia nervosa as a mental disorder

Anorexia nervosa (AN) is characterised as a mental disorder (Hebebrand, Casper, Treasure, & Schweiger, 2004). Diagnosis of anorexia nervosa requires the individual to experience a set of difficulties mainly surrounding behavioural manifestations of irregular eating patterns. According to the Diagnostic and Statistical Manual of Mental Disorders – Fifth edition (DSM-5), a psychiatric diagnostic system for mental disorders, the definition of a mental disorder is a “clinically significant disturbance” in “cognition, emotion regulation, or behaviour” that contributes to dysfunction in the person’s life. (American Psychiatric Association, 2013, p. 20). Dysfunction is regarded as diminished ability and/or significant distress in vocational, relational, or other significant areas of functioning. Aspects of anorexia nervosa fulfil these criteria of dysfunction, as has previously been described.

The definition of anorexia nervosa contains the following criteria as described by the DSM-5 (American Psychiatric Association, 2013):

1. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.
2. Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
3. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Another aspect of the criteria for anorexia nervosa is the weight requirement (American Psychiatric Association, 2013). This criterion quantifies severity of AN through body mass index (BMI; a measure of how healthy weight is in comparison to height; James, 2005) where 17 kg per m² of height and above distinguishes ‘mild’ cases from more severe ones (American Psychiatric Association, 2013). This is in comparison to ‘normal’ BMI between 18.5 kg/m² and 24.9 kg/m² (James, 2005). The weight specification has broadened to
“significantly low weight” defining it as less than is “minimally normal” and is potentially problematic given the vague reference to ‘normal’ (Hebebrand & Bulik, 2011).

Anorexia nervosa is further defined by specifying a sub-type: restricting (AN-R) or binge-eating/purging types (AN-BP). Restricting type describes those who primarily lose weight through energy restriction and exercise, and who very rarely or do not engage in binge-eating or purging behaviour. Binge-eating/purging type thus refers to those who engage in recurrent episodes of binge-eating and/or purging (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas) (American Psychiatric Association, 2013). A binge can be defined as an episode of eating where an unusually large amount of food is eaten and a sense of losing control of eating during this time (Fairburn & Harrison, 2003). The amount consumed during a binge can vary, but is typically between 1000 kcals and 2000 kcals (Fairburn & Harrison, 2003). Bulimia nervosa (BN) is characterised by binging and purging as with AN-BP but weight is within the normal range, and severe dietary restriction is classified as a compensatory behaviour, rather than a preceding feature (American Psychiatric Association, 2013).

It should be noted that there are controversies over the adequacy and relevance of diagnostic criteria for eating disorders in general and criteria relating specifically to anorexia nervosa. A key criticism of diagnostic criteria for eating disorders suggests that the majority of people diagnosed with an eating disorder receive an ‘eating disorder not otherwise specified’ (EDNOS) diagnosis (Fairburn & Harrison, 2003). An EDNOS diagnosis is one where the person meets some criteria characteristic of part of other eating disorder categories (e.g., AN), but not all as required for specific eating disorders, and their symptoms are not better classified by another diagnosis (American Psychiatric Association, 2013). Thus, the value of the category of eating disorders is diminished by the apparent lack of differentiation for the majority of those receiving a diagnosis.

Specific to anorexia nervosa, the emphasis on “extreme concerns” about weight and shape in criteria has been questioned (Fairburn, Shafran, & Cooper, 1999; Palmer, 1993), where the value of this as a key feature in modern-day AN may be over-emphasised (Palmer, 1993). One reason for this argument is the lack
of these features in early descriptions of anorexia nervosa such as accounts by Gull (1873-1965), Lasegue (1873-1965), Russell (1985) and Habermas (1992; as cited in Palmer, 1993). Although such absences could occur as a result of mistakenly attributing these early conditions to that of anorexia nervosa or of these early writers lacking the skill or perception to recognise concern for weight and shape in these patients, it may also be possible that weight/body/shape concern were not significant features during this time. Furthermore, concerns for weight and shape are much less common in non-Western countries and cultures (Fairburn, Shafran, et al., 1999; Palmer, 1993). For example, in research examining 16 people exhibiting the features of anorexia in China, most only partially met the criteria due to a lack of concern about weight, thinness, or obesity (Lee, 1991).

Overall, anorexia nervosa is a disorder with significant impacts and implications for those affected and those involved in treatment. Within the field there has been variation and debate in the way in which it is conceptualised and what features are most pertinent. The forthcoming section aims to provide a comprehensive review of the theory of the aetiology of anorexia nervosa (AN). Current trends and findings relating to research into personal accounts on cause, relapse, and recovery from people who have experienced anorexia nervosa will also be reviewed.
CHAPTER TWO: LITERATURE REVIEW

Aetiology of anorexia nervosa

There are a variety of models of aetiology for anorexia nervosa. These typically vary with the theoretical perspective from which they are based and the date at which they were formulated. As with all specialised models, some which encapsulate a specific perspective (e.g., biological focus) may have difficulty providing a complete representation of AN, or account for the variation within the disorder. The benefits and limitations of these perspectives will be outlined.

Biological models

Biological theories of aetiology have been investigated to a large extent in AN. The following models are those which are primarily biologically based in their conceptualisation of the aetiology of AN.

Connan, Campbell, Katzman, Lightman, and Treasure (2003) reviewed risk factors relating to genetics, perinatal development, social and biological impact of adolescence, the hypothalamic-pituitary-adrenal (HPA) axis, serotonergic system, social ranking, and stress. These factors are largely oriented to neurobiology, and the model created is especially focused on the impact the HPA axis has in maintaining a catabolic cycle which initiates and perpetuates low appetite and weight loss. Figure 1 shows the graphic of their model. It does take into account early pre-disposing factors which add to underlying vulnerability. Psychological, social, and biological changes are also seen to provide added risk to developing AN which become more prevalent during the time of adolescence and puberty. They propose that when this is combined with stress, it can develop into a chronic stress response by the body, and result in dysregulated HPA. This is suggested to cause a decrease in appetite and weight which can become a downward spiral if stress continues; AN is said to develop from this cycle.
This model is interesting and unique in that it specifies a very specific trigger, stress, as the point at which vulnerability becomes a disorder. The authors mention in their article that if stress and dysregulation of the HPA axis were the sole determinants, people with PTSD may be more likely to develop AN (Connan et al., 2003). It is the case that significant psychological stress, including PTSD, is an associated comorbidity with eating disorders and PTSD can be a risk factor for developing an ED (Brewerton, 2007). Similarly, although high levels of psychological stress are correlated with an increase in disordered eating, the epidemiology of AN does not reflect the proportion of people who likely experience high rates of psychological stress (Ball & Lee, 2000). The correlation between PTSD and EDs may be related to a lack of psychological coping strategies seen in those with EDs, but this is not accounted for effectively in this model. There is also a lack of discussion about why this might be more likely to occur in females than males which is evident in the prevalence rates of AN (Keel & Klump, 2003).

This model by Connan et al. (2003) also assumes that the attempt at maintaining and ensuring weight loss, which are features of the disorder (Bulik et al., 2006), begin after the chronic stressor. This is suggested by the fact that
dysregulation of the HPA axis causes weight loss/starvation and “underlying susceptibility factors and the impact of starvation upon psychological and biological systems maintain the vicious cycle of AN” (Connan et al., 2003, p. 19). Another issue with this causal concept is that it limits the reliability of this model in describing relapse (assuming relapse of AN retains some or most features present during initial development). This model suggests that relapse would have to be sparked by a stressor unless the HPA axis and dysregulation became permanently affected by starvation and AN was able to ensue without this environmental aid. Another aspect of this model that could be further assessed is how it might relate to people with lifetime AN who have perpetual relapse and remission and how this system might change over time.

Another prominent model in American literature is the comparison between AN and addiction models (Giordano, 2005). AN is described by many who suffer from the disorder as being ‘addictive’ and is associated with descriptions of being difficult to control, especially with the binge-purge subtype. Eating disorders have also been documented as having a high co-occurrence with substance use disorders suggesting some correlation with addictive behaviour; however, there is a stronger link with BN than AN (Davis & Claridge, 1998; Giordano, 2005). The following describes various hypotheses relating to addictive components of AN that attempt to explain the aetiology and maintenance.

The auto-addiction opioid theory proposes that people can become addicted to neurological opioids perpetuating behaviours which increase these opioids within the brain. This concept fits within the context of AN as opioid production is related to intermittent binging on sugary foods following starvation, such as that which is likely to occur with the binge-purge subtype of AN (Colantuoni et al., 2002).

Consuming palatable foods has been found to release opioids and dopamine in the limbic system in the brain of rats (Colantuoni et al., 2002). Bulimia has also been modelled using an addiction model which emphases that intense food cravings evident in BN patients are similar to the intense cravings of drug addicts. The evidence suggests that rats with periodic food restriction broken by binges on palatable food causes sensitization to opiate-induced food consumption as well as evidence of opiate withdrawal (Colantuoni et al., 2002;
This may relate to the binge-purge subtype of AN; however, it fails to adequately explain how a person gets into the cycle of severe dietary restriction accompanied by addiction to intermittent binging on palatable food. Furthermore, this model is largely based on animal studies so lacks the contextual elements present in human experience (e.g., social influences).

For the restrictive sub-type of AN, a theory of addiction to exercise and food restriction has been proposed (Meyer, Taranis, Goodwin, & Haycraft, 2011). The combination of food restriction and exercise stimulates the hypothalamic-pituitary-adrenal (HPA) axis (system described in Connan et al.’s model) along with the release of β-endorphins. Subsequently, dopaminergic (DA) neurons in the mesolimbic brain structures are released which constitute the typical reward pathway (Davis & Woodside, 2002; Davis & Claridge, 1998). However, reported reasons from those with AN with excessive exercising symptoms indicate compulsive exercise is not for euphoric effects but for affect regulation and due to withdrawal symptoms after ceasing exercise (Meyer et al., 2011). The following model indicates the inclusion of cognitive elements to the role that excessive exercise may play in EDs.

Animal models of exercise-based anorexia have contributed to activity hypotheses. For example, the study by Routtenberg and Kuznesof (1967) showed
that rats who had a severely restricted diet and access to a running wheel at all times except for feeding time progressively ate less calories at feeding time until finally starving themselves to death. Comparatively, the rats who either had no running wheel or *ad libitum* access to food with a running wheel regulated their consumption of food and maintained normal weights (Kim, 2012; Routtenberg & Kuznesof, 1967).

Limitations of these models are that they seem to over-simplify the experience of AN and exclude other experiences consistent with people that suffer from AN, such as trends of perfectionism, low self-esteem, correlations between dieting and EDs, other forms of weight control (Polivy & Herman, 2002). The aetiology and experience of AN is multifactorial thus animal models can only provide small evidence and application to the more complicated nature of human experience (Kim, 2012). These theories separate purposeful behaviour and choices from psychologically determined addiction, and fail to adequately explain how a person gets to a state of addiction. Additionally there is no indication of the interplay between the body’s response to starvation and malnutrition and how this may interact with systems of addiction (both causative and changes as a consequence of starvation) (Giordano, 2005). However, exercise as a moderator of negative affect as well as forming a part of compulsive and rigid lifestyles prevalent in those with AN seems a more likely explanation and an example of the role of biologically rewarding processes in the aetiology of AN.

**Cognitive behavioural models**

Cognitive behavioural theories emphasise the role of thoughts on behaviour and emotions. The following models represent some prominent conceptualisations of AN within this framework.

Early cognitive behavioural conceptualisations of AN tend to focus on the concept of extreme concerns and overvaluation of weight and shape as the key feature contributing to the disorder (Fairburn, Shafran, et al., 1999). Other models have also been based on cognitive and information-processing theories (Williamson, White, York-Crowe, & Stewart, 2004). In their review of cognitive behavioural theories of eating disorders, Williamson and colleagues (2004) featured a summary model of key aspects of main cognitive behavioural models since 1970. The model, indicated in Figure 3, emphasises the influence of
predisposing risk factors and triggering stimuli, their interaction with schema and subsequent cognitive biases, and the associated cycle of eating disorder behaviour which serves to confirm and perpetuate further dysfunctional core beliefs related to the eating disorder.

Figure 3. Integrated cognitive behavioural model focused on body, weight, and shape concerns in describing the aetiology of eating disorders (Williamson et al., 2004, fig. 1).

Similar to early cognitive behavioural models of aetiology, the model suggests that preoccupation and excessive importance of thinness on body, shape and weight are the most significant underlying causes (e.g. Vitousek & Ewald, 1993). The significance of these are evident throughout the different components. This model is based on the theoretical perspective that entrenched beliefs about the self in relation to others and society are most relevant to the development and maintenance of disordered eating. These beliefs concern body, weight, and shape concerns, internalisation of societal values for ‘thinness’ and ‘fatness’, along with personality traits or perspectives relating to perfectionism/obsessionality. These beliefs then react with internal and external weight, eating or food related stimuli, produce cognitive biases in the understanding and meaning of these stimuli, leading to disordered eating behaviour (Williamson et al., 2004).
Williamson and colleagues (2004) discuss the impact that the misinterpretation of eating-related stimuli has on the emotions of this individual, postulating that these typically produce negative emotional experiences, such as anxiety about the thought of being ‘fat’. These negative feelings produce a negative reinforcement contingency whereby the person feels an urge to engage in compensatory or other behaviours to escape, avoid or reduce these feelings. These actions include the behaviours listed in the model such as restrictive eating and compulsive exercise.

The summary model by Williamson et al. (2004) is useful in illustrating how predisposing beliefs and values can interact with current internal and external stimuli and produce a cycle of thoughts, emotions and behaviour characteristic of AN and other EDs. However, there is criticism of models which emphasise the role of weight/shape/body in relation to aesthetic as the main belief or crux of anorexia as it is often not cited by patients as the only or main cause (Fairburn, Shafran, et al., 1999). Research of risk factors indicate that there are no significant differences between those with AN and BN or psychiatric control groups in exposure to factors predicted to influence dieting such as family dieting (Fairburn, Cooper, Doll, & Welch, 1999; Pike et al., 2008). As illustrated earlier in this review, AN or features of disordered eating seemingly similar to modern EDs have been present for hundreds of years and have not until recently contained concerns about body aesthetics (Keel & Klump, 2003; Schmidt & Treasure, 2006). Weight concern, especially in connection to aesthetic evaluation, can be seen as one possible motivation to engage in AN but not the sole or ultimate motivation (Palmer, 1993).

Another particular limitation of Williamson and colleagues (2004) model its general focus incorporating the spectrum of eating disorders. This is problematic in that it generalises issues across the types of EDs. For example, in their own description of the relevance of ‘internalisation of the thin ideal’ they emphasise the relevance of this for BN and onset of binge eating, rather than food restriction or AN. This is consistent with other research indicating internalisation of the thin ideal or other body image concerns is not a clear risk factor for AN, rather has been shown as a risk factor for EDs in general and partial ED symptoms (Jacobi, Hayward, de Zwaan, Kraemer, & Stewart, 2004; Striegel-Moore & Bulik, 2007).
An alternate a cognitive behavioural model of the maintenance of anorexia was proposed by Fairburn, Shafran, and colleagues (1999). Although it is a maintenance model it partially serves to indicate aetiology after the individual begins to reduce energy intake. Anorexia nervosa is defined in the DSM-5 based on weight requirements. However, features of anorexia are very likely to dominate prior to the individual meeting these weight requirements. Thus, maintenance of the cognitions, behaviour, beliefs, and other features pertinent to the disorder are also relevant in understanding the aetiology of ‘pre-anorexia’ behaviour (i.e. that which precedes meeting the weight requirement).

Fairburn, Shafran, and colleagues’ (1999) maintenance model of AN focuses on the role of control in anorexia, rather than preoccupation with appearance or aesthetical components as in the previous cognitive behavioural model (Williamson et al., 2004). The model was developed using Slade's (1982) functional analysis of AN and BN and behavioural model of aetiology as a reference point. Onset of the disorder is said to originate from a general need for self-control which then becomes focused on control of eating. This becomes valued through perceptions of successfullness and achievement in comparison with perceived failure in other areas of functioning (Fairburn, Shafran, et al., 1999). Self-control is speculated to become realised through control of eating for a number of reasons. Successful dietary control provides clear and direct evidence of self-control which contrasts with other areas of functioning which are likely to have greater external influences, especially from others (Fairburn, Shafran, et al., 1999; Slade, 1982). Control of eating can also elicit strong reactions from others which may serve to perpetuate the problem. Thirdly, some families and social groups exhibit eating behaviour or beliefs around food which make control of food more salient and thus disordered eating may be encouraged (Jacobi et al., 2004; Polivy & Herman, 2002). Control of eating may also be encouraged or rationalised based on societal norms within Western society emphasising dieting and low weight (Polivy & Herman, 2002). Fairburn, Shafran, et al. (1999) also present one other reason, but this is not well supported: attempts to prevent or reduce the impact of puberty (Jacobi et al., 2004; Polivy & Herman, 2002).

Extreme drive for self-control and coexisting low self-esteem can lead to dietary restriction according to Fairburn, Shafran and colleagues’ model (1999) depicted in Figure 4. Restriction then begins to represent sense of self-worth and
sense of self-control, becoming markers of each. Dietary restriction contributes to weight loss and subsequent physiological changes associated with low weight and low net energy. Changes in weight or eating become illustrations of level of control, with gains in weight representing threats to self-control and self-worth. Perceived failures in dietary restriction are also evaluated through these factors, contributing to further dietary restriction (Fairburn, Shafran, et al., 1999).

Figure 4. Cognitive behavioural maintenance model of AN based on extreme drive for self-control and coexisting low self-esteem (Fairburn, Shafran, et al., 1999, fig. 1).

This model presents a different perspective of AN, rather than relying on the assumption of body image concerns as being key concerns for aetiology. The concept of control as being the most important aspect of AN is interesting and has been cited in other models of aetiology in the past (e.g., Bruch, 1974; Minuchin et al., 1978). However, empirical assessment on the relevance of self-control has been plagued with methodological issues and lack of adequate research in evaluating its link with AN (Surgenor, Horn, Plumridge, & Hudson, 2002). In addition, concepts of self-control have often been examined from perceptions of self-control and locus of control, rather than the relationship between disordered eating and perception of self-control. ‘Control’ is also a broad construct and
evaluation of ‘self-control’ has often only incorporated a few of these elements excluding other elements of control, for example, targets of control, and motivation for control (Horesh, Zalsman, & Apter, 2000; Surgenor et al., 2002). Despite the lack of rigorous research supporting this construct (Surgenor et al., 2002) it is endorsed by a proportion (approximately a third) who have been diagnosed with AN as being important in their disorder and anecdotally by professionals treating those with AN (Surgenor et al., 2002; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003).

Concepts of low self-worth and low self-esteem are also ones utilised strongly within models of AN but lack strong support from robust studies (Jacobi et al., 2004). Difficulties assessing self-worth/self-esteem, ineffectiveness, and self-concept include limitations in the selection of control groups (e.g., college students with higher prevalence of EDs). In addition, depressive symptomatology is often not accounted for (i.e., confounding the unique contribution to EDs given low self-esteem and depression are highly correlated) (Jacobi et al., 2004). However, despite these limitations some research suggests that low self-esteem may pre-date the development of a ED, get worse during the course of the ED, and serve to maintain it (Forsén Mantilla, Bergsten, & Birgegård, 2014). However, the causality of these relationships to AN is unclear.

Fairburn, Shafran and colleagues (1999) also describe how concerns about body shape and size can be applied to this model through re-conceptualisation of these features being ‘cultural factors,’ rather than universal key concerns. Thus, measures of body weight, shape, and size are integrated into the model where these become further indicators of self-control and self-worth. They are speculated to manifest further behaviours such as body checking and consequential evaluation of self-control through aspects of body and appearance. Conceptualisation of concerns for weight, shape, and size as culture-bound symptoms are consistent with other research and historical accounts of similar symptoms (Keel & Klump, 2003; M. N. Miller & Pumariega, 2001; Palmer, 1993).

A significant limitation of this model is the described theoretical nature of this model and lack of adequate supporting findings. In addition, given there is significant overlap or convergence across different EDs (Fairburn & Harrison,
2003) this model would benefit from some comment on its discriminant validity from other EDs.

Fairburn, Cooper, and Shafran (2003) later developed a ‘transdiagnostic’ model of EDs in an effort to address the common interchange of people between diagnostic categories of EDs and the majority of those with EDs being ascribed an EDNOS diagnosis (Fairburn & Harrison, 2003). A transdiagnostic model is one which transcends individual diagnostic categories, in this case EDs, and describes an overarching theory. Figure 5 indicates their general maintenance model. It emphasises similar features to Fairburn, Shafran and colleagues' (1999) model emphasising the role of low self-esteem and over-valuation of controlling aspects of eating, shape, and weight. This model also includes the physiological impact of starvation as mentioned in the previous model.

Figure 5. ‘Transdiagnostic’ theory of the maintenance of eating disorders. ‘Life’ is shorthand for interpersonal life (Fairburn et al., 2003, fig. 4)

These models deviate in terms of the maintaining mechanisms. In Fairburn, Shafran and colleagues' (1999) model, the reinforcing relationships between different factors presented is fairly obvious and comprehensively explained. In the proceeding model, Fairburn et al. (2003) suggest that the maintaining mechanisms between BN and AN are very similar and thus gives
additional justification for a transdiagnostic model. They explain how each main domain relates to BN, for example, explaining the relevance of specific and global low self-esteem shown in those with BN. This is then said to apply to AN and other EDs. However, there is a lack of explanation of how these categories or domains interact with one-another and perpetuate EDs; the nature and interactions of the relationships are largely left to the reader to evaluate. It is interesting that in this model Fairburn et al. (2003) combines issues of eating, weight, and shape seeming to ignore or supersede cultural differences which were proposed in their earlier model (Fairburn, Shafran, et al., 1999).

Overall the cognitive behavioural models of aetiology for AN have contained a range of factors which vary in terms of their empirical support and endorsement from those who have the disorder. In addition, there is variation as to the key issues which maintain and contribute to the disorder as outlined in the range of models reviewed. In comparison to other theoretical positions, cognitive behavioural theories tend to include a broad range of factors including: internal and external factors; specific cognitions, biases, and beliefs; behaviours; in general a clear description of the mechanisms influencing proposed factors. Cognitive behaviour therapy (CBT) is one of the preferred treatment modalities, especially for adult patients, thus this suggests that theories underpinning these treatments may be better predictors of the disorder (Vitousek, 2005). However, evidence from a randomised control trial suggests current applications of CBT for AN are not significantly distinguishable from interpersonal therapy (IPT) or a control group of supportive psychotherapy with a weight restoration focus (avoiding key foci of CBT or IPT) at long term follow-up (F. A. Carter et al., 2011). At short term follow-up, the control group of supportive psychotherapy was significantly superior to IPT and CBT (McIntosh et al., 2005). Hence, the predictive value of these models may be questionable.

**Psychosocial models**

This category of models is termed broadly as psychosocial models and contains psychoanalytic, psychodynamic, feminist, and family systems theories.

A psychodynamic-based model developed by Blank and Latzer (2004) attributes the aetiology of AN to a defence mechanism that arises due to anxiety caused by a lack of self-worth. Self-worth in the model is related to four main
areas: belonging, mastery, pleasure, and meaning, with factors which relate to successes in areas of: self, parents, school, and social circles. Throughout their explanation they refer to female adolescents as they represent the “majority of ED patients” (Blank & Latzer, 2004, p. 46). They explain that when developing normally, the adolescent can develop a high self-esteem and progress to being well-adjusted. However, when the boundaries developed from these factors are lacking, the psychological needs of the adolescent cannot be met and low self-esteem, anxiety, and helplessness can result. The main underlying premise for this model is that the adolescent gains a feeling of control over their body and weight by engaging in AN. This creates a false sense of mastery and control to compensate for the lack of control they perceive in other areas of their lives; thus, they meet some of their psychological needs. Their model is depicted in Figure 6, and shows the inter-relationship between these factors. This model is similar to the key elements described in Fairburn, Shafran, and colleagues' model (1999).

<table>
<thead>
<tr>
<th><strong>Self:</strong></th>
<th>Inadequacy, deficits in various skills, deficits in external appearance, high anxiety level.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parents:</strong></td>
<td>Deficit in parental skills, deficit in authority, adversity in family life.</td>
</tr>
<tr>
<td><strong>School:</strong></td>
<td>Deficit in teacher(s) skills, deficit in authority, traumatic experiences.</td>
</tr>
<tr>
<td><strong>Society:</strong></td>
<td>Chaotic environment, inadequate law and order, lack of security.</td>
</tr>
</tbody>
</table>

Loss of sense of belonging and mastery.

Loss of pleasure and meaningfulness.

---

**Enhancing and fixating**

**Anorexia Nervosa**

Allowing sense of orderliness, control, pleasure, belonging, meaningfulness.

Need to regain control, pleasure, belonging and meaning: Media and culture-bound.

**Anxiety**

Loss of control

Low self-esteem

---

*Figure 6. Model indicating deficits in a range of areas and subsequent lack of self-esteem and control, causing AN (Blank & Latzer, 2004, fig. 2).*
As depicted in Figure 6, the beginning of this process is with complete or partial failure in the areas relating to themselves, parents, school, and society. According to their theory, this must persist for an extended period of time to have a significant impact on the adolescent (Blank & Latzer, 2004). They then develop sensitivity to criticism along with heightened anxiety, low self-esteem, and a sense of insecurity and confusion. They strive to fulfill some of the psychological needs that they are lacking and attach to eating behaviour. By controlling their eating they start to control an aspect of their being and derive reinforcement from their ability to control their diet, and potentially their surroundings. Blank and Latzer (2004) posit that the anorexic also starts to gain control of their peers, for example, parents, teachers, friends, through their concern and the focus on the person’s anorexia. Control over others becomes another secondary source of reinforcement for the person with anorexia. Over time self-worth and self-control become connected to eating behaviour and weight control; the increasing of self-worth becomes extremely reinforcing and perpetuates AN.

The model by Blank and Latzer (2004) correlates with other models by emphasising psychological control and mastery. They also include the influence of a range of factors within, and external to, the individual. However, although they call it a bio-psychosocial model there is not a lot of biology included or explained in the aetiology. This directly contrasts with the previous biological models, and to a lesser extent CB models which indicated the physiological effects of starvation. Thus, in this model, they do a poor job of accounting for predisposing factors including genetics, family history of ED’s, perfectionist traits, childhood trauma, negative affect (Jacobi et al., 2004; Polivy & Herman, 2002; Stice, 2002). They also fail to indicate how changes in physiology while restricting energy intake may influence development or maintenance (Zandian, Ioakimidis, Bergh, & Sodersten, 2007).

Blank and Latzer (2004) do not explain a clear onset or trigger in their theory, only that after a certain time-frame the struggle that the person has with not meeting their psychological needs will manifest itself into AN. It fails to specifically distinguish between different types of EDs and why an individual would develop AN in comparison to other EDs, or other disorders, such as depression or an anxiety disorder. Their model is very non-specific and the
contributory factors cited seem relevant to a wide range of potential issues and are not related to food or eating behaviour until the condition supposedly develops.

An earlier feminist psychoanalytic model was developed which is rooted in the aspects of family dynamics during upbringing, the significance of adolescence representing a period of change and independence, as well as the relationship between the woman with AN and men (Boskind-Lodahl, 1976; Keel, 2005). This model suggests that during childhood there is a mother who is controlling but powerless, and a father that was largely absent but idealised by the child. The girl grows up with a demand to conform and defines herself based on her perceptions of the reactions of others. During adolescence there is conflict between the social pressure to develop and become more involved with men [or other romantic involvement]; however, the child’s ability to interact with men is affected by her low self-esteem and lack of social abilities. She then perceives being rejected by males, develops a pre-occupation with body and appearance, begins dieting but is unsuccessful and thus has intensified feelings of inadequacy. This last cycle of perceived rejections from men, dieting and so forth is what is proposed to lead them to anorexia, bulimia or obesity (or “bulimarexia”) (Boskind-Lodahl, 1976).

This feminist psychoanalytic model is dated and clearly rooted in the social values of the time. It is also very culture-bound in its description of a nuclear family and the mention of males as the only romantic option. Thus, it is limited in its relevance or validity across cultures, with people who are not heterosexual, and those who are not brought up in a nuclear family (mother and father). The recognition of dieting as a strong predictor of developing eating dysfunction as well as the cyclic nature of AN (especially BP subtype) are well-supported by other evidence (Bulik et al., 2006). In addition, females with AN report a greater number of psychosocial stressors, especially those relating to inappropriate parental pressures; however, this may be confounded by the finding that general psychiatric populations typically experience a greater number of stressful life events (Jacobi et al., 2004). This model is relevant as formulations related to parental relationships similar to this continue to be described in the literature (e.g., Horesh et al., 2000).
Bruch proposed that the development of AN was related to the interaction between mother and child during development (as cited in Keel, 2005). Bruch’s hypothesis was that the mothers had difficulty responding to the appropriate cues of the daughters during infancy (Keel, 2005). As the daughters developed, they learnt to adapt their behaviour to match the environment which was not responsive to their cues. This meant that they portrayed the image of ‘perfect daughters’ reported by many families studied by Bruch (Bruch, 1974). As the child grew older the lack of response of the environment to match their cues created a sense of ineffectiveness in the child. Bruch also remarked that although preoccupation with food and weight dominate the condition, she thought that the true underlying issues related to the anorexics disturbed self-awareness and defective interpersonal skills (Bruch, 1974). This relates to the main issues posited by Bruch that AN related to “a struggle for control, for a sense of identity, competence, and effectiveness” (Bruch, 1974, p. 251).

Evidence for control as a central principle in AN has been previously described. Issues of identity have been posited as central to EDs by other theorists (e.g., Hall, 1982; Polivy & Herman, 2002). Further, it is often also described by those who have AN where anorexia becomes a part of the person’s identity and sense of self (Tan, Hope, & Stewart, 2003). Thus, it can serve as a maintaining factor and contribute to resistance to treatment and change (Vitousek et al., 1998). It is also described as something that has to be overcome to recover, i.e. separating oneself from their AN (Federici & Kaplan, 2008; Tan et al., 2003). Issues of ineffectiveness and competence have been investigated and are often connected to low self-esteem and perfectionism (Jacobi et al., 2004). Ineffectiveness is included in key measures of EDs, for example the Eating Disorders Inventory. In line with findings of low self-esteem, ineffectiveness has been indicated by some longitudinal studies as being high prior to ED onset (Jacobi et al., 2004). The Ineffectiveness subscale of the widely used Eating Disorder Inventory (EDI; Garner, Olmstead, & Polivy, 1983) was developed from this theoretical premise. A majority of studies using this measure show lower self-esteem, a more negative self-concept or higher levels of ineffectiveness in comparison with control groups in patients with AN but inconsistent results when psychiatric controls are included (Jacobi et al., 2004). Other measures of competence indicate that those with AN may perceive a greater deficits in their
abilities. For example, Bers and Quinlan (1992) found that adolescent females exhibited significantly higher disparities between their interests and their abilities (perceived-competence deficit) in comparison to psychiatric inpatients, and nonclinical controls. This remained significant after controlling for depression.

Minuchin and colleagues (1978) pioneered the examination of the role of family systems in the development of AN in children and adolescent girls. This work was based on foundations of modelling and shaping within the family. These concepts were used to describe how transactions within the family serve to reinforce or discourage ways of being in the family. Thus, over time the punished transactions are less used by the child and the encouraged transactions are perpetuated. The authors state that the familiar ways of being are then more likely to become part of the child’s sense of self.

The two key areas which relate to Minuchin et al.’s (1978) description of “the anorectic family” (p. 51) are boundaries and family response to change. According to these authors, the anorectic family has marked enmeshed boundaries between members. This is manifested as a lack of differentiation between members, diffuse social roles within the family, and reduced individual autonomy. The symptomatic child in the anorectic family is also likely to: exhibit subordination in the family, an over-involvement in the family compared to developmentally expected involvement in extra-familial relationships, and be highly aware of intra-familial interactions. The anorectic family is very sensitive to change and issues experienced by family members. Increase in autonomy or individuation within the family is resisted, even when developmentally expected, e.g. in adolescence. A member of the family that defies the current systems or expectations is challenged by other family members. Anorectic families were noted to be more preoccupied with somatic concerns and have a focus on diet, weight, and/or nutritional concerns. Figure 7 shows the relationships and observations noted by Minuchin et al. (1978) within an open systems framework of dysfunction and is adapted by combining two figures and in-text information (Minuchin et al., 1978).
This model is reliant on the individual with AN developing it within a family environment so the predictive power for those that develop it during late adolescence and beyond may be reduced. Although family interactions are important, this model seems to disregard other important relationships, such as peer influence. These relationships may be particularly important in initiating known risk factors such as dieting (Stice, 2002).

There is some supporting evidence for the role that families can play in the cause of AN. For example, research into attachment has indicated that insecure attachment is common in individuals with an ED (Ward, Ramsay, & Treasure, 2000). There is evidence suggesting that adverse parenting is correlated with AN, specifically family discord and high parental demands in case controlled studies of risk factors (Fairburn, Cooper, et al., 1999; Pike et al., 2008). This is not consistent with Minuchin et al.’s (1978) aetiology which described avoidance of conflict within the family and an over-involvement of family members, rather than low contact. Critical comments about weight, shape, or eating from family members has been implicated in AN development. Parent perspectives and dieting histories are also important predictors of child preference for thinness (Pike & Rodin, 1991; Wertheim, 2002). This is consistent with the open systems model indicating a family awareness of food/diet/weight; however, it was noted by other
researchers that family and individual history of weight, shape and dieting concerns are not significant in predicting the development of AN when other risk factors are accounted for in comprehensive models (Fairburn, Cooper, et al., 1999; Pike et al., 2008). High concern parenting has some support in distinguishing AN from controls and was often predicted by birthing difficulties or obstetric losses prior the birth of the person with AN (Jacobi et al., 2004).

Overall, these models attempt to attribute more of the cause to systems external to the individual. This is done with varying success. Key support are for AN being linked to perfectionism, self-esteem, and effectiveness/competence. Additionally, there is evidence supporting the role of interpersonal factors, such as familial conflicts, overprotection, and childhood physical and sexual abuse as significant retrospective correlates common to the AN and psychiatric controls (Fairburn, Cooper, et al., 1999; Pike et al., 2008).

**Sociocultural Influences and models**

There has been significant debate about the influence of culture and social contexts which promote a thin body as ideal in contributing to AN or EDs in general (Keel & Klump, 2003). This is most prevalent within the current Western world, with the use of very thin models in industries relating to beauty, fashion, advertisement, and others. Fashion models and image manipulation for advertisements can promote an underweight appearance (Grabe, Ward, & Hyde, 2008). Similarly for males, it may promote a slim but muscular image (Barlett, Vowels, & Saucier, 2008). There is prevalent discourse in the media about issues of people's weight (e.g. ‘too fat’, ‘too thin’), issues of diet (e.g. how to lose weight, what to eat, promoting rigid dichotomies of food such as good/bad, healthy/unhealthy) (Hill, 2009; Lupton, 2004). These have not been widely studied in relation to ED’s, but more widely studied in relation to dieting and obesity (e.g. Carels, Konrad, & Harper, 2007; Oakes, 2005). Overall exposure to Thinness-Depicting and Thinness-Promoting media (TDP; Harrison & Cantor, 1997) have been suggested to increase dieting behaviours in women, increase muscle gain attempts in men, decrease self-esteem, increase body dissatisfaction, and be related to eating disorders in men and women (Agliata & Tantleff-Dunn, 2004; Barlett et al., 2008; Grabe et al., 2008; McCabe & Ricciardelli, 2001; Stice, 2002).
However, although there have been correlations made and there is evidence from experimental research showing the immediate negative impacts of viewing TDP media but there is a lack of research looking at the long-term effects (Harrison & Cantor, 1997; Stice, Spangler, & Agras, 2001). There is also evidence that suggests exposure to this type of media only relates to the development of BN, not AN, and that it only effects those that are already vulnerable or sensitive to perceived pressure to be thin, experience body dissatisfaction, and have poor social supports (Polivy & Herman, 2002; Stice et al., 2001). Media consumption and internalisation has been shown to be relevant to women desiring to be thinner and being dissatisfied with their bodies in a New Zealand undergraduate sample (E. Miller & Halberstadt, 2005). New Zealand males sampled did not show thin-ideal internalisation; however, the study did not alter the Socio-Cultural Attitudes towards Appearance Questionnaire (SATAQ; Heinberg, Thompson, & Stormer, 1995) to account for masculinity so males may have undetected muscle-idealism as shown in other studies (Agliata & Tantleff-Dunn, 2004; E. Miller & Halberstadt, 2005). However, the link between media consumption and EDs is relatively indirect; it requires the individual develop sustained dissatisfaction with their body which then interacts with other personal and interpersonal factors causing an ED. Keel and Klump (2003) described AN as a universal disorder which is experienced at similar rates across cultures and where the prevalence has not changed significantly over time. BN was described by these authors as a culture-bound syndrome which is influenced by culture and evidence indicated the prevalence changes depending on the social context.

Thompson, Coovert, and Stormer (1999) developed the tripartite model of sociocultural influence on body dissatisfaction and relationships to eating disturbances including restriction based on the Eating Disorder Inventory–Drive for Thinness Scale (EDI-DT; Garner, 1991) and bulimia based on the Eating Disorder Inventory–Bulimia Scale (EDI-B; Garner, 1991). This model was developed using structural equation modeling to link measures of parent, peer, and media influences to comparison to others, internalization, body dissatisfaction, and AN and BN. The relation to BMI and global psychological functioning have also been evaluated (Keery, van den Berg, & Thompson, 2004; Shroff & Thompson, 2006; van den Berg, Thompson, Obremski-Brandon, & Coover, 2002). These models have some variation but in general have suggested
that sociocultural influence significantly correlates with restriction scores. Van den Berg and colleagues (2002) found that peer influence significantly and directly correlated with restriction in their sample of 196 female undergraduates aged 18-22. This study also found that global psychological functioning directly correlated with bulimia scores. Shroff and Thompson (2006) found that the media, not peers, directly and significantly correlated with restriction in their sample of 391 female students aged 10-15; their results also supported the link of bulimia to psychological functioning. Keery and colleagues' (2004) resulting model supported the previous findings with their replication with 433 female adolescents (11-15 years old) but also contained a direct correlation between internalization and restriction. A summary of these three models is depicted in Figure 8.

In relation to AN, total media consumption does not appear to directly cause EDs but could be related to dysfunctional eating. According to these studies, TDP media consumption may influence eating and weight and body satisfaction but not directly contribute to AN. In addition, the finding that the relationship between TDP exposure and change in self-esteem is moderated by pre-existing awareness of weight and body dissatisfaction indicates the media may have a amplifying or justifying effect for some people rather than being causative.
Body dissatisfaction appears to be a stronger predictor of dysfunctional eating of both restrictive and bulimic subtypes and is supported by other research (Jacobi et al., 2004). This factor appears mediated by sociocultural influences for women but these may not represent the origin of body dissatisfaction nor do dysfunctional eating patterns mean a person will meet diagnostic criteria for AN or BN. Additionally, development of AN dieting may be another significant factor mediating the relationship between body dissatisfaction and disordered eating (especially for BN or AN-BP) (Jacobi et al., 2004). However, it is difficult to separate dieting from the general progression to AN given that dieting or restrictive behaviours are necessary in order to lose weight and meet the weight requirements for AN (Jacobi et al., 2004).

Overall, based on longitudinal research weight concerns, negative body image or dieting seems to be a significant risk factor for development of EDs, especially for those that binge (BN and AN-BP). Anorexia nervosa has been argued as not being a culture-bound experience when historical and cross-cultural accounts of self-starvation or AN are taken into account (e.g., Keel & Klump, 2003; Palmer, 1993). However, that does mean changes within social groups will not influence prevalence rates as suggested by Keel and Klump (2003). Despite this there are a range of studies to suggest that prevalence has not changed greatly since Western culture began emphasising thinness (Keel & Klump, 2003; Smink, van Hoeken, & Hoek, 2012). In addition, there is inconsistent results and methodological difficulties in assessing the causal link between media exposure and significant independent contribution to EDs (Levine & Murnen, 2009).

**Risk factor research**

The previously described theories have typically been created from a particular psychological approach, for example, psychoanalytic, systemic theory. Some evidently reflect the research trends at their conception, for example, addiction models, feminist theory. However, there has been a wealth of current research in the field of AN focussing on identifying significant risk factors that seem to distinguish those who develop AN from other eating disordered individuals, general psychiatric, and nonclinical populations. Risk factors identified have ranged broadly across different domains partially described across models, such as the strong evidence suggesting a genetic predisposition and
inheritance to AN (Bulik et al., 2006). Table 1 indicates identified risk factors is reproduced below from Jacobi et al. (2004) and Pike et al. (2008).

Table 1. *Fixed and variable markers, retrospective correlates and correlates for AN, and variable risk factors for EDs (adapted from Jacobi et al., 2004; Pike et al., 2008).*

<table>
<thead>
<tr>
<th>Anorexia Nervosa</th>
<th>Eating disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fixed Marker: Birth/biological</strong></td>
<td><strong>Variable risk factors (Not specific to AN: all EDs)</strong></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Gastrointestinal problems in childhood</td>
</tr>
<tr>
<td>Genetic effects</td>
<td></td>
</tr>
<tr>
<td>Early pubertal timing</td>
<td>Picky eating/eating conflicts in childhood</td>
</tr>
<tr>
<td>Very preterm birth</td>
<td></td>
</tr>
<tr>
<td>Birth trauma</td>
<td>Sexual abuse/physical neglect</td>
</tr>
<tr>
<td>Female</td>
<td>Low interoception</td>
</tr>
<tr>
<td></td>
<td>Self-reports as unpopular, aggressive in adolescents</td>
</tr>
</tbody>
</table>

**Retrospective correlates (case-control, family history, comorbidity studies)**

- Acculturation
- Difficulties with infant sleep
- Pregnancy complications
- Gestational age
- Obsessive-compulsive personality disorder/Obsessive-compulsive disorder

<table>
<thead>
<tr>
<th>Overanxious disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Dysmorphic disorder</td>
</tr>
<tr>
<td>Early feeding and severe gastrointestinal problems</td>
</tr>
<tr>
<td>Greater level of exposure to personal, environmental, and dieting risk domains [comparison with nonclinical CG]</td>
</tr>
<tr>
<td>Negative self-evaluation [comparison with psychiatric CG]</td>
</tr>
<tr>
<td>Premorbid perfectionism [comparison with psychiatric CG]</td>
</tr>
<tr>
<td>Less exposure to parental obesity [comparison with BN group]</td>
</tr>
<tr>
<td>Sexual abuse</td>
</tr>
<tr>
<td>Adverse life events (number and type)</td>
</tr>
<tr>
<td>High level exercise</td>
</tr>
</tbody>
</table>

| Alcohol consumption (adolescents) |
| Weight |
| Concerns/dieting/negative body image |
| Low self-esteem/ineffectiveness |
| Escape-avoidance coping |
| Low social support |
Anorexia Nervosa  
High-concern parenting (two or more factors of those measured)

**Variable markers**  
Adolescent age

**Correlates**  
Family function/interaction style, attachment style  
Familial psychopathology (eating disorders, depression, anxiety disorder, substance use disorders, etc).  
Perfectionism  
Low self-esteem, negative self-concept  
Participation in weight-related subculture (e.g., fashion modelling)  
Negative affectivity

Jacobi et al. (2004) conducted a large review of studies relating to risk factors, prospective studies, longitudinal studies, and aetiology of eating disorders in order to synthesise the above risk factors. They categorised their risk factors according to a general risk factor classification for psychopathology (Kazdin, Kraemer, Kessler, Kupfer, & Offord, 1997, as cited in Jacobi et al., 2004). According to this classification, fixed markers as indicated in Table 1 refer to a risk factor that cannot be changed. Correlates are those which show a statistically significant relation between the factor and ED. Variable markers are risk factors which cannot be changed by manipulation, but change of their own accord. A risk factor is defined as being both statistically and clinically significant in predicting EDs; variable risk factors are those which can be modified by manipulation.

Comparing these risk factor results to previous models, it is obvious that some features are better supported than others. This does not mean to say that other models are incorrect but may indicate a range of issues, such as overemphasising a present but not significant factor, certain factors not yet being adequately researched, and so forth. The benefits of reviewing these studies in relation to risk factors is to allow confirmation of relevant factors above and beyond clinical judgment or supposition. However, the greatest limitation of this approach is the lack of continuity and explanatory power when describing how a
person with certain factors comes to develop AN. Given the aim of this research is to compare theoretical models to participant perception, the accuracy of the models is less significant, compared to their ability to capture people’s experiences. However, this information is included as well as general comparisons throughout to allow the reader to evaluate those models which have greater empirical foundation. Jacobi et al. (2004) include a developmental model of their risk factors, shown in Figure 10.

Figure 9. Developmental model of pertinent risk factors indicated in Table 2 and associated potency for AN (Jacobi et al., 2004, fig. 2). OCPD: Obsessive-compulsive personality disorder; BDD: Body dysmorphic disorder; OCD: Obsessive-compulsive disorder.

Authors of texts focussing on AN have synthesized risk factor research into a range of models of aetiology. This contrasts to published journal articles which show a dearth of models summarising this current wave of risk factor findings, with the exception of Connan et al., (2003). One model developed by Nicholls (2007) in a book on Eating disorders in childhood and adolescence is reproduced in Figure 10. This model was selected as it was based on a wide range of current and past psychological evidence relating to the aetiology of AN and portrays one way in which factual risk factor research can be categorised into a model. However, as it is reproduced from a selected text it is not necessarily a popular model.
This model has its benefits as it summarises evidence from many studies into AN. It also covers a wide range of the ‘categories’ of risks, such as puberty and culture. It adheres to the properties of simplicity in that the ideas and concepts are simple and easily interpreted, as well as being meaningful. Additionally, there is not one factor that is focussed on as more important than others; each contributes to the overall picture for a particular individual. The author gives an indication of triggers that may cause a preoccupation with weight and eating-related pathology.

Issues with this model include its vagueness, i.e. culture is particularly non-specific. Thus, a person must have a good awareness of the research relating to culture to interpret and understand what aspects of culture do or do not potentially contribute to AN. It also seems to ignore ideas of the biological abnormalities present in those with AN and how that may impact the development of the disorder; neuro-developmental profile seems focused on developmental changes.
rather than actual differences consistent across the life span to adequately address this point. Although all the general categories labelled have been implicated as areas of risk for the development of AN, this particular model could apply to any eating disorder due to its lack of specificity.

**Summary**

A range of models have been reviewed which describe the aetiology, and in some cases maintenance, of AN. The models have differed in terms of their specificity in describing AN and their theoretical orientation. They also vary widely in terms of their empirical support from risk factor research and research describing perspectives of those who have experienced AN. These models will be used as baseline comparisons to the perspectives investigated in this research. They will be used to evaluate how well they relate to how those who have had AN conceptualise the aetiology of the onset of their problems and any continued problems with EDs.

**Personal experiences and perspectives**

Personal experiences and perspectives of those with AN is not an unknown type of research but certainly less common than abstractive styles of research that do not take the person’s perspectives into account (Button & Warren, 2001). For example, people’s experiences may differ from risk factors based on correlations of shared historical features present for those with a particular disorder as outlined in the previous section. Assessing the experiences and perspectives of those who have experienced AN involves a qualitative approach: interviewing, transcribing, and analysing to deduce meaning from the content. This method gives a more personalised and comprehensive picture of people’s experiences of AN and their subjective thoughts about different aspects of the disorder (Button & Warren, 2001). Gaining this insight has implications for treatment outcome and enhancing engagement in treatment for a disorder that is recognised as typically having a poor outcome (Button & Warren, 2001). The following will review key articles relating to using a qualitative, interview approach to assess the perspectives of those with AN, especially those relating to aetiology, and relapse.
**Perceptions of experiencing anorexia nervosa**

Few studies have examined how people with AN perceive their disorder (Button & Warren, 2001). However, there is evidence to suggest some people with AN perceive it to be an illness, or part of an illness (Button & Warren, 2001). People describing this emphasised the role of biological predisposition and problems in thinking associated with having a mental illness which contribute to the problem. Furthermore, the illness conceptualisation allows for those with AN to see it as something bigger than themselves; a consuming disease similar to other potentially dangerous and fatal medical diseases (Williams & Reid, 2010). Some may also perceive others as attributing their AN to ‘normal’ behaviour such as wanting to be thin so dieting to the extreme, rather than a specific and significant problem in their thinking and experience of the world (Button & Warren, 2001; Williams & Reid, 2010). Others may disagree with the term of mental illness associated with AN and diagnosis but still agree that difficulties such as disordered thinking, perception of the world, and personality, characterise AN (Button & Warren, 2001).

People with AN often personify the disorder describing it as a friend and an enemy (Serpell, Treasure, Teasdale, & Sullivan, 1999; Williams & Reid, 2010). Serpell and colleagues (1999) presented themes where those with AN conceptualised their AN as a ‘friend’ and an ‘enemy’. They found that the main ‘friend’ factors related to viewing AN as: a guardian/security; sense of control, attractiveness, and confidence; mechanism of avoidance from emotional distress; and distinctiveness from others. They found the main ‘foe’ factors related to viewing AN as: taking over them/losing control of it; loss of social support; health conditions; hating it/fighting against it; a waste of life; negative implications on others (e.g., concern); and negative symptoms (e.g., low mood). AN can also be conceptualised as a part of the person’s identity (Tan et al., 2003). In this way, AN typically represented a significantly ‘bad’ or negative part of the individual. This perspective can contribute to thinking AN will never be completely eliminated because it represents a part of one’s self (Tan et al., 2003).

**Perceptions of cause**

Tozzi and colleagues (2003) conducted a study on patient perspectives on the causes and recovery of their AN. This study included 70 participants who
were chosen from a pool of cases that had received treatment at an eating disorder treatment service in Christchurch, New Zealand between 1981 and 1984. The women had to meet the criteria for lifetime AN according to the DSM-III and DSM-III-R (American Psychiatric Association, 1980; American Psychiatric Association, 1987; as cited in Tozzi et al., 2003). They were interviewed on average 12 years after initial diagnosis.

Tozzi et al. (2003) performed comprehensive interviews to assess perceived causes. In addition, their method of coding subscribed themes or topics to one level, rather than further categorising them under higher-level groups (e.g., ‘Family’ to describe all family-related issues). The long time between onset of the disorder and asking participants of their views is a potential limitation. Thus, their account is more likely to be affected by memory biases which can increase with time. In addition, autobiographical memories are affected by sense of identity and usually biased to matched people’s current sense of self (Wilson & Ross, 2003). Therefore, using predominantly recovered patients may further bias results, although they did not report significant differences between unrecovered and recovered patients. All participants in this study had received treatment including: weight stabilization, individual and group supportive psychotherapy, family counselling, medication if necessary, and nutritional rehabilitation. Hence, particular issues may have been emphasised through treatment as being significant and thus influenced reported perceptions of aetiology. For example, family contributions to development emphasised through family counselling.

Another significant limitation of this study (Tozzi et al., 2003) is diagnosis of participants using the DSM-III and DSM-III-R. These diagnostic criteria require the fear of becoming fat or obese and gaining weight (in DSM-III-R). In addition, the DSM-III required “disturbance of body image, e.g., claiming to “feel fat” even when emaciated” (Sunday et al., 2001). The change from DSM-III to DSM-III-R also introduced the criterion that the person had to have amenorrhea. The specific focus of the DSM-III and DSM-III-R criteria in relation to body image may mean that participants in this study are more likely to report these issues (as they are required to be diagnosed) in comparison to others diagnosed based on DSM-IV or DSM-5 criteria where this criterion is more broadly defined (Garfinkel, 2005).
The most common endorsed cause from participants was family dysfunction, as shown in Table 2. Weight loss/dieting, and pressure/stress/frustration had similarly high endorsement with over a fifth of the participants. Two other studies (Nevonen & Broberg, 2000; Nilsson, Abrahamsson, Torbiornsson, & Hägglöf, 2007) are included for comparison. These show some similar endorsement but categorisation varies across the studies as well as the types of questions asked to assess perceived causes.

Table 2. Endorsed causes for AN from those diagnosed across three studies (Nevonen & Broberg, 2000; Nilsson, et al., 2007; Tozzi et al., 2003).

<table>
<thead>
<tr>
<th>Defined category</th>
<th>Percentage of participants</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tozzi et al. (2003), n=69</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family dysfunction</td>
<td>34.8</td>
<td>‘A lot of fights and problems’</td>
</tr>
<tr>
<td>Weight loss/dieting</td>
<td>21.7</td>
<td>‘Diet got out of control’</td>
</tr>
<tr>
<td>Pressure/stress/frustration</td>
<td>20.3</td>
<td>‘Stress, part of a bad time in life’</td>
</tr>
<tr>
<td>Inappropriate comments</td>
<td>15.9</td>
<td>‘Teacher at school constant put-down’</td>
</tr>
<tr>
<td>Control</td>
<td>14.5</td>
<td>‘Eating was one thing that could be controlled’</td>
</tr>
<tr>
<td>Family weight and food issues</td>
<td>13.0</td>
<td>‘Lived with obese aunt, always dieting; mother fat...’</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>13.0</td>
<td>‘Raped by older boyfriend’</td>
</tr>
<tr>
<td>Mood</td>
<td>11.6</td>
<td>‘Depression’</td>
</tr>
<tr>
<td>Low self-esteem</td>
<td>11.6</td>
<td>‘Low self-esteem, lack of confidence’</td>
</tr>
<tr>
<td>Loss (grief)</td>
<td>10.2</td>
<td>‘Father’s sudden death’</td>
</tr>
<tr>
<td>Adolescence</td>
<td>10.2</td>
<td>‘Adolescence—unprepared for changes’</td>
</tr>
<tr>
<td>Perfectionism</td>
<td>10.2</td>
<td>‘Wanted to be seen to be perfect’</td>
</tr>
<tr>
<td>Achievement</td>
<td>10.2</td>
<td>‘Wanting to achieve something, be excellent at something’</td>
</tr>
<tr>
<td>Parental expectation</td>
<td>7.3</td>
<td>‘Parents strict, high expectation’</td>
</tr>
<tr>
<td>Other</td>
<td>15.9</td>
<td></td>
</tr>
<tr>
<td><strong>Nilsson et al. (2007), n= 68</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self (Category)</td>
<td>Most common</td>
<td></td>
</tr>
<tr>
<td>Own demands/ high achievement,</td>
<td>19</td>
<td>“Ambitious and high own demands”</td>
</tr>
<tr>
<td>perfectionism/compulsory traits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Defined category</td>
<td>Percentage of participants</td>
<td>Example</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>----------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Developmental crisis or physical or mental symptoms</td>
<td>NR</td>
<td>“I have always felt different, developed early”</td>
</tr>
<tr>
<td>Dieting, high degree of body dissatisfaction, overweight</td>
<td>NR</td>
<td>“I did not like my body”</td>
</tr>
<tr>
<td>Low self-esteem, negative self-value</td>
<td>NR</td>
<td>“Poor self-confidence”</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties in family interaction and communication too little care or overprotection</td>
<td>NR</td>
<td>“My parents had no time with me and did not see that I was feeling bad”</td>
</tr>
<tr>
<td>Stressful event in family; e.g., death of family member, illness or handicap, sexual abuse</td>
<td>NR</td>
<td>“A very difficult and traumatic childhood, with abusive relations”</td>
</tr>
<tr>
<td>High demands from family members for achievement or appearance</td>
<td>NR</td>
<td>“Heavy demands and expectations from my father”</td>
</tr>
<tr>
<td><strong>Sociocultural stressors outside the family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with peer/bullying, bad situation at school, incident</td>
<td>NR</td>
<td>“It was awful in school, I had no friends”</td>
</tr>
<tr>
<td>Ideals</td>
<td>NR</td>
<td>“The ideals of society”</td>
</tr>
<tr>
<td>Moving to new place/separation</td>
<td>NR</td>
<td>“my boyfriend [and I] broke up”</td>
</tr>
<tr>
<td>Sports</td>
<td>NR</td>
<td>“I was in gymnastics and was told by coaches to lose weight before competitions”</td>
</tr>
</tbody>
</table>

*Nevonen & Broberg (2000), n=25*

**Weight-related problems (Category)** 36.4  NR

Dieting initiated during sickness
I was overweight
I was determined to change my weight
I felt overweight

**Interpersonal problems** 22.7  NR

Separations
Conflicts
Death-related themes
Teasing and comments
Social influence

**Combinations of categories** 27.2  NR

36
<table>
<thead>
<tr>
<th>Defined category</th>
<th>Percentage of participants</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal and weight-related issues</td>
<td>13.6</td>
<td></td>
</tr>
<tr>
<td>Other combinations</td>
<td>13.6</td>
<td></td>
</tr>
<tr>
<td><em>Eating-related problems</em></td>
<td>9.1</td>
<td>NR</td>
</tr>
<tr>
<td>Had been eating a lot lately</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoughts about food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Started to eat healthy</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Psychosocial problems</em></td>
<td>4.5</td>
<td>NR</td>
</tr>
<tr>
<td>Psychological problems (unhappy, worthless, suicide attempts)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social problems including employment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Calculated estimate of number of participants from percentages; not directly reported in study. NR: Not reported.*

Nilsson and colleagues (2007) conducted a study of adolescent’s perspectives of the onset of AN. They interviewed AN patients 8 and 16 years after admission to child and adolescent clinics in Sweden. The median age of first admission was 15 years and they had to meet the DSM-III-R criteria for AN. They asked the following question in two separate interviews (one follow-up conducted at a later date): “What do you think today about the reasons why you got anorexia nervosa? (p. 126).”

Nilsson and colleagues' (2007) results rely on two separate responses at two interviews to one question (provided the participants had an answer). This may pose a limitation to the depth and quality of the answers received and may elicit more variation depending on varied interpretations of the one question. For example, some may perceive the retrospective content of the question to suggest how has this opinion changed in comparison to past opinion. Similar to Tozzi et al. (2003), the participants were asked at extended follow-ups from their initial admission to ED clinics: 8 and 16 years later for each interview. Details of treatment experienced by participants was not mentioned thus it is difficult to draw conclusions to the relevance of this in determining perspectives of aetiology. Furthermore, they are likely to have the same issue with regard to the AN population defined by the DSM-III-R.
Nevonen and Broberg (2000) studied people who had sought treatment for an eating disorder (AN, BN, EDNOS) at an outpatient hospital unit in Sweden asked a question similar to the previous study (Nilsson et al., 2007) but provided more probing into the responses. They asked questions regarding the development of the disorder in relation to three categories: age of onset, why it occurred, and what the person did at the time. Perceptions of aetiology were assessed by posing the key question: “Could you please tell me about the way your eating disorder emerged? (p. 281)”. Following the response to this, further questions were posed to elicit an indication of why, when, and how the ED developed. This study developed the same categories of codes for all EDs thus some variation between groups may be lost. Contrary to the other two studies, Nevonen and Broberg (2000) had participants diagnosed based on the DSM-IV. Participants in the study were also asked during their initial diagnostic assessment interview when accessing treatment. Thus, retrospective bias from time and exposure to treatment is less likely. Comparison between this study and the other two is made more difficult due to the differing diagnostic versions. The DSM-IV further defined body image disturbances to reduce ambiguity from earlier version. Evidence suggests that there may be significant differences in the number of people diagnosed with AN when comparing the DSM-III-R and DSM-IV (Sunday et al., 2001), and thus the range of reasons provided may be broader in Nevonen and Broberg (2000) due to the more inclusive criteria.

Across the groups there are similar groups of causes listed but proportions of reported causes vary between studies (Nevonen & Broberg, 2000; Nilsson et al., 2007; Tozzi et al., 2003). For example, interpersonal/family, and weight concerns were more important in the other two studies than in Nilsson et al. (2007). In addition, issues of self-esteem or self-worth were barely endorsed for Nevonen and Broberg's (2000) study, especially when compared with the other two. Also, dieting which was rated relatively highly in the other studies, was not as evident in Nilsson and colleagues (2007) as they amalgamated it into the category of ‘Self’. High incidence of this may reflect dieting being a confound for AN, especially in Nevonen and Broberg (2000) where they coded across ED diagnostic types so nuances in meaning across diagnostic groups may have been lost. Although control was only mentioned in one study it was also reported as
most commonly reported in a longitudinal study where perceptions of cause was a small part (Button & Warren, 2001).

Other smaller studies (e.g., Serpell et al., 1999) have presented additional contributing factors. For example, Williams and Reid (2010) conducted a study of people wanting to maintain their AN, recruiting them through websites promoting AN. They found that AN is perceived as a way of feeling in control, achieving valued goals, and as a form of coping. As a coping mechanism, some may perceive AN as solving unrelated problems in life through achieving thinness or other goals related to AN. In addition, AN was “used as a way of feeling safe, a way of expressing emotion, as an escape or a focus to avoid negative situations and emotions, a way to disappear, to feel strong and successful, to feel happiness, a way of fighting puberty and a way of punishing themselves or others” (p. 558). Some of these factors are present in the larger studies; however, some are additional such as the role of punishment, avoidance, problem solving, and competence.

Differences in reasons from the smaller studies may be due to design, as they were designed to specifically investigate the perspectives of participants and were not part of larger study (e.g., longitudinal studies). In addition, the smaller studies typically asked a broader range of questions or had greater expectancies for responses (e.g., to write a letter). Hence, it is likely that some of the additional factors stated are applicable but the power of these findings to be generalized is much lower.

Overall, issues of self (e.g., self-esteem, self-worth, self-confidence), interpersonal conflict (e.g., family, friends, others), weight/body dissatisfaction-related factors (e.g., comments, own perception, resolutions), food/eating-related factors (e.g., dieting, change in diet, health), and stress in response to life events (e.g., death, moving, abuse) appear consistently important in the larger studies. Other issues such as mood, control, and perfectionism/high standards for achievement were less consistent across studies. Smaller more in-depth studies indicated additional factors: punishment, avoidance, problem solving, and competence.
Perceptions of relapse

Although there have been a range of qualitative studies examining perspectives and accounts of recovery in AN (e.g., Dawson, Rhodes, & Touyz, 2014; Hay & Cho, 2013; Tozzi et al., 2003), very few have examined relapse. Federici and Kaplan (2008) conducted a comparison study between recovered and relapsed participants from an inpatient treatment service. They found that relapse is associated with greater ambivalence or doubt about the efficacy of the treatment. Some participants described ‘not being ready’ for treatment and that their main motivation had been to please others in attending, thus they relapsed as soon as they could as they were not invested. Recovery can also be perceived as something that is too difficult to sustain so lead to relapse in the long-term by slowing returning to past AN behaviours. Following treatment, some attribute relapse to being unprepared for the difficulties of remaining recovered in the ‘real’ world, outside of the structured and closed treatment setting.

Those with AN who view their treatment as being inadequate or not addressing important content (e.g., poor coping strategies for negative emotions) can also view this as contributing to subsequent relapse (Federici & Kaplan, 2008). Specifically, failure of the treatment programme to focus on key (perceived) aetiology or maintaining factors is associated with clients viewing their AN is being unaffected. This was particularly important for the emphasis on weight restoration as a treatment goal/approach, rather than focusing on more significant causal factors for each individual (Federici & Kaplan, 2008).

Judgment from others in the person’s life can also contribute to relapse (Federici & Kaplan, 2008). Family and friends who lacked understanding or were negative towards the person’s issues with AN were associated with relapse. Further, general social isolation and loneliness was cited as contributing to relapse. This could be exacerbated by others expecting the individual to be ‘normal’ due to being weight-restored and thus acknowledging challenges was difficult, on top of misunderstanding about the experience (Federici & Kaplan, 2008).

Difficulties in coping with negative affect is often a perceived reason for relapse, especially following discharge or times of stress (Federici & Kaplan, 2008). As AN may have been seen as a coping mechanism, if other adequate
Coping strategies were not in place, relapse was likely. Negative thoughts and mood extends to difficulties accepting a body at a higher weight (within the normal range) and requires managing persisting anorectic thoughts. Struggling to accept being at a ‘normal’ weight is endorsed as contributing to relapse. Furthermore, difficulties in self-validation was seen to contribute to relapse, for example, severe self-criticism and worthlessness, fears of failure, and hopelessness (Federici & Kaplan, 2008).

The main suggested causes presented by this study (Federici & Kaplan, 2008) relate to issues of treatment readiness (motivation), treatment adequacy, negative or absent relations with others, inadequate coping strategies, discomfort with body weight, persistent/residual anorectic thoughts and behaviours, and pessimistic view of self and future. Due to the small nature of this study, these results can only be indicative, rather than definitive.

**Rationale for present research**

Based on the literature reviewed, this research aims to enhance the understanding of the perspectives and experiences of New Zealand residents who have experienced AN. There is limited literature describing how those with AN describe the cause of the experience, and even less in New Zealand. Similarly, there is seemingly very little research describing how participants describe the causes of relapses. Although there are many models of AN, along with risk factor research, few studies have systematically compared the two with the perspectives of those with AN. Comparison which has been done generally seems to have been somewhat superficial.

The aim of this research was to explore causes of initial development and relapses (subsequent episodes) of AN from the perspective of those that have experienced it. The three main objectives of this research were to:

1. Explore causes for anorexia nervosa through the participants’ own experiences and perspectives;

2. Explore unique causes for relapse, or subsequent episodes of anorexia nervosa, compared to causes for initial development; and
3. Compare lived experience and perspectives to theoretical models of aetiology.
CHAPTER THREE: METHOD

The focus of this chapter is to provide a detailed overview of the methods of this study. The research design is composed of qualitative methodology to collect and interpret the data. Qualitative methods provided comprehensive understandings of participants’ experiences through semi-structured interviews and allowed comparison between participants who have experienced anorexia nervosa. Within this chapter, the rationale for using qualitative methods as the overall research design is described. The design and implementation of the initial and follow-up interviews is outlined followed by the recruitment procedures and an outline of participants is described. Ethical considerations are then outlined and to conclude, the procedure and reasoning for data analysis is provided.

Qualitative research design

Qualitative methods were employed in this study as they are well-suited to the collection regarding the participants’ subjective experiences and their perception of these experiences (Merriam, 2002). The semi-structured interviews provided a means to gather a depth of information around a specific phenomenon, but with the flexibility to make the process idiographic and responsive to the participants (Patton, 2002). This supported the purpose of this research by allowing perceptions of people who have experienced anorexia nervosa, specifically relating to the views of aetiology and relapse, to be explored in depth. In this context, qualitative methodology was also useful in providing an open structure by which to investigate and develop understanding of the perceptions of the initial and subsequent causes of anorexia nervosa where little is currently known. Hence, it supports an exploratory, theory-building structure for collecting data consistent with the research aims (Patton, 2002). In addition, qualitative methodology allows the selection of a small range of participants to provide a range of perspectives and experiences on the phenomena investigated. The small sample provides limitations as it cannot be reliably representative of the general population; however, findings are relevant from the depth of information provided and the insight in complex subjective understandings (Merriam, 2002). The participants in this research had a breadth of demographic variables, including age, gender, and age at onset.
Participants

**Recruitment**

The participants were recruited through a variety of means. One method of promotion for this research was through the media, including articles in local free newspapers, and in the Waikato Times. Additionally, a post was made to the researcher’s Facebook page, and a public Facebook event was created and promoted, with information about the research made accessible to all Facebook users. Posters were produced and placed in public places around the University of Waikato, in Adult Mental Health reception in Hamilton, and the student health centre at Wintec in Hamilton (Appendix A).

People who enquired about participating either by phone or email, were provided additional information (see Appendix B). This sheet outlined the purpose of the research, the focus and structure of the study, what the selection criteria were, issues of confidentiality, information about the researcher and supervisors, and that the project had gained ethics approval. Those that did not qualify were respectfully declined with the reasons why outlined, and offered a copy of the research once completed. Participants were required to meet the following to be able to take part: be over the age of 16, not currently receiving psychological treatment for anorexia nervosa, received a diagnosis for anorexia nervosa from a professional and within the last ten years (extended by a year to accommodate one participant) but not in the last 12 months. The most common reasons for not qualifying were: time since diagnosis greatly exceeding cut-off, or the individual was currently in treatment for an eating disorder. Multiple people enquired from overseas or from the South Island, although they may have qualified they were declined due to the practicalities of including them in face-to-face interviews.

After a person was sent the research specifics and indicated they would like to proceed with participating they were phoned by the researcher to confirm that they qualified for the study. All of the participants that were phoned qualified for participation. During these calls any questions regarding the research or researcher were answered. The options for the location of the interview were also presented which depended on the location of the participant. For participants located in Hamilton, a room at the University of Waikato library, a room in a
psychology practice centre, or the participants’ homes were raised as potential locations. For those in Auckland, a private room in a local community centre, a private residence, or their homes were presented as options. Participant recruitment was ended due to time constraints.

**Participant characteristics**

The participants were eight women, four located in Auckland and four located in Hamilton. Demographic information is provided in the following table and was collected as part of the initial interview, following consent (see Appendix C). The participants’ have been anonymised by providing a pseudonym to protect their identity. Additional information is presented in the timelines of each participant’s history with anorexia nervosa. Verbal consent was given to allow the addition of this material on the basis of this material being pertinent to understanding the diverse experiences of each participant.

**Table 3. Participants’ demographics**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Recruitment Source</th>
<th>Time since diagnosis</th>
<th>Relapse experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natalia</td>
<td>22</td>
<td>Belarusian</td>
<td>Facebook</td>
<td>5 years</td>
<td>Partial, bulimia, restricting</td>
</tr>
<tr>
<td>Colette</td>
<td>20</td>
<td>NZ European</td>
<td>Facebook</td>
<td>2 years</td>
<td>Yes, anorexia</td>
</tr>
<tr>
<td>Eva</td>
<td>23</td>
<td>NZ European</td>
<td>Newspaper</td>
<td>2 years</td>
<td>No</td>
</tr>
<tr>
<td>Kate</td>
<td>22</td>
<td>NZ European</td>
<td>Newspaper</td>
<td>11 years</td>
<td>Partial, restricting</td>
</tr>
<tr>
<td>Maliha</td>
<td>19</td>
<td>Indian</td>
<td>Online</td>
<td>4 years</td>
<td>Partial, restricting</td>
</tr>
<tr>
<td>Kora</td>
<td>27</td>
<td>Māori / NZ</td>
<td>Newspaper</td>
<td>10 years</td>
<td>Yes, anorexia, bulimic features</td>
</tr>
<tr>
<td>Scarlet</td>
<td>17</td>
<td>NZ European</td>
<td>Online</td>
<td>2 years</td>
<td>Yes, anorexia</td>
</tr>
<tr>
<td>Anabelle</td>
<td>23</td>
<td>NZ European</td>
<td>Online</td>
<td>7 years</td>
<td>Yes, anorexia</td>
</tr>
</tbody>
</table>
As indicated, the participants were aged between 17 to 27 years. The majority of participants identified as New Zealand European, one as Maori and New Zealand European, one as Indian, and one as Belarusian (from Belarus). The mean time since diagnosis was 5.34 years. Most of the women had experienced relapses as defined by engaging in abnormal eating patterns (e.g., behaviours consistent with bulimia), or readmission into treatment for an eating disorder and/or hospital. Only one participant reported not relapsing or experiencing prolonged struggles with aspects of an eating disorder (e.g., restrictive eating without significant weight loss).

Data collection measures

Semi-structured interviews

Semi-structured interviews were selected as the method to gather information about the participants’ perceptions as it is well-suited to the exploration of personal opinion and experiences (Patton, 2002). Semi-structured interviewing allows prompting and clarification for answers, especially in regards to sensitive or complicated personal experience. Furthermore, the variety in educational, cultural, and other participant characteristics meant that the semi-structured interview allowed flexibility in the way in which questions were asked, overcoming the rigidity of a structured interview. This flexibility also allowed changes to questions and agenda depending on what was salient to the participant (Patton, 2002).

During this research an interview guide was used which outlined general areas to be covered and standard questions that could be used. A flexible, conversational style was employed so that the questions were tailored to the individual and topic areas could be covered in a manner which permitted variation in the exploration of perceptions. One limitation that can arise from the flexibility in this approach is that questions become too individualised and there is little similarity and standardisation between participants. Throughout this study the interview guide provided structure and consistency in the topics covered across participants. In this regard, the follow-up interviews (to be described) provided a forum for re-visiting any areas not consistently canvassed.
Interviews were conducted face-to-face and provided a safe, trusting environment which encouraged more open discussion of difficult and sensitive topics. Conducting the interviews in person allowed all topics to be covered with an awareness of how well each participant understood each question as well as how they were attending (e.g., whether a break was needed). This ensured greater consistency across participants in how they interpreted and responded to questions, in comparison to other methods which could have been employed such as written submission of answers.

**Initial interviews**

The initial interviews were conducted with the aim of covering the following topic areas:

1. How the participant perceived the development of their condition of anorexia nervosa. This included understanding how participant’s viewed the beginning of their problems.
2. The subjective conceptualisation and understanding each participant had of the causes of their anorexia nervosa.
3. Perspectives on what drove or motivated the development of their anorexia nervosa.
4. Participant’s subjective definition of anorexia nervosa. This included how they distinguished anorexia nervosa experiences from other mental or eating issues, for example, dieting.
5. The impact of any salient external factors that may have influenced the participant’s perspectives on the causes of their anorexia nervosa, for example, treatment experiences.
6. The perceptions of the development of any relapses experienced after their primary episode of anorexia nervosa.
7. Understandings of the causal factors involved in relapses. This included reflection on the similarities and differences between the causes of subsequent episodes in comparison to the first (or in general between episodes).
8. Any additional information or reflection relevant to the topic of causal factors.
The interviews with participants were conducted in participants’ homes for five of the eight participants, in a private room on the University of Waikato campus for two of the participants, and in a private room of a community centre for one participant. All participants attended the meetings alone; however, other family members were present in the homes of two of the participants during their interviews but did not interpose. The interviews began with introductions where developing rapport was emphasised and to address any residual questions or concerns they had regarding their part in the study. The participant information (see Appendix B) was discussed with a focus on the limits of confidentiality, the ability for them to stop or withdraw at any point, the process of anonymisation, and the feedback process in the second follow-up interview. Each participant was then asked if they were willing to also be audio-recorded via a Dictaphone for the purpose of transcribing their responses verbatim to preserve the accuracy and integrity of the interview. They were informed that they could request copies of these at the second interview. Provided the participant was happy with these processes, the consent form was signed, and a copy given to them along with the information sheet (Appendix B and C). After the consent form was signed demographics information was collected (see Appendix D).

The interview guide was used as a prompt to cover key topic areas. It was used in a flexible manner to allow variation in response to the participants’ perspectives on each topic area. Flexibility was especially important to allow exploration of additional relevant details, and for adapting questions to varying relapse experiences. Open questions were used primarily to allow participants to reply freely about their experiences without being guided. Closed questions were used occasionally, typically to clarify information or understanding of explanations given. Prompting and summarising responses were used throughout the interview to elicit further information, link additional questions to earlier experiences described, and to further check understanding. In three of the interviews, participants were interrupted by external events, such as the phone ringing, and in these cases small prompts were given to remind them of their responses prior to being interrupted.

The interviews ranged in length from 40 minutes to 1 hour and 30 minutes duration. At the end of the interviews, participants were offered the opportunity to add anything they perceived to be relevant to the topic but had not been covered.
At the close of the interview, an approximate timeframe was provided for when the follow-up interview would take place. As a gesture of appreciation, participants were given a $20 gift card at the conclusion of the interview.

**Follow-up interviews**

Initial interviews were transcribed verbatim. Following preliminary data analysis, main themes under the general areas of ‘causes’, ‘relapse’, and ‘features of anorexia nervosa’ were extracted. At each follow-up interview the participant’s individual themes were shared and they were asked to comment on the accuracy of the themes in terms of describing their personal experience. Participants were also asked to rate the themes which they perceived were most important for them in each category, and to also rate any which were of little or least importance.

As well as reviewing the preliminary data analysis, participants were asked any missing or supplementary questions not covered in the initial interview. These were questions that had become relevant during an interview for another, typically later, participant. Adding them to the follow-up interviews ensured greater continuity across participants and allowed discussion of new topics found to be relevant to one, to be shared with other participants.

During the follow-up interview, participants were asked if they would like to add, remove, or alter anything from the initial interview. They were asked if they would like a copy of the themes shared, and also offered a copy of the thesis once completed. Participants were queried as to whether they had struggled with managing their eating disorder following the initial interview. This was done to check whether discussing the topic again might cause further difficulties as protecting participants’ safety was treated as paramount throughout the study. All participants confirmed that they did not perceive participation as having had a negative effect on their ability to manage their eating following the initial interview.

**Data Analysis**

Interpretive Phenomenological Analysis (IPA) was used for data analysis. IPA focuses on examining people’s lived experience and how they make sense of that experience (Eatough & Smith, 2008). IPA is a type of phenomenological method which assumes the impossibility of having direct understanding of
participant’s lived experiences. This method also acknowledges that the ‘essence’ of phenomenon are always hermeneutically experienced, and that the ‘facts’ of that experience must be expressed through language which is invariably interpretive (Giorgi & Giorgi, 2008). IPA is interpretive whereby the findings rely on interpretation of the researcher; it is phenomenological in that it aims to represent the participant’s perspective of their world (Willig, 2008). IPA is an idiographic interpretative process where detailed analysis of individual experiences occurs prior to collective comparison. Furthermore, it is an inductive method where interpretations and themes are derived from the data, as opposed to being directed by existing models or conceptualizations (Eatough & Smith, 2008). There were multiple stages in using IPA to interpret the data, following the guidelines by Willig (2008):

**Individual transcripts**

1. The interviews were transcribed verbatim. These were read and re-read while marking initial thoughts and reflections in response to the each transcript. This allowed familiarisation with the content and preliminary reflection. The content of these notes were generally summary statements describing key concepts of a section of a transcript.

2. Once familiarised with a transcript, each section of text was reviewed and key themes or concepts which represent the ‘essence’ or quality of the text were noted. For example, themes such as ‘addiction’, ‘self-control’ and ‘power’ might be apparent in certain descriptions.

3. The themes were then listed and grouped as relating to perceived causes of anorexia nervosa, relating to the experiences and perspectives on relapse in AN, and relating to the experience or features of AN itself. This preliminary analysis was the material shared with each participant at the follow-up interviews.

4. Once themes were reviewed with participants, ranked with importance and reviewed for relevance, they were examined in relation to one another to create a structure. Themes for each transcript were then grouped into clusters based on sharing a common meaning or principle. Some clusters were also hierarchical where they could be described as linking to a key theme but not necessarily concerning the same topic. For example, themes
such as ‘long term health’, ‘vulnerability to relapse’, and ‘hopelessness’, could form a cluster ‘afraid of my future’ (quote) or ‘future’ (descriptive).

5. Feedback received from participants on the most important themes was used in reviewing and refining clusters and themes described by the clusters. Those themes ranked as being more integral to participant’s perspectives and understanding were prioritised when considering clusters.

6. Some themes identified in the preliminary stage were excluded from the final interpretation. Primarily, exclusions for individual transcripts were based on participant feedback, whereby if a participant deemed a theme as not being relevant, it was removed.

7. Finally, a summary table for each transcript was produced outlining the specific clusters, corresponding subthemes, and related quotes or extracts.

Integration of cases

8. To integrate the cases, a systematic process was used where the summary table of the first participant was used as a framework for integrating each subsequent transcript. The second participant’s themes were compared to the first’s and integrated where similar clusters had emerged extending each existing cluster. Where a cluster appeared to represent a unique concept, this was added to the integrated list. This process was repeated for all participants in order of initial interview until a complete integrated list of master clusters and themes was produced.

Ethical considerations

A research proposal and human ethics application were approved by the University of Waikato Psychology Research and Ethics Committee. Ethical considerations considered in planning and during the research include:

1. Informed consent: Participants were provided clear information about what the research was about, the purpose of the interviews and what their participation included, the people and university involved in the project, how their anonymity would be protected, confidentiality and limits of this in cases of risk of harm to self or others (Appendix B). Participants were also given information on the contact details of the ethics committee and were informed that they could withdraw at any time (Appendix C).
Participants were given the opportunity to ask questions about the possible risks or benefits throughout the study from the initial phone call.

2. **Risk and safety:** Potential negative effects of participating were investigated at the start of the initial interview. Participants who rated their current difficulty for managing their eating disorder at 8 or above (out of 10) could be excluded given the potential negative impacts of discussing the reasons why they developed the disorder. This was also the case if they themselves indicated that they thought participating would have a negative impact on them. In this instance the procedure was developed to refer these people to services or support, and for the researcher to review the options with a supervisor. No participant presented with these ratings.

   After completing the initial interview every participant was given information about possible sources of support if they needed additional support for their eating disorder, in general, or following participation (Appendix E). Participant wellbeing was also reviewed in the follow-up interviews.

3. **Anonymity and confidentiality:** The anonymity of participants was ensured by giving pseudonyms to describe each participant. Potentially identifying information was removed. However, verbal consent was sought and given to include each participants’ timeline (Appendices F to M). The costs and benefits of this was outlined and discussed with each person emphasising that this more specific information could increase possible identification, especially for those who had extensive histories with anorexia nervosa treatment.

   Confidentiality was discussed prior to consent and presented in the information sheet, affirming that interviews would be confidential between the participant, researcher and supervisors. However, it also indicated that confidentiality could be broken after consultation with supervisors, if a risk of harm to self or others was expressed and action needed to be taken to protect people’s safety.

4. **Use of results and conclusions:** Participants were offered a copy of their preliminary themes, transcript, and an electronic copy of the thesis once completed. Participants were informed during the initial interview about
how their transcripts would be used and that this would involve the publishing of sections of their quotes in the research results.

**Data Integrity**

Qualitative research and interpretation can be influenced by subjective bias of the interpreter and research process (Merriam, 2002). In this case, the internal validity, or capacity of the findings to accurately reflect participants’ meaning, can be varied. Additionally, dependability of the data collection and interpretation processes was also considered to control additional factors which could compromise the accuracy of the findings (Merriam, 2002). The following processes were employed to manage the integrity of the findings:

1. **Professional review** (Merriam, 2002): The first two interviews completed were reviewed with supervisors to evaluate the quality of the questions asked and review the structure of the interviews. This was done to maintain the integrity of key interview aspects such as having open-ended questions, remaining on topic, and clarifying concepts without leading.

2. **Quality recording**: Transcribing the interviews verbatim. When a particular phrase or word was distorted the recording would be replayed until such time as the meaning could be ascertained.

3. **Reducing early interpretation bias**: Each of the transcripts was read first, without analysis, then re-read while proceeding to analysis the data. These processes ensured that the interviews were reflected on more than once and reviewed for accuracy by the researcher following initial impressions.

4. **Participant feedback** (Merriam, 2002): Reviewing the key themes extracted from each participant’s initial interview with them in the second interview allowed for their input on their perceived validity of the data in describing their experiences. This feedback on the accuracy of themes allowed them to be reviewed again if certain aspects were not supported.

5. **Evaluating alternatives** (Patton, 2002): Rival explanations were actively and systematically sought with the data to test possible biases in the development of themes. This involved inductively searching for alternative ways of organising the data. It also involved assessing other possible explanations and evaluating whether they were a better fit for the data.
The ability of the findings to be generalised to a wider population of women who have experienced anorexia nervosa is limited given the focus of this study on understanding in-depth perceptions and experiences of cause and relapse in a small sample. Despite this context-bound extrapolations or working hypotheses are made in relation to the findings (Merriam, 2002). The ability of the reader to assess transferability to other cases is attempted in this study by providing rich detail and description of participants and methodology. This allows the reader adequate information to evaluate how similar the current participants are to other people. In addition, variation in the sample was increased through variable participant ethnicity, time since diagnosis, treatment experiences, and relapse experiences which provides a greater range of people for which the findings can be evaluated (Merriam, 2002).
CHAPTER FOUR: FINDINGS

The interviews with the women yielded results within three domains: definitions, initial causes, and subsequent causes of relapse. These three sections represent perceptions and experiences of anorexia nervosa. Within each section, overarching themes will be presented with constituent subthemes and each will be supported by evidence from participants’ interviews. Themes are presented as separate from one-another for ease of comparison but it should be noted that they are inherently linked as they do not occur in isolation for each participant.

Section 1: Defining anorexia nervosa

This section focuses on the participants’ perceptions of anorexia nervosa and how they personally define anorexia. These findings direct how the subsequent sections are interpreted based on the participants’ idiographic definitions of anorexia, rather than assuming a clinical definition. For example, when discussing the perceived causes, participants are likely to be answering in response to their concept of anorexia, as opposed to a clinical definition. This section will present individual participants’ definitions first, followed by themes surrounding the defining and distinguishing features of anorexia.

Individual definitions

All participants were asked how they would define anorexia. This section presents each participant’s definition of anorexia and their comments about different features of anorexia which they thought were relevant to their experience. Amalgamated themes will be presented in the following part of this section. Individual definitions are provided here to give context to the participant’s contribution to this study and consideration for how their perception of anorexia itself may impact their perception of the aetiology and cause of relapse.

Natalia

*For me it’s: your whole focus becomes your body, that’s the only thing you’re going to focus on, and it becomes your weight. It doesn’t even matter how you look anymore; it’s weight. And you become so focused on it that food is the only thing that matters except you can’t eat it... I really*
struggle to define it in clinical terms because I mean I know the clinical definition of it yet, when you’re actually going through it, it’s a completely different experience... tunnel vision, it’s all you can think about. Nothing else matters.

Natalia defines her experience of anorexia in terms of her obsession with not eating food and focus on restriction above everything else in her life. She discusses her drive for thinness through controlling her weight. Natalia’s definition is interesting as it indicates an early concern with her appearance and the way she looked but that this became less significant as the anorexia developed. Her definition relates to the clinical criterion of undue influence of body shape and weight on self-evaluation as defined by the DSM-5.

Collette

I could define an eating disorder but people perceive anorexia as being about body image and that’s where it’s really hard to – like I haven’t technically had anorexia if you think it’s about the media. But I have. I’ve been really sick from it too. But, I guess an eating disorder is where you interpret your emotions through your food and it either makes you eat or not eat but you, you know, you’re interpreting if you feel bad about yourself or whatever, you’re interpreting that through food and you’re using food to control that side of your life, or to deal with parts of your life. And I guess anorexia is that but that you would – it’s the restrictive side of that.

Collette defines anorexia as the control of her emotions through managing her food intake and aspects of her body. In this sense, control of food and weight created certain feelings and/or alleviated others causing distress and was maintained through this. Collette described symbolic use of restriction to manage her life and specifically mentioned her perception that others misperceive anorexia as originating from a superficial drive for thinness related to the media and attractiveness. Weight was not relevant to her anorexia at the start becoming more meaningful after treatment but still in relation to managing her emotions.

When I relapsed I didn’t want to gain weight, so then I guess to some extent it was about [body image] but not when I got sick. But it wasn’t really [about body image]. I didn’t want to gain weight but why not? It
was still the emotional side; it was still dealing with life; it was still feeling bad about myself and self-image and self-esteem and perfectionism, and all that sort of thing.

Collette’s definition is difficult to compare to the DSM-5 or IV criterion; however, there are aspects of persistent restriction as a result of her trying to manage her feelings through food restriction. During relapse her body and weight became more important in determining self-evaluation but more in relation to control and emotional management than the insinuated attractiveness indicated in the clinical definition.

Eva

A struggle every day. Yeah. That’s not really a [definition] – I don’t know. It’s just a massive struggle: every single day, everything you do. All your daily activities are a struggle when they all just – your whole brain is just consumed all the time with it. It takes up all of your time. It’s very tiring. [Consumed with] constant thoughts about food and eating and weight and control and [pause] so exhausting to be thinking about it all the time.

Eva defines anorexia in terms of the obsession and possession of restriction over her life. She emphasises the struggle of a constant focus and drive to control her eating, food, and weight and how this reduces her ability to do anything else. Eva’s definition revolves around being trapped in a cycle of control: in control of AN, but simultaneously controlled by control. Tasks and responsibilities external to this cycle become a source of fatigue and difficulty. Eva’s definition is difficult to relate to clinical definitions such as the DSM-5 as this criteria relate to issues of: restriction behaviour; weight gain; disturbances in perception of weight or shape; lack of insight; and self-evaluation. Whereas Eva’s definition relates most strongly to concepts of preoccupation on food and weight with associated restrictive behaviour.

Kate

When you kind of buy into the obsessive controlling pattern of it and it’s like this black box and once you open the door and step inside it’s really hard to get back out of it. And I think that metaphor was quite a good way of understanding it for me. And it’s giving into that obsession and control and stuff [laughs] ... I think I would define it as an obsession. And in
relation to food and body image I would probably describe it as people taking society’s norms to extremes… [Food is] a real daily function but then it’s also given so much importance in that a lot of people are obsessed with food. Like with trying to be healthy. And then it’s also given so much value with like extreme fine dining. Like there’s so much meaning that you can attach to food. Yeah so it’s one of those things that you can easily transfer a different kind of meaning to it.

Kate’s definition of anorexia has two key components. Firstly she suggests the need to be obsessive with an associated desire to control the focus of the obsession. The second part of her definition refers to anorexia as being a focus on food in an extreme application of existing meanings and value given to food by other groups in society. She identifies a difference between the socially unacceptable degree of obsession and control directed toward food in anorexia, within the context of an acceptable level of food obsession within today’s society. As with Eva’s definition, Kate’s is also difficult to relate to clinical definitions of AN.

Maliha

It’s like your best friend but your worst enemy. Like [pause] it makes you feel like it’s helping you get to a better place or helping you with something. It makes you feel like ‘I’m here to help’ but it’s really not. And you don’t realise that. And it just becomes so much of you, it just takes over you that you just don’t even realise it.

Maliha’s definition suggests anorexia is something which allows you to manage and cope with your life. She perceived it as helping her, like a friend, but that it ultimately burdened her. Furthermore, Maliha perceived herself ‘becoming’ anorexia: she was her anorexia and that was all she was until she could separate herself from it. Maliha’s definition aligns quite closely to the clinical criterion in terms of disproportionate significance of weight, body, and eating on the person’s self-concept or self-worth.

Kora

For me it was like an obsession with food but the not eating it. So the obsession with not eating food and severely starving myself and the over-exercising. I knew – I know that when you get to a certain weight your
body, like the organs and that, start to shut down and I think maybe that’s what I was striving for. It never happened but I know I was kind of bordering it because my periods stopped and I think if I had have gotten further then that could have happened. But I don’t actually know what the actual definition of anorexia is because I think every person is different. But I think it’s actually a psychological thing first and it’s the physical that is the effects or the consequence of it. Because it’s all in the mind and your thoughts and the way you think and that effects the way your body is – the physical.

Kora’s definition of anorexia relates to the obsession with not eating food as well as manipulating other aspects of net energy. She emphasised the physical features of anorexia occurring as a consequence of her thoughts and emotions, rather than necessarily being the goal of her thoughts and emotions. Kora suggests her preoccupation with the role of anorexia in destroying herself and providing the potential for dying.

Kora’s definition acknowledges restrictive behaviour but defines AN based on the psychological processes, rather than behavioural outcomes. Criteria suggesting resistance to weight gain would again occur as a consequence of this focus on food according, rather than resistance to weight. The most consistent with the DSM-5 criteria seems the lack of recognition of the seriousness, as seriousness is desired and thus unlikely to be concerning.

Scarlet

Sometimes it’s kind of like a friend almost but then it just kind of – I think it’s like a friend but then when you’re really close with a friend then they start to tell you things and you’re like, ‘well, they’re telling me that because they are my friend and they care’, so you start listening to that. And so that’s why it becomes more believable because you’re like, ‘well, they care or like, they want to tell me’. So it’s kinda like that... It’s like well, if I listen to this then everything will be better, like all my problems will disappear, and, cause. I don’t know. Even though you know they’re not going to it’s kind of like, ‘well if they don’t then at least I have – at least I’m thin or at least I have this’, kind of thing. So it’s like: it doesn’t matter either way.
Scarlet’s definition is similar to Maliha’s as she mentions that anorexia is like a friend who provides advice, guidance, and helps her cope more effectively with life. Anorexia is functional by this definition, providing options to problems and suggesting a solution. In addition, Scarlet suggests the pursuit of thinness as a solution to problems or distress in her life. Interestingly, Scarlet acknowledges that the problems will not be resolved through her anorexia but that it is a valued alternative (being thin) that she can obtain even if it is unsuccessful in addressing other problems. Scarlet does suggest a drive and value for thinness as indicated in earlier clinical definitions of anorexia.

**Anabelle**

*I reckon there’s two types. There’s the type of people that do it to look a certain way and there is the type of people that do it to feel a certain way... they can merge in the middle but just depends on what starts it first... It is an illness in itself as well. I think it’s like a cancer of the mind. You start off with one negative thought and it multiples and multiples... Unless you target that main cell it’s still going to keep coming and that’s why I think it’s like – it’s like a negative thing that just multiples and encompasses all of you. Until there’s no more of you left. And the longer you have it the less of you there’s ever going to be as well because you kind of lose your direction in where you want to go.*

Anabelle’s definition describes an obsession with controlling eating and other features (e.g., weight), becoming more severe during the course of anorexia. She describes this obsession as becoming all-encompassing, suggesting an identity defined by anorexia. The drive for these obsessions is distinguished into two main types: emotional management, or appearance management. Thus, her definition acknowledges some of the clinical criteria relating to weight and body being important to self-evaluation for those that want to look a certain way.

**Summary**

The participants emphasised varying aspects of anorexia as being important for defining the experience. There were some similarities across participants especially relating to the notion of obsessive or excessive focus on aspects of eating, food, weight and/or body. The idea of being consumed by anorexia and unable to develop a separate sense of self was common. Participants
emphasised the role of anorexia in providing certain feelings. They also discussed a drive for thinness, typically separate from drive for attractiveness. There were limited similarities to DSM-5 or IV definitions of AN possibly due to the emphasis of these definitions on restrictive behaviour during anorexia and behaviour or attitudes toward weight gain. Moreover, even the criterion relating to self-concept only encompasses body and weight and specifies self-evaluation suggesting negative self-evaluation in relation to larger body size or weight. However, participants suggested the impact of self-evaluation as being mediated by other issues such as strong negative emotions or distress. Anorexia may be positive for participants through the meaning attached to restriction (e.g. control) where the effects of restriction are evaluated as achievement toward valued goal(s) (e.g., signs of control). The value of this reward is likely mediated by strong negative emotions in most other areas of life.

**Collective definitions**

This set of themes relates to how participants described their experience with anorexia and what distinguished it from other experiences in their life. These themes will include both themes from their individual definitions and additional evidence provided during their account of their experience with anorexia. Participants varied with the concepts which they considered important; however, topics individual participants considered significant will be indicated. Figure 11 outlines the interaction of the themes which participants described.

**Fears**

This theme describes participants’ fears during their anorexia and what they actively worked to reduce, avoid, resist and change. These distinguish anorexia as they underlie many of the participants’ experiences with anorexia and predict their reactions to others trying to affect change in their behaviour.

**Losing control**

Fear of losing control was an important feature of anorexia, as well as a prominent theme of perceived causes of anorexia for the initial episode and relapses. Participants described that once the feeling of control was developed they feared losing it. This created reluctance and overt resistance to gaining weight or stopping their anorexic behaviours (e.g., calorie restriction) due to
seemingly losing this control. Participants mentioned both the fear of losing control of themselves and fear of others taking control away from them.

For example, Kate considered her fear of losing control as significant during her anorexia and describes both her fear of letting others influence her
(relinquishing some control over herself) and her fear of losing control of her eating.

Kate: It started off there being a real fear of – like with the resistance to people trying to make me eat – there was the fear – a fear behind their gift kind of thing. Like, ‘if I take this, what does that mean? What’s coming with it?’ And in the early stage there would have been the fear that, ‘oh, I had such a big stomach when I was younger and one or two chocolate biscuits is just going to bring it straight back’. So I guess there’s the fear in trusting what other people say a little bit more and not buying into my own extreme fears.

Other participants also illustrated the fear of losing control when describing violating some of their rigid eating habits and the distress they experienced from this. For example, Kora described being significantly distressed after breaking her restrictive eating patterns after years of anorexia to enjoy dessert at her birthday party. Kora emphasised the significance of her fear of losing control throughout her anorexia as it prevented her from breaking her dietary control and restriction.

Kora: When I turned 21 I went out for a meal and I thought maybe I do deserve to eat a meal. It’s my 21st and I deserve to celebrate. So I had some um [pause] it was like a vegetable stack and I thought, ‘yeah, that’s ok because it’s just vegetables’. And then I had, I actually had an ice cream for my dessert and it was a lot of hesitation, like, my sister’s like, ‘oh, do you want an ice cream? You should have a dessert’ and I was thinking about it throughout the whole meal and weighing it up, whether I should have this ice cream or not and I just thought, ‘Ok, maybe I should just have it’, so I did. And I felt ok at the time, then I thought it was yum. I hadn’t had ice cream in like 5 years and it was yum [laughs]. And then I got home and I just lost the plot. Like, I just thought, ‘I cannot believe I allowed myself to eat that ice cream! It’s just so ridiculous’.

Being seen as fat
Fear of being fat or being perceived as fat by others was relevant. This was not exclusively linked to attractiveness or appearance but was also related to alternate meanings attached to food. For example, Anabelle described how she
was scared during her initial development of anorexia to be weighed at school for fear that they ‘discover’ how ‘big’ she was.

Anabelle: They were buying new chairs at school and everyone had to get weighed to check the average weight to see what it had to hold and I was like, ‘Oh my goodness they are going to know how big I am – ah!’.

The role of comments from others about weight and shape were relevant as they impacted participant’s perception of themselves at the time. Natalia described the role that comments from others had on her anorexia, indicating their magnification and heightened significance. Conversely, Anabelle described the negative impact of other people’s comments on the amount she ate or her increases in weight during her recovery.

Natalia: At first some people might go, ‘oh, you look really great; you’ve lost weight’ because, you know, when you’re on a diet, just on a normal [diet], for normal people, they’re like, ‘oh yeah, I do look pretty good I’ve lost weight’. But when you’re actually in a – an anorexic mindset, it’s completely different. When people tell you you look great you’re like, ‘I do, so I have to lose another 10 kilos’... it’s 100 times magnified.

Anabelle: You’d never go up to anyone else in the public and go, ‘you’ve gained: that’s good’. No, you wouldn’t, so don’t treat us any different. If you wouldn’t like someone to come up to you and say you’ve gained without an ED [eating disorder] don’t come up to someone with it and say it. Or comment on how much you’re eating – that’s the worst.

Being normal
A feature of anorexia described by participants was the perception that it made them different from peers and unique. In this way, anorexia was seen as something they had worked hard to achieve and even if it was not respected by others, it was something they valued in distinguishing them from others. There was a fear of losing this, especially in recovery, for example, Kate described having to accept being normal when deciding whether to live and eat after she was hospitalised for anorexia.

Kate: I guess it was like really putting the choice onto me. Like, ‘do you want to eat and live, or do you – are you almost going to die?’... One of
the things that helped me come out of that was all the kids in my class wrote me a letter in hospital. And I was just like, I really just wanted to be back there with them. And, I guess deciding that being normal wasn’t too bad almost.

Behaviours

This theme describes behaviours attributed to anorexia and the perceived differentiating characteristics from other similar patterns or objectives (e.g., separating AN from people who ‘diet’ without AN). In this theme behaviours do not exclusively relate to the control of consumption of calories. Patterns of controlling net energy include patterns of exercise and manipulating the body’s natural energy expenditure. In addition to these direct behaviours, additional patterns or rules which moderate these factors are included, for example, food avoidance. Markers of anorexia will be used to describe features which were important to the individual (e.g., weight, eating, size, shape, skeletal frame, etc).

Progressive

This describes the behaviour of participants which supports losing more and more weight over time, thus working to become more anorexic. Although the behaviour is directed toward becoming progressively worse, participants did not necessarily have the awareness or intention to get worse. Instead, participants were more likely to suggest that their behaviour was directed to maintain their anorexic behaviours (e.g., repeated patterns around eating) or maintain the progression of their anorexia for the markers significant to each individual (e.g., degree of control, weight, shape, amount eaten, exercise, type of food eaten). Therefore, anorexia is something that individuals did not necessarily want to escape at the time, or it suggests there are aspects of it which are desired.

Natalia described her perception that anorexia was different from other mental disorders because of the way that people work towards it, rather than away from it and lack awareness that something is wrong.

Natalia: With depression you want to get out, whereas with an eating disorder you want to stay in... you don’t want to lose control over it, whereas with depression – because I’ve been there again so I can say that you – you’re in it [but] you want to get out of it because it hurts. And you
want to leave but you can’t. And you know it’s not right. That’s the
difference.

Collette indicated that she did not consciously know or think that she
wanted to get worse but that she wanted to take more control and anorexia was
her means of doing that.

Collette: I didn’t want to get sick. I don’t think anybody wants to, but I
guess – I guess I did [pause] like I wanted to take control [of my life].

For many a key feature of anorexia involved trying to obtain successively
extreme goals related to key markers. For example, Maliha described making
successive weight goals and that she was never satisfied after meeting her target
weights. Other participants described becoming progressively more restrictive
over their food or other markers of their anorexia.

Maliha: I couldn’t gain weight: that was like a big no. No, you can’t gain
weight. Maintaining was okay but still like no. You had to lose weight. You
had to lose weight. And, you know, you’d get to a point and you’d be like,
‘okay, 45 kg’s, okay’, you’d get there and be like, ‘yeah, what about 43?
What about 41? What about -’ and you just keep going down and down
and down.

Participants were asked what they considered distinguished anorexia from
a ‘normal’ non-anorexic diet. One aspect consistently mentioned was the
difference in goals and end outcomes compared with AN. For example, Eva
illustrates the difference between her anorexia and a relative who was on a diet;
Scarlet describes how diets generally have an end point compared to anorexia
which generally does not.

Eva: She would never take it too far. She has a goal weight and once she
hits that goal weight she would never make that goal weight smaller like I
would. My goal weight was 38 [kilograms] ... I’m sure [her] goal will be a
lot more sensible.

Scarlet: I think the difference is [pause] a diet more ends because most
people who diet they just fall off but with anorexia it just gets worse.
**Extreme tools or techniques to manage eating and/or weight**

When describing anorexia, participants noted that it was characterised by extreme behaviours, similar to Kate’s individual definition of anorexia. Participants often did not think that their behaviour was extreme or unnecessary at the time but developed this insight after recovery. When discussing the difference from non-anorexic dieting, anorexia was characterised as an extreme version of normal dieting behaviours such as eliminating all starches and fats from your diet, rather than just reducing them.

*Scarlet: It’s more insane of a diet [laughs]. It’s like more strict and stuff… on a diet you’d just take out chocolate or the obvious foods. Whereas with anorexia you won’t have bread or something or weird things [pause] but it’s more a range of things, the things that you don’t eat or won’t eat. It’s not just like the fatty foods or the obvious things [it’s more than that].*

This extreme behaviour extended to other aspects of energy intake or expenditure such as exercise and body functions which increase energy use. These behaviours used for their calorie-burning qualities as opposed to being used for comfort or health reasons (e.g., others exercising for physical wellbeing). For example, Maliha sarcastically described some of the extreme behaviours she used to engage in when she was anorexic.

*Maliha: If I’m in class, this might burn more calories: tapping my fingers on the desk. Oh, wow, that’s burning so many more calories. Should I wear a cardigan today? No, I’ll take it off then I’ll be colder and burn more calories. That’s not a diet.*

Similarly, Kora described how she would go without sleep to exercise, despite hardly eating during the day.

*Kora: I was staying up late to exercise as well… I’d be doing sit-ups and doing press-ups and just like running on the spot and standing because it takes more calories to burn to stand so I would hardly sit down and I’d always be on the go.*

Some participants mentioned the use of medication or drugs to manage aspects of their anorexia. For example, Eva mentioned that she used ecstasy for a
period of time as both an appetite suppressant and as it reduced some of the other negative effects of anorexia and being extremely underweight.

_Eva:_ I did have a period where I was using some drugs to help with my energy levels. I was taking ecstasy for a few months, quite a lot of it. Because it, you know, appetite suppression and the fact that I actually had the energy to go out with my friends.

Another strategy used to manage intake was to consume non-nutritious items in an attempt to feel fuller without the associated consumption of calories. Maliha described that at one point in her anorexia she ate grass, plastics, and paper as a means to feel full.

_Maliha:_ Just really bizarre things I would start eating. I remember I was at school one time and I was just eating grass because I was like, ‘grass has no calories, so I can eat grass. I’m really hungry but I can’t eat. But grass has no calories so I’ll just eat grass.’ And then I was like, ‘what else has no calories? Well, paper, I’ll eat paper, and plastic’, and I just started eating really weird things. And people just looking at me like, ‘you can’t do that, that’s really dangerous’. And I was like, ‘no, it’s-it’s, it has no calories! It’s good and I’m full now.’

Maliha also described the significant role online pro-anorexia communities had. She did not see them as causal; instead they were a strong motivating factor contributing to her anorexia being maintained. These communities provided both social support and information on additional techniques for managing her weight and eating.

_Maliha:_ I spent a lot of time on pro-anorexia sites because those really fascinated me. You know, just thought those were really cool, like giving me tips and stuff. And they were just so harmful. And you just have a whole community of people out there and it just eggs you on. It just keeps you going.

It is not uncommon for people in the community without anorexia to seek social reinforcement during diets or to motivate them for weight loss. Pro-anorexia communities and the role of social support for maintaining anorexia is presented in this theme of behaviour as the extent of the behaviour may be
extreme (e.g. how frequently these sites are visited per day), and the extremity of the practices promoted in these communities.

**Compensation**

Participants described the role of compensatory behaviours when they had breached their rigid diet rules or other rigid routines. Compensation was also linked to inflexibility in anorexic behaviours which will be discussed further in the next theme. Compensatory behaviours included both short-term and long-term compensation. Typical short-term compensation revolved around purging food that had been consumed shortly after it had been eaten. Longer term compensatory behaviour included exercising and increasing calorie restriction for a period of time. For example, Collette described developing both short-term purging behaviour and long-term exercising and restricting behaviour during her first relapse with anorexia in response to having to eat food that she did not want to eat during recovery.

*Collette: I would refuse to eat, I’d throw the food away, all that kind of thing. I started purging and then started running away from home and exercising for hours on end and not eating.*

Similarly, Kora described over-exercising when she broke one of her dietary restrictions.

*Kora: I ate that chocolate and I just was like livid with myself. Oh, and around about that time too I was staying up late to exercise as well. And then that night, after I ate that chocolate, I just didn’t sleep at all [because I was exercising].*

**Avoidance**

Avoidance of food or eating-related experiences occurred in situations where the expectation to eat was high, such as social gatherings or avoiding the kitchen when family were there. These activities reduced the temptation and pressure to eat. For example, Eva described social withdrawal, in part because of her fatigue, but also because of the temptation to eat especially when having difficulty keeping her hunger under control.

*Eva: When I went out with my friends, first of all I was just so tired that I could barely do anything. I didn’t have the energy to stand around or even*
talk very much. And then, like the hunger was quite debilitating at times if it got really out of control while I was out, it was quite hard to sometimes hold in – hard not to eat almost because I was so hungry.

Kora also described using her nephew as a distraction from food. This occurred both as a means to avoid the likelihood of eating at home and was associated with exercise.

Kora: When I had my nephew I was going to dedicate my time to him to take my mind off the not eating. And then taking him for walks and stuff. So that was like, ‘oh, I’m just going to take the baby out for a walk’ when really it was more about me than him.

**Enjoying food in other ways**
An alternative to active avoidance of food-related activities was engagement with food and not consuming it. Food was then enjoyed in other ways and served to moderate hunger. Natalia discussed the role of looking at food in shops or on television as another way to satisfy her desire for food without consuming any.

Natalia: I watched food commercials every day, like magic bullet and stuff. You want to look at food and it kind of becomes an escape... because you can’t eat it you [pause] find a new way to experience it, and for me that was looking.

Kora thought her projection of eating onto others was especially important. She discussed how she would give things she would want to eat to her nephew whom she cared for, and would vicariously experience his pleasure eating it without having to have any herself.

Kora: And then as [my nephew] got older and started eating, I kind of put on what I should have been eating on him. So instead of me eating it, I’d make him eat it [laughs].

**Restricting and other behaviours become my normal**
After a pattern of restrictive and other AN behaviours are established they can become automatic. This was especially important for participants who struggled with relapse where an established pattern of anorexia resumed following recovery, partly due to habit. For example, Maliha discussed how when she is
uncertain about how to eat somewhere, she can automatically start restricting in that particular environment.

_Maliha:_ How am I going to sit down and eat here? I don’t know where to eat here. Where do I -? You know. I remember when I was recovering, back in this period here [points to timeline], and I had to go back to school because I’d recovered over the holidays and I had to go back to school. And I was just like, ‘I’m going to have to eat lunch’. And [my therapists were] like, ‘yeah, just pull out your lunch box and eat’. And I’m like, ‘Nooo. There’s going to be people [laughs].’ How do you do that? I don’t know how to do that.

Kate described how her obsession with food and control can develop without awareness, contributing to her relapsing. She also described how the habit of being controlling with food can cause confusion about what is actually normal for her compared with what should be her normal (i.e., ‘ideal’ control around food and eating compared with current norms around control of food).

_Kate:_ When I’m not aware that my thoughts are getting obsessive then I can easily start reacting and start counting the calories of the food or trying obsessively to only eating healthy things or cut certain foods out and stuff.

**Perceptions**

This theme describes patterns of thinking and participants’ perception of their experience with anorexia. It includes both reported thought patterns at the time of onset and perception of the experience gained from hindsight.

**Unaware in the beginning**

Participants often described their lack of awareness that there was a problem during onset. Some indicated that although they may have recognised that their behaviour was not entirely normal they did not see strong reasoning to change what they were doing. Most participants discussed how their anorexia felt reasonable at the time. As indicated in the title, this was mostly significant in the initial episode or early stages where their behaviour was less likely to be challenged by others and when they had not been through recovery.
Although some perceived this as contributing to their disorder (causal factor), others viewed it as just a feature of their disorder at the time (defining factor). However, it may act as both a feature of anorexia and a cause for decline over time. For example, Collette emphasised how she was not aware of her hunger, despite doing more exercise and beginning to restrict intake. She considered this lack of insight contributory as she there was nothing to amend, if there was no perceived problem.

*Collette: I probably started having issues with eating in intermediate school but not realising. And then, um, I stopped getting hungry in high – in my first year of uni because I got really stressed and so, well, I didn’t realise that I was hungry and I was doing a lot more exercise and stuff.*

Maliha and Scarlet both talked about how initial dieting started off as relatively innocuous but later developed into anorexia.

*Maliha: It wasn’t like I was hiding it. It wasn’t like a secret. It wasn’t like I was like, ‘I’m going to do this on my own and I’m going to be really secretive about it’. It wasn’t an eating disorder at first. It was – it was: this is a new diet. It was a diet at first… No, I didn’t call it a diet because I didn’t want people to think it was a diet. I was like ‘it’s a lifestyle change’.*

*Scarlet: I think I started like “dieting” in like, year – end of year 9. And then year 10 I lost weight and then I put it back on and then I, at the end of – I made like a new year’s resolution and I lost like heaps more weight and then I went into hospital [laughs].*

**I am anorexia**

Many participants discussed the way anorexia took over their life and became their full focus and direction (see Preoccupation). A consequence of this preoccupation and importance of anorexia in their life meant that their self-concept became strongly linked with their anorexia. This was often cited as both a feature and a cause for it developing.

*Natalia: When you’re in it, you can’t separate yourself from it.*

*Anabelle: It’s like a negative thing that just multiples and encompasses all of you. Until there’s no more of you left.*
In Collette’s definition of anorexia, she discusses the role of anorexia in managing emotions suggesting that you use anorexia to control how you feel about parts or all of your life.

_**Collette:** I guess an eating disorder is where you interpret your emotions through your food and it either makes you eat or not eat but you, you know, you’re interpreting if you feel bad about yourself or whatever, you’re interpreting that through food and you’re using food to control that side of your life, or to deal with parts of your life._

**Anorexia as a friend**

As featured in a few of the participant’s definitions of anorexia, the experience of it as a friend was important. This theme describes the feeling that anorexia was helping, imitating how a friend would offer advice and guidance. This can then develop into a habit of thinking about events in their lives in relation to aspects of their anorexia, i.e., where the perceived problem-solving aspects of AN are generalised to a range of issues. For example, Maliha described how her anorexia started off like a friend telling her things but later became habitual with her developing a pattern of anorectic thoughts.

_Maliha: It presents itself to you and you’re like, ‘yeah, I like this’ and then it just keeps telling you things and then eventually you hear them so often that you just start thinking that way yourself._

Viewing anorexia as akin to a friend was also important to Scarlet’s conceptualisation of anorexia. She interpreted all her problems as being related to her weight as this was much easier for her to cope with.

_Scarlet: I think because I didn’t have any answer as to why they weren’t replying or they weren’t doing this, so when it gave me an answer I was like, I took it even when it didn’t make sense or wasn’t true. I just wanted an answer… you just kind of tie it all in to that. Because it’s just easier – it’s easier to deal with one thing than each little bit of your life. So, you just tie it in to that and then fix that._

Eva also described AN as being like a friend, and saw herself as more likely to relapse when feeling vulnerable and experiencing difficulties in her life.
Eva: It's like an old friend that comes knocking... ‘I'd like to help you out’ [laugh]. But not really, you're not helping me out at all.

**Inflexible and rigid**

Inflexible and rigid patterns were important, especially in distinguishing AN from other attempts at weight or diet control. Participants were often unwilling to change their behavioural patterns and restrictions. Their goals and dedication to their anorexia frequently surpassed any willingness to be more flexible: anorexia was more important. This inflexibility relates to both patterns of anorexia (e.g., patterns of eating) and future plans related to anorexia (e.g., planned food for the following day).

Natalia: I literally couldn’t have a crumb outside of my meal time. That was the hardest thing for me: I felt so guilty if I had anything little outside of that.

Collette: I started to cycle **every single day**… I had to cycle: I couldn’t handle not doing it... I’d eat less and less and less and then again it became like a control perfectionism type thing so if I’d eaten less the day before, well of course I’d eat less than that; I couldn’t handle more than that or the same amount, or – same amount probably could handle but had to be less than that. Just a little bit.

Eva: With me, my plans could not change. If they changed I was just - I lost it. But if she’s on her diet and something happens that day and she can’t stick to it, she’s okay. She was hav - she was on one of her weird diets the other week and [a relative] died a couple of weeks ago and she had to eat at the hospital and it was a different meal than what she’d planned, her diet plan, and she was relaxed and fine about it. But if that was me, it would have stressed me out for weeks. But she just handled it.

Maliha described how nothing had greater importance than her anorexia and as a result normal events or activities involving food were no longer seen as important, or were sacrificed to maintain anorexia.

Maliha: With anorexia, it’s like, ‘No, I don’t care if it’s a birthday party. I don’t care if it’s a death. I don’t care.’ There’s no excuse. You are 24/7 on a diet, essentially, but you’re 24/7 immersed.
**Preoccupation**

Constant or extremely dominant thoughts about food and control of food (or other markers of anorexia) were common. This preoccupation translated into behaviours to manage or avoiding eating, such as distracting themselves, or spending a long time planning what they would eat as a substitute for the act of eating.

*Maliha:* With anorexia you are 24/7 thinking about food. Even like, in the middle of class you’re thinking about food, at night time when you’re trying to sleep you’re thinking about food. Yeah. You’re just always thinking about food.

Preoccupation and obsession with not eating food was also important in Kora’s and Natalia’s individual definitions of anorexia. Natalia thought it especially significant for her.

*Kora:* For me it was like an obsession with food but the not eating it. So the obsession with not eating food and severely starving myself and the over-exercising.

*Natalia:* Your whole focus becomes your body, that’s the only thing you’re going to focus on.

**Compelling and invested**

Anorexia was difficult to let go of even when they started to become aware of how it was negatively impacting their life or when it no longer provided a sense of satisfaction. There was a sense of investment in anorexia and an associated fear of what might be lost by recovering. In addition, many participants described their perception that they could not escape their anorexia; it was with them constantly and compelled them to continue. For example, this was an important part of Kate’s definition of anorexia along with her concept of anorexia becoming part of her identity.

*Kate:* It’s like this black kind of box and once you open the door and step inside like it’s really hard to get back out of it... when I was gaining that weight again I guess I was quite scared of what things would be like. If I didn’t have that then what would I have? [laughs]. But you kind of realise
that there are other things you can have [laughs]. Or that you don’t need to have something like that.

**Food is aversive**

Another theme was that food and eating often became aversive. Some participants had pre-disposing difficulties with food which are described further in the next Chapter which looks at cause. Others experienced food becoming aversive over time due to their thoughts, beliefs and interpretations of food. Food became something to be feared and associated with painful thoughts, emotions, and sometimes punishing compensatory behaviours. For example, Eva described how eating was unrewarding and became aversive through her partner’s anger when she tried but failed to eat.

*Eva:* I would put it in my mouth and try and chew it and I couldn’t chew it or I couldn’t swallow it. Or it just felt like it was turning to dust. And I just couldn’t do it. And I was trying so hard. Didn’t help that he used to get really angry with me about it when he’d made me food and I couldn’t eat it.

Typically breaches in rules or patterns were associated with very high levels of guilt and regret. Thus, breaches became highly aversive and many described them as not being worth it. For example, Kate described her struggle to break her patterns and the aversion this caused.

*Kate:* It just got to the point like why – I’m not getting any satisfaction about eating this. I’m just so stressed out about eating it. Why should I do it? Like I don’t want to try and do it. It’s not worth it for me to try so hard to eat this because it just feels so terrible.

**Interventions**

This theme describes how participants reacted to and perceived various interventions from others during the onset of AN and beyond. Both active attempts at intervention and indirect interactions with others are included. Interventions are included in response to anorexia rather than an integral part of the experience as in order for the following themes to be applicable, anorexia had to already be present (i.e. preceding intervention).
Others don’t understand

Participants commonly stated that they believed other people did not understand what anorexia was like unless they had experienced it. Anorexia was something that was difficult to explain and dissimilar to other experiences, thus others did not or could not understand them. This belief comprised of most people, including both friends and family, and professionals such as therapists.

Natalia: Unless I think, somebody’s really been through it they don’t know the exact mind-set that you go into.

Scarlet: Because they, [the people that have not had anorexia], they don’t really understand I guess. But someone who does, they know what they’re talking about. And also like, if they’re recovered and stuff they know the difference between them and all that other stuff.

When discussing what others had suggested to them as the cause of their anorexia, lack of understanding was often raised as an issue for participants. For example, Scarlet perceived that her treating professionals did not really know what anorexia was or how it manifested itself with her because they suggested things which she saw as being irrelevant or incorrect.

Scarlet: I feel like they don’t really know what they’re talking about [at my old treatment centre] [laughs]. So it’s kind of like, well, so it’s kind of pointless. Because they’d say, ‘oh, you could do this’ but then it wouldn’t make a difference. And they’d say ‘oh, like this contributed’ and you’re like ‘well, not really actually’.

Anabelle described how people who judged how well she was doing in terms of recovery by her appearance, showed that they did not understand her situation. Comments about what she ate or how much she ate were specific aggravations which indicated to her that others did not comprehend what it is like to have AN. However, she did admit that these might be difficulties that other people with anorexia might not find distressing or vexatious.

Anabelle: When people say, ‘oh, you’re looking so good!’ and I’m like, ‘I feel like crap!! But thanks for that’. Because it’s too much based on the way you look. It’s like, you don’t go up to someone who’s got cancer and say ‘oh, you’re looking so good so your cancer must be gone!’ . No, it’s
probably still there but you don’t – you’d never go up to anyone else in the public and go, ‘you’ve gained, that’s good’. No, you wouldn’t, so don’t treat us any different. If you wouldn’t like someone to come up to you and say you’ve gained without an ED [eating disorder] don’t come up to someone with it and say it. Or comment on how much you’re eating – that’s the worst. It’s like ummm no! ... And then they go, ‘wow, that’s a lot’, even if it’s just a bowl of lettuce. I had a support worker and she was like, ‘wow!’ . I was like ‘well, that’s a whole of 3 cals [calories] but yeah, I know, it was too much.’ So next time I wouldn’t have it again. But for some people that might be different for. Everyone is so unique.

Judgments and persecution

Anorexia was commonly associated with critical judgments from others. Participants experienced this both from friends and family, as well as external organisations or groups and as a result, perceived being stigmatised because of their anorexia. They also reported others viewed them as fully responsible for their condition and thus deserving of reproach. Collette and Anabelle considered the judgments they received from others to be a significant feature of their anorexia, especially when coming from within their families. Collette added in the follow-up interview that the negative and critical comments she received from others were unhelpful.

Collette: My family who would yell at me all the time about eating and tell me that I was a horrible person cause I wasn’t eating and why was I being so stupid... [they] would blame me like, ‘look at what you’re doing!’.

Anabelle: [My family would tell me] ‘oh, you’re ruining this’, and ‘I’ve had to give up this’.

Similarly, Anabelle, Eva, and Maliha explained how others blamed them or became angry at them for their anorexia. Anabelle and Maliha both mention the impact of their schools at the time and the blame and criticism they received in response to them having anorexia (or behaviours associated with it).

Anabelle: The school was terrible. My school blamed me. When I came back from [treatment overseas] the first time, my school wouldn’t have me
back. Said I’m attention-seeking and I’m too much of a hassle and disruption on the others.

*Maliha:* My school was really weird... they just thought that I was being a delinquent because of AN... they would blame things [I did] on the anorexia... they just didn’t understand.

*Eva:* Didn’t help that [my partner] used to get really angry with me about it when he’d made me food and I couldn’t eat it.

Anabelle described people making negative judgments about her volition in regards to her anorexia, suggesting that anorexia is something she chose for herself and that she should therefore deal with the consequences.

*Anabelle:* The mental health nurse who brought me up from Dunedin, who I must admit made me carry my own suitcase which was 30 kilos which was more than myself at the time. And I walked into the hospital and they said, ‘why is this girl not in a wheelchair!’ and the nurse was like, ‘she needed to carry it herself. She wants to be like this, this is how it is.’ [pause]. I know. I was just like, that’s so mean.

Lastly, people who were patient and understanding with regard to AN often had a positive effect on recovery. Eva compared this to the negative impact of those who would blame her for not eating.

*Eva:* My dad was one of those, ‘why don’t you just eat’-types but my mum, I don’t know, she has no experience with eating disorders and she doesn’t know anyone that has an issue with food but she just seemed to know the right things to say. Like, not telling me to ‘just eat’. That doesn’t bloody help. And she would invite me over for meals and she would just like do whatever she could to make the situation comfortable, like not having too many people there.

Overall, having anorexia invoked a range of reactions from other people in the participants’ lives but, the negative impact of people judging and blaming them for their anorexia was significant. Judgement and blame from others is likely due to a general lack of understanding (to be discussed) in knowing how to manage someone with anorexia and not understanding their experience. From the
participants’ perspective others incorrectly assumed that anorexia was a self-determined choice and resistance to recovery was also a choice. The inability to help someone with anorexia is likely to engender frustration and possibly anger, although the participants did not consider it necessary to be directed at them.

Concealment and denial

A common consequence of dealing with others expressing concern and pressure towards those with AN was denial of any problems and concealment of anorexia. Denial was generally overt and participants described telling others that they did not have a problem. Denial overlapped with lack of insight, hence some participants attributed their denial to not recognising they had a problem. For example, Collette discussed how she denied having a problem for a long time, did not accept her diagnosis, and she said that this originated from her lack of understanding that her behaviour was a problem.

Collette: I knew in my head that it was wrong but I didn’t believe that it was wrong... I was in denial for such a ridiculously long time that there weren’t any causes because there wasn’t anything wrong.

Although Collette would not accept a diagnosis of having AN, other participants described a different type of denial, where they were aware they had a problem but denial was purely functional and self-serving; it prevented people from stopping them. For example, Kate described denying to her mother that she was not eating, Eva described denying to concerned friends and family, and Kora described denying to medical professionals.

Kate: Mum and I were like walking out checking some cows and we were trying to talk about why I wasn’t eating and stuff and I was denying it.

Eva: I got thinner and thinner and thinner and everyone started saying to me constantly like, ‘what’s wrong?’, ‘are you okay?’ I’d just make heaps of excuses and I didn’t see what anyone else saw... Everyone just kept at me to do something about it and I was adamant that there was nothing wrong with me.

Kora: She said: ‘you’ve got a condition called anorexia’. And I knew what it was but I was like, ‘nah, nah I don’t have anorexia’. So in denial. Well I
wasn’t in denial but I just didn’t want to accept it or anyone to know that I had it.

Secretive and masking behaviours were used to conceal anorexia. These were typically used to try and reduce concern, reduce the likelihood others would notice anorexia and ultimately reduce any interference. Participants regularly described trying to make it seem like they were eating when they were not.

*Anabelle*: [A treatment programme I attended] is pretty not that good. Like you can get away with anything. I was sticking whole sandwiches in my pocket if I wanted to. Seriously! 5 out of 6 pieces of sushi.

*Eva*: I, you know, had lots of tricks: pushing it around my plate and like using conversation to distract from the fact that I hadn’t really eaten much.

*Collette*: I’d go to uni and not eat from six-o’clock in the morning when I had breakfast to when I got home basically... then I’d eat like half of dinner and say I wasn’t hungry cause I’d already eaten.

**Resistance to change**

Participants discussed how they were resistant to change throughout their anorexia until they decided to recover. Resistance to changing their anorexia and recovering was emphasised as being a very significant for a few of the participants. Resistances were partly displayed through denial and concealment; however, other covert and overt resistance to changing their lifestyle were present, especially when the interventions of others transitioned from concern to direct attempts to control and manage their anorexia. For example, Natalia, Collette, Maliha, Kora, and Anabelle all described overt acts of resistance.

*Natalia*: My mum used to try and make me drink [a nutritional weight gain drink] – hated the taste of them, and I used to just pour them down the sink.

*Collette*: I resisted more and more until I started doing ridiculous things.

*Kora*: They started to like, ‘oh, you need to eat’ and started monitoring it and I was really adamant, ‘no, I’m not eating’. But I still like drank water and had coffee. But there was no food. And then they had to get the
dietician down and I had to have [nutritional weight gain drinks] and that was like quite horrible because I had to sit with them and there was a point where they literally [pause] shoved it down my throat. So that was quite horrible. I kind of brought it on myself; I wasn’t being helpful.

Interestingly, both Maliha and Anabelle described a sense of paranoia about covert ways other people were trying to make them ingest calories.

Maliha: Paramedics came and they tested my blood sugar and everything and my blood sugar was really low. And, um, they were trying to give me glucose and I was like, ‘I am not going to eat your glucose!’ It’s glucose.

Anabelle: Last time I was there [in hospital] I was like pulling drips out, ‘No, you’re not giving me –’ I wouldn’t even have IV fluids because I was adamant that they were putting calories in it.

Another way participants showed resistance was through more covert acts. For example, Scarlet described seemingly agreeing to treatment but secretly not wanting to recover and disagreeing with the treatment focus. She later relapsed suggesting that she had gone along with what others wanted and now it was her turn to do what she wanted.

Scarlet: When I went into hospital I didn’t exactly want to get better... when I went into hospital it was like, ‘I can show you – I’ll show that I can do what you want but I can also do it [the anorexia] wants’ kind of. And then when I got out it’s like, ‘well, I’ll show you that I can do it again.’

Confusion about services
Receiving services for anorexia and how this process worked was seen as confusing. Some expressed disagreement about not being referred to specific treatment services for anorexia. Overall, there was a general lack of understanding across participants in the process of being referred (how, when, why, and with what criteria), and was seen as contributing to additional problems with AN. For example, Collette described being rejected three times from an eating disorder service because she did not meet the criteria. When she did qualify she was sent to hospital soon after because her low heart rate was potentially fatal.

Collette: I got declined because my BMI wasn’t low enough. Um, and it was obvious that I was starting to get sick but they – the stupid funding is
basically that they – the definition of anorexia is a BMI of something ridiculously low and, you know, it’s got to be about body image, it’s got to be about this and that and I didn’t fit the criteria so I didn’t have it. And I just wasn’t sick enough for them to have funding for me so they declined me – I think it was three times [laughs].

Anabelle described confusion in her family about why she was not referred to her local eating disorder service when she first developed anorexia.

*Anabelle: I’d never been referred to them. I know – and that’s what my parents – ‘cause we’ve had a few arguments in recent weeks. And, um, they were like, ‘why didn’t we get referred when you were younger’. Like, all this time we didn’t even know it existed till I came back from overseas, then I was under them.*

In addition, Anabelle described a range of other difficulties she has experienced with eating disorder services, including being discharged when continuing to struggle with anorexia. She described how professionals had “given up” on her and started commenting that she is unlikely to get better. Overall, her difficulties can be summarised by the following quote:

*Anabelle: That’s what they said to us when they kicked me out of [the eating disorder service] pretty much, ‘oh, you can go privately’. And it’s like, well we can’t afford privately... So, ok, if you want good treatment then you have to go private when we have a regional service specialised for this. And any other illness you keep going until the person either signs a ’do not resuscitate’ order, you don’t just let someone die unless it’s palliative care. But this isn’t a palliative illness; it doesn’t have to be.*

**Others adapting to me as anorexic**

Lastly, one outcome of slow, incremental weight loss was that others could become accustomed to participants’ anorectic habits and low weight. Thus, their anorexic state became normalised within their social group and people were less concerned than they may have been if the weight loss occurred at a faster pace. For example, Eva described how her partner became accustomed to her being very thin and not eating.
Eva: He got used to me as I went so he didn’t notice weight loss immediately.

Anabelle also described how other people in her life have become accustomed to her anorexia and that there are different (less ambitious) expectations for her which differ from when she first developed it.

Anabelle: I think that’s the worst thing because you get adapted so [treating professionals] think that they can push it further before admitting you to hospital but then there is just a stage, it’s like a switch and it could just flick and you’re just gone, forever.

Impact

This final theme relays the perceived impact of anorexia on the participants’ lives relating to the consequences of it as separate from the day-to-day experience. Sub-themes within this group primarily focus on long-term social, emotional, cognitive, and physical outcomes of anorexia.

Losses

Anorexia had negative impacts and were frequently discussed by participants when noting long-term consequences or when reflecting on the experience as a whole. For example, most had the view that they had lost or wasted that portion of their life. For Natalia, an important feature of AN is the perceived loss of life and feeling as if it is synonymous with being a ‘zombie’ or deceased until you recover.

Natalia: I wouldn’t wish that upon somebody because you lose track of your life. It’s, you know, however long you go through it, you have lost that part of your life.

Anabelle: And the longer you have it the less of you there’s ever going to be as well because you kind of lose your direction in where you want to go... I can’t get anywhere in my life if I have it.

Collette: It wasn’t the best way to spend [laugh] quite a few years of my life.

Although they may have been goal-directed and filling their time with aspects of their anorexia, the women did not consider it as contributing to their
life. In this respect, anorexia is perceived to hinder long-term goals and limit participants’ ability to develop a fulfilling or enjoyable life. Among these losses were relationships, opportunities, and experiences.

Collette: Everything that I lost through getting sick, I wanted that back [when I was recovering].

Anabelle: That’s when you go, ‘Oh my gosh, I can’t handle this anymore. I’m never going to get the life I want – I’ll just give up’. In the last three years three people have killed themselves - every year. And I’m just like, ‘oh my goodness, I can see why they do it now’. Because it’s so – you go – you get to a certain stage in your recovery and [professionals] go, ‘we can’t help you anymore; this is as good as it’s going to get’ but you realise in yourself that I’m never going to get my degree while I’m living like this... I’ve been in and out of hospitals. I wouldn’t know how to do half the stuff normal one my age would do. I’m just like ‘the bank [pause] yeah’. [laughs]. Uh, I have no idea.

In addition, the physical ramifications of having anorexia were concerning, with participants expressing their desire to reduce the impact of them long-term, with others mentioning their fear of what their life will be like in the future given the damage they have done to their body.

Eva: My bone density a couple of years ago was pretty shocking. I had the bone density scan and they said, ‘you better start doing something about this’ and that was quite a big thing as well. I don’t want to be breaking when I’m older for no reason. I’ve never broken a bone; I don’t want to start. They said the way I was going I would probably start, you know, become osteoporotic at some point... that was bit of an eye-opener and the fact that they said that if you don’t eat then you’re not going to be able to conceive a baby, and I want one.

Anabelle: I’ve had surgeries, I’ve had this, all to right the things the damage that I’ve done and it’s like – then I think about aging and I’m thinking if it’s like this now, then what am I going to be like when I’m older? What’s the point? Like I’m not going to be functioning when I’m like 50 if I’m like at this stage. In the past three years I’ve lost 10 % of my
mass, [my bone] density and it’s like, well, if I do that again then there’s not going to be anything left! If I’m at [the bone density of an] 80 [year old] now, another 10% of that it’s 80-something. It’s like, ‘Oh goodness!’ [laugh].

**Depression**
A common theme discussed was the development of low mood, depression, and thoughts of suicide. Maliha indicated that her anorexia may have played a role in one of her drug overdoses.

*Collette:* [When I relapsed] I didn’t want to live really. I kind of lost a lot of that and it wasn’t like I was going to commit suicide but I didn’t really see the point in eating.

*Maliha:* Depression goes hand-in-hand with anxiety, and then eating disorders go hand-in-hand with depression/anxiety and then, you know, all these things go hand-in-hand.

*Anabelle:* I’ve tried my best in doing it [recovering from anorexia] by myself and I can’t, and it’s like, ‘well, what’s the point then? I might as well just [pause] [commit suicide].’ I don’t want to go backwards again, I’ll just end it now. And then they go ‘Ah!’ [laughs]. ‘Respite!’

Others discussed how they experienced depression following anorexia. For example, Natalia viewed anorexia as contributing to her depression after she managed her own recovery. In addition, Kora described how she developed depression during the second phase of her anorexia (or bulimia) when she was purging after eating (see Appendix K).

*Natalia:* It did trigger depression, after that, but nothing before that.

*Kora:* I was depressed, and then suicidal, and that’s when I went into hospital. And then so all of that plus the eating disorder, I got treatment in [an inpatient service].

**Lack of positive, knowledgeable support**
When participants were recovering or considering recovering, there was perceived to be a notable lack of positive and knowledgeable supports available. They described being socially isolated because of the lack of understanding and
persecution described earlier, which impacted their recovery process. Knowing more people who had recovered may have been beneficial, or at least to share the experience and receive guidance from others who were judged as understanding.

Collette: I wanted to know that there was a way out but I didn’t know anyone who’d recovered and so I – like I’m the first person I know that’s recovered [laugh] which makes it really interesting [laugh] … of course you’ve got to have something to live for and [before I recovered] I didn’t have any hope that anybody else had recovered because I didn’t know them [laugh].

Kate: I was unlucky and lucky at the same time. When you don’t know someone else with it, there’s no one else that can understand why you’re doing what you’re doing. Um [pause] but it also meant that there wasn’t any – like as I got out of it there wasn’t anyone I could look at and think, ‘oh, she’s still skinnier than me. Why can’t I be skinny again?’

Scarlet spoke specifically about her ability to connect with others through social media and internet groups and that this could help by feeling like others understood her, including during recovery. She suggested that she is more likely to listen to others who write about recovery after having experienced it, rather than others who have not experienced it.

Scarlet: Someone who does [understand anorexia after having experienced it], they know what they’re talking about and also like, if they’re recovered and stuff, they know the difference between them and all that other stuff. Just gives you insight and stuff.

Purging/bulimia

Transition of anorexia into bulimia was noted along with expansion of AN to include purging in later stages or episodes of AN. This was a distinct feature where participants acquired these behaviours after starting anorexia with a more select set of behaviours (e.g., primarily food restriction). Some participants discussed the onset of purging occurring after or during treatment for anorexia. For example, purging was not a part of Collette’s anorexic behaviour until after her initial period in treatment and subsequent relapse.
Collette: I got discharged and I went home and that would have been the end of [year] ... I started purging and then started running away from home and like exercising for hours on end and not eating. And, it all turned to custard and by [year], last year, I was back at [the treatment service] [laugh].

Natalia and Kora both described developing bulimia or purging behaviour after their first episode of anorexia. Natalia’s was in response to wanting to lose weight. Kora’s developed after she lost control of her restrictive anorexia and she then developed pattern of purging after eating but with no co-occurring binges. Below she may have still been experiencing anorexia, binge/purge subtype, although she was not diagnosed during this time.

Natalia: There was a lapse of bulimia after that as well, that was 17 [pause] 16? Must have been about 16/17. It wasn’t long but it was again, still really painful. But this time I was eating I was just throwing it up.

Kora: From there it kind of developed into bulimia. And it wasn’t that – apart from that night [where I ate a lot of ice cream] – that I ate a lot of food it was because I had eaten. I started eating breads and cereals and the normal foods, but healthy foods. But it wasn’t that I had over-indulged in it, it was because I had eaten and I didn’t like that and so I would make myself sick. And I think it kind of went on for one or two years. Until [pause] I actually had drunk turps [turpentine]. Because the longer the bulimia went on the harder it would be to make myself sick so I would take things that would help actually do it. So that was – and then after I had that turps I burnt my throat and had to go to hospital for it and was on a liquid diet for a long time before I could eat solids. And then from there I stopped.

Death
A significant factor impacting those with anorexia are the health risks, especially those which cause fatalities. Many of the participants described that their anorexia progressed to the point that they were hospitalised and told they might die. This experience of their mortality and the extreme risks of their anorexia was intense. In addition, this often occurred abruptly conflicting with
their anorexic patterns and mind-set, forcing them to accept food which they had been controlling for an extended period of time.

*Collette: I got discharged [from hospital] because my vitals were no longer [pause] fatal. And I was out for less than 48 hours and then I was back in... the first time I got threatened with an NG [nasal gastric tube]... I had to eat a certain amount or I would get one so I ate it because I didn’t want one.*

*Scarlet: No matter what happens [when you relapse] you’re always going to have to like – you’re either going to die or you have to go through everything again.*

*Kate: When I went to hospital it was really like, this is reality you’re – you’ve got to eat now [laughs]... It was really putting the choice onto me. Like, do you want to eat and live? Or, do you-, are you almost going to die? [laughs]... It is quite an intense time like you’re feeling quite immediate life and death. Like, this food is deadly and I just want to keep running and escaping.*

*Anabelle: I don’t think anyone would be very good if they saw their daughter just about to die. When I came back from [an inpatient service] I will never forget the way [my mother] looked when she walked into the room... she came in and she fell to the floor and started sobbing... [When I came back from that service] I was just so excited to be coming home so I could say goodbye to my family [because I was told I was going to die].*

Anabelle discussed the impact of making friends with others she had met through treatment. She described how three of them had died recently, two possibly from complications with their anorexia and one from suicide. Further, another of her friends had recently been hospitalised for anorexia and it looked as if she might die. The collective impact of these losses on Anabelle was significant and made her feel as if there is no point trying to recover anymore as many of her friends had failed.

*Anabelle: In the last three years three people have killed themselves, every year. And I’m just like, ‘oh my goodness, I can see why they do it now’... [Anorexia’s] killing [people] and you don’t actually know how many other*
people are dying because of it because we’ve got another friend who has just – who admitted herself to [a] hospital and they kicked her out and said she’s too hard. Her BMI [Body Mass Index] is like nine. Nine! ... And she’s going to die.

Summary

The experience of anorexia is complex and has social, mental, physical, and practical impacts. The participants in this study described their experience of anorexia with themes relating to fears, behaviours, and perceptions. These features were interrelated and give a sense of what participants did during anorexia, why they did what they did, and what their thoughts and perceptions were at the time and after. In addition to the personal and internal experience of anorexia, participants were aware of how this impacted their lives, and those around them. Interventions came in different forms, from different people, and participants were able to describe some of the successes and difficulties associated with these attempts. There were short-term and long-term positive and negative implications with some consequences occurring during or immediately following anorexia, and others developing over a longer period of time.

These grouped features of anorexia are important in placing perceptions of cause and relapse into context. Individual definitions can be used in conjunction with the collective themes to provide further background to later views.
Section 2: Causes of initial development

The focus of this section is to illustrate the participants’ perceptions of the causes of the initial development and episode of their anorexia nervosa. The participants discussed the contributing factors and what they thought did and did not contribute to it developing. It should be noted that the development of anorexia nervosa occurs over a period of time, as necessary to lose the required amount of weight to meet the current psychiatric diagnosis, i.e. cannot be diagnosed without being underweight and thus there is often a period of time prior to being underweight where causes of AN are present but the label of AN is not yet applicable. Thus, the perceived factors relate both to pre-development of the disorder, from a diagnostic sense, for factors that were significant prior to a participant meeting the weight requirement outlined in the DSM. Perceived factors also relate to the period when participants started to meet the diagnostic criteria. In addition, some influences were noted to be more or less significant at different points in the progression of their disorder and will be indicated where possible. Table 4 shows the themes and sub-themes for each category.

Table 4. Major themes and associated sub-themes for initial causes

<table>
<thead>
<tr>
<th>Power and control</th>
<th>Self-worth</th>
<th>Symbolism</th>
<th>Body Image</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling overwhelmed and unable to cope</td>
<td>Low self-esteem</td>
<td>Coping strategy</td>
<td>‘Fat’ and the desire to change</td>
</tr>
<tr>
<td>Autonomy</td>
<td>Self-worth</td>
<td>Anorexia as part of defining my identity</td>
<td>Extreme thinness in relation to attractiveness</td>
</tr>
<tr>
<td>Controlling the perceptions of others</td>
<td>Self-punishment</td>
<td>Food, weight, or body representing something else</td>
<td>Social desirability</td>
</tr>
<tr>
<td><strong>Rewards</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excitement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Successfulness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addiction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alleviating other mental illness or negative mood states</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Obsession</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obsession</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Possession</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perfectionism</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insight and reasoning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceptual and physical dispositions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hunger</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative association with food or eating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior concerns with weight and shape</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Modelling from others</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Power and control**

The women in the study described how controlling their eating practices, their weight, and their body, related to issues of power and control in their life in some way. In discussing these factors they raised issues relating to a lack of control in their lives, feelings of being overwhelmed and lacking direction, and wanting to exert some power over themselves and in relation to others.

**Feeling overwhelmed and unable to cope**

One of the factors raised was the impact of uncontrollable external stressors, especially conflict, in the participants’ lives at the time. They perceived that this stress was difficult to cope with and also was often out of their control. In this sense, the stress was often perceived as inescapable and participants described having felt powerless within this context. Their experience of controlling their eating and developing AN allowed them to increase their sense of control over themselves and in some cases their external environment.

*Collette:* That was probably the worst year that my sister and dad got on or didn’t get on I mean. But yeah, they used to fight a lot… I hated that – I’d have nights where I’d just go curl up in the dark and cry and stuff like that and I just couldn’t handle it – cause that would always get to me and then my dad would come in and blame us [laughs] even though we weren’t part of it… that kind of emotional pressure I guess.

One of the participants describes parental discord and that she observed a strain in her parent’s relationship, with one often becoming upset. Part of her reasoning for developing anorexia was her trying to reduce any impact on her mother especially, making life easier for her.

*Anabelle:* It was kind of like, ‘ah, my mum’s upset; I can’t take from my mum and make her do things or make me things – she’s too upset’ so that kind of just feed into it.

Kora spoke about the impact of having been sexually abused when very young, and the additional impact in her teenage years of having little say in having to raise her cousin’s child. She perceived her life as being out of her control and very punishing. Her experience with anorexia allowed her to gain a sense of power and direction within this context.
Kora: I felt about 14/15 when my nephew was born that my life was out of control. Because I got abused when I was a child and wasn’t in control of that and when my nephew was born his father was also abusing me as well. And then I was raising his son. And I just thought everything in my life is just falling to pieces and out of control, and I kind of felt like I needed something to have that control.

**Autonomy**

Autonomy is another feature of power and control related to anorexia, where a person acts on the ability to independently control eating and food aspects in their life, sometimes in direct contrast with other aspects over which they have little or no control. In this way, participants exercised their autonomy and achieved a feeling of independence through the control of their body.

*Kora:* I had full control over it. Well, it kind of got out of control but I was in full control of it and I liked that because I felt that I had the power. Because I didn’t have any power over anything else in my life.

One participant discussed the impact of losing the external support and controls from her family and partner around her eating which had prevented her from getting worse earlier in her life. She perceived that being alone and fully in control of her own eating meant that there was nothing stopping her anymore, so her disorder became progressively worse.

*Eva:* I was by myself and I had more freedom to do it. That was when it really took hold because I didn’t have anyone telling me that I needed to eat more really, because no one was watching me at meal times.

Another aspect of exerting independence related to being able to retain your ‘skinniness’; in that, it was something other people could not change in you. Some participants discussed how losing lots of weight was something they worked towards as it was safe from the impact and influence of other people in their lives.

*Kate:* They’re all justified [the sacrifices you make to lose weight] because no one can take away the fact that you’re that skinny. Even if they can take away everything else and control everything else in your life, you can still control the fact that you are going to get absolutely as skinny as possible.
Controlling the perceptions of others

An aspect of controlling eating and participants’ bodies was linked to the way that others reacted to and perceived them. In addition, controlling eating was discussed as a way to show others that they could do something; that they could get really thin despite their friends and family or to make a statement to others through their weight.

Scarlet: There’s so much that I can’t control. I can’t control how other people feel and I can’t control how I feel and I can’t control what happens. But I can control what I look like, and, what I eat, and how other people interpret me.

Summary

Overall, a large majority of the participants discussed the reinforcement they received from feeling in control of themselves through their anorexia and how this gave them a greater sense of control over their lives. At times this related to perceived causal factors such as those relayed above, and at other times the desire and enjoyment derived from having control over eating was described as a defining feature of anorexia.

Rewards

The women discussed how the process of losing weight was rewarding and pleasurable in a range of different ways. These features related to both initial development but also maintaining factors relevant for the participants to continue losing weight and reach the level of anorexia, despite the costs associated, such as extreme fatigue or hunger. They described feeling excited about weight loss, feelings of successfulness and personal achievement, and an increase in their mood. They also said that the experience of AN was addictive.

Excitement

Weight loss and the subsequent meeting of weight goals was described by participants as often being very exciting. Some participants also discussed that the initial idea of losing weight or at least even the possibility of meeting these weight-goals was extremely exciting and had filled them with hope or positivity for their future.
Maliha: I remember at first I was just really excited about this idea. It wasn’t like I was hiding it. It wasn’t like a secret… it wasn’t an eating disorder at first… it was just like, ‘yeah, I’m doing this, I’m doing this, it’s really cool, it’s really exciting, you guys should join me, it’s so much fun’.

Losing weight also gave participants a sense of purpose. Weight loss was a very structured task where very specific weight or body goals (e.g., feeling bones) and eating practices could be established. In this respect, once the process was started, excitement about the process of losing weight and meeting goals could serve as a maintaining factor, spurring on the progression of anorexia.

Natalia: It almost makes you feel excited when you start losing weight and then see a reward. It’s driving you to keep doing it. For some people it did stop; for me it was as the scales went lower and lower it was driving me to keep doing it because I’m like, seeing the results, so I’m going to keep doing it.

Successfulness

The women discussed the impact of feeling successful and accomplished when restricting and how this contributed to their anorexia. Anorexia and continued weight loss in spite of the physical, mental, and social sacrifices made, contributed to feelings of success and being able to do something well. For example, Scarlet thought that restricting and losing weight distinguished her from others and initially, the weight loss made her feel successful.

Scarlet: I was good at it, so I was kind of like ‘oh, this is my thing’… You know how you do something and you do it good, and you’re like ‘Yeah!’; it’s kind of like that.

Many of the women discussed the progressive nature of the disorder and how once a weight goal was achieved they would make a lower weight goal. At different times, the achievement of these goals would be rewarding. For those that did not weigh themselves, other physical markers, or achievements, could also serve as reinforcement.

Natalia: It was like, get to this weight, then it was get down to this weight and you almost feel like you’re winning this battle with yourself the lower down you go. You are kinda going, ‘yeah, I’m actually doing really well
because I’m getting skinnier – so it’s good’... It does feel like you’re winning a victory by getting thinner, by getting a BMI lower.

Eva: The light feeling; I really liked it. I miss it a lot. I feel very heavy now [laugh and sigh]. I still get a glimpse of the feeling sometimes when I first get up in the morning before I’ve had any food and it makes me want to go back there a lot.

Although the successive achievement of increasingly more extreme goals could be rewarding, many also described how this reward lessened over time, the more severe their anorexia became. Some participants described trying to recreate the initial feelings they had even though it was no longer as satisfying. For example for Maliha, who felt quite excited in her initial phases of losing weight, progressively felt less satisfied with her body and she started to perceive her anorexia as being in control of her.

Maliha: You had to lose weight. And, you know, like you’d get to a point and you’d be like, ‘okay 45 kg’s, okay’, you’d get there and be like ‘yeah, what about 43? What about 41? What about- ’ and you just keep going down and down and down. And it was just this constant feeling of I don’t like this. I just don’t like the fat over here ... Like, if I don’t eat today maybe I’ll be able to eat tomorrow. It will eventually go away. I’ll eventually be able to eat normally. If I just do this for this amount of time it will all go away... So, I’ll just push through the pain now and I’ll get there and then it will be really good.

Scarlet had a similar experience of trying to pursue her initial feelings of success and pleasure at having been successful losing weight. She described continuing her eating practices, even though she was not feeling as rewarded anymore.

Scarlet: I think at the start I felt good so then, once I lost it I thought, ‘well, if I keep going it might come back’, kind of thing. I was just waiting for it to come back and it just never really did.

Addiction

In talking about the causal aspects of anorexia, some of the participants expressed the sentiment that anorexia felt like an addiction. Those that described
it this way indicated that although they had never been addicted to any illicit substances it seemed close to others’ descriptions of addiction. The similarity to addiction revolved around the concept of feeling rewarded initially, then feeling like the disorder was out of control and that they could not stop even if they wanted to.

_Eva:_ I think that once I started it just became like an addiction. It just stuck with me; I couldn’t get rid of it. I tried sometimes... Sometimes [my partner] would make me food and I would put it in my mouth and try and chew it and I couldn’t chew it or I couldn’t swallow it. Or, it just felt like it was turning to dust and I just couldn’t do it.

The theme of addiction also emerged when the participants described being resistant to seeking or receiving treatment, where the costs were of the disorder were not significant enough at the time, and/or the reward was too great. This was most prominent with those who had relapsed in close succession with their initial admission, perceiving that they were not ready to recover yet.

_Natalia:_ You don’t want to get out because it makes your life so much more colourful, but then you get to a stage where you’re losing everything.

There was debate with some participants between the concept of obsession and addiction. They indicated that they have similar properties but many who did not mention that it was similar to an addiction, thought it was an obsession.

_Kora:_ I know with an addiction it’s like that craving. I don’t know if it was just an obsession and not an addiction. But I don’t think I could have stopped if I wanted too... But then can that happen with obsessions as well?

Unsurprisingly, most participants did not have specific scientific knowledge or understanding of the distinct features of addiction or obsession, as revealed during these debates and from the answers they offered in response to the question of how they would define AN. Thus, the idea of addiction has been presented in this section from the participants’ own definitions of each concept regardless of the formal accuracy.
Alleviating other mental illness or negative mood states

Anorexia was linked by participants to alleviating some of their negative affective states they were experiencing at the time, for example, depression or anxiety. However, it was also discussed as increasing negative mood states or psychological distress as it progressed. Despite this, it was identified as a partial causal factor with participants feeling more in control of their emotional states. This was particularly prominent for Eva who had many difficult life events occurring during the times where she started being more restrictive in her diet. She partly related the difficulty coping to having to deal with these problems alone, and being overwhelmed with: “all these feelings, and I didn’t know what to do with them so I was controlling food.”

Eva: The bout when I was sixteen was very similar because I had just miscarried a baby and then my partner at the time had gone away on foreign exchange [overseas] and left me on my own to deal with it. So I wasn’t eating anything then. So I think that’s mainly my biggest trigger I guess. When I’m alone. I don’t cope well by myself.

Maliha reported having issues with anxiety and depression prior to developing anorexia. She indicated that her experience of anorexia both increased her mood but also masked her symptoms of depression and anxiety which progressively worsened over time.

Maliha: I think [anorexia] came with the depression and the anxiety... I had really high levels of anxiety, like I had really severe anxiety, and that was another really big problem. And, I think when I had the overdose I was getting panic attacks... [After the return of severe depression and anxiety without prominent eating difficulties] I saw my same therapist again at ICAMHS and she said, ‘we treated you for an eating disorder but we overlooked the depression and anxiety’. And so that just came back; it never really went away.

Summary

Description and identification of the different aspects of anorexia which were rewarding or encouraging differed across participants, but they all mentioned at least one aspect. Reinforcing qualities related to both positive reinforcement through feelings of pleasure and success, as well as negative reinforcement...
through reducing negative feelings of depression, or anxiety. Many of the rewards cited tied into other aspects of the participants’ lives such as feeling out of control. For example, within the context of their life, a participant experiencing feelings of being ‘out of control’ may be more likely to be reinforced by experiences of success achieved through AN. Similarly, someone experiencing feelings of depression and loneliness may find an AN-related activity or regimen which gives them immense pleasure comparatively more reinforcing. Hence, the reinforcing properties of anorexia were important in the participants’ descriptions of the causes as they served to maintain their disordered eating behaviour allowing them to become anorexic.

**Obsession**

Another prominent theme which emerged focused on participants becoming obsessed with aspects or features associated with their eating disorder. Participants discussed becoming consumed with their anorexia and that, once committed, their world tended to revolve around food, weight, and their body. Within this, the idea of possession was also raised, whereby participants described being consumed by their eating disorder and that they were no longer separated from it: anorexia was their identity. Part of their obsession revolved around a drive for perfection, whether that be in relation to body or other aspects of self, achieved through their eating disorder. Lastly, associated with obsession was the concept of denial and lacking insight. Participants discussed how they commonly lacked insight at the start and that their eating felt justified and relatively normal.

**Obsession**

Nearly all of the participants described themselves as becoming or being obsessive about food and their eating disorder. This was often attributed as the cause of the progression of their anorexia, and regularly described in conjunction with personal definitions of anorexia by most participants. Obsession was usually defined in relation to the extreme focus on aspects of their eating disorder and to rigid adherence to behaviours related to their obsession (e.g., compulsive-type behaviour).

*Eva: Your whole brain is just consumed all the time with it… constant thoughts about food and eating and weight and control.*
Collette described how she was obsessed with biking to university everyday despite weather conditions or other factors, she was rigid about doing this. After a period of time, her focus broadened to also starting to obsess about her meals and eating.

*Collette: I started to cycle *every single day*. It could be bucketing down – well it did bucket down or hailing or whatever, I had to cycle: couldn’t handle not doing it... Gradually as my hunger went down despite doing more exercise, I’d eat less and less and less and then it became like a control perfectionism type thing. So, if I’d eaten less the day before, well of course I’d eat less than that; I couldn’t eat more than that or the same amount.*

Anorexia was described as taking over people’s focus in one of the key aspects of participants’ description of obsession; AN became more important than them. In discussing what obsession meant for her, Kate identified that obsessive traits and behaviours had been modelled to her by her parents but she had applied these concepts to her eating.

*Kate: It’s acceptable to be obsessed with farming. Coming from an agricultural background, the farm is more important than you. So, I was kind of having the same mind-set as my parents and I was obsessed with food and food was more important than me, yet it was something that we’re not really allowed to be obsessed about. Or, we’re allowed to be obsessed about it but it would kill us [laugh].*

Furthermore, participants also described obsessive behaviours, or compulsions related to their anorexia which often contributed to weight loss (e.g., having to reach a specific weight). However, the behaviours associated with obsession with eating, restricting, and other practices like exercise, were more likely to be related to features of anorexia, so will be discussed further on.

**Possession**

Another theme that emerged was the concept of being possessed by anorexia, in that participants often felt as if anorexia was their ‘whole self’ and that nothing else mattered to them; they had been ‘taken over’ by the disorder. The extreme focus on weight, eating, food, their bodies and so forth, along with
excessive amounts of time spent thinking about all aspects of AN or engaging in
behaviours associated with it were repeatedly described by most as being outside
of the individual’s control. Furthermore, once possession had been established,
they could no longer control their anorexia; anorexia controlled or dictated their
thoughts and behaviours.

Kate: The importance of it had become, it had really taken over for me –
the whole mental thing... [Talking to her mother about not eating] I was
like, ‘I do want to want to eat’ kind of thing, but this mental thing, it’s
bigger than me. I can’t control it.

Natalia: It takes complete hold of you. It’s something that you can’t
separate from yourself.

Anabelle: With an eating disorder, you become your diet.

Maliha described, similar to an earlier statement noted by Anabelle, that
her anorexic thoughts and behaviours multiplied and increased over time. At first
they felt to her as if presented by someone else, then over time became adopted by
her, taking over her thoughts.

Maliha: It just takes over you and you just don’t even realise it... it’s just
your thoughts but you can hear it being like, ‘just lose some weight’. It’s
there, and it’s like someone’s telling you all these things but eventually
you hear them so often that it becomes your own thoughts.

Perfectionism

Perfectionism or striving towards things being perfect was a key concept
raised by many participants. Although there may be a stereotype that this refers to
the ‘perfect body’, most participants referred to perfectionism in other aspects of
their disorder, tending to associate it more with meeting the rules and expectations
they set for themselves in relation to their anorexia. Furthermore, the concept of
perfectionism was often explained as striving for things to be ‘just right’ or in
connection with obsessions and wanting aspects of their anorexia to be a certain
way.

Eva: I have always been a perfectionist and me being a dancer as well.
And I’ve always been OCD and then like, if my weight was 43.2, that
would really bother me, and I would want it to be an even number. And so I thought, okay, well, I’ll get it to the next even number and when I got down to the next even number I wanted the one below that.

Anabelle discussed perfection in a different way from the other participants in that she wanted to be perfect for her family. Her method of achieving this when her anorexia first began was through her anorexia and, in this way, it became the means by which she achieved a sense of working towards being ‘perfect’ within her family and with others.

Anabelle: I just want to be perfect for the family and I thought if I’m taking and being greedy then that’s a bad person and I don’t want to be a bad person.

Although many of the participants noted that they were perfectionistic or had these traits it was generally not a pivotal feature of their perceptions of a cause of AN. This feature was more likely to be viewed as a personality trait they already possessed, which contributed to the broader picture and increased determination during AN.

Insight and reasoning

Lacking insight during their time with anorexia was a key part of participants’ descriptions. Different degrees of insight were described, some viewed that they were in denial. Others suggested they recognised something was wrong but not the extent of the problem, or that it felt reasonable at the time but did not make much sense to them with hindsight. One woman explained how she felt AN was justified for herself but not for others (e.g., may show concern for others with extremely low weight but not themselves).

Scarlet: I kind of didn’t know for ages… I actually started thinking it was more normal almost, when I was younger. This is what happens to people because I had seen it on documentaries and stuff and it just happens. But the older I got, I realised that a lot of people don’t.

Often lack of insight was associated with their description of causes because they needed insight and acknowledgment of the problem in order to recognise and consider possible causes.
Collette: I knew in my head that it was wrong but I didn’t believe that it was wrong... I was in denial for such a ridiculously long time that there weren’t any causes because there wasn’t anything wrong.

Kora talked specifically about how she lacked insight or concern for her own eating disorder but would be concerned for others experiencing the same thing. For her, anorexia was justified and reasonable but in her opinion others with AN should be helped.

Kora: I just didn’t see it as a problem. And I knew it was anorexia but I didn’t see the problem on me. If I saw someone else with anorexia or anything else I’d be concerned and like you need to eat and it’s not good and stuff but when it came to me it was like, ‘it’s a different story’. It’s okay for me but it’s not for you, you know [laughs].

Lack of insight or awareness was also discussed in relation to increasing the initial reward or pleasure derived from anorexia. In contrast, awareness of the costs of the disorder often decreased this value during relapses.

Anabelle: When you’re in denial it’s so much easier. I was so much happier when I was losing and I was like, ‘this is cool’, like I’m feeling good because I’m losing [weight].

Lacking insight was found to be an important element of perceived causes of anorexia for the participants; the need to gain, or have insight in order to be able to perceive causes was often cited. This suggests that other factors such as the recovery process, including treatment, are likely to have influenced the perception of causes in most of the women. Lacking insight or thinking that their anorexia was rational perpetuated their behaviour and thus was perceived as contributing to anorexia.

A state of denial is often ascribed to people with AN and although it may appear relevant within this subtheme it has not been interpreted in this way for two main reasons: (1) definitions of denial typically suggest contradiction of reality or refusal to accept the truth, but this assumes that there is one truth and that the clinical perception of AN as a ‘problem’ is paramount, (2) denial can be reinterpreted as someone defending their own beliefs and reasoning for particular thoughts, feelings and behaviours as is described above. Within this
reinterpretation the person then has control of changing these beliefs or reasoning and control over what they become, rather than them having to convert from denial to acceptance of a particular set of beliefs. Interpreting ‘resistance to dominant beliefs regarding AN’ as denial is arguably unhelpful as it places pressure on those with AN to conform to dominant beliefs about AN and suggests that their beliefs are unfounded, irrational, incorrect, or delusional. The interpretation of resistance and denial also appears to assume that they share these same beliefs but are willingly opposing them. Thus, terms of insight and reasoning have been used here to incorporate participants’ judgements of their insight, rather than applying a judgment of denial. In addition, this has been separated from the act of denying as described in previous sections, whereby the person denies actions performed, for example, eating.

**Summary**

The participants highlighted the impacted and central role of obsession during their experience of anorexia. This contributed to feelings of being possessed or fully dedicated to their anorexia with little time for anything else. In addition, they participants described personality features of perfectionism which contributed to them striving toward desired outcomes. The concept of obsession was related to the idea of lack of insight as it relates to the complete focus on the eating disorder and the associated lack of insight into the extreme nature of the obsession. Overall, obsession with food, body, eating, exercising, and other markers of their anorexia contributed to continued decline and progression of the disorder, allowing the acceptance and drive toward greater extremes.

**Self-worth**

The women discussed how a low sense of self-worth and self-esteem influenced their anorexia. A low sense of self-esteem and self-worth were perceived as contributing to the drive to want to be good at something, wanting to perceive themselves more positively, and yet also wanting to punish themselves in connection with these same beliefs. Furthermore, for those who described low self-esteem there was often also the perception of being more vulnerable to feeling negatively in response to stressful events or circumstances in their life at the time.
Low self-esteem

One of the aspects of self-worth was low self-esteem. This is distinguished from sense of self-worth by the severity of the self-doubt and how it related to the development of anorexia. Those who described low self-esteem often attributed this to feelings of insecurity, uncertainty about their standing with peers (e.g., popularity), and a high degree of self-criticality. However, self-esteem was sometimes still intact in other areas of life where the participant felt they were capable, prior to the onset of anorexia.

For example, Collette considered that it was her low self-esteem and negative association with food which developed at an early age that was a significant precursor to her developing anorexia. Part of her development of anorexia was related to the impact of low self-esteem and her inability to cope with social and academic stressors at the time, as well as regular interpersonal conflict.

Collette: I got bullied in primary school and I didn’t realise [until engaging in treatment], but it did have major effects on my self-esteem... like, if I felt bad about myself, I’d feel bad about what I’d eaten.

Maliha described how her self-esteem was quite low prior to her starting restricting and continued to decline during the course of her eating disorder. For her, continually getting into trouble escalated her anxiety and depression at school and made her feel more isolated within the school context, which in turn contributed to her anorexia.

Maliha: It was high school, and especially year ten, was when my mental health just really took a turn for the worse... I was getting in trouble a lot of the time and that was really killing my self-esteem... being told you’re really naughty and you’re really bad, and you need to stop doing this and you need to stop being this and you need to just conform.

Self-worth

As discussed above a distinction has been made between self-esteem and self-worth, in that comments about this conceptualisation of self-worth were how the participant perceived their entire self as being unworthy or ‘bad’, as opposed to a part of themselves. Although there is some overlap between both concepts.
with those describing themselves as being ‘bad’ often implying a lack of self-esteem, a distinction in the level of self-denigration is made here. Those participants who chronicled causes relating to self-worth described that they saw themselves as being a ‘bad’ person, and through their anorexia this was feeling alleviated. In addition, this concept was often associated with suicidal thoughts, self-harm, and the general sense of having to justify to themselves their right to live. For example, perceiving herself as being a ‘bad’ person was seen as the central cause for Anabelle to start restricting and develop anorexia.

Anabelle: I thought if I’m taking and being greedy then that’s a bad person and I don’t want to be a bad person. They’ll go and trade me in for somebody else.

For Anabelle, her values of being a ‘good’ or ‘bad’ person were directly aligned with the types of foods she could and could not eat, especially when she first developed anorexia.

Anabelle: My theory was: if I’m putting bad in me, I’m going to be bad. [The media and teachers] called it a ‘want’ food, not a ‘need’ food, and I didn’t want to want things.

Another participant, Kora, perceived her low sense of self-worth as key to the development of her anorexia. This included both the concept that she was a ‘bad’ person, and that she perceived herself as not deserving to be alive. In this sense, her anorexia was connected to her desire to harm herself.

Kora: I think from the [sexual] abuse it probably just left me, I don’t know, with no sense of self-esteem and confidence and worthiness. Like, feeling worth being alive and treating myself properly... [and] when I was 8, my mum, she kind of pretended that she was going to kill herself and made me the blame of it... there was several incidents like that when she would threaten to kill herself or myself and that. And that’s obviously had a major impact on how I felt. I must be such a bad person for someone to want to kill themselves because of me.

Self-punishment

There was a correlation between the concept of low self-worth and level of self-punishment, especially for Kora and Anabelle. Anorexia was used as a tool to
inflict harm on themselves justified by their perceptions that they deserved it. The desire to punish themselves and the potential reinforcement from inflicting harm on themselves to control these thoughts and feelings perpetuated their anorexia. For Anabelle, her anorexia was a way to deal with feelings of being a ‘bad’ person needing to be punished, and as a means to reduce her perception of how bad she was.

Anabelle: I think my eating disorder is my punishment for being a bad person. And so... if I was to kill myself then that would be like stopping that punishment and that would be bad. That would be even more of a bad person. That would be greedy and selfish so why would I do that?

For Kora, anorexia was one of a number of ways she was punishing herself at the time. It was intimately linked with behaviours of self-harm, which were congruent with her view of herself as being ‘bad, and therefore deserving or needing punishment.

Kora: It was self-damaging and I felt the pain of starvation and over-exercising. Because I did used to self-harm at that time as well. And it was just another way to self-harm. I just felt like I needed that punishment and that was another way to punish myself.

Average and lacking distinction

The development and progression of anorexia was encouraging for some participants as it contributed to them feeling more distinctive and accomplished. Part of this originated in beliefs that they were ‘average’ or unremarkable. Anorexia then provided a distinction from others and became something they were good at. This theme relates very closely with the concept of the rewarding aspects of the anorexia but is outlined here through the participants viewing their concept of themselves as ‘average’ as a contributing factor.

Scarlet: It’s that age and everyone’s like ‘oh, I’m dieting’ and I was like ‘uh, I might as well join the club’. And it just kind of went too far, but in a sense – like I didn’t really have anything I guess. Everyone was good at something and I wasn’t; I was average at everything.

Kate: I kind of felt like there wasn’t anything that I was particularly good at, so maybe it was me trying to find something, a way that I stood out.
Summary

Self-worth and issues of the value of their qualities and abilities were important. The participants ranged in the degree or number of deficits they perceived in themselves. There was a correlation between those who had perceptions of more severe deficits and it playing a more central role in the development and persistence of their anorexia.

Issues with self-esteem and self-worth were viewed by participants as having a range of influences on the development of anorexia. It was seen as something that increased a person’s vulnerability to problems and increased the value of anorexia as a coping mechanism for dealing with them. In addition, eating and issues related to eating disorders often became associated with the participant’s sense of their own value, hence successful control of eating allowed greater control of their perception of themselves.

Symbolism

For many of the participants their experience with anorexia was symbolic in one way or another where markers of AN such as weight, shape, amount of food consumed, become representative of less direct reinforcers. A key part of this theme relates to AN as a coping strategy which involved alleviating negative emotions and stress occurring during that time and was quite common among the participants, especially those that felt overwhelmed. Using AN as a coping strategy is categorised under this theme of symbolism as it was acknowledged that AN did not help with the initial stressors, but it did make participants feel as if they were coping better. Thus, even though it was not a very effective problem solving strategy or coping mechanism in the long-term, it allowed participants to feel more in control of that part of their life, even if they continued to feel overwhelmed or stressed in other parts (i.e., AN was symbolic of increased problem-solving or coping but did not actually achieve this long-term).

Symbolism presented in the interviews with participants when describing their perceptions and beliefs about the causes of anorexia, and how it played a role in defining a person’s identity. Food and eating were perceived by some as symbolic of much more than weight or the appearance of their body, it was a physical manifestation of what was important to them.
Coping strategy

In relation to the context of some participant’s lives as being stressful and contributing to feelings of being overwhelmed, anorexia was often seen as developing as a way to manage and cope with these emotions. Anorexia as a coping strategy is distinguished here as it was a distinct feature of participants’ descriptions of causes and was not exclusively related to a response to stressful events. For example, Eva talks about her eating disorder in relation to her experiencing difficult situations and feeling unable to cope.

_Eva:_ I think I just struggle to cope with like, emotional situations and being on my own. Like, losing my child when I was only 16. That was hard. And then losing my partner when he moved out. I think I just don’t cope with stressful situations. That’s how I cope, which is not really coping at all.

Collette specifically mentioned that her anorexia developed initially from the perspective of feeling like she could cope better; it felt like a solution at the start. However, as it progressed this factor became less important and other factors such as continued conflict at home, low self-esteem, a growing obsession around food and exercise and other factors, became more integral in maintaining it.

_Collette:_ It was my way of dealing with life and, sadly, it did help at the time, for a while – no, I thought that it helped... And it doesn’t, but it feels like it does for a while because it makes you feel more in control, it makes you take away some of that anxiety and stuff like that.

An interesting aspect of participants’ views of anorexia as a coping strategy was the belief that it is helping the individual cope, but with hindsight this perspective changed to one of AN being unhelpful, or even harmful.

_Scarlet_ spoke about the way that her anorexia felt like a problem solving strategy, condensing her problems into one form with a single solution. For her a range of problems could be re-framed as relating to her weight and size, thus she could solve this by restricting and losing weight. This contributed to her feeling as if she was being proactive about her problems, even if she knew they were not likely to be solved.
Scarlet: If somebody didn’t reply to a message or something you’d be like, ‘well, that’s because you need to lose weight or something’. Now I’m like ‘what?’, but then it made sense. But yeah, I think because I didn’t have any answer as to why they weren’t replying or they weren’t doing this, so when [my anorexia] gave me an answer I took it even when it didn’t make sense or wasn’t true. I just wanted an answer... It’s like: ‘well, if I listen to [my anorexia] then everything will be better, all my problems will disappear’. Even though you know there’re not going to it’s like, ‘well if they don’t, then at least I’m thin or at least I have this’.

Anorexia as part of defining my identity

For some participants anorexia occurred in conjunction with self-expression and in defining their sense of self. As a result, anorexia became something that gave them a tangible sense of self and identity. Furthermore, for these participants there was a hesitation and uncertainty about themselves which was then reduced by having such a strong sense of purpose and ownership during anorexia.

Identity was a very key issue contributing to the development of anorexia for Kate. She described her hesitation in creating an identity and explained that control over her body and her eating became more and more important to her in defining her identity (e.g. thinking “this is how I am, don’t try and change me”, in response to people trying to encourage her to get help).

Kate: I was probably also growing up and trying to figure out where I belonged as such... it was proving that no matter how hard I tried to be something that someone else wanted to be it would never, it would still not be enough for them or for me. And I guess I was proving that to myself and to everyone else. Or I thought I was proving it to everyone else but really I was only proving it to myself.

Kora described the fact that she lacked direction and felt like her life was quite disorganised and lacked purpose. Anorexia became part of her way to establish a purpose and direction.

Kora: I was quite lost. I had no direction... there wasn’t really any normal parenting about life and society and that. And I was quite lost about where
my place was in the world. Like all that sort of thing kind of contributed to the punishments and the anorexia.

**Food, weight, or body representing something else**

Aspects of anorexia were meaningful in literal and alternate ways for different people and at different times. More literal interpretations of food and the implications for size and body will be covered within theme of body image. In this section, the focus is on participants describing broader interpretations of their eating disorder and how these interpretations contributed to it. Symbolic meanings attached to food included here are all which extended beyond issues of body image. For example, Kate described the view she had of food and eating as equated to accepting her family’s values, practices, and expectations. Food became greater than just something which contributed to her weight, it had these additional meanings which contributed to her reasons for restricting.

Kate: *We all come together for meals usually and so I guess at meal times there’s like the combined energy of the family, and it was kind of like saying ‘look I don’t accept – I don’t accept this. I can’t handle this’... The meaning that I’d attached to it, like you’re accepting the energy of the family and the life that’s going to come.*

Another example of weight becoming symbolic of other aspects of participants’ lives was weight reflecting how much control they had over their lives. In addition, progression or control of their anorexia started to reflect how good they were at managing their initial reasons for developing anorexia, for example, how ‘good’ they were as a person. Anabelle’s symbolic interpretation of food has been outlined previously as she interpreted food as representing selfishness, being a ‘bad’ person, and that restricting represented giving and providing for others.

Anabelle: *I thought that having food used money and I was already big enough and if I eat more then I’ll be taking and I want to give. I’ve always wanted to give and I was like, ‘oh my gosh, I’m being selfish. I don’t want to be selfish because it’s bad’... I used to go to people’s houses and I wouldn’t even drink their water because I’d be taking from them, let alone have their meals.*
Collette interpreted her emotions through her food and body noting how this was both a contributing factor and a defining feature of anorexia. In the following quote she describes the meaning of her weight on her self-esteem and sense of value, and how this was impacted by events suggesting she was not severe enough to receive help.

*Collette: I was starting to interpret the way I felt through food and through my body and so I guess it was like, while I was being told I wasn’t sick enough [through being denied treatment multiple times for not meeting the requirements], so I kind of thought, ‘well then I’m not a good enough person’. And it was kind of reinforcing those ideas.*

**Summary**

Eating practices and features of eating disorders were important to the participants in more ways than one. The additional meaning and associated consequences they began to perceive during the course of their anorexia contributed both to its development and/or maintaining the progression. Markers of the participants’ eating disorders became attached to feelings of increased coping and problem solving. Furthermore, aspects of food and weight were also meaningful in other ways such as representing the expectations of others, or how virtuous someone was. Lastly, some participants commented on the way anorexia had developed as a method of defining their sense of self, especially during a time when their concept of their own abilities, future, or values was vulnerable or indistinct.

**Body Image**

A major theme with participants centred on the concept of body image and ideas of attractiveness. Many of the participants also commented on the over-emphasis of issues of body image and attractiveness as causing anorexia. Participants discussed the role of perceiving themselves as fat and wanting to change this, especially at the beginning stages of their disorder. Only two participants mentioned their anorexia stemming from a desire to be more or less attractive. Others specifically disagreed with the common assumption that they experienced anorexia for vanity or beauty-related reasons. Aside from perception of self, the importance of being more socially desirable as a contributor was outlined.
‘Fat’ and the desire to change

Perceiving oneself as ‘fat’ and wanting to lose weight as a result of that perception, was emphasised as an initial cause of anorexia for some. For those who also had a continued distortion in the way they looked (i.e., perceived themselves as ‘fat’ even when underweight), the perception served as an additional perpetuating factor, contributing to the progression of anorexia. For Natalia, the change in her perception of herself was the key trigger to starting anorexic patterns.

Natalia: It was a comment, [it] lead to me looking in the mirror and the next day just, boom, it started... It just set something off in my head.

Some of the women had a longer history of seeing themselves as larger, or at least not being slim, which combined with other contributing factors resulting in them developing anorexia. For example, Eva described struggling with body dysmorphic disorder and how this prevented her from being able to see the extent of her anorexia.

Eva: I was adamant that there was nothing wrong with me. Then one day my brother, he took a video of me walking across a room, and for some reason when he showed me the video I saw what everyone else saw. And it’s the only time that I’d ever seen myself as thin. I looked horrible, it was really distressing. ... For as long as I can remember I have never thought I was smaller than other people.

An extension of perceiving oneself as being fat was being very critical of any evidence of body fat, and then working through anorexia to eliminate this. Maliha considered that this intense self-criticism was an important contributing factor, along with her continued belief that she had excess fat in spite of her actual weight or appearance.

Maliha: I used to write really derogatory terms on my like self in vivid... like just “huge” or “fat” or “ugly”... It was just this constant feeling of I don’t like this, I just don’t like the fat over here, I just don’t like this, I’ll just lose this little bit of weight here, I just don’t like this, I’ll just try and get rid of this little bit.
Extreme thinness in relation to attractiveness

There was a mixture of opinions with regard to the concept of striving for thinness due to wanting to be more attractive. The majority of the participants did not perceive the desire to appear a certain way because of its relationship to social norms of thinness emphasised in some media significant. Primarily, participants were more likely to perceive their thinness as important to themselves, with their own set of beliefs and values attached to thinness, rather than in relation to the value of thinness to others.

Natalia was the exception in that she associated thinness with attractiveness especially at the start, and this was considered a key cause for her anorexia, but tended to become less important as it progressed.

*Natalia:* My mum's really skinny, so for me, obviously that's kinda the first role model, your parents. And my dad's really slim as well. He runs every day, he works out every day. My family are all very fit and quite small. So, yes, I thought I kinda had to be more like that.

Contrarily, Kora’s motivation to avoid further sexual abuse contributed to her desire to be more severely anorexic. As she viewed extreme thinness as being less attractive, she believed she could potentially reduce the likelihood her abuser would find her attractive, and then potentially reduce re-victimisation.

*Kora:* It was more about the control and [to] look hideously ugly that I wouldn’t be wanted by men.

Other participants specifically disagreed with the emphasis that treatment providers and other sources of information placed on the role of the media in causing or contributing to eating disorders. Many of this group felt that the promotion of this perspective meant that as a result, there was a lot of misunderstanding and assumptions made by others that people with AN wanted to look like runway models.

*Collette:* I don’t think it’s about the media and I think that’s where people go wrong because they think, ‘well if you deal with that side of it then you’re going to be fine and we’re never going to have them again’...

People often treat them as being like this person’s really superficial and they’re just wanting to lose weight to get skinny and look good. Well, hell
no! [laugh]. Why would you go through all that hell to lose weight, you know?

Anabelle: There's the type of people that do it to look a certain way and there is the type of people that do it to feel a certain way. The type to look a certain way is a bit easier, I reckon, to treat, usually the younger ones who are just coming in and they want to look like those models and everything and it's easy for you to go then, 'oh, no but you're small, look compare yourself to this and this and this'. Whereas if it's a person that's doing it to feel a certain way it's really hard for someone to go no just don't feel like this you can feel like this. You can't objectively see it.

Social desirability

The beginnings of disordered eating or eating restrictions were often related to social relationships. A key aspect of this was in relation to dieting and the start of some participants experience with anorexia beginning with a diet. In addition, the desire to be more like others in the participants’ life, or strive towards something valued by others, was also a theme.

Both Scarlet and Maliha started their development of anorexia with dieting. Scarlet began dieting in response to peer dieting and concerns about weight. Maliha started dieting and considered it exciting and fun at the time, presenting it to her peer group as something to participate in (prior to her having a diagnosis of an eating disorder).

Scarlet: It's like that age and everyone's like 'oh, I'm dieting' and I was like 'uh, I might as well join the club'. And it just kind of went too far.

Maliha: I'd tell my friends about it, I'd be like 'Oh guys, this is like the coolest thing ever' and they'd just look at me like 'that's really weird', and I'm like 'No, no, it's like the best thing ever, like you don't understand, it's just so cool'.

Similar to the suggestion from the quote above from Scarlet, there was the additional factor of striving towards something valued by other people and that this was taken to the extreme. For her there was an undertone of working towards something not initially valued by her but that became valuable because she was
good at it. Similarly with Kate, she described trying to keep up with others in her family and also work towards something other people valued.

Kate: *I wanted to really, probably, maybe look really good but at the same time I knew that it wasn’t going to work. I could never be something or look some way that someone else wanted me to because it would never be enough. Because it was proving that no matter how hard I tried to be something that someone else wanted to be it would still not be enough for them or for me.*

**Summary**

Overall, there was a variety of perspectives around the influence of body image and issues related to body image contributing to participant’s anorexia. There were a number of participants for whom perceiving themselves as having excess fat was a primary reason to start engaging in methods to lose weight which became extreme. The influence of this perception on the maintenance of these behaviours was significant in those who experienced persisting distortions of their weight, seeing themselves as much larger than they were. Another theme was the control of weight and eating in relation to social desirability and peer expectations. This contributed to anorexia by increasing the value of weight loss or other aspects initially, before the participant started to value it for themselves.

**Perceptual and physical dispositions**

A noticeable theme emerged around the impact of early experiences and perceptions occurring prior to the participants developing anorexia. These were considered causal in the sense that the participants already had problems with aspect related to eating disorders and these experiences or dispositions made anorexia more likely for them. In addition, some participants mentioned changes in their physical state which made anorexia easier or more tolerable. These dispositions included physical components: tolerance or lack of hunger, negative association with food or eating. Moreover, concerns about weight and shape, including prior to anorexia starting. Lastly, there were many participants who described the impact of modelling from other people, especially family, around eating, exercise, weight, and body issues.
Hunger

The concept of hunger was described by many in relation to their eating disorder and how either their control of hunger at the time, or the lack of hunger they felt contributed to their anorexia. For those who described a high level of control of their hunger, they often also described the realisation that food was optional for them, that they could function without it.

Anabelle: When you can find that you can survive without food then you’re fine. Yes! I don’t need any food.

Eva: I just found that I wasn’t hungry because, you know, when I went out with my friends, first of all, I was just so tired that I could barely do anything. I didn’t have the energy to stand around or even talk very much… Yeah I sort of figured out that if you are starving and feel like are going to die because you haven’t had any food you just wait 20 minutes. It goes away, the feeling disappears… I found that really helpful, like when I was trying to stay thin and not eat. I was just like, if I just wait I’ll feel better.

There were also a subset who had reduced levels of hunger prior to the onset of anorexia where reduced eating and perceiving that they did not need food contributed to the onset of anorexia.

Collette: I stopped getting hungry in my first year of uni because I got really stressed and so, well, I didn’t realise that I was hungry, and I was doing a lot more exercise and stuff and I just started to restrict a lot… but I didn’t know I had an eating disorder.

Negative association with food or eating

Another theme was the impact of having a pre-existing negative association with food or eating. Participants who experienced this indicated that their prior experiences with food or eating meant that it was easier for them to sacrifice this. In some instances this was a subconscious process whereby the person was not aware that they had a particular dislike for food or eating at a particular time or place, but this became apparent with hindsight and treatment.

Kate: I had stomach aches when I was growing up and stuff and I guess food and my stomach and stuff had always felt like something I couldn’t
really control. Like I wasn’t that attached to it, you know. I didn’t really understand or know why I got stomach aches and things and so, yeah, it was something that I could easily distance myself from and be like right [laughs].

Kate, as well as some other participants, also experienced difficulty with the process of eating which developed during her anorexia and this contributed to it being maintained.

Kate: When I was a kid and sitting around the family dining room and that feeling of the food really feeling like concrete going down my throat. It just got to the point like why – I’m not getting any satisfaction about eating this. I’m just so stressed out about eating it. Why should I do it? I don’t want to try and do it. It’s not worth it for me to try so hard to eat this because it just feels so terrible.

Kora had a different experience where she had many negative experiences with being deprived of food and the development of this as a method to punish herself as well as a growing acceptance during childhood to feeling hunger.

Kora: One of the forms of abuse that I had when I was little from my mum was deprivation of food... And I probably think that it’s why I’ve got disordered thoughts from eating. And I think I remember my mum saying that I don’t deserve to eat because I’ve been a bad person and obviously that’s carried right through and thinking thoughts about myself and that probably did contribute a lot towards the anorexia thing. Because I already knew how it felt to not eat for a certain amount of time and I knew that I could make it.

Collette had a history of not eating lunch, especially if she felt lonely or was isolated from her friends. She perceived this as originating from early bullying occurring at lunchtimes during primary school. Although she did not recognise this as a potential cause until after treatment, lunch was one of the first meals that she had started to reduce or eliminate during her time with anorexia.

Collette: I got bullied in primary school and I didn’t realise but it did have major effects on my self-esteem and stuff... I only realised this when I was in treatment last year or something – but it always happened around
lunchtime so I started to hate lunchtime... And, that [feeling] actually lasted the whole of my schooling... even in intermediate and high school I’d associate lunchtime with feeling alone... [It was significant] because it meant lunchtime was the first time that I stopped eating.

Prior concerns with weight and shape

As discussed in the theme relating to body image, some participants struggled with the perception that they carried excess fat or weight, even when they were a normal weight or underweight. For some this perception occurred primarily during their eating disorder, but for others they had a distorted sense of body image prior to the development of their anorexia and thus they thought it contributed both to onset and progression.

Maliha: I lost a lot of weight [in intermediate], just naturally. Because you grow out of your baby fat and stuff. Just naturally lost a lot of weight but I still I didn’t see that. I don’t think I saw that in myself. I didn’t see that. I just still saw myself as a really chubby person.

In addition to a distorted sense of their weight or shape, some had concerns about their weight prior to their anorexia. For example, Eva illustrates that she had always seen herself as bigger and had been concerned about her weight before.

Eva: I think that I have always had that problem [with body dysmorphia]. Even before I was 13. As a dancer I always, kind of, was concerned about my weight and stuff.

Modelling from others

The majority of participants described events which occurred primarily with their families at a young age where they were influenced to be concerned about their weight, shape, body, eating, or exercise. The strength of this as a perceived cause was relatively small for each individual participant; however, as a group the majority mentioned these experiences as contributing to some degree.

One of the ways in which concerns about body and eating were established was in relation to participants’ families overtly expressing concern or critique about the participant’s body.
Maliha: I was a really chubby child, I remember that. And, so I think maybe that has something to do with it. Like I remember as a kid like my family would say to me, you know, ‘you’re quite big’ – they’d be like ‘oh, you should play netball. It’ll be fun”, but they were doing it because they wanted me to lose weight.

Natalia: I had never really thought about my body as not being normal but a relative made comments, said, ‘Jesus, how many months pregnant are you’.

In addition to overt comments about weight there was also differential treatment around food, especially between siblings. This emphasised a more covert management of weight.

Anabelle: You saw my sister. She never used to be like that, she used to be this [signal thinness] and they used to give her lots and lots of food but me I was never. I was always quite – So they were like ‘no, can’t have this, can’t have this’ so in the end I was like, ‘ok I’m not going to ask’. So I was just like, ‘no, I’ll cut out this and I’ll cut out this and I won’t’.

Maliha: My grandmother would go there and she’d cook us something and she’d give me half the portion of everybody else. And I’m like, why do I get half a portion? And so I guess I kinda learnt that I have to eat half a portion because I’m bigger than everybody else... Because my brother was really skinny and I was quite chubby and, like, not like over-weight but just chubby. And, she’d give him twice as much as she’d give me. She’d be like, ‘you need to gain weight, and you need to lose some weight, so I’ll feed you twice as much and I’ll feed you less’. And so I guess I kind of just learnt that if you want to lose weight you just eat less.

There were also influences around the types of foods eaten, exercise and general lifestyle factors relating to food. These were significant for some participants as they wanted to embody these values but took them to an extreme through their anorexia.

Kate: And then I guess another influence of it, just coming from a really healthy eating kind of family and parents who are both really active and
so I was more inclined to be that way and it was me that took it to that extreme.

Also, sometimes the norm of the family played a part in the development of anorexia, primarily the participant having a different weight to others in the family.

Kora: I guess my family were an influence because I saw myself as the fattest of the family. My mum’s side of the family they’re quite slim naturally. And my sister – she was actually on a whole lot of drugs which caused her to be really skinny – but I wanted to be like that as well.

Lastly, there was a significant influence of other family members modelling disordered behaviour relevant to anorexia. Namely, this was a family member for Kora modelling anorexia and family members modelling obsession for Kate. The exposure to these two problems showed Kora and Kate a way that other people manage and cope with their life. For Kora her aunty experiencing anorexia showed her this possibility and made it easier for her to develop it as she already had an idea of what it looked like.

Kora: My mum’s oldest sister probably still has anorexia. I was about 12 when I sort of noticed her eating. Because we went over there and she was cooking up this massive meal for her husband, they sit down to have the tea and she’s just like eating a leaf of silverbeat. And I was really confused. Like, why did you just cook that whole thing up and not eat it. So I went home and I was talking to my mum about it and she’s like, ‘oh, she’s anorexic’. So I sort of thought internally about it... I think because of knowing that my aunty had anorexia it was sort of like an idea about it – about punishing myself.

Kate’s family mind-set and obsessive focus on farming and other things modelled this lifestyle for her from a young age which she later adopted in relation to her food and eating.

Kate: I’d grown up with that obsessive mind-set so food just became the thing that I used it on because I didn’t have anything else.
Summary

Overall, there were a range of factors which participants mentioned pre-empted their focus on aspects of their eating disorder. These factors were quite widely ranged from aspects about body to aspects about eating. They also spanned different types of influence from overt suggestions or experiences with aspects of eating or appearance, such as digestive pain, or negative comments about weight. There were also more covert forms of modelling and treatment from others which became associated with aspects of eating or appearance, such as the normalisation of obsessions or negative associations with eating at a particular time. Finally, experience of hunger was important for many women with different experiences contributing from a lack of awareness of hunger to direct control of hunger.
Section 3: Causes of subsequent relapses

The focus of this section is to illustrate the participants’ perceptions of the causes of subsequent relapses of AN. The participants discussed the contributing factors and what they thought did and did not contribute to subsequent episodes developing. Although the focus of this section is on relapse with anorexia, some participants also experienced other eating disorders following their struggle with anorexia. Therefore some of the causes may also relate to these general forms of relapse into disordered eating but will be indicated as such. The main focus will be on unique or additional causes although as factors from the initial cause were typically similarly relevant.

There was variety in the type and timing of relapse experienced. Some participants described mini relapses where they were not hospitalised or may not have engaged in treatment but they themselves considered it a relapse. A selection of participants described not ‘fully’ recovering prior to relapsing from their initial episode and others. As the definition of recovery is relatively indefinite, it is difficult to necessarily distinguish these participants as having a different perspective of relapse compared to others who defined their episodes as being distinct. However, it could be assumed that those who had episodes in close succession lacked an established period of time living a ‘recovered’ life. For the purpose of examining different perspectives on the causes of relapse, all are considered relevant provided the participant deemed the experience a relapse. Furthermore, participants were asked to consider what they predict might contribute if they did relapse, i.e. projection of predicted causes. For information about the context and extent of relapses for each individual participant refer to Appendix F-M.

Parallel to original causes

The women discussed a range of factors which related to the initial reasons they considered they developed anorexia. There were typically fewer reasons or causes provided for relapse and these were often synthesised to factors which were important to the participant in the development of their anorexia. This pattern of the participants thoughts in regards to the main causes are most evident in this theme relating to parallel causes.
The factors relating to original causes varied between participants and related to what they perceived were very important from the initial causes, such as loneliness. The depth of explanations for initial causes was typically reduced when describing relapse experiences, hence in comparison there are fewer similarities across participants. Table 5 indicates the links between participants and the themes endorsed from the original conceptualisation of aetiology. The proceeding section will cover the themes significant by utilising the same structure from the section on initial causes.

**Power and control**

One of the factors raised was the impact of feeling out of control again. A desire for control was a key factor for most of the participants. All of those who considered it an important factor in the initial development also considered it important in contributing to relapse. As discussed in the previous section, issues of control mainly revolved around feeling out of control or that they were losing control over their lives. Anorexia served as a way to exert control over their life and gain some autonomy and power within their life. The concept of having little control over their life was similar during the initial cause; however, relapse experiences relating to treatment were different with regard to the extent to which participants lacked control and autonomy in their life. Participants typically perceived the same feelings of lack of control regardless of this distinction.

Feeling overwhelmed contributed to feelings of being out of control, especially not being able to effectively manage or control emotions. Hence, anorexia became a way to cope with these feelings and was easier to engage in during relapses, since it had served as a method to deal with these feelings previously.

During AN, a lot of autonomy was removed to enforce recovery and this loss of control had significant impacts for Collette, Anabelle, Scarlet, and Kora. During treatment they had little control or choice over their life. Much of their day may have been determined, their food chosen, their treatment chosen, and so forth.
Table 5. Endorsed causes of relapse which paralleled initial development.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natalia</td>
<td>Body image</td>
<td>Extreme thinness in relation to attractiveness</td>
<td>Feeling unattractive due to weight</td>
<td>General importance</td>
</tr>
<tr>
<td>Collette</td>
<td>Power and control</td>
<td>Feeling overwhelmed and unable to cope Autonomy</td>
<td>Feeling out of control Life being governed by others Stress and pressure</td>
<td>High importance</td>
</tr>
<tr>
<td>Eva</td>
<td>Power and control</td>
<td>Feeling overwhelmed and unable to cope</td>
<td>Stress and pressure</td>
<td>General importance</td>
</tr>
<tr>
<td>Pleasure</td>
<td></td>
<td>Alleviating other mental illness or negative mood states</td>
<td>Loneliness</td>
<td>High importance</td>
</tr>
<tr>
<td>Kate</td>
<td>Power and control</td>
<td>Autonomy</td>
<td>Feeling out of control Controlling other areas of life Life being governed by others</td>
<td>High importance</td>
</tr>
<tr>
<td>Obsession</td>
<td>Obsession</td>
<td>Obsession in myself and others</td>
<td></td>
<td>General importance</td>
</tr>
<tr>
<td>Symbolism</td>
<td>Anorexia as part of defining my identity</td>
<td>Uncertainty about identity</td>
<td></td>
<td>High importance</td>
</tr>
<tr>
<td>Maliha</td>
<td>Pleasure</td>
<td>Alleviating other mental illness or negative mood states</td>
<td>Depression, anxiety, panic attacks</td>
<td>General importance</td>
</tr>
</tbody>
</table>
Table 5. *Endorsed causes of relapse which paralleled initial development.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kora</td>
<td>Symbolism</td>
<td>Coping strategy</td>
<td>Stress</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Perceptual and physical dispositions</td>
<td>Hunger</td>
<td>Lack of hunger</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Power and control</td>
<td>Feeling overwhelmed and unable to cope</td>
<td>Feeling out of control</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autonomy</td>
<td>Life being governed by others</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Self-worth</td>
<td>Self-worth and self-punishment</td>
<td>Memories and thoughts triggering low sense of self-worth (e.g., distressing memories)</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Perceptual and physical dispositions</td>
<td>Negative association with food or eating</td>
<td>Past distressing memories</td>
<td>High importance</td>
</tr>
<tr>
<td>Scarlet</td>
<td>Power and control</td>
<td>Feeling overwhelmed and unable to cope</td>
<td>Feeling out of control and overwhelmed</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Self-worth</td>
<td>Average and lacking distinction</td>
<td>Perceiving myself as not having any other strengths</td>
<td>General importance</td>
</tr>
<tr>
<td>Anabelle</td>
<td>Power and control</td>
<td>Autonomy</td>
<td>Lack of input in treatment: no control</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Obsession</td>
<td>Possession</td>
<td>Myself as anorexia; cannot separate it from myself</td>
<td>General importance</td>
</tr>
</tbody>
</table>
Table 5. *Endorsed causes of relapse which paralleled initial development.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-worth</td>
<td></td>
<td>Self-worth and self-punishment</td>
<td>Thoughts relating to being a bad person, taking too much, a burden</td>
<td>High importance</td>
</tr>
<tr>
<td>Symbolism</td>
<td></td>
<td>Food, weight, or body representing something else</td>
<td>Weight as representing greed or being ‘bad’</td>
<td>High importance</td>
</tr>
</tbody>
</table>
Collette, Anabelle, and Scarlet referred to loss of autonomy in treatment for anorexia, whereas Kora referred to inpatient treatment for general mental health issues. For Collette and Anabelle, the lack of control over their weight and the role of their parents in either enforcing treatment conditions, and/or providing their view of the problem often to the exclusion of their own perspective, was a key trigger to feeling out of control and with little self-determination. Both Collette and Anabelle endorsed the theme of lack of control as highly significant in contributing to relapse.

Collette described a series of events illustrating her lack of control. She began her process with treatment by being hospitalised, and during this time was threatened multiple times to comply with eating and treatment engagement. Later, Collette began to resist the strict weight gain rules enforced as part of her treatment, until she was discharged from inpatient care. Following this, her parents took responsibility for enforcing weight gain and diet, monitoring every meal and her activities:

Collette: The conditions for [working after discharge] was that my mum would come in for every meal and every break under the sun and sit there with me and make sure I ate and if I didn’t eat she would tell my [employer]. So, I just had to eat and she just took all the control away. I couldn’t choose what I ate or whatever because I think she knew I wasn’t very well to [be discharged]. And my parents would try and control my weight through [out-patient treatment] and get weight updates and stuff... I hated it... everybody was controlling my life, my eating, except for me.

Following this series of battles with her parents and a growing feeling of being out of control, Collette started to resist their efforts, relapsing into disordered eating, exercise and compensatory behaviours:

Collette: They would try and control it but I’d just had enough and so I resisted it more and more until I started doing ridiculous things. I would refuse to eat, I’d throw the food away, all that kind of thing. I started purging and then started running away from home and exercising for hours on end and not eating.
In addition, Collette felt both out of control when she was restricting and rebelling against recovery, and when she was forced to recover. These feelings of perpetually being out of control over her life or behaviour made her feel worse during this time and in turn contributed to greater issues with relapse during this time.

Collette: I purged once and after that it started happening and I hated it but I couldn’t control it and again, I felt like I wasn’t in control of my restricting or my eating, or my eating and my purging or my not purging and then it was a two-way thing. Like, I wasn’t in control of the eating disorder side but I wasn’t in control of the non-eating, like the rest of it... my life in general.

Scarlet described a similar experience to Collette, giving into the demands of parents and professionals during her treatment, feeling out of control and without power, then exerting this through relapse at a different time.

Scarlet: When you’re listening to [the anorexia], to everyone else it’s like, ‘well, I’ll show you that I can do this and that I can lose the weight’, so then when I went into hospital it was like, ‘I can show you – I’ll show that I can do what you want but I can also do what [my anorexia] wants kind of’. And then when I got out it’s like, ‘well, I’ll show you that I can do it again’.

Compared to other participant, Anabelle had a greater number of relapse experiences. Her description of control related mostly to the degree of influence she had over treatment. She perceived the professionals as making assumptions about her and the reasons for her anorexia. She considered these to be damaging as she would receive treatment she disagreed with, and would start covertly or overtly resisting, possibly leading to relapse.

Anabelle: The stereotypes around it put barriers to the treatment people give because you’re not going to ever address what needs to be addressed if you’re just going to have this assumption. Like personally mediated racism but without the racism. Because if you go into the assumption that this is what we are going to provide you because this is what we think you
need, you don’t provide them all the options. You exclude some things and that option that you excluded might be the one that could fix them.

In addition, Anabelle perceived the preference for professionals to take other people’s perspectives over her own a contributing factor to relapse and resistance, especially in relation to her parents.

Anabelle: They [the treating professionals] don’t listen to us! We’re crazy! Why would you listen to someone who’s crazy? I’m not completely crazy. That’s why I got taken off the [Mental Health] Act because there was no reason for them to put me on it because I could still articulate myself... when I was younger as well there was too much – Everything was taken from what my parents had to say, rather than what I had to say. And it’s still kind of the same, like, if they say I’m doing something then that’s what goes. It’s not because I’ve said that.

Kora who discussed inpatient treatment for other mental health difficulties, found that she also had little say in her day, activities, treatment at the time, or freedom, contributing to her feeling like she had little control. During this time she started to relapse with her anorexia as a way to exert some control.

Kora: When I was in there I sort of felt, again, like I was out of control. And you kind of are when you’re in there because you don’t have full control of what you want to do and where to go and even the medications and treatment that you have. And so I started to not eat again so I spent like about 2 months not eating and it was quite easy to do at the start.

Although only experiencing periods of increased restriction in her diet and weight loss, Kate predicted that she too would relapse if she was in a situation where her life was governed by others and where she had little say.

Kate: Yeah, like if I went and married someone and they were like you are going to do what I want you to – like you’re going to go and start a fruit shop and that’s all you can do for the rest of your life then I would relapse probably [laughs].

Kate was more inclined to relapse and restrict when she could not control the outcome of her behaviour, i.e., when she felt like what she was doing was not
having the outcome or effect that she expected. In this way, she felt ineffectual and another way to feel in control of her abilities was to restrict food.

*Kate:* I felt like I didn’t really have control in the way that my work wasn’t really producing results. So I was like, ‘why isn’t, why aren’t I getting there. Why don’t I have control over this? I study and then I should get the marks I want and it’s not happening and I can’t control it’ – so food, I can control that [laughs].

As described, another factor contributing to relapse was the experience of stressors or challenging events which many participants considered increased (or would increase in the future) their potential for relapse. For example, Eva described the impact of stress on her risk of returning to anorexia and also illustrates a degree of uncertainty about her ability to prevent relapsing under these circumstances:

*Eva:* I just don’t cope with stressful situations. That’s how I cope, which is not really coping at all. But in therapy, you have to do like a relapse plan. Like, what are you going to do if another stressful situation arises? How are you going to cope? Are you going to stop eating again? And, I don’t really know what I’ll do exactly but I think the first step would just be to ask someone or tell someone that I’m having trouble: My mum or my partner... Hopefully that will work long term.

**Rewards**

Although a common and significant part of descriptions for initial causes, a sense of accomplishment or successfulness was less important for participant’s sense of relapsing. Rather, the role of anorexia in alleviating other mental illness or negative emotions was perceived as important. Eva was one of the main participants who rated this as important for both initial development and relapse, along with Maliha.

*Eva:* There are days where I screw it all up and don’t eat anything... Usually [I stop eating because of] loneliness or I’m more depressed than usual that day or if something shitty happens.

*Maliha:* But generally like low mood – if I’ve had a panic attack I won’t feel, you know, you just get so [pause] [Interviewer: Worked up?] Yeah.
You don’t want to eat. Yeah, just depends on my other sort of mental health, how that’s going. And if it’s not going well, I’ll think about going back to the anorexia.

There were those who described the role of depression in contributing to relapses or difficulty eating; however, for these participants it was an additional factor not raised when describing the initial causes. Thus, for these participants it is described in a later division of this section, relating to causes that were present in the initial development but were altered due to the experience of their initial episode.

**Obsession**

A factor described frequently in the initial cause of anorexia was less commonly endorsed as a component of relapse. Nevertheless, Kate described the impact of general obsessiveness on her potential to relapse. Kate’s own level of obsession in other areas of her life could contribute to becoming more obsessive about food.

*Kate:* When I’m not aware that my thoughts are getting obsessive then I can easily start reacting and start counting the calories of the food or trying obsessively to only eating healthy things or cut certain foods out and stuff. Or even just constantly worrying about something. Yeah, then I will – [I] could easily relapse.

In addition to her own level of obsession, Kate described also being sensitive to obsessive traits and behaviours in others and that this could increase her own obsession around food and restriction.

*Kate:* I really pick up on obsession quite quickly... If I was in a really obsessive environment then I would easily relapse. If I maybe were to go and join NZ ballet then I would be completely obsessed.

Hence, for Kate, the content and level of obsession in her thoughts, regardless of whether it is exacerbated by being in an environment with others who model obsession, will contribute to this obsession migrating into control of food and eating as it was with her anorexia.
Possession was also important for Anabelle in the sense that she continues to struggle to separate herself from her anorexia. She described the solidification of anorexia as part of who she is and the impact on being able to find direction or have other goals.

*Anabelle: [Anorexia is] like a negative thing that just multiples and encompasses all of you. Until there’s no more of you left. And the longer you have it the less of you there’s ever going to be as well because you kind of lose your direction in where you want to go.*

Furthermore, Anabelle’s struggle with separating herself from her anorexia and the thoughts and behaviours associated with it contributes to her relapsing. For her, anorexia is ongoing, without pause, and is conceptualised as herself, i.e. suggesting that she is her anorexia and she cannot escape herself.

*Anabelle: I’m not with [my parents] 24/7 and sure, I might be at the back of [their] mind, that, ‘what am I going to do’, but I have to live with myself all this time. And you just get sick of it. And if you don’t sleep well, that’s even worse because you rely on your sleep to get that time of relief. But if you don’t get that then it’s just like, [pause] I’m stuck with myself even more today.*

**Self-worth**

Another theme of note related to self-worth, self-punishment, and thinking that they are average and lacking distinction from others. The areas of self-worth and self-punishment are relevant to Kora and Anabelle who both considered these crucial in their original development as well as subsequent problems with relapse, or desire to relapse. For example, Kora describes the impact of remembering difficult experience in her past which can contribute to restricting again.

*Kora: It’s the thoughts too that are there and the memories and the triggers. So sometimes if I have them it can trigger me to stop eating.*

Kora also described some continued hating of herself and it contributing to her restricting again. Originally, this related to her perceiving herself as being a bad person in general and needing punishment; however, now it is specifically related to eating practices and perceiving that she has overindulged.
Kora: And then sometimes you have those random days where you might pig out [laughs] and then I’m like, ‘Uh! I’m not eating tomorrow’. And so I won’t, and then I won’t eat for like a week, and then I’ll start eating again. But I’m not actually too sure of that’s anorexic thoughts or because I pigged out and hate myself for it.

Perceiving herself as a ‘bad’ person was a significant contributor for Anabelle; however, she recognised that although these thoughts are the same for developing relapses, the factors contributing to her thinking she is a ‘bad’ person have changed in some ways. For example, below she describes that thinking she is a ‘bad’ person will contribute but that the reasons have changed; in that, if she perceives herself as causing her mother distress or pain she will start to relapse. This differs from her original reasons as a child which related to her mother being distressed by other people and Anabelle responding by trying to reduce her impact on her and be “perfect”.

**Anabelle:** The fact that I’m a bad person keeps it going but the reasons why I thought I was a bad person initially doesn’t – isn’t so much applicable now... As soon as I start thinking that I’m a bad person to [my mother] then it’s all over. That’s when I start going backwards.

And, tied inexplicably with this is Anabelle’s desire to punish herself through her anorexia when perceiving herself as a ‘bad’ person.

**Anabelle:** I think my eating disorder is my punishment for being a bad person.

Thus, her reasons are slightly different now than when it originally developed but those thoughts are still significant in contributing to developing anorexia again. Her continued conceptualisation of anorexia as a way to reduce the impact of this problem of being a ‘bad’ person also contributes to relapses. The practical, day-to-day process of restriction and of denying herself food (or other things in relation to her anorexia, e.g., warmth) may be especially important in perpetuating self-punishment.

As described in the previous section, Scarlet’s perception of herself as being average and lacking a clear sense of success or distinction contributed strongly to her developing anorexia after beginning dieting. This cause remained
significant to her developing relapses. For example, when describing what would be necessary for her to have to prevent further relapses, Scarlet indicated a better sense of her strengths:

Scarlet: [I would need] more awareness of myself: what I’m capable of other than anorexia. Like, what I’m good at.

**Symbolism**

Aspects of symbolism were repeated as contributing to relapses or the possibility of relapse, including the role of AN as a coping mechanism. In addition, the symbolic representations of food, weight, and body as relating to other aspects of life were important.

In response to stress, AN continued to be seen as a coping strategy, even after treatment. Maliha identified the role of anorexia in acting as a coping strategy for her, allowing her to feel more in control of her emotions and life.

Maliha: [My anorexia] wouldn’t have come on as strongly but it would have just been a coping mechanism that I would have gone back to just because I find it familiar. And then – like even to this day, there will still be days where I’ll miss a meal if I’m having a bad week or something.

As illustrated previously, Anabelle considered her continued use of symbolism in food and weight as representing her being a bad person as contributing to her relapses.

Issues of identity continued to be important for Kate in contributing to restricting or relapse. She discussed continuing to form the identity she wants for herself and how this insecurity can contribute to her controlling food instead. Kate perceived this issue of identity and susceptibility to wanting to change her sense of self as highly significant in contributing to relapse.

Kate: I guess your body image is attached to your identity quite a lot but then taking it to the more extreme extent and for me probably – so someone with anorexia might have extra pressures or a vulnerable perception of their life at that time and so they’ll attach more importance to food and the need to kind of disintegrate their identity more.
Body image

Issues of body image were important for a selection of participants in relation to relapse. Natalia emphasised the significance of feeling unattractive and how her perception of her own attractiveness can contribute to the potential for relapse. For example, below she explains the impact of thinking that her partner wanted her to look differently and how this made her re-evaluate her attractiveness in relation to her weight.

Natalia: ‘This girl, you want me to look like that. You want me to be skinny. ’ I think it just kinda triggered something in me... he was the only person that I had in the world and I was like, ‘oh my god. He doesn’t find me as attractive as maybe I thought he did.’

Scarlet continued to view her social context as important for her potential for relapse. She emphasised the role of her friends in supporting dieting and the continued value within her social group to be thin and to restrict calories. For example, in the following quote Scarlet describes how a change in her social environment could reduce her risk of relapsing.

Scarlet: Just a better environment. When you’re an adult I guess there’s like less diet[ing], or talk of it because it’s what everyone talks about it at school. And when you’re an adult it’s not really there I guess. So more of a different, more stable environment.

Perceptual and physical dispositions

Past events or physical experiences which impact the ability to manage weight were relevant to risk of relapse. Maliha explained that she often lacks hunger and can experience repulsion towards food. This was viewed as a significant factor contributing to risk of relapse as it required conscious monitoring and strategies to overcome it.

Maliha: That’s one of the things that I constantly say: ‘I don’t have a hunger mechanism and I don’t have a sleep mechanism.’ Those are the two things that I’m missing as a human being. Okay. It’s just what I’m missing. And so I know I have to eat so it’s like, ‘I know that human’s eat three times a day, so I’m just going to eat three times a day. This is what I’m going to do, even if I’m not hungry, I have to eat three times a day.
because that’s what you do. I know I don’t feel hungry but this is what you have to do’… sometimes I’ll even feel repulsed by the idea of food.

Kora described the impact of past distressing memories on her ability to manage her anorexia as outlined previously. Part of this also relates to her negative associations with food formed through past traumatic and difficult situations, such as, neglect.

Summary

Issues of control and autonomy continued to be important in contributing to relapse, especially for those who have experienced full relapses. The engagement with treatment and experience of autonomy within treatment was also important for some. Overall, the factors endorsed and described within this section are the factors typically perceived as important in explaining the initial development with anorexia. Descriptions of initial causes tended to be more extensive in comparison, thus a greater number of causes were also described. This may be due to participants suggesting that relapsed involved very similar reasoning and did not require as much explanation.

Influenced by initial episode

There were a range of causes presented when discussing relapse which were not novel but became important after having already had an experience with anorexia. These influences were often present during the participants’ first experience of anorexia but were not perceived as causes during that time; instead, causes in this theme became important for future experiences of anorexia. Sub-themes are distinguished from other themes for this section on relapse by the named presence of these issues prior to discussing relapses, but where they were not endorsed as causes (as with the previous theme). Furthermore, sub-themes in this group should primarily be present or possible across both experiences (initial and subsequent episodes of anorexia), rather than inexplicably linked to having recovered (or to having attempted to recover). Table 6 indicates the distribution of these types of causes for each participant. As indicated, some participants did not perceive any specific causes of this type.
Table 6. Endorsed causes of relapse which became more significant following initial episode.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natalia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collette</td>
<td>Power and control</td>
<td>Accepting the consequences</td>
<td>Lost so much of the things I wanted I might as well retain this (my anorexia)</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Undermining recovery</td>
<td>Resistance to weight recovery</td>
<td>Weight started to be important; did not want to gain and lose control</td>
<td>General importance</td>
</tr>
<tr>
<td>Eva</td>
<td>Power and control</td>
<td>Accepting the consequences</td>
<td>Negative consequences sometimes do not matter; do not care about them</td>
<td>General importance</td>
</tr>
<tr>
<td>Kate</td>
<td>Power and control</td>
<td>Accepting the consequences</td>
<td>Negative consequences sometimes do not matter; do not care about them</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Rewards</td>
<td>Security</td>
<td>Sense of security and protection</td>
<td>General importance</td>
</tr>
<tr>
<td>Maliha</td>
<td>Power and control</td>
<td>Change and uncertainty</td>
<td>Difficulty coping with change, transition, and uncertainty</td>
<td>High importance</td>
</tr>
<tr>
<td>Kora</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scarlet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6. *Endorsed causes of relapse which became more significant following initial episode.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anabelle</td>
<td>Undermining recovery</td>
<td>Resistance to weight recovery</td>
<td>Cannot cope with weight gain</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quality and continuity of care</td>
<td>Disjointed care, lack of support for family, losing gains, poor engagement, judgments from treatment providers</td>
<td></td>
</tr>
</tbody>
</table>

139
Power and control

Accepting the consequences.

The negative consequences of AN on health and other areas of life were accepted due to the perceived benefits. This was described in relation to sacrifice and investment in anorexia, along with the concept of having lost so much in the progression of the disorder that anorexia or thinness was all that they had to hold on to.

Acceptance of the negative consequences of anorexia (e.g., fatigue, social withdrawal) were often observed and noted when describing initial development; however, these consequences were not perceived as a significant cause during this time. Once participants experienced more loss in their life, of autonomy, control, and other factors, the reward from anorexia became more significant. Thus, during relapses when the negative and positive consequences are known as they have already been experienced, this factor of accepting anorexia in spite of the negative was important.

Collette described the positive aspects of anorexia and how her perception of these prevented her from letting go of it and recovering. During her initial development she was aware of the reinforcing aspects of anorexia and the negative aspects (such as feeling dizzy, lacking energy, and fainting). However, this was mostly described in relation to her lack of insight as the cause.

Collette: I think it was when it stopped helping me that I could actually get over it; because I realised that it didn’t help at all.

During her relapse after partial recovery, she noted having lost many valued parts of her life, and how this contributed to low mood and a lack of concern about the negative consequences of AN.

Collette: It wasn’t that I wanted [the anorexia] to kill me but I was just like, ‘well, I don’t want to gain weight and I don’t care what happens’… So I relapsed at the time, and at the time I think I also told myself that I didn’t care what happened if I wasn’t going to uni that year cause my parents had already said you’re not going to uni… I was like, ‘well I don’t have anything to live for so I don’t care what happens; don’t care if I don’t go to uni’.
Eva had a history of restricting her diet prior to the development of full anorexia. She described accepting some of the negative consequences of anorexia during her initial development, such as bruising in bed due to lack of fat, and her role in making the decision to sacrifice her body.

Grace: *In the end it was me that made the decision at some point to stop eating and wreck my body.*

However, she did not attribute these specifically as a cause, more an indication of severity and as a part of the whole experience of anorexia. When describing her recovery, she discussed the necessity of reminding herself of the costs of her anorexia, such as low bone density, and infertility. When considering relapse Eva suggested the dismissal of these consequences as significant, i.e. that if she were to no longer care about these things, she would be highly likely to relapse.

Eva: *It is quite a struggle to stop going back to that. It is a struggle to find something as an alternative. I still don’t really know what my alternative is, apart from, you know, stay healthy enough to have children one day and preferably not be, like, not have osteoporosis because apparently my bone density a couple of years ago was pretty shocking.*

Lastly, when describing the reasons for relapse, Kate discussed the role of accepting anorexia to make up for other things which do not work out in her life. This was important in both her initial development and for relapses, but its identification as a cause only arouse out of discussion about relapse.

Kate: *And, yeah, something about if these circumstances don’t work out at least I can fall back on knowing that I’m skinny and I’ll accept that as a result almost. Like it’s something that I’ve got; no one can take that away from me [laughs].*

**Change and uncertainty**

Fear and uncertainty about change or transition was a theme which extended across participants but was not frequently perceived as a contributing factor. As some participants only noted the stress of change and transition as important when discussed relapse (rather than as part of the initial development)
so for these people it will discussed in the proceeding theme on novel causes for participants.

Maliha discussed the role of transitioning to a new town, new school, and a lack of friends on setting the scene for her developing anorexia at high school. The influence of these stressors and transitions were related to their impact on her sense of identity and ability to re-create how she was to become more popular among her peers. Thus, her anorexia was born out of this desire to be different and the impact of these changes on her self-esteem at the time, such as being more rebellious and frequently getting into trouble.

Maliha: I left all my friends behind and everything: had to start over. And, I just didn’t like intermediate; I didn’t really have any friends. It was kind of like lame. And when I started high school I was like, well okay, I’m going to do something different. I’m just going to be different.

The impact of transition and change, especially on her level of anxiety, became more important as a perceived cause when discussing the possibility of relapsing. For example, Maliha described the impact of starting university and the struggle she experienced with eating lunch in a different environment.

Maliha: [Talking to my counsellor] ‘I’m not, I’m not really eating lunch. I’m struggling with lunch.’... So that would have been a new stressor, like a new environment, new stressor so, coming into uni, starting uni, adapting to... How am I going to sit down and eat here? I don’t know where to eat here.

Rewards

Security

Anorexia could provide a sense of security for participants, giving them a sense of safety or reassurance. This related to both the expectancies and predictability of anorexia in that they know how to achieve certain results, what will happen to their body, and how they will feel. This feature was more significant for relapse as there was a greater understanding of how each woman would feel and how it would impact their life. Kate discussed a sense of security from the feeling of bones which was during her initial development but only
identified as a cause when discussing relapse (i.e., seeking out a sense of security).

Kate: Security – I still got the same sort of security from it. Like, feeling [pause] even just the feeling of being able to feel your bones and things. It kind of is a very real feeling, like this is how the world feels to me; it’s so hard. And there’s just no soft kind of support or good things.

Undermining recovery

The theme of undermining recovery relates to the experiences which hindered recovery. Recovery can only occur after developing AN, hence these factors could be considered as having to occur after the initial development; however, the two sub-themes presented within this category were also present during initial development. These two sub-themes include: resistance to weight recovery, and quality and continuity of care. Participants often acknowledged these factors during their initial development but they were not determined causal. In this category, the process of attempting recovery made these factors more significant and thus were more likely to be perceived as contributing to relapse.

Resistance to weight recovery

This theme was present for many participants during their anorexia, both first and subsequent. Resistance to weight recovery was more frequently described as a feature of anorexia. During the initial development it was also perceived as a consequence of lack of insight or denial, rather than a cause in and of itself. However, this became a more significant feature for participants who struggled with the process of weight recovery during treatment and the acceptance of being a greater weight.

Collette struggled with her process of recovery and the loss of control she experienced during her initial period of treatment. She had described not wanting to recover her weight during her initial experience with anorexia but that this had related to her denial of a problem and that her weight did not matter per se. For her, the control of her food and exercise was what mattered. During her experience of treatment the forced weight gain was too much for her to accept and became a strong contributor to relapsing.
Collette: I resisted [others’ control of my weight and eating] more and more... It was also more about the weight. To me, the numbers started to show whether or not I had control over my life. So like, if it went down and I wanted it to go down; if it went up and I wanted it to go up but I didn’t [want it to] at the time.

Anabelle how she resisted weight recovery and the impact on developing relapses. Resistance to weight recovery was present during her first experience with AN but has become more important in subsequent episodes, preventing her from fully recovering or maintaining recovery for any extended period of time. Anabelle’s difficulty accepting an increased weight once discharged along with the increased freedom to lose that weight contributes to her relapsing.

Anabelle: I’ve had the re-feeding but I’ve never had the headwork to go with the feeding. So as soon as I come out it’s like, ‘OK, what am I going to do with this weight gain now... I can’t handle it’. And I go [sound to represent plummeting down].

Quality and continuity of care.
This theme relates to the quality and continuity of treatment care provided and the way that participants have experienced care. Quality of care refers to the perceived value of the treatment in addressing what they needed in order to increase their likelihood of recovering. Continuity of care refers to the transition from in-patient or out-patient services to discharge and support during this time.

This was a significant issue for Anabelle who had experienced many different treatment types and services, both in New Zealand and Australia. She discussed the impact of being heavily medicated at 12 years old for anxiety and the impact that this had on the masking of her symptoms of AN. Her perception was that these medications, and the misdiagnosis of obsessive-compulsive disorder contributed to her not receiving help earlier; however, it did not necessarily represent an initial cause of her anorexia, rather an exacerbating factor.

Anabelle: [Child and adolescent mental health] were just like, ‘no, just got some OCD’. And I was like, ‘Okay, I’m cool with that, that’s fine with me’. But my parents said that the first thing they noticed was that my weight
just went [sound to represent going down] ... I started cutting things out when I was like 12; then was the worst. Like I would only eat oranges; only oranges and pink jellybeans... But then, they put me on a lot of medication until I was 16 and then they took me off it and then by the time – a year later – I was in psyc. In child and adolescent [for anorexia].

When describing the causes of her relapses her experience of treatment during and when transitioning out, was perceived as very significant. The key aspects of care perceived as important were: discontinuity of care, lack of training or integration of family, poor support for family, not enough cognitive therapy to change thoughts and beliefs, and the gradual acceptance of poorer health.

Discontinuity of care was important to Anabelle as the lack of continuity between past treatment and new treatment or past treatment and returning environment meant that treatment gains were often lost and she would regress into relapse. Lack of family involvement was also partially related to this factor. After treatment Anabelle returns to live with her family and without integration of treatment, she perceived that nothing within this dynamic had changed.

Anabelle: For my continuity of care, like, I never had – like I came back from Aussie and then there would be no care. So I’d make all these gains and then it would all just go [sound to represent going down]. Because my parents – obviously when you’re over there you’re not living with your family, you’re there by yourself. So they hadn’t learnt the skills on how to deal with me now and provide and all that sort of stuff so then you just kinda end back in your old routine. And go backwards.

Poor support for the family, and even perceived blaming of AN on members of her family, were additional causes of relapse or disengagement with treatment for Anabelle. This was especially significant in relation to her other whom she views as her primary support person. Furthermore, thinking that she is the cause of stress for her mother often contributes to her restricting. Therefore, poor treatment support for her mother was perceived by Anabelle as important and that it could have prevented full relapses or prevented partial relapses from developing into more severe episodes of anorexia.
Anabelle: They were always really mean to my mum which wasn’t helpful. Like they used to blame her a lot. I was like, ‘well if it wasn’t for her then I wouldn’t be alive’. Don’t blame her... There was no support for my family. And then as soon as my mum gets stressed, that’s it. Like, because she’s my number one support. As soon as I start thinking that I’m a bad person to her then it’s all over. That’s when I start going backwards.

Furthermore, Anabelle reported the impact of her beliefs and thoughts related to her anorexia becoming more entrenched over time. She considered the focus of treatment on re-feeding, especially in the beginning, as unhelpful and over time serving to make her more likely to relapse because she could not cope with gaining weight.

Anabelle: This is such a lie – ‘get your weight to a certain level and your thinking changes’. It’s bull-crap. It doesn’t change!... Especially if it’s been entrenched in there in a while. That’s your thinking pattern. It’s like a pathway. You’ve dug that trench; you’ve got to try and cover it, or make a new one.

Lastly, Anabelle indicated that she sees herself as never having fully recovered, always being in a state of relapse or semi-recovery. In addition, she has been in and out of psychological services, especially in relation to AN, for a number of years. As a result, she described a general shift in professionals’ expectations of her health, suggesting that their tolerance for her being underweight has increased over time. She considered this as contributing to her relapses as she views it as them giving up on her and that her malnourishment is likely to impact her thinking.

Anabelle: Yeah and I think relapse, if you never really get to the stage that you’re out of semi-recovery then you’re not [recovered]. I’ve never gotten back to the weight that I was before I lost. Which is good because I would never want to go back there. But, then you’re still in semi-starvation... they just become accustomed to your bloods not being alright or your nutrients levels not being alright but I reckon they must still impact your thinking if they’re not right.
Summary

Participants discussed a range of factors present for the participants during their initial episode of anorexia but were not labelled causal until relapse. Some of these influences relate to previously discussed categories, such as power and control. In this way, they were an additional facet of this themes. Other factors related to a new theme of undermining recovery which related to barriers to recovery. Often these were discussed during the initial development as hindrances, rather than specific causes to decline into anorexia.

This group of themes are interesting given that the value of them as a potential cause appears to have increased when considering relapse. This transformation suggests a change in the experience of AN following an initial experience. Moreover, subthemes such as sense of security and accepting the consequences, indicated a level of knowledge about the outcome of anorexia for each person which was likely not present when they were first developing the disorder.

Unique causes following initial episode

A range of novel causes were discussed and were especially evident for those who had experienced distinct relapse events, rather than speculating about future relapses. In contrast to the previous set of themes, these contributing factors seemed to be a direct cause of, a) having experienced anorexia previously, b) weight recovering, c) treatment experiences, and/or d) subsequent relapse experiences. Table 7 indicates the distribution of these types of causes for each participant.

Undermining recovery

This theme was introduced in the previous category and describes causes which were significant in undermining recovery to the point of contributing to relapse. The causes presented in the previous group were those which the participant had previously mentioned as occurring during the initial development but at that time was not a significant factor until trying to recover. In this section, an additional set of causes were suggested which related to the impact of others on recovery, which was tied to person having already developed anorexia.
Table 7. *Endorsed causes of relapse unique compared to the initial episode.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natalia</td>
<td>Undermining recovery</td>
<td>Impact of others</td>
<td>Criticism from others about my appearance and weight</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia still there and I have to manage it</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Problems maintaining</td>
<td>Gradual return of my anorexic</td>
<td>Slowly slipping back into controlled eating unknowingly</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>recovery</td>
<td>patterns</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative perception of</td>
<td>Ambivalence</td>
<td>Losing my sense of care for others or myself would lead to relapse</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collette</td>
<td>Undermining recovery</td>
<td>Impact of others</td>
<td>Criticism from others about my struggle to eat and forceful ways of</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>trying to manage me</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative perception of</td>
<td>Hopelessness and resignation</td>
<td>Lost my reasons for living because everything was taken away except</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>future</td>
<td></td>
<td>for my anorexia</td>
<td></td>
</tr>
<tr>
<td>Eva</td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia still there and I have to manage it</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Problems maintaining</td>
<td>Lack of equal alternatives</td>
<td>Anorexia still there and I have to manage it; afraid I will relapse</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>recovery</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 7. *Endorsed causes of relapse unique compared to the initial episode.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kate</td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia still there and I have to manage it</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Difficulty knowing what is normal for my body and thoughts; ‘normal’ levels of obsession or control</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Problems maintaining recovery</td>
<td>Gradual return of my anorexic patterns</td>
<td>Slowly slipping back into controlled eating and obsession unknowingly</td>
<td>General importance</td>
</tr>
<tr>
<td>Maliha</td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia still there and I have to manage it</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Problems maintaining recovery</td>
<td>Gradual return of my anorexic patterns</td>
<td>Slowly slipping back into controlled eating unknowingly</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Negative perception of future</td>
<td>Ambivalence</td>
<td>So fearful of going back to it and the struggle to recover; without this fear I would relapse</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Rewards</td>
<td>Security</td>
<td>Sense of security and familiarity</td>
<td>General importance</td>
</tr>
<tr>
<td>Kora</td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia still there and I have to manage it</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Difficulty knowing what ‘normal’ levels of obsession or control or thoughts are around food and my body</td>
<td>General importance</td>
</tr>
</tbody>
</table>
Table 7. *Endorsed causes of relapse unique compared to the initial episode.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scarlet</td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia is still there and I have to manage it</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cognitive fatigue</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>May not have the strength to fight it; tired of fighting my anorexia</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Perception of future</td>
<td>Ambivalence</td>
<td>More likely to relapse if I don’t care; can be ambivalent to staying well and will relapse</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>Power and control</td>
<td>Change and uncertainty</td>
<td>Difficulty coping with change, transition, and uncertainty</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Rewards</td>
<td>Security</td>
<td>Sense of security and familiarity</td>
<td>High importance</td>
</tr>
<tr>
<td>Anabelle</td>
<td>Ongoing struggles</td>
<td>Persistence</td>
<td>Anorexia still there and I have to manage it</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cognitive fatigue</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Exhausted fighting myself constantly about eating; cannot maintain this level of internal conflict and relapse</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>Problems maintaining</td>
<td>Gradual return of my anorexic patterns</td>
<td>Slowly slipping back into anorexic patterns after weight recovery</td>
<td>General importance</td>
</tr>
<tr>
<td></td>
<td>recovery</td>
<td>Equal alternatives</td>
<td>Not sure what else to do; if I knew how to fix myself I would</td>
<td>General importance</td>
</tr>
</tbody>
</table>
Table 7. *Endorsed causes of relapse unique compared to the initial episode.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Categorical theme</th>
<th>Sub-theme</th>
<th>Concept</th>
<th>Endorsed Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Negative perception of</td>
<td>Hopelessness and resignation</td>
<td>Think that I will never recover; I will have to struggle with this for the rest of my life; what’s the point in fighting it when I keep failing</td>
<td>High importance</td>
</tr>
<tr>
<td></td>
<td>future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Undermining recovery</td>
<td>Impact of others</td>
<td>Criticism from others about my struggle to eat and forceful ways of trying to manage me; my impact on others because of my anorexia</td>
<td>High importance</td>
</tr>
</tbody>
</table>


**Impact of others**

As mentioned above, this theme relates to the impact of others on recovery. Other people have been described as being impactful in previous sections (such as the impact of critical comments on Natalia); however, this theme revolves around the person’s anorexia and either the perceived effect of this on others, or the impact of others’ reactions in trying to manage the participant’s anorexia.

Collette described the impact of her parents and siblings in her relapse following her initial treatment for anorexia. She perceived that their difficulty managing it contributed to a very harmful home environment. She had been experiencing conflict in her home during her initial development, but during this period of attempting recovery, the focus and conflict was surrounding her and her eating: she was the target. Collette considered the judgment from her family and the anger about her being unwell as important in contributing to her relapse.

*Collette: I lost a lot of my desire to live because I had nothing in my life other than my parents who would yell at me all the time about eating and tell me that I was a horrible person ‘cause I wasn’t eating, and why was I being so stupid, and why would I not just eat.*

Collette experienced hostility from her parents during this time as her parents developed a punitive way of managing her as her rebellion and resistance to being heavily monitored increased. Collette also viewed this conflict within the home as significant.

*Collette: I guess things got a bit violent at home and... I wasn’t allowed to move out because my parents would call the police, and they’d be like, you know, ‘you can’t move out!’. So I just ran away.*

In addition to the impact of her family, Collette considered her perception of her friends and siblings as important at the time. She conceded that most of her friends probably did care or did not know about her being sick, but at the time her perception that they did not care about her was significant. This social isolation from her friends was compounded by her inability to spend time with them alone during meal times because her parents wanted to ensure she ate so would either join or
follow up with her friends about what Collette had eaten. As a result, Collette withdrew more and more, not wanting to spend time with her friends. Lastly, her siblings no longer wanted to be around her and would report to her parents if Collette had done something related to her anorexia, such as purge. Overall, this contributed to her feelings of loneliness and depression.

Collette: *If I wanted to go out with my friends, my mum had to be there or it had to not be around a meal time, which was relatively frequent so, you know, I stopped wanting to have contact with a lot of my friends... my sisters didn’t want to be around me... nobody wanted to be around me... I’d lost so many friends by being sick. A lot of my friends didn’t know but I felt like they didn’t care because they didn’t say, ‘Hey, where’s Collette?’*, and I think they did but I just filtered it out.

Anabelle thought that she is the cause a significant amount of family distress and that she burdens others with her AN and this perception is likely tied to her thoughts of low self-worth and being a ‘bad’ person.

Anabelle: *As soon as too many people became involved in my care I got like, I was too much of a burden, and that would just send me backwards again... That’s why I stuck with my one therapist because she chose, because she didn’t have to see patients but she chose to so I didn’t feel like I was burdening her because she was choosing to see me. I wasn’t going to some psychologist, like “f**k, I’ve got to see her now”. She was like, “no, no, no, I want to. It’s my choice”.*

However, it is also supported by similar experiences to Collette of guilt and failure when her family or other people blame her for her anorexia and failure to recover.

Anabelle: *My parents go: ‘oh, you’re ruining this’, and ‘I’ve had to give up this’.*

Anabelle: *My school blamed me. When I came back from aussie [for treatment for anorexia] the first time my school wouldn’t have me back. Said*
I’m attention-seeking and I’m too much of a hassle and disruption on the others. And that was it. Because school was what kept me going all those years as well because I wanted to achieve. I needed to achieve and when they said nah: disruption. They wouldn’t have me... That’s definitely a contributing factor.

Lastly, Anabelle reported being impacted by professionals commenting that she is complex, and difficult, suggesting it is unlikely she will successfully recover. This attitude undermines Anabelle’s recovery in the sense that her ideas about being a burden to services is reinforced and the idea that there is no point trying to recover because even the professionals trained in this area cannot help her.

Anabelle: I’m too hard [to treat], apparently [laughs]... people telling you you can’t do it. Telling you you’re too hard makes me think that I’m more of a burden... when I went to [regional public service], like general psyc, they don’t understand. They’re like, ‘we can’t help you with it because we can’t comprehend how your mind works’. And I was like, ‘uhhh, neither can I’ [laughs]. But you’ve just trained to find out why.

Ongoing struggles

Participants described a distinct set of causes related to difficulties which are ongoing after recovery. These causes related to changes in thinking or persisting difficulties in their thinking which contribute to relapse, including: persisting anorexic thoughts or desire to return to anorexia, cognitive fatigue from managing these thoughts, and confusing about what is normal thinking or eating patterns after being anorexic.

Persistence

Almost all participants described the impact of persisting anorectic thoughts on their likelihood of relapsing. These thoughts are similar or the same as during initial development except that they are not underweight when weight recovered and thus less frequently engage in behaviours associated with these thoughts. This creates a dissonance for participants; experiencing thoughts supportive of anorexia but having to act in accordance with recovery.
Natalia: I don’t think you ever fully recover from it.

Eva: I still struggle, every day, but having a goal kind of keeps things in perspective.

Maliha: It’s getting so much better but it’s like: I know it’s always there and it always will be.

Scarlet: Most people don’t get rid of it completely they just live alongside it and it’s quieter and stuff... The strength, almost, of you instead of the strength of the anorexia kind of thing. It would be greater than her [in order to recover completely].

Some participants described their thoughts as becoming less obsessive with time and that these thoughts were slightly less severe, especially those who had experienced treatment. Others suggested it was difficult to manage them and that the thoughts are relatively the same as when anorexic, such as the quote from Scarlet above.

Eva: I still think about it a lot but [I am] much better with my thoughts and not quite as obsessed. I still get really obsessive about food but more now, like, obsessive about wanting to make healthy dinners, rather than not wanting to have anything at all.

Participants who endorsed this cause typically perceived it as being a very important cause of relapse. Even those who experienced treatment specifically for AN mentioned this feature of continued anorectic thought patterns after recovering physically.

**Cognitive fatigue**

This theme runs alongside the above theme of persisting anorectic thoughts once physically recovered, where strength was needed to overcome these thoughts and that it was a struggle to maintain recovery. This theme relates to participants describing being fatigued by this battle or conflict within themselves and how it contributes to relapsing. For example, Anabelle describes the fatigue she feels from
having to fight herself to eat and the demoralisation and exhaustion from consistently failing to remain in recovery.

Anabelle: My relapses now are more to do with I’m too tired to keep going. Like, I’ve had enough of fighting. I can’t explain it like [pause] when you’re someone who wants to not fail but every day you’re getting up and you’re trying your hardest to recover and you can’t. Like these thoughts in your head just get you. Every day I go to sleep going, ‘I failed again’. And then it’s like I’m going to get up again in the morning and I’m going to not do it but then you do, you fail again. And you just get tired of failing over and over again and it’s like... uh. Why try? I’d rather not try and not fail then try my hardest and people say ‘you’ve just got to do it, you’ve just got to try harder’ and you’re actually going, ‘I’m trying my hardest and I’m still not doing it’. And it’s like, that’s probably the hardest. That’s what causes me to go backwards. You just get too tired.

What’s normal?

A sub-group of participants were confused following recovery about what constitutes normal thoughts and behaviours around their food, shape, and weight. This sub-theme was more prominent for those who did not receive treatment specifically for AN or where treatment did not include other professionals who might comment on this such as a dietician.

Kate specifically mentioned the change in her perceptions of what is normal for her body after anorexia and that it is difficult to accept her body at a ‘normal’ weight. Furthermore, she struggled to know what is ‘normal’ for her body, as well as ‘normal’ thoughts around food and eating. This confusion about what is ‘normal’ can contribute to relapse in that she can rely on her misperceptions of ‘normal’, i.e. being more obsessive about food, or maintaining a low weight, rather than what may be more healthy for her body.

Kate: It’s hard to know what the normal thought process is around food and then what a lapse is... I’m still kind of growing up and stuff and it’s hard to know what your body wants or, um, what is normal for your body and how it’s supposed to look and what way it’s meant to be and stuff.
The impact of this confusion increases the likelihood that she will be controlling of her food and eating, as there is a difficulty trusting her body to indicate what she needs. Kate suggested that when she has given up control of her life, and given into herself, she can maintain a higher weight. However, when she attempts to be more directive in her life, she is more susceptible to controlling her weight to her perception of normal.

Kate: Sometimes when I kind of have just almost given up to the circumstances I’ve got to a normal weight. But then sometimes when I’m like, ‘okay I’m going to do this and I’m going to take control of my life’, my weight will be more – like it could lead to a relapse. But, it’s still [pause] what I have got perceived as normal.

Kora also described a sense of not knowing what ‘normal’ thoughts around food and eating were compared to eating disorder or anorexic thoughts. For her, this could contribute to her being more likely to accept her thoughts as typical and then act accordingly, for example, starve for a period of time.

Kora: Sometimes it’s like you have those random days where you might pig out [laughs] and then I’m like, ‘Uh! I’m not eating tomorrow’. And so I won’t, and then I won’t eat for like a week and then I’ll start eating again. But I’m not actually too sure of that’s anorexic thoughts, or because I pigged out and hate myself for it. I don’t actually know.

Maintaining recovery

This theme relates to the practical implementation and management of recovery for participants and the difficulties that can arise with this. Participants talked about ideas relating to a gradual decline back into thoughts and behaviours associated with anorexia. They also described lacking equal or better alternatives to coping with life and/or feeling the same way as that provided by AN.

Gradual return of my anorexic patterns

This theme encompasses causes linked to a gradual shift in behaviour and thoughts away from recovery toward similar patterns during the participants’ anorexia. They described that these changes often occurred without them noticing
until later on or only with hindsight. This feature was signalled as a contributor to relapse as it reflected the possibility of these patterns becoming more severe and ultimately leading to relapse.

For example, Kate discussed the importance of being aware of herself becoming obsessed with her eating, and being more controlled over her eating, so that she can prevent relapse.

Kate: *A lot of it is just understanding my - kind of like creating a relationship with the mind almost. And just be aware like, ‘okay, this is the mind trying to take control. This is getting obsessive’... When I’m not aware that my thoughts are getting obsessive then I can easily start reacting and start counting the calories of the food or trying obsessively to only eating healthy things or cut certain foods out and stuff.*

Natalia discussed how she had developed a very controlled style of eating, although still consuming enough calories to not be significantly underweight. This was a risk for her which could have led to relapsing.

Natalia: *I’d say about a year ago, I was eating fine, but I was very controlling over my eating and I know that for me, once that starts it gets worse and so I’m happy that I kind of [pause] got myself out of that.*

Anabelle has talked about the impact of gradually slipping back into old routines related to anorexia leading to her relapsing. For example, she described the impact of returning from treatment overseas and the gradual change back into her old anorexic (and other) routines with her family.

Anabelle: *So I’d make all these gains and then it would all just go [down]... then you just kinda end back in your old routine. And go backwards.*

**Equal alternatives**

Another theme talked about was the lack of alternative strategies which would provide the same feelings. This lack of equal alternatives contributed to some participants’ reasons for relapse as they could not effectively impact or know any other ways of meeting the same needs as what they get from anorexia. For example,
Eva specifically discussed the difficulty she has in not returning to anorexia and the lack of equitable alternatives.

_Eva: Yeah, it is quite a struggle to stop going back to that. It is a struggle to find something as an alternative. I still don’t really know what my alternative is, apart from, you know, stay healthy enough to have children one day and preferably not be, like, not have like osteoporosis._

**Negative perceptions of the future**

This theme relates to the impact of the participants’ view of the future and their willingness to manage their anorexia and hence, risk of relapsing. Most participants discussed either the role of hopelessness and despair about the future, and fear or ambivalence towards the future on contributing to relapses. This theme is distinguished from other themes such as ‘alleviating other negative emotions’ as the participants tended to talk about the future in terms of their anorexia. In saying that, a few women described these sub-set of causes in combination with depression or other negative emotions. Those that described hopelessness and despair did not describe their anorexia as alleviating this, rather it was the only other thing they had at the time.

**Hopelessness and despair**

A few participants discussed the role of giving up on their future and the feeling of hopelessness, despair, and sometimes resignation about their anorexia. They talked about the way that these emotions and views of their anorexia contributed to relapse as it seemed like there was no point and that anorexia was all they had left. Collette and Anabelle both mentioned this and both experienced symptoms of general depression or lack of concern for life during these times. For example, Collette described her loss of care about life other than her anorexia when she relapsed because she perceived that she had nothing much to live for.

_Collette: I didn’t want to live really. I kind of lost a lot of that and it wasn’t like I was going to commit suicide but I didn’t see the point in eating. It wasn’t that I wanted it to kill me but I was just like, ‘well I don’t want to gain weight’, and ‘I don’t really care what happens’... My desire to get back into life is what saved me therefore it’s also what killed me when I got sick._
Anabelle who has experienced many relapses also thought this was a very significant contributor to her relapses, especially more recent ones. She described how her constant failure to recover and her frequent relapses contribute to her feeling like she is not capable. Anabelle described wanting to stop fighting and to give up because at times it seems like there is no point trying to be anything other than anorexic.

Anabelle: Now it’s more like I’ve come to a realisation that I can’t get anywhere in my life if I have it. It’s when you get to that realisation that everyone’s gone, like there’s no support, no professionals to help me... That’s when you go: ‘oh my gosh, I can’t handle this anymore, like I’m never going to get the life I want; I’ll just give up’. Like, in the last three years three [of my friends who had anorexia] have killed themselves, like every year. And I’m just like, ‘oh my goodness, I can see why they do it now’. Because it’s so – you get to a certain stage in your recovery and they go: ‘we can’t help you anymore, this is as good as it’s going to get’ but you realise in yourself that I’m never going to get my degree while I’m living like this. But it’s like, I’ve tried my best in doing it by myself and I can’t and it’s like, ‘well, what’s the point then? I might as well just [pause]’. I don’t want to go backwards again I’ll just end it now. And then they go ‘Ahhhh!’ [laughs]. ‘Respite!’ But yeah, it doesn’t really fix the problem... But I have no suicide policy... So instead you just struggle along.

Although Anabelle’s despair that she will not get better and cannot achieve the things she wants in life contributed to her wanting to end her life, it also contributes to her relapsing. As she cannot morally commit suicide these types of thoughts lead her to the conclusion that anorexia is the lesser option of these evils because neither can she see herself recovering, or escaping it.

**Ambivalence**

Recovering from anorexia was described by many participants as requiring internal strength and commitment to change. Others, as previously mentioned, described the strength required to maintain recovery despite some persisting thoughts, behaviours, and at times desires related to anorexia. Thus, participants who
experienced ambivalence about recovery and not relapsing often also cited this as contributing to them relapsing. For example, Natalia mentioned the needing to want to manage anorexia, rather than being resistant or indifferent to monitoring it. She endorsed that losing the willingness to actively manage her anorexia would contribute to relapse.

Natalia: *I don’t think you ever fully recover from it but you can learn to manage it just fine after a while, if you want to.*

Scarlet thought that her ambivalence about recovery was highly influential in causing her relapses. Although she did not explicitly state in her initial interview she had been ambivalent there were indications in her description of her loss of strength and commitment to recovery embedded in the interview. During the follow-up she endorsed this is a significant contributor.

Scarlet: *I went into hospital I didn’t exactly want to get better so when I came out I was like, kind of alright, but then I was still not alright. And then eventually I just lost a lot of weight and then I, and then in 2013, like around May or June or something, I was like, I don’t know, something in me just like clicked and I was just like, ‘I could just like, not do this’. Well, not necessarily that I could just not do this and I’d be fine but that I was strong enough I guess to not do it... And then towards October, in the October holidays and then up until Christmas and stuff I just like relapsed again. And again I was just like, I could just not do this.*

Maliha discussed her change in attitude in first saying that she could relapse during the initial interview, to not thinking she would during the follow-up. She attributed this change to a change in her view of relapse where, instead of being ambivalent about the possibility, she was highly fearful of the prospect. For example, she described proactively overcoming her lack of hunger in order to make things easier for herself, and the over-riding fear of becoming anorexic again without which she could relapse.

Maliha: *I might as well eat now when it’s easy or semi-easy compared to what it’s gonna be like later if I don’t eat now. So I think it’s that fear, like if I*
didn’t have that fear – yeah. I think that’s the main driver: fear. I can’t go back there. I don’t want to. That must have changed because I do not want to go back there.

Other factors from previous themes

Power and control
Scarlet described that after her initial development of anorexia, her relapses were often triggered by fear of the future and change. She would relapse at times when she had more time to reflect on her life and the fact that she is leaving high school soon and her life will change significantly. For her, the fear of uncertainty and large changes in her life is a strong contributor to relapse as she finds anorexia a comfort (see following theme). This differs from her initial causes which did not specifically occur around change or fear of a transition.

Scarlet: The closer I get to like leaving school and stuff it’s like I’d – I’ve been in school since I was like five so I know what school is I know what it’s like but I’ve – like uni or tech I haven’t been out in the big world so I don’t know what it’s like but then with this I know what it does, I know what it’s like. It’s comforting almost, kind of. So when things are like scarier I just go back to that kind of... [I might relapse due to] maybe like sudden change or something. Where all of a sudden you wake up and something’s different or something’s happened or something... I think just change and like something that’s unknown.

Rewards
Maliha and Scarlet both described relapses occurring as a consequence of anorexia feeling familiar and comforting. This differed from the initial development where these feelings were not the main causes. Scarlet specifically mentioned that her relapses were different from her initial episode for this reason as initially anorexia was relatively new and unknown; she did not know how she would feel and what it would be like until it progressed. Conversely, relapses gave her a sense of security because she knew what would happen. This was especially significant within the context of her fear of things changing in the future.
Scarlet: If you do this, you know what the outcome’s going to be and you know what it’s going to do to your body and you know you’ve done it before so you know what it’s going to do. It’s not nothing. It’s not something new... So I don’t think the outcome ever really mattered necessarily. But I think it’s like that everything around you is changing so then if there’s this one thing you know won’t change. So it’s like dependency and it’s like something you know and that’s safe and stuff.

Maliha: It would have just been a coping mechanism that I would have gone back to just because I find it familiar.

Summary

These themes focused on those which seemed to occur exclusively after having recovered from anorexia, rather than existing prior. In many cases the causes within this group can only occur as a result of attempting to recover, such as the impact of others on recovering. In addition, there were causes for a few participants which developed later in their process with anorexia but occurred earlier for others (such as suggesting that anorexia provided a sense of security). Overall, these themes have related more to the impact of experiencing anorexia on the person and others in their life compared with initial causes. The initial causes included more extraneous factors not necessarily directly related to the experience of anorexia, for example, the influence of feeling out of control because of external events.
CHAPTER FIVE: DISCUSSION

This chapter focuses on comparing the results of this study with relevant research findings, specifically: definitions of AN, causes of initial AN development, and causes of subsequent episodes of AN. First, the findings of the current study will be discussed comparing it to literature reviewed in Chapter Two and other relevant evidence. Following this, the implications of these findings for treatment and prevention of AN in New Zealand will discussed.

Discussion of findings

Comparison of the current findings to previous models and perception research indicates a number of factors or cycles which are similar; however, there are also discrepancies, especially when comparing the perceived importance of different factors for aetiology. The findings will be discussed in four parts: definitions of AN, initial causes of AN, unique causes of relapse, and overall modelling of participants’ perspectives of aetiology. The first three sections will compare findings with both theoretical models and previous research of perspectives of people with AN. The last section describes how these comparisons can be utilised in developing models of these categories which are more salient to people with AN.

Section 1: Participants’ definitions of anorexia

In this study, the participants described their fears, behaviours, and perceptions which were interrelated in the experience of AN. In addition, AN was associated with interventions from others, and with significant negative consequences. As previously emphasised, although gaining insight into participants’ definitions of AN was not an initial objective of this study, the distinct differences observed between described conceptualisation of AN and definitions of AN warranted further investigation of this. Furthermore, participant’s definitions were seen as necessary to understand given the potential impact this has on understanding what they think caused AN.
Fears

In diagnostic definitions of AN, fear has been predominantly ascribed to weight phobia (American Psychiatric Association, 2013; Garfinkel, 2005). The current version of the DSM, specifies fear of gaining weight or of becoming fat (American Psychiatric Association, 2013). However, this has frequently been debated (Hebebrand & Bulik, 2011) due to the lack of evidence of this feature in historical accounts (see Palmer, 1993) and differences in a proportion of those presenting with self-starvation but not meeting this criteria, especially within non-American, non-European, ethnic groups (e.g., Keel & Klump, 2003; Lee, 1991; Lee, Ho, & Hsu, 1993). Participants in this study described a fear of themselves or of others perceiving them as fat. This included how others’ encouragement of them eating more during recovery could be perceived as criticism of their weight, and draw attention to the fact that they had put on weight.

Other fears were described, the most prominent being fear of losing control. Many of the participants described AN as contributing to a sense of control over themselves and/or others. This increase in perceived power was accompanied by a fear of losing it, and is consistent with the theory that control is important in AN both in its form and maintenance (Fairburn, Shafran, et al., 1999; Slade, 1982). It is also consistent with studies of illness perception where AN was associated with a sense of control (Serpell et al., 1999; Tozzi et al., 2003). The findings of this study suggest that the perceived benefit of control is protected due to fears of losing it.

Participants described the fear of losing what defines them and makes them special. Recovering from AN was connected with normality and for some this was undesirable, especially where AN was a strong part of their identity. Research supports this as a theme with people with AN, where it is valued for its distinguishing qualities (Serpell et al., 1999). It is possible that reported feelings of achievement in the development and maintenance of AN (Serpell et al., 1999; Tozzi et al., 2003; Williams & Reid, 2010) may act as a mediator between AN and perceiving oneself as special. The transdiagnostic model of eating disorders (Fairburn et al., 2003) theorised that control of eating, shape, and weight was a form of dysfunctional self-evaluation. This theory could describe how the ‘achievement’ of meeting certain
goals in AN may then be used as a factor in self-evaluation, heightening perceived elitism. Contrary to other eating disorders though, AN might contain greater ‘achievement’ in comparison to other eating disorders such as BN where the eating, shape, and weight goals may be less likely to be achieved (Fairburn & Harrison, 2003). In addition, how special one is could represent a facet of self-worth and self-esteem. Models and risk factors suggesting low self-esteem or self-worth might support this finding (e.g., Blank & Latzer, 2004; Fairburn et al., 1999; Jacobi et al., 2004). Other theories which suggested a sense of ineffectiveness in those with AN could connect with this, where the value of achievement would alleviate feelings of ineffectiveness (e.g., Bruch, 1974).

Overall, these findings support part of the DSM-5 criteria for AN but simultaneously support change in the scope, wording, or inclusion of fears. Some theorists argue that the weight phobia criteria should be abolished with a greater focus on observable behaviours (Hebebrand & Bulik, 2011). Alternative criteria for AN proposed by Hebebrand and colleagues (2004) include fear of gaining weight or becoming fat as one of seven potential cognitions and subjective experiences which could be present in AN, rather than requiring one specific fear for diagnosis. Findings in this study support this, especially if the specified fears were broadened. A different approach could be to retain fear criteria but alter the specifics, where self-starvation is maintained by fear(s) of perceived negative implications for eating or weight recovery, thus including a range of fears. A comparative disorder criteria could be specific phobia in the DSM where the physiological state (self-starvation), has associated behaviours (maintaining behaviours), and associated fears (specific to the individual but produce the same underlying condition) (American Psychiatric Association, 2013). However, this avoidance/fear-based approach would have to be balanced to include ego-syntonic aspects of AN (Vitousek et al., 1998).

**Behaviours**

Participants described anorexia as being a progressive disorder. Once they were committed to or involved in it, the nature of their relationship with AN meant that it was sustained, usually to extreme sickness. Elements of the relationship with AN which facilitated this progress was having progressive goals, and maintaining
rigid rules supporting progression. In addition, participants described how AN did not have a specific end point. This suggested that rather than being reinforced by reaching a certain point of success, control, weight, and so forth, the person is more likely to be reinforced by the process of achieving these markers. This feature of the disorder is not described in the diagnostic criteria but is implied by the person presenting with AN, i.e. that they have progressed to the point of assessment or intervention (American Psychiatric Association, 2013). In comparison to other illness perception studies, there is a lack of information regarding this part of AN apart from concepts suggesting AN as taking over the identity of those with it (Serpell et al., 1999).

Research implicating dieting as a strong risk factor may describe the progressive feature of AN (Jacobi et al., 2004). As was discussed in Chapter Two, separating prodromal states of AN which may easily imitate dieting is difficult. Hence, the progressive nature of AN as indicated by participants is likely to include what could be measured as pre-diagnosis dietary restraint similar to that which characterises the individual’s disorder.

The current findings indicated a range of practices which ultimately maintained a negative energy balance: extreme tools or techniques to manage eating and/or weight, compensation strategies, avoidance, and enjoying food in other ways. The techniques and compensatory aspects described are similar to those described in the diagnostic criteria of AN (American Psychiatric Association, 2013; Garfinkel, 2005). However, participants described broader ranges of eating management strategies and compensatory behaviour than is typically described (e.g., drug use, non-nutritious eating, long-term versus short-term compensatory behaviour). Not all of these reported practices relate to energy intake as specified in the diagnostic criteria, nor are all practices which control energy usage related to purging (as in AN-BP) (American Psychiatric Association, 2013; Hebebrand & Bulik, 2011). Hence, a potential disagreement with the current criteria and these findings is the strict focus on restriction of energy intake. An alternative approach is to define AN based on a net negative energy balance (intake versus usage) (Hebebrand et al., 2004).
The normalisation and habitual nature of behaviours associated with AN is expected given research on habit development (Wood & Neal, 2007). Implications for definitions of AN are relatively negligible given this is a factor influencing most, if not all, behaviour and mental disorders. However, awareness of the automatic nature of some of these behaviours may be helpful with treatment, especially relapse prevention approaches as participants usually described this in relation to struggling after weight recovery. In a recent review of habit formation and intervention, Wood and Neal (2007) described how effortful inhibition is likely to be unsuccessful in long-term habit reformation. It can increase negative affect, preoccupation and unwanted behaviours. Hence, this approach as a method of relapse prevention is likely to be ineffective in the long term.

Some research suggests that AN-BP has a poorer predicted likelihood of recovery than AN-R (J. C. Carter et al., 2012). Within a habit formulation, the stimuli associated with binging may be more susceptible to relapse given these stimuli will be more similar to recovered patterns. For example, whereas in AN-R you might expect restriction of eating so little food in consumed, in AN-BP food is more regularly consumed but has been strongly associated with purging. Hence, a ‘recovered’ state of eating in the community followed by no compensatory behaviour may be more difficult to manage in AN-BP, than in AN-R. Furthermore, these results may also be skewed by AN-BP having more pathways to relapse compared to AN-R: Low body weight and relapse in binge purge behaviours (J. C. Carter et al., 2012).

**Perceptions**

Anorexia was described as having begun innocuously, without specific intent to become underweight. Transition to AN typically included an intensification of existing eating and exercise behaviours. These findings are supported by risk factors such as prodromal dieting, and other eating-related issues pre-anorexia (Jacobi et al., 2004). These findings add value to those suggesting people with AN endorse biological conceptualisations of ‘illness’ and dislike attributions of AN to exclusively being a conscious weight-loss motivated process (Button & Warren, 2001; Williams & Reid, 2010). Hence, implications that AN is fully controllable and self-determined are often viewed as erroneous by those with AN (Williams & Reid, 2010).
The DSM-5 criteria which indicate “persistent behaviour that interferes with weight gain”, have been suggested to perpetuate a pejorative and paternalistic perspective in AN (Hebebrand & Bulik, 2011), with ‘interfere’ being associated with self-directed words such as hinder, obstruct, and impede. Persistent also implies stubbornness, obstinacy, and rebellion to recommended weight gain. Past DSM criteria have been more explicit in citing such terms as “refusal” and “denial”, clearly suggesting a self-determined and resistant individual (Hebebrand & Bulik, 2011). The current findings support the slow change toward criteria which are more inclusive of individuals who do not actively seek to become severely underweight; this is not to suggest active resistance is not present in some, rather the assumption of this in all cases is unhelpful. The perceived negative consequences of these assertions by professionals and others are discussed in further detail in this section.

Anorexia has been described as being like a friend (Serpell et al., 1999). Furthermore, it is described as being a part of one’s identity or part of one’s self (Tan et al., 2003). Both of these were described by participants in this study. In some, these two concepts could occur simultaneously, suggesting they are not mutually exclusive experiences despite one suggesting input external to oneself. The dichotomy described in Serpell and colleagues’ (1999) study of ‘friend’ and ‘foe’ aspects were present in the current findings. Those who described AN becoming their identity often described it as incrementally eroding other values and goals in their life, indicating aspects of it being like a ‘foe’ or something they needed to fight against. Even suggestions that AN was analogous to deadly diseases such as cancer were similar to previous research (Williams & Reid, 2010).

The personification of AN is not that helpful for diagnosis given its subjective nature (Hebebrand & Bulik, 2011). However, it is potentially helpful in understanding maintenance of AN, as it denotes a love-hate relationship with it. In the current findings it was represented to act as a friend, by supporting and providing solutions. On the other hand, it is represented as a terminal illness and something synonymous to a parasite, occupying its host and eventually killing it if the host cannot ‘fight’ back. Hence, intervention of this conceptualisation would aim to substitute ‘friend’ aspects with more adaptive processes, enhance reasons to ‘fight’ or
recover (without increasing hopelessness), and potentially increase perceptions of the ego-dystonic aspects of AN.

Rigidity and inflexibility in plans in relation to food and exercise was described as a feature of AN. The literature around AN typically associates rigidity with Minuchin’s theories of rigid family structures (Minuchin et al., 1978; Tozzi et al., 2003). Or, it is associated with cognitive rigidity, including perfectionism (Bulik et al., 2007; Jacobi et al., 2004; Polivy & Herman, 2002). Impaired ability to move between tasks and plans is hypothesised to contribute to rigid and obsessional behaviour. Deficits are present in AN, and may explain the participants experiences (Bulik et al., 2007).

As mentioned, inflexibility may correlate with perfectionism, which is defined as having an uncompromising goal-directed approach to achieving high personal standards despite negative consequences (Shafran, Cooper, & Fairburn, 2002). Within the field of eating disorders, the target of a person’s perfection can be defined for them, for example, suggesting relentless pursuit of the ‘thin ideal’ (Stice, 2002). However, participants in this study did not specifically endorse this. Rather, they described the relentless pursuit of their goals with high levels of self-blame and self-criticism associated with perceived ‘failure’ or transgression from goals. Assertions that perfection occurs exclusively within predetermined areas of body image is potentially a fallacy. Shafran et al. (2002) argue that AN is often the expression of perfectionism in the control of eating, shape, or weight. Relevant to the definition of AN is inflexibility in relation to eating which likely correlates with treatment-interfering behaviour but would not be explicitly stated if this were a key criterion.

Many participants described AN as being preoccupying, where it required substantial time and energy. Preoccupation with food and eating is supported by accounts of barriers to recovery (D’Abundo, 2004). Preoccupation can be considered a sign of obsession where thoughts and behaviours associated with the obsession are very difficult to ignore or delay (American Psychiatric Association, 2013; Serpell, Livingstone, Neiderman, & Lask, 2002). Preoccupation, obsessions, and compulsions, especially around preparation and consumption of food, have been evidenced in those in a state if semi-starvation but without any known eating disorder.
(Keys, Brozek, Henschel, Mickelsen, & Taylor, 1950, as cited in Keel, 2005). Hence, part of the preoccupation described could be a factor of starvation, rather than anorexia nervosa alone (Serpell et al., 2002). It is described in a few of the reviewed models of aetiology (e.g., Fairburn et al., 2003, 1999). However, evidence suggests that although there can be a reduction in obsessions after recovery from AN, premorbid obsessive-compulsive traits are more likely to continue after recovery, for example, the need for symmetry and exactness (Srinivasagam, Plotnicov, Greeno, Weltzin, & Rao, 1995, as cited in Serpell et al., 2002).

Preoccupation is not specified in the DSM-5 criteria (American Psychiatric Association, 2013) but it is relevant to note that some participants described developing a preoccupation very quickly, before a starvation state could be expected to occur (at least physiologically). Part of this preoccupation may be relevant to AN outside of physiological and ‘normal’ responses to restricted intake. This may be related to those with AN being in charge of their restriction within the context of available food, differing from Keys and colleagues study (1950) of ‘normal’ individuals’ obsessionality when others were restricting their food intake (as cited in Keel, 2005).

Anorexia was compelling for some participants and difficult to let go of when considering recovery because for them it could provide a functional role and sense of security. This is well-supported by accounts of recovery and ambivalence (Federici & Kaplan, 2008; Vitousek et al., 1998; Williams & Reid, 2010). The DSM-5 criterion that the person may exhibit persistent behaviours which interfere with weight gain (American Psychiatric Association, 2013) may relate to the description of AN as being compelling, as well as uncertainty about change, and ambivalence.

Findings in this study that food can become aversive during AN does not appear to be well-researched. Animal studies indicate that putative food aversion training can contribute to significant reduction in intake (Bernstein & Borson, 1986). In human studies of food aversion, especially specific taste aversion, it is significant when it is paired with transient illness (e.g., aversion to a certain type of alcohol after heavy intoxication) (Bernstein, 1999). This could be relevant for those that purge during AN as food aversion may play a role in maintaining restrictive intake.
Emotional distress during eating can contribute to a reduction in eating especially if
the emotion is intense, and negative (e.g., sadness, self-hatred) (Macht, 2008). Given
that some of the participants described AN as a method of controlling emotions
through control of eating it is surprising there is not more literature relating to
emotional processing during food consumption and avoidance in AN.

Interventions

A perception held by the participants that outsiders who have had no
experience of AN have difficulty knowing or understanding what AN is, appears to
be a relatively common thought found in this study and others (Federici & Kaplan,
2008; Johnston, Smethurst, & Gowers, 2005; Williams & Reid, 2010). The belief that
others who have not experienced the same thing will not be able to adequately
understand or help with recovery is mirrored in other disorders, such as substance use
(Urbano, 2011). This belief may be erroneous if it follows the trends of substance use
disorder literature, indicating little significant difference in therapy outcomes between
recovering counsellors and those without a history (e.g., Culbreth, 2000). However,
recovering/recovered therapists have been argued to contribute in alternate ways to
treatment programmes which may not be as tangible as measuring outcomes between
two therapists, for example, they may effectively use their own experiences to inspire
hope (Johnston et al., 2005; White, 2000a, 2000b, as cited in Urbano, 2011). These
beliefs are relevant because they could contribute to resistance to intervention.
Negotiation within therapy may be necessary to determine how to establish a shared
understanding of the experience between therapist and client, and how conflicts in
understanding can be acknowledged and resolved by the person with AN.

According to participants, lack of understanding and empathy for those with
AN could sometimes be expressed through judgments and persecution. This is
supported by survey evidence suggesting that a large proportion of the public
(approximately a third) consider eating disorders to be self-inflicted, and that the
person could recover if they wanted to (Crisp, 2005). Those surveyed in Crisp’s
(2005) study suggested that those with eating disorders ‘felt differently’ and were
more difficult to communicate with in comparison to ‘normal’ individuals.
Furthermore, a significant age bias suggested that those aged 16 to 19 years were
three to four times more likely to rate those with EDs extremely negatively compared to other age groups (Crisp, 2005). This age group is significant given the average onset of AN is between 15 and 19 years old (Bulik et al., 2006). It could be speculated that the majority of those developing AN do so within an age range where stigmatisation and lack of empathy for the disorder from peers is at its greatest, thereby priming the person to be mistrustful of others perceptions.

Similar to participants in this study, parents of those with AN in New Zealand noticed judgment and hostility toward their daughters from some healthcare professionals and peers (Bellingham, 2012). Parents endorsed attitudes similar to those with AN, suggesting that those who have not experienced it do not understand and thus tend to act in unhelpful ways, such as trivialising EDs (Whitney et al., 2005). However, parents can exhibit distortions in the attribution of responsibility previously described, suggesting those with AN ‘choose’ their disorder (Whitney et al., 2005). Overall, AN has been linked to high stress within families, contributing to carer distress and arguments between family members (Bellingham, 2012; Whitney et al., 2005; Zabala, Macdonald, & Treasure, 2009). Angry reactions from carers such as violence, verbal threatening, shouting, and blaming can be associated with strong negative emotions elicited from caring for someone with EDs (Treasure, Williams, & Schmidt, 2009). Treatment and psychoeducation for carers may be relevant to reduce these occurrences as well as providing ongoing support, especially as these types of reactions have been linked with maintaining the disorder (Treasure et al., 2009).

Specific reference to “denial” and “refusal” have been removed in the current DSM criteria (Hebebrand & Bulik, 2011) but interestingly participants described some concealment and denial of a problem. Some of these occurred with conscious awareness of a problem (i.e., recognised AN or that they had an ED) but others engaged in these without necessarily recognising that there was an issue (i.e., perceived others as enforcing an issue upon them). Behaviours associated with this finding are likely to correlate with the DSM-5 criteria of “persistent behaviour that interferes with weight gain” and “persistent lack of recognition of the seriousness of the current low body weight” (American Psychiatric Association, 2013). One issue with the ‘lack of recognition of seriousness’ criterion is the possibility of denying
having an ED but recognising or being concerned about health. This may be more prevalent in non-Western groups where somatisation is more frequent, and thereby decrease the utility of this criteria across cultures (Lee, 1995; Lee et al., 1993).

Resistance and ambivalence to change has been well-documented both in accounts and treatment reviews (Federici & Kaplan, 2008; Vitousek et al., 1998; Williams & Reid, 2010). This is to be expected with AN typically being ego-syntonic (Vitousek et al., 1998) and the strong positive and negative outcomes perceived for both recovering, and not recovering (Williams & Reid, 2010). Resistance to change may be exacerbated by perceived coercion into treatment, as it compromises the person’s autonomy (Tan, Stewart, Fitzpatrick, & Hope, 2010). However, patient accounts indicate that perceived coercion can be overcome or reduced if it occurs within trusting relationships where the event is interpreted as care and help (Tan et al., 2010). Barriers to this include mistrustfulness of the intentions and sincerity of others, especially professionals and family (Williams & Reid, 2010) and signify important considerations for treatment.

Confusion about services has been mirrored by parents of children with AN in NZ (Bellingham, 2012). This may be a function of the smaller population in New Zealand and hence fewer resources dedicated to EDs, and AN specifically. Similar to participants, parents in New Zealand report that intervention typically occurs after significant physical deterioration where earlier access to treatment may have prevented such a significant decline (Bellingham, 2012). This is likely a function of funding issues and the previous focus in mental health on treating the most severe 3% (Mental Health Commission, 2012). Furthermore, weight definitions in the DSM-IV and now even further defined in the DSM-5 (American Psychiatric Association, 2013), are likely to provide easy methods of stratifying cases; however, the focus on weight as level of severity is problematic given it can be considered just a symptom of underlying psychological problems. Rejection at earlier points in AN may mean that when the patient comes to meet the physical severity requirements, they are more likely to do so at a point where they are already discouraged, demoralised, and disenchanted with treatment.
Studies of parents indicate that AN can be undetected by them for a time and dismissed as a normal part of development, especially if onset is during adolescence (Bellingham, 2012). Awareness increases as behaviour or physical signs become more manifest. Parents also describe lowering their goals for their child’s recovery over time, for example, rather than encouraging them to eat a range of foods, encouraging them to eat at least one type (Bellingham, 2012). This may explain how participants could perceive others as becoming used to them, through a reduction in the number of ‘battles’ over food, eating, and weight. No research could be found regarding signs of this with professionals during treatment or case management as was reported.

Impact

This set of findings correlates strongly with other research. Studies of accounts support the loss of opportunities and perception of ‘wasted life’ when actively anorexic (Serpell et al., 1999; Williams & Reid, 2010). Depression is highly comorbid with AN (O’Brien & Vincent, 2003), and significantly increased rates of major depressive disorder have been implicated even 10 years following recovery (Halmi et al., as cited in O’Brien & Vincent, 2003). A lack of positive and knowledgeable support relates to the previous finding of the perception that others do not understand AN. Where lack of understanding was a hindrance, positive supports relates to the benefits of knowing others who they considered knowledgeable. Social isolation was described by some when unable to discuss shared experience (AN) with others. In this instance, professionals who have experienced AN and recovered could potentially act as a reference point for recovery (Urbano, 2011). Alternatively, the results of this study and others suggesting despair at the ability to recover (Nordbø et al., 2012) suggest that having people who have recovered from AN available during parts of treatment may be helpful, especially in inpatient facilities where the context of being surrounded by those with AN may exacerbate hopelessness.

Anorexia nervosa has been argued to be similar to other eating disorders such as BN due to the convergence and migration of people between diagnostic criteria (Fairburn et al., 2003; Fairburn & Harrison, 2003). Thus, increase in purging behaviours is an expected result, including both bulimic-type presentations at normal
weight (Fairburn & Harrison, 2003), and movement from AN-R to AN-BP (Hebebrand & Bulik, 2011).

The last theme of this section related to exposure to death. Death experiences during AN, during an arguably ‘impaired’ state of functioning, is likely to have significant impacts. It might be expected that those with AN who develop friendships with others experiencing AN are at increased risk of exposure to death given the increased mortality rate, especially violent death (Smink et al., 2012). If the meaning of deaths related to AN become related to hopelessness and despair, complications in the confidence to recover are likely to follow (Currier, Holland, & Neimeyer, 2006). Unfortunately there is no known research in this area specifically relating to AN.

For those admitted to hospital, they were often abruptly confronted about their weight loss by medical professionals, threatened in order to comply with medical aid, and typically told they may die. There is no known research investigating the potential impact of this on individuals with AN. The findings of this study suggest that there are a variety of reactions: sadness at having distressed family, acceptance, lack of concern, and fear of accepting food. Discussion of the meaning of these experiences may be a beneficial contribution to treatment (Currier et al., 2006), although it is difficult to generalise from this study alone.

Section 2: Causes for initial development of AN

The findings of this study highlight a range of significant factors seen as contributing to the development of AN. The themes from this section will be presented in comparison to research, with a specific focus on models of aetiology.

Power and control

Control has been speculated to be a core feature in some theoretical models of aetiology and maintenance (e.g., Blank & Latzer, 2004; Bruch, 1974; Fairburn et al., 1999) which is consistent with the current findings. AN occurred within the context of lack of control and where this was the case, the reinforcing value of control and autonomy was high.

Bruch (1974) described AN as relating to a struggle for control which is certainly related to the participants’ emphasis on control in contributing to their
disorder. The foundation of Bruch’s theory related to disturbed self-awareness and defective interpersonal skills which, although potentially present, were not typically perceived by participants. In addition, lack of control over external distressing events is arguably more related to coping strategies, than deficits in insight or interpersonal skills (e.g., in the case of verbal or sexual abuse).

The maintenance model by Fairburn et al. (1999) placed control at its centre, and this was extremely consistent with the current study. Control and self-worth were not necessarily connected as proposed in the model but self-control was related to increased satisfaction and pleasure. A slight divergence in this study is the value of general control, as opposed to specifying self-control. As many in this study described lacking control of persistent, negative events in their life, AN gave them a general sense of control over their life through controlling themselves.

Blank and Latzer’s model (2004) suggests a lack of control can develop in external contexts, such as the familial environment, and ultimately leads to a desire to gain control. An interim process posited in the model involves a loss of belonging/mastery, and loss of pleasure/meaningfulness as mediating the desire for control. These additional factors were raised in the current findings but lacked connection to control and were deemed contributory of their own accord. In addition, the interaction effect of AN where its development in turn starts to effect other aspects of life is not well described for this model, whereas direct implications were discussed in this study (e.g., judgments from others regarding AN).

In relation to risk factors, the notion of control may be more prolific in those with AN given strong correlations with OCD, OCPD, and perfectionism (Jacobi et al., 2004). Those with AN have been shown to experience greater adverse life events (Jacobi et al., 2004) and the current results indicate control of food as a coping response when these events were viewed as inescapable, distressing, and where lack of control was viewed as negative. Family discord is supported as a risk factor for AN (Pike et al., 2008) and implicated in systemic models (e.g., Minuchin et al., 1978). Furthermore, motivations to control the perceptions of others may fit within a systemic framework. The correlation between familial psychopathology and AN (including EDs) may suggest modelling of unhelpful coping strategies which become
inadequate during life stressors, and genetic links. However, this was only specifically mentioned for one participant in this study.

Valuing control combined with external lack of control has been endorsed in previous accounts (Nilsson et al., 2007; Tozzi et al., 2003; Williams & Reid, 2010). Other correlates from these studies are contextual factors which could contribute to a sense of being out of control (or wanting to increase control), for example, stressful life events, neglectful parenting, sexual abuse, family dysfunction, and perceived pressure/stress (Nilsson et al., 2007; Tozzi et al., 2003).

**Pleasure**

The reinforcing qualities of weight loss, control or other aspects of AN have not been significant in models of aetiology. Connan and colleagues’ neurobiological model (2003) proposes that physiological processes involved in starvation sustain the disorder which could imply some physiological processes are involved in difficulty discontinuing AN (i.e., comments of addiction). Addiction was described in the opioid theory of AN (Colantuoni et al., 2002); however, this model mainly describes addiction occurring from intermittent binging, not starvation. Furthermore, participants did not derive pleasure from eating when they did eat, rather the progression of the disorder was rewarding. Meyer and colleagues’ model of addiction (2011) in compulsive exercise is similarly restricted in scope. Despite this, they do comment on positive and negative reinforcement as producing psychological dependence, and that this modulates affect. The positive reinforcement they suggest is mood improvement which does correspond with the current findings. The authors describe negative reinforcement as avoidance of withdrawal symptoms of addiction to exercise, but this principle could be applied to affect regulation through avoidance of negative emotional states. For example, AN providing distraction and preoccupation, diverting from negative emotions. Other models propose that negative reinforcement plays a role in maintaining a cycle of AN (Williamson et al., 2004).

Blank and Latzer (2004) outline pleasure in their model where AN provides a sense of pleasure through physiological changes, such as endorphins, due to starvation. This assumption is difficult to accept as it would assume that those who are in a state of starvation in other conditions, such as medical, would be likely to
experience similar pleasurable effects. However, this may be due to the interpretation of these physiological changes which are likely to be more positive with those with AN compared to other groups who are significantly underweight. Previous accounts of patients expressing pleasure at their weight loss were used and indicate continuity with the current findings, with the exception of physiological origins (Vitousek & Ewald, 1993, as cited in Blank & Latzer, 2004).

Body image concerns and societal values have been widely implicated in the aetiology (Levine & Murnen, 2009; Thompson & Stice, 2001). Experiencing AN within a society popularising thinness in women could contribute to interpreting the meaning of weight loss positively. Being ‘successful’ at a ‘diet’ is something that is often viewed positively (Lupton, 2004). Thus, these messages might contribute to further distortions or attributions of the negative side-effects of AN (e.g., fatigue, dizziness, social isolation) to positive values such as success.

Ineffectiveness suggested in risk factor research (Jacobi et al., 2004) and theories of aetiology (Bruch, 1974) are relevant to perceived feelings of accomplishment and excitement. Given that participants in this study experienced a period of ‘successfulness’ (e.g., by the achievement of successive goals) during their AN as it progressed, this is likely to reduce feelings of ineffectiveness and increase positive feelings of accomplishment. Within an aetiological framework, ineffectiveness describes a risk factor but appears only relevant to the development of AN when it is accompanied by success when engaging in AN behaviours and/or meeting goals.

Perfectionistic traits may contribute to the perceptions of addiction, where high standards set cannot be reduced (Jacobi et al., 2004; Shafran et al., 2002). Perfectionism could increase the reinforcing value of meeting high perfectionistic standards related to eating, shape, weight, or control. This may be exacerbated by low self-esteem and negative self-evaluation (Jacobi et al., 2004) where the relative reinforcement derived from feeling highly successful is likely to be much greater in someone who perceives they have little to no value or talents, compared with someone with higher self-esteem and positive self-evaluation.
Positive aspects of AN were consistent with other patient accounts (Serpell et al., 1999; Williams & Reid, 2010). However, participants in many of the larger studies did not state positive or beneficial aspects of AN, rather the focus was on significant experiences predating AN (Nevonen & Broberg, 2000; Nilsson et al., 2007; Tozzi et al., 2003). The positive aspects in these findings are very similar to those that wish to maintain their AN, hence addressing these perceived positive aspects of AN may be important for treatment (Williams & Reid, 2010).

**Obsession**

Obsession is described in models of aetiology to varying degrees. Obsession and/or compulsion is proposed as its own feature of AN (e.g., Meyer et al., 2011; Williamson et al., 2004). Other models align obsession to the consequences of starvation, describing a ‘starvation syndrome’ (e.g., Fairburn et al., 2003). However, overall these features do not link well with the current findings, at least not in one particular model.

As mentioned, Meyer et al. (2011) presents ‘compulsive behaviour’ in their model of compulsive exercise and AN. They focus on compulsion and exercise but they are the only model reviewed which mentions possible compulsive behaviour. The current results indicated possession where AN was perceived to be in control of the person, which is possibly a similar concept to compulsion where the behaviour is very difficult to inhibit. Unfortunately, the current study did not examine why the women felt possessed or what thoughts and beliefs were maintaining these possessed behaviours; however, other perceived causes may provide evidence, such as being scared of change, feelings of fatness, positive attributions to AN. Meyer and colleagues’ suggestion of guilt when not engaging in AN and perceived negative consequences of stopping may fit within these reasons. Williamson and colleagues (2004) refer to obsessionality and perfectionism in their cognitive-behavioural review model. In this theory, obsession relates to body size, eating, weight, and so forth. This obsession and a perceived discrepancy with their current state (e.g., weight) is postulated to increase negative emotion and create a sense of needing to do something to escape these feelings: an ‘urge’. These concepts are synonymous to possession and conceptualise the participants’ experiences well.
As has been previously outlined under preoccupation, being in a state of starvation has been associated with an increase in obsessiveness around food preparation and consumption. Fairburn et al. (2003) indicate this in their transdiagnostic model limiting obsession to a state of starvation. The rigidity and intense narrowing of focus to important markers of participants’ EDs in this study, occurred prior to emaciation in some, highlighting obsession as a more omnipresent feature. The correlation of OCD and obsessive compulsive personality disorder (OCPD) with AN has been argued previously, including the debate that AN is a form of OCD (Roncero, Perpiñá, & García-Soriano, 2011; Serpell et al., 2002).

Evidently obsession within this theme correlates with risk factors indicating increased incidence of OCD, OCPD, and perfectionism in those with AN (Jacobi et al., 2004; Pike et al., 2008). Correlates of high level exercise pre-dating AN can support Meyer and colleagues’ model (2011) where it could provide the foundation for AN as they present. Familial psychopathology correlated with AN include anxiety and obsessive disorders, where genetic predisposition and modelling of these responses may be prominent (Bulik et al., 2007; Jacobi et al., 2004). Familial psychopathology may also contribute to increased stress from exposure to this, as indicated in risk factors and personal accounts (Jacobi et al., 2004; Tozzi et al., 2003).

Themes of possession have been presented in other account studies (Serpell et al., 1999) along with endorsements of perfectionism or striving towards an idea of perfection (Nilsson et al., 2007; Tozzi et al., 2003). The overall reports of participants describing themselves as obsessive are low (Tan et al., 2003). However, parent reports support obsession with eating practices (Bellingham, 2012). This may indicate a lower level of awareness that anorectic behaviours are obsessive and/or this self-awareness is not admitted to others.

**Self-worth**

Low self-esteem is a common part of many theories of aetiology (Blank & Latzer, 2004; Bruch, 1974; Fairburn et al., 2003; Fairburn, Shafran, et al., 1999; Thompson et al., 1999; Thompson & Stice, 2001). Often it is described as a predisposing factor which AN then serves to reduce or moderate. Models which display the most overlap with the findings of this study are Fairburn and colleagues
models (1999, 2003) and Blank and Latzer’s model (2004). These models both emphasise the important role of self-esteem and/or self-worth, rather than specifying it as a key risk factor or one of many predisposing factors.

Fairburn and colleagues’ cognitive behavioural model (1999) presents self-worth as an integral part of the disorder. They do not define self-worth but do distinguish it from self-esteem. Their model mimics the findings of this study where the women described the control of food as symbolic of their sense of self-worth or achievement. This model emphasises that self-control becomes an index of self-worth, predicting that those with AN are “more likely to judge their self-worth in terms of success at restricting eating” (Fairburn, Shafran, et al., 1999, p. 9). However, most of the participants in this study attributed AN as a way of avoidance or control of this negative state caused by low self-esteem or low self-worth, such that positive aspects of increased self-worth or self-esteem were uncommon. With regards to treatment, the authors argue that issues of self-esteem are not integral to treatment unless they are interfering with progress (Fairburn, Shafran, et al., 1999). Rather, issues of control of food, eating, shape, weight, and so forth should be altered which will in turn positively influence self-esteem. This may not align well with perspectives of those with AN where it is used as method of controlling/reducing these negative thoughts and beliefs and not addressing them can be detrimental to sustaining recovery (Federici & Kaplan, 2008).

Fairburn et al. (2003) described their concept of self-esteem in the transdiagnostic model as: “unconditional and pervasive negative view of themselves which is seen as part of their permanent identity” (p. 516). They present a different argument compared to their previous article (Fairburn, Shafran, et al., 1999) that this form of self-esteem is useful to treat. In the model, self-esteem is linked to more determined action toward valued goals (i.e. AN). This is consistent with the current results but only if ‘valued goals’ include negative or self-deprecating ones. For example, in this study self-punishment was a theme and could be determined a ‘valued goal’ as it was actively pursued by participants, and was congruent with their sense of self as requiring punishment.
Blank and Latzer (2004) argue that low self-esteem is a key contributor to anxiety and a desire to increase pleasure, belonging, and mastery. This is consistent with those that suggested low sense of self-esteem or efficacy was associated with ‘successes’ in AN being reinforcing. However, those that saw AN as a validation of negative views of themselves would not match this. In addition, rather than endorsements of pleasure being associated with low self-esteem, participants inferred that AN reduced emotional distress (i.e., if on a continuum, moved from high distress due to low self-esteem to less distress associated with low self-esteem). It could be that participants do not recognise a link between relative pleasure of AN as occurring due to low self-esteem and perceived failure in other areas of life which is proposed in the model (Fairburn et al., 2003).

Low self-esteem, negative self-concept, negative self-evaluation, and perceived ineffectiveness are all established risk factors for AN (Bers & Quinlan, 1992; Jacobi et al., 2004). Of interest is the link to self-worth and self-punishment in the current findings. Although self-injurious behaviour (SIB) can be defined as that which causes minor to moderate intentional physical damage to the individual and occurs while the person is in a distressed state (Favaro & Santonastaso, 2000), it may be relevant to descriptions of self-punishment. Rates of self-injurious behaviour in AN are relatively high (at least double estimates of psychiatric controls) and are associated with increased clinical symptomatology, suicidal ideation, cluster B personality disorders, trauma histories, and impulsivity (Claes, Vandereycken, & Vertommen, 2003; Favaro & Santonastaso, 2000). In addition, SIB and AN share some similar risk characteristics: similarities with OCD, compulsive (habitual, ego-dystonic) SIB and impulsive (episodic, ego-syntonic) SIB patterns, negative affect intolerance, self-criticism, desire for control, and trauma experiences (Favaro & Santonastaso, 2000). Other account studies support accounts of AN as part of intentional self-punishment (Favaro & Santonastaso, 2000; Williams & Reid, 2010).

Low self-esteem is endorsed much more frequently as a cause than low self-worth in this study and others (Nevonen & Broberg, 2000; Tozzi et al., 2003). Anorexia nervosa as a form of achievement, distinction, or superiority from others was frequently endorsed (Nilsson et al., 2007; Serpell et al., 1999; Tozzi et al., 2003;
Williams & Reid, 2010), but as a means of punishment to self or others was mentioned in only one study (Williams & Reid, 2010). This could be due to high rates of harm avoidance in AN, where self-punishing behaviours would typically be incongruent. Hence, self-punishing reasoning may describe a subtype of AN, distinguishing from those that are largely acting to overcome low self-esteem or self-worth, this motivation occurs to validate these negative beliefs.

**Symbolism**

Anorexia nervosa is not typically described in models of aetiology as a coping strategy but is implicated as one through proposed reductions in negative experience, for example, emotional distress. The other factors in this theme are not well accounted for in models but are better supported by other accounts of AN (Serpell et al., 1999; Tan et al., 2003; Williams & Reid, 2010). Research of risk factors suggests that escape/avoidance coping styles are common in EDs which may support the idea that indirect coping strategies are utilised (e.g., dietary restriction) rather than directly challenging problems (Jacobi et al., 2004). Overall, this section of factors appears mostly subjective and as such is difficult to relate to more concrete theories or evidence. Additionally, these factors were idiographic even though sharing a similar theme, for example, food and weight represented a range of things for different participants including: family values, personal values of ‘good’ and ‘bad’, and emotions. Thus, these symbolic interpretations of AN are more difficult to apply to generalised models. These findings may be more useful when considering individual formulations and that abstraction may be common within AN, where it is applied to different components of life.

**Body image**

Two of the findings within this theme related to the aesthetics of weight loss and body size, which is described frequently in models of aetiology (Fairburn et al., 2003; Keery et al., 2004; Meyer et al., 2011; Shroff & Thompson, 2006; Thompson et al., 1999; Williamson et al., 2004). The other prominent finding related to social desirability where social reinforcement gained for participating in a shared practice of dieting or for weight loss was perceived as significant; this represents an aspect less accounted for in models.
Williamson and colleagues (2004) present the most comprehensive model containing body image issues as an integral component of AN. Consistent with the current findings were fear of ‘fatness’ and internalisation of the thin ideal as evidenced by linking ‘thinness’ to attractiveness. They also mention over-concern with body size/shape which is present but not necessarily with respect to aesthetic concerns. For example, if a participant interpreted food and body as a measure of (valued) control, then evidently they may be ‘over-concerned’ with shape and size given this relative importance. However, the model suggests that this occurs exclusively in relation to “fatness interpretations” (Williamson et al., 2004, p. 714) which is largely incongruent with approximately half those in this study. Social influence is only taken into account as influencing the development of the thin-ideal, rather than specific pathways of social reinforcement (Williamson et al., 2004). In general this model accounts for the findings of this study but not well. There were women in this study who specifically objected that they developed AN due to aesthetic or vanity, indicating it is not a good foundation for a patient-perspective model of AN. The transdiagnostic model (Fairburn et al., 2003) and compulsive exercise model (Meyer et al., 2011) are more consistent with the current study where body concerns are a part, but not the central cause.

Risk factors support the role of dieting, weight concerns, and negative body image in the development of EDs (Jacobi et al., 2004). Furthermore, those with AN have high correlations with body dysmorphic disorder which may contribute to distorted body image around weight or shape which contributes to AN. Greater exposure to dieting risk domains is shown to be risk factor for AN, and may increase potential for body image distortions (Jacobi et al., 2004). Self-reports in studies of AN were consistent with these themes, including: body dissatisfaction (Nevonen & Broberg, 2000; Nilsson et al., 2007), attractiveness (Serpell et al., 2002), resistance to being labelled as doing it for vanity or dieting reasons (Button & Warren, 2001; Williams & Reid, 2010), and initiating in relation to others’ (Nevonen & Broberg, 2000).
Perceptual and physical dispositions

Issues within this theme relate to predisposing factors and physical conditions which contribute to AN. The concept of a ‘starvation syndrome’ discussed previously may accurately model some of the physiological responses to starvation which mean that the person does not experience relentless hunger (Guisinger, 2003). Bruch (1974) proposed that low interoceptive awareness could account for low awareness of appetite and fatigue in AN and thus sustain restriction. However, the link between appetite and interoceptive awareness has not been supported for AN (Guisinger, 2003), but is a general risk factor for EDs (Jacobi et al., 2004).

Models indicating an influence from others on the development of AN are relevant for this theme, such as the model by Minuchin et al. (1978). Family influence was particularly important in setting values for eating values, and achievement/perfectionism and is mirrored in other accounts (Tozzi et al., 2003). These findings support the focus of the family on diet in Minuchin et al.’s model. Somatic concerns of the family in general were important for some participants where modelling of AN, food deprivation, and emphasis on healthy eating were described. However, in others this was not an important feature. Minuchin et al.’s model also focused on aspects of family dynamics especially rigid and enmeshed aspects of the family but these were not described as factors in the current study, although aspects of enmeshment and over-involvement were present seemingly as a result of AN (i.e., due to concern and involvement required for care).

Risk factors related to body image concerns are relevant here, as are modelling factors. Negative experiences of food, such as feeding and gastrointestinal problems in childhood, are supported in the literature (Jacobi et al., 2004). Although some unique experiences were reported in this study, such as childhood neglect contributing to acceptance of hunger and are difficult to find similarities in personal account studies. This category may represent another more idiographic one and be sensitive to low number of participants.

Section 3: Causes of subsequent relapses

There is a lack of theoretical models for relapse in AN. The discussion of this section will compare current findings to accounts in other studies. Correlates to risk
factors will be made where relevant and additional supporting or contradicting evidence will be discussed.

A previous account of relapse (Federici & Kaplan, 2008) reviewed in Chapter Two covered six areas related to relapse: Internal motivation for change, recovery as a ‘work in progress,’ perceived value of treatment experience, developing supportive relationships, awareness and tolerance of negative emotion, self-validation. The first three of these relate predominantly to relapse occurring after treatment, i.e., dependent on an initial experience with AN. The last three could potentially be significant during initial AN (consistent factor) or impacted by initial experience (variable factor).

Developing supportive relationships as suggested by Federici and Kaplan (2008) was reflected in this study, mainly after initial recovery or experience. Relationships were undermined during recovery by lack of control and coercion from others to maintain gains, as well as criticism about appearance following recovery. Awareness and tolerance of negative emotion was also significant, where participants described distress, negative emotions (e.g., depression), cognitive fatigue, and not knowing more appropriate coping strategies (i.e., relapse for sense security). These are extensions of the original study which focused on tolerating negative affect, and managing anorectic thoughts. Results were very similar for self-validation: self-criticism, continued low self-esteem and low self-worth, negative perceptions of the future (e.g., hopelessness), and continued difficulty managing anorectic thoughts. However, the theme of being scared of failing at recovery was not evident compared to Federici and Kaplan (2008).

Many causes prominent after initial development were covered by the comparative study in the remaining categories (Federici & Kaplan, 2008). For example, ambivalence about recovery and/or treatment, reverting to anorectic patterns, dissatisfaction with treatment with too much focus on weight goals, and poor support after treatment. A key difference in emphasis was the persistent nature of anorectic patterns and thoughts which were more significant in the current study. In addition, lacking knowledge of what were ‘normal’ thoughts, behaviours, sizes, shapes, and so forth for their body was raised as a problem following recovery. The
role of AN providing a sense of security in the face of fear-inducing change, uncertainty, or transition was also an added cause.

Risk factors for relapse indicate that those with a history of suicide are significantly more likely to relapse (J. C. Carter, Blackmore, Sutandar-Pinnock, & Woodside, 2004). This potentially correlates with perceptions of low self-worth, fatigue at struggling with AN, despair and hopelessness about the future, and lack of concern about personal wellbeing in relapse (Beautrais, 2000; Franko & Keel, 2006; Youssef et al., 2004). Those that have received treatment in a specialised eating disorder service are more likely to relapse. This is seems counterintuitive but may be a result of more severe or chronic cases requiring specialised treatment and hence poorer predicted outcome (J. C. Carter et al., 2004). The perception of having received ‘poor’ treatment was related to relapse and this typically described specialised services. The majority of those who accessed specialised services in this study were forced to do so due to extreme health concerns so it was associated with much greater loss of control and ambivalence or resistance, another risk for relapse (J. C. Carter et al., 2012). This may be a more significant factor in New Zealand compared to studies in more populated areas due to the limited resources and thus demands on services to accept the most severe cases.

The implications for treatment are that it can aim to better support and prevent relapses occurring. Issues of ambivalence, readiness for treatment, and perceived coercion into treatment could be targeted through motivational and rapport aspects of treatment (Federici & Kaplan, 2008; Tan et al., 2010). Post-discharge support and continuity of support into the released environment appears a significant component, especially with regard to theories of aetiology (e.g., Minuchin et al., 1978) and risk factors (Jacobi et al., 2004) which both implicate the negative effects of contextual factors (such as conflict). Therapy or respite for carers may be beneficial due to significant carer strain in AN (Bellingham, 2012) and relapse indicated by critical and aversive management by others. This is not suggesting family therapy to address AN specifically, rather therapy to improve the coping resources of social supports caring for those with AN. Post-discharge support may also be helpful in reducing small incremental reengagement with anorectic patterns.
The results indicate that AN remains a prominent and familiar coping strategy following recovery. This could be due to inadequate alternatives, therefore increasing coping resources and confidence in implementing them might be appropriate. Alternatively, those attempting to recover may possess skills and confidence to implement substitute strategies but AN is the preferred method of coping. Thus, intervention could target managing the desire to use AN as a preferred coping strategies such as in motivational interviewing (W. R. Miller & Rollnick, 2012). For example, components of motivational interviewing such as cost/benefit analysis, awareness of long-term goals, and personal values which conflicts with AN may be useful in making AN a less desirable option (Nordbø et al., 2012). Intolerance of negative affect and continued low self-worth suggest that these issues need to be addressed in treatment. It is difficult to assess to what degree these are covered within treatment programmes in NZ (Beumont et al., 2004).

**Combined model of aetiology**

This research has supported some theories of aetiology more significantly than others and indicated different ways of conceptualising AN, see Figure 11. A natural progression of this is to consolidate the most relevant models, research, and findings into a unified model. The following models were most consistently referenced in relation to the current findings: Blank and Latzer (psychoanalytic model; 2004), Fairburn et al. (transdiagnostic model; 2003); Fairburn, Shafran, et al. (cognitive behavioural maintenance model; 1999, and Meyer et al. (compulsive exercise model; 2011). Figure

*Figure 12. Consolidated model of aetiology.*

indicates the combined model. It follows a similar format to the transdiagnostic and cognitive behavioural models. The top half of the model denotes factors external to the disorder and is distinguished by a typical lack of adequate coping. External context encompasses the related ‘life’ factors which contributed, including both distal and proximal factor (e.g., predisposing physical factors compared to current interpersonal problems).
Instead of assuming a specific interpretation of the markers of AN, ‘interpretation of AN markers’ allows idiographic differences in what aspects are important and how these are interpreted. It may be common for people to describe weight as a key marker, and symbolic of ‘fatness’ and undesirability. However, markers could also include the amount of food eaten, where is food being representative of greed, or a range and combination of other factors. Obsession with these markers can occur where the person develops frequent rumination or assessment (e.g., body checking, calorie counting, planning). Energy control behaviours refer to those which contribute to a frequent negative net energy, and deviates from typical ‘weight-control’ behaviours to allow broader encompassing of behaviours. In line with accounts of AN, compulsion, urges, or possession can contribute to behaviours. After this occurs for a period of time, the person can become underweight, and potentially alter physiological responses of the body contributing to obsession and preoccupation with food. Perpetuating factors are those involved in the feedback and re-interpretation of low weight. Meaning of low weight may perpetuate this cycle as the value attached to it can encourage further
progression. Similarly, rewards derived from the process of AN are likely to perpetuate it.

The benefit of the combined model is that it encompasses a broader range of perceptions and behaviours which were described in this study and are inclusive of key aspects of existing research and theory. Ideas of control and body shape are not imposed on the model, rather they can be attached as is relevant in each case. An important feature of the model is that the meaning attached to markers of AN for each person must be significant enough to motivate change (i.e., stimulate energy control behaviours). In addition, it assumes there is a discrepancy with current state where actions relevant to AN must be taken in order to reach a desired state or achieve a desired effect. For example, a person may perceive being very ‘out of control’ in their life and want to gain more control, thus AN facilitates the action from current state/effect to desired state/effect. This model puts obsession and possession as influences which contribute to aspects of AN. Furthermore, AN typically occurred within the context of inadequate coping resources in response to negative internal and external experiences, thus aspects of AN developed becoming interpreted as increased coping. This is different from models commonly suggesting low self-esteem as integral (e.g., Fairburn et al., 2003; Fairburn, Shafran, et al., 1999). Low self-esteem is an established risk factor (Jacobi et al., 2004); however, it seemed in this study that it interacted with external factors (e.g., abuse) and involved difficulties managing these negative stimuli.

This study examined the additional reasons perceived for developing relapses after initial recovery. As presented in Results, there was overlap between initial causes and the perceived development of relapses in AN; however, there were also factors which became significant after having experienced AN once before, and factors which only became influential after going through treatment or a recovery process. Figure Figure 13 indicates the influences of suggested reasons for relapse within the initial model of aetiology and predominantly focuses on perceived causes which became relevant due to having experienced AN (i.e., those exclusive to relapse). Perceived causes for relapse which mirror those present initially are obviously contained within the original model. Causes which became significant after
experiencing AN represent an exacerbation or transformation of reasons for AN unique to the individual, thus would be represented as relevant additions to the categories in the consolidated model (e.g., AN becoming a ‘sense of security’).

Six main factors related to relapse were evident from this study and others. First of these was pressure to recover both personally and interpersonally. This pressure can cause strain and scrutiny over aspects of recovery contributing to the magnitude of perceived failures in recovery. Specific to aspects of the self, hopelessness and despair can develop about the ability to recover or sustain recovery. This pessimism can facilitate relapse because alternative to AN seem inaccessible. Interpersonally, the process of recovery often came with increased pressure and conflict from others who were invested in recovery. Increased conflict in this domain can create further risk for relapse, especially if AN has been used as a coping strategy. Across these domains, participants described how during relapses there were an increase in demands on coping (e.g., increased conflict) and/or reduced ability to cope (e.g., depressed). Factors for relapse directly related to AN were persistence of AN and resistance or ambivalence to recovery. Persistence incorporates a range of

Figure 13. Influences of relapse on aetiology of AN. Bolded text indicates factors relating to relapse.

Six main factors related to relapse were evident from this study and others. First of these was pressure to recover both personally and interpersonally. This pressure can cause strain and scrutiny over aspects of recovery contributing to the magnitude of perceived failures in recovery. Specific to aspects of the self, hopelessness and despair can develop about the ability to recover or sustain recovery. This pessimism can facilitate relapse because alternative to AN seem inaccessible. Interpersonally, the process of recovery often came with increased pressure and conflict from others who were invested in recovery. Increased conflict in this domain can create further risk for relapse, especially if AN has been used as a coping strategy. Across these domains, participants described how during relapses there were an increase in demands on coping (e.g., increased conflict) and/or reduced ability to cope (e.g., depressed). Factors for relapse directly related to AN were persistence of AN and resistance or ambivalence to recovery. Persistence incorporates a range of
features if AN which act as reminders or habits and contribute to relapse (e.g., anorectic thought patterns). Ambivalence and resistance to recovery was described mainly with respect to the perpetuating factors of AN, such as being ambivalent about losing the rewarding aspects of AN.

Understanding the causes for relapses is important in treatment, especially for relapse prevention. Reasons for relapse which mirror initial development suggest that treatment which addresses initial reasons for developing AN should theoretically reduce the risk for further relapse. Causes suggested which became more important after developing AN or experiencing relapse indicate a need in treatment to examine how the experience of treatment or AN can exacerbate other issues in the person’s life (e.g., social isolation). Lastly, novel causes for relapsing in AN are particularly important when considering relapse prevention. In this study, these were factors which became significant over time due to experiencing AN and are emphasised in Figure 13. Understanding how aspects of AN challenge maintaining recovery is useful for targeting during treatment or post-discharge support so that those with AN are more prepared and can manage these factors.

**Recommendations for intake, treatment, and relapse prevention**

Based on the findings of this study and relevant research, a number of recommendations for professionals and services were developed. Recommendations for diagnosis, understanding AN, and care during treatment, include:

- **Diagnosis:** Broadening of the diagnostic criteria which includes net energy deficits, rather than focusing solely on restricted intake; inclusion of obsessive or possessive aspects of AN
- **Understanding AN:** Awareness of a range of possible fears in AN, in addition to the typical ‘fear of fatness’; reduction in pejorative terms used to describe treatment interfering behaviour in AN; reduced emphasis on thin-ideal aspects to incorporate other motivations for engaging in AN; working with denial and resistance to weight gain in a client-centred, possibly motivational interviewing approach; and, awareness of additional difficulties which may accompany AN and management of these, for example, risk of death, death of friends who have had AN, hopelessness, and development of other EDs.
• **Care during treatment:** Support for family or key caregivers, especially if the family are showing signs of distress. Education around AN and support for family post-treatment may also be beneficial. Clearer pathways for referral and easier access to information about available public and private services for AN in New Zealand would address confusion around diagnosis and available treatment.

Treatment recommendations:

• **Assessment and associated intervention:** assessment of the level of obsession associated with AN and action to address this, especially if there is a pattern of obsession in other areas of life. Furthermore, assessment of how AN may interact with low self-esteem or self-worth and addressing how these may beliefs may perpetuate AN. Likewise, self-punishment should be assessed and the degree to which AN acts as a method of self-punishment. The results also suggested that assessing the degree of knowledge around eating and experiences which may have predisposed the person to AN would be helpful; developing more accurate and healthy thoughts about food and body may be useful for treatment and relapse prevention.

• **Treatment content:** Foster motivation for change and addressing any feelings of coercion early in treatment; incorporate power and control elements of AN and review its relation to perceived negative life events; and, address positive and negative reinforcement derived from engaging in AN, and alternative ways to achieve these results. Findings indicated that treatment of AN which is based on the interpretation and relevance of aspects of AN to each individual, rather than presuming the meaning of a person’s AN may increase engagement or perceived relevance of treatment (e.g., due to wanting to be thin). Anorexia as a form of coping was prominent, thus intervention related to increasing alternate forms of coping is recommended.

Relapse prevention recommendations:

• **During treatment:** Acknowledgements of habits related to AN and possible habit-reversal or management of these post-treatment; separation of self from AN and development of healthier identity; methods for coping with negative
or judgmental reactions from others regarding AN; relapse prevention plan based on previous triggers or influential factors for initial development.

- **During and after discharge:** The process of recovery can also increase risk of relapse. Acknowledgment of the difficulties associated with this and specific intervention prior to discharge and support after discharge may reduce this risk. Support for caregivers after discharge was also suggested with a plan for dealing with lapses, difficulties in recovery, and full relapses. Ambivalence to remaining in recovery was common, hence intervention to enhance this prior to discharge and strategies for sustaining motivation.

- **Specific issues for relapse:** For chronic cases of AN, hopeless and despair may be likely and thus intervention to develop a sense of successfulness with recovery, or some hope in the possibility of recovery may be helpful. In addition, in those that have experienced treatment for AN previously, investigation of positive and negative aspects of previous treatment may be beneficial, especially why previous experiences were unsuccessful (or what occurred after these which contributed to relapse).

**Limitations**

A strength of this study is gaining insight into the subjective understandings of those who experience AN. The results can enhance connection with people who experience AN through more explicit descriptions of their perspective. However, this subjectivity also presents limitations. It relies on the person’s insight into themselves and their ability to express themselves adequately. Deficits in either of these are likely to skew the validity of the data. Subjective perspectives are not necessarily reflective of reality, especially when considering what contributes to problems. Participants who stated that they lacked insight at the time of the onset of AN likely engaged in retrospective meaning-making processes, potentially restricting the results to people who have recovered. Despite this, people experience their life through their own experiences and perception of these experiences; understanding this is relevant to treatment.

The small sample-size is a clear limitation. It allowed in-depth discussion but reduces generalizability. In addition, participants were self-selected to participate so a
potential bias in respondents may be present. For example, the focus of study on aetiology may have encouraged those who perceive they have good insight into reasons for developing AN and discouraged those with little perceived understanding. All participants were female, reducing possible generalisation to other genders. There was a small range of ethnicities as the sample was predominantly New Zealand European and may lack cultural sensitivity and relevance to people with alternate world views. Furthermore, as New Zealand is considered a ‘Western’ country influenced by media of this type, exposure to the ‘thin-ideal’ is likely greater in comparison to non-Western countries. This may have increased the frequency of concerns about aesthetic appearance in comparison to other countries where this is less prevalent.

The majority of participants experienced some form of treatment but this varied extensively across participants. Many of them described that their experience of treatment helped with some of their understanding so it is likely to impact results. Because the type of treatment, the focus, duration, intensity, and total number of times in treatment varied so widely, it is difficult to assess how this impacts participants’ responses. To better account for the influence of treatment interviewing before and after treatment with a clearer understanding of treatment content so this could be linked to observed changes would be recommended.

Ages were indirectly capped through the criteria for participation in this study. As onset of AN is most prevalent in adolescent ages the restriction of needing to have been diagnosed in the last ten years (or close to this) meant ages were biased toward those in their adolescence and twenties which is observed in the demographics of participants. There were people who contacted the researcher who were older than this but were also over the ten year threshold and therefore excluded. This means the results of this study may not represent perceptions of those who are older and have experienced AN. Moreover, many people contacted the researcher from overseas wanting to participate and due to the focus on face-to-face interviews were declined. Future research of this type could include a broader approach in gaining information (such as video interviewing) and include comparisons across countries.
Lastly, there is the possibility that participants engaged in impression management, especially around topics which could be seen as reflecting undesirably on their character. A good example of this is around body image and the assertion from some that it is not a significant factor for them. Some of this vehemence may come from vanity being seen as socially undesirable and potentially from experiencing a history of others negative judgments around this, leading to this component being denied. However, given the evidence for non-aesthetic self-starvation historically and cross-culturally, it is unlikely that impression management is the only explanation.

**Conclusion**

The purpose of this research was to understand perceptions of the causes of anorexia nervosa in people who have experienced it, as well as their perceptions about the causes which contribute to relapse. The results of this study were largely consistent with other research examining subjective experience. However, it was difficult to compare the current findings with accounts of relapse given the dearth of research in this area. Furthermore, psychiatric definitions of anorexia nervosa often conflicted with personal experience or definitions. Perceived causes were consistent with aspects of aetiological models but again, this varied widely across models. The most consistent comparisons occurred with those which incorporated a range of factors, rather than focusing on one theoretical point. The findings of this study suggested anorexia nervosa is a complicated disorder which interacts strongly with internal states, external factors, and personal values. Furthermore, causal aspects of anorexia nervosa can change after having experienced it before, and negative experiences can accompany the process of recovery contributing to relapses. A better understanding of the experiences and perceptions of those with anorexia nervosa for both initial development and relapse is needed to better inform treatment, and possibly more especially, relapse prevention, given that relapse is a very real and sometimes fatal, issue with this disorder.
REFERENCES


Urbano, A. (2011). *Clinicians’ understanding and use of their personal recovery in the treatment of eating disorders* (Doctor of Philosophy). The University of Georgia, Georgia, USA.


APPENDIX A: RESEARCH ADVERTISEMENT

Have you been diagnosed with anorexia?

As part of a Masters research study with the University of Waikato I am trying to find out about what people who have been diagnosed think about the causes of their difficulties.

This research aims to explore the perspectives of people who have struggled with anorexia nervosa relating to what may have caused or contributed to it developing.

The following is needed:

♦ That you received a diagnosis in the last 10 years (2003+) excluding this year.
♦ Not currently in treatment.
♦ Are over 16 years old.
♦ Would be willing to share your experiences with me.

Please contact me (Gabrielle Batenburg) for more information, I would love to hear from you if you are interested.

Any contact you have with me will be confidential.

This research study has been approved by the University of Waikato School of Psychology Ethics Committee.

Contact:

ANstudy@live.com

Or

020 401 99699
APPENDIX B: PARTICIPANT INFORMATION

PARTICIPANT INFORMATION

Perspectives of the causes of eating difficulties in people with anorexia nervosa: A comparison to theoretical models of aetiology [a master’s thesis].

Research process: What is involved?

The research consists of three parts. The first is a preliminary phone call to check the details outlined on the participation poster, i.e. over 16, time of diagnosis, not currently in treatment. This conversation will not be recorded. The diagnosis should be from a professional; if you are unsure please let me know. The other parts consist of an initial interview and then a follow-up interview later on.

In the first interview I will go through the consent process with you and talk you through any questions you may have. If you feel comfortable with continuing and sign the consent form, there will be a range of questions asked about how and why you think you developed anorexia nervosa. There are also some questions about your perceptions of relapse. This is estimated to take 30 minutes to an hour, but these times are estimates. We have the option to do this in an office at the University of Waikato, at a psychology office in Hamilton city centre, or in your home/someplace else; whichever is preferable for you. The responses will be recorded so that I can transcribe the conversation. After this the recordings will be destroyed.

After we meet for this interview I will spend some time writing up our discussion and identifying the main themes. The second interview is an opportunity for you to get a written copy of the first interview and to comment on the themes identified. You can check to see whether the themes match what you were thinking. I may also ask you some questions that developed after reviewing the first interview, particularly around clarifying ideas that may have been unclear. This meeting is projected to be much shorter than the first, likely less than 30 minutes. This will conclude your participation in this study.

Confidentiality

Your information and any contact we have will remain completely confidential. You will not be able to be identified from your responses as you will be given an alternative name. Any details you may provide that could identify you will be omitted in the transcribing, in addition to anything you do not wish to be recorded. Per university requirement, the anonymised records will be kept in a locked filing cabinet.
on the University of Waikato campus for 5 years and then destroyed. Please note that if you disclose a current risk of serious harm to yourself or others, confidentiality may be broken to the extent that your statements referring to risk of harm may be discussed with my supervisor, and possibly referred to an agency that can help if the risk is perceived as imminent.

My details

I am Gabrielle Batenburg. This research will contribute toward my master’s degree in social science. I am also studying to complete my post-graduate diploma in clinical psychology; both at the University of Waikato. Please contact me if you have specific questions.

Mobile: 020 401 99699  E-mail: ANstudy@live.com

Supervisors: Dr Jo Thakker (Registered clinical psychologist and senior lecturer at the University of Waikato)

Phone: +64 7 838 4466 ext. 6809   E-mail: jthakker@waikato.ac.nz

Dr Joshua Myers (Clinical psychologist at The Psychology Centre, Hamilton)
APPENDIX C: CONSENT FORM

PARTICIPANT’S COPY

Research Project: Perspectives of the causes of eating difficulties in people with anorexia nervosa: A comparison to theoretical models of aetiology.

Name of Researcher: Gabrielle Batenburg

Name of Supervisor (if applicable): Jo Thakker and Joshua Myers

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Nicola Starkey, phone: 838 4466 ext.6472, e-mail nstarkey@waikato.ac.nz)

Participant’s
Name:______________________Signature:_________________Date:_______
APPENDIX D: DEMOGRAPHICS FORM

Demographical information

Record information that you feel comfortable with, omit anything you do not wish to answer.

1. Name by which you would like to be identified (for anonymity): __________________________

2. How old are you? ____________________

3. In which country were you born? ______________________________________

4. What is the ethnic/cultural background(s) of your biological parents and yourself?
   Mother: __________________________
   Father: __________________________
   You: __________________________

5. What was your childhood and/or current religious affiliation (indicate)?
   1. Anglican
   2. Catholic
   3. Hindu
   4. Buddhist
   5. Not Affiliated
   6. Other, Specify: __________________________

6. What is your current marital status?
   1. Married
   2. Separated
   3. Divorced
   4. Widowed
   5. Never Married

7. How many children do you have? ____________________

8. Are you living alone or with others?
1. Alone
2. With partner (for at least one year), but not legally married
3. In own home with spouse and/or children
4. In home of parents or children
5. In home of siblings or other non-lineal relatives
6. In shared home with other relatives or friends
7. In residential treatment facility
8. Other, Specify: ____________________________

9. What is your present occupation? ____________________________
   If currently not working:
   What kind of work have you done? ____________________________

10. What is your highest qualification/education?
    1. < Year 12/Form 6
    2. High school/NCEA Level 3/Form 7
    3. Some university
    4. Certificate/diploma
    5. Bachelor’s degree
    6. Master’s degree and above

The following information regarding your personal details will be used for future communication but as discussed will not be associated with responses. The contact information is helpful for contacting you for the second follow-up interview and so that I can indicate when key findings are available and send them to you if you are interested.

Full name: ________________________________________________

Contact phone number ________________________________________

Email or address ____________________________________________
APPENDIX E: SOURCES OF SUPPORT

Support Information

Eating Disorders Association of New Zealand
A service and support site aimed mostly at supporting families and parents of those who have a child with an eating disorder. However, they provide information and resources regarding support groups around the country. They also provide information about how to gain access to help and the pathways/professionals that are part of that process.

Website:  http://www.ed.org.nz/
Email:     info@ed.org.nz
Telephone: 09 – 5222 679

Overeaters Anonymous
Overeaters Anonymous is a fellowship of men and women from all walks of life who meet in order to help solve a common problem – compulsive overeating, which includes obesity, anorexia and bulimia. OA offers meetings all over New Zealand – not all with a anorexia focus; however, all who attend have eating-related issues they would like to overcome.

Email:     info@oaregion10.org

Lifeline Aotearoa
Service is a 24/7 helpline which offers free, anonymous and confidential support. “Whenever you need to talk, we’ll be here to listen.” It is not a specific support network for eating disorders but available for general mental and emotional wellbeing and support.

Lifeline Aotearoa also provides Face-to-Face counseling service in major cities, such as Auckland. This service is charged on a scaled basis based on what the individual can afford.

Website:  http://www.lifeline.org.nz/
Email for face-to-face enquiries:  face2face@lifeline.org.nz
Telephone:
Within Auckland: 09 5222 999  
Outside Auckland/toll free: 0800 543 354  
Office and counseling enquiries: 09 909 8750

Your GP/Doctor
Your GP is the first step in getting a referral to community mental health/other mental health services if you feel that you are struggling significantly and needing support from a professional.

CATT (Emergency or Immediate help)
If you are in a psychological crisis and there is significant and serious concern for you or someone else’s safety or you are significantly concerned about your mental wellbeing and are unable to access other mental health support, you can call the Crisis and Assessment Team.

Phone: 0800 800 717
# APPENDIX F: TIMELINE – NATALIA

<table>
<thead>
<tr>
<th>Early factors</th>
<th>14</th>
<th>15</th>
<th>16–17</th>
<th>21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trigger: perceived negative response to body and weight from partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Began extreme dietary restriction and exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rapid decline in weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor: diagnosed with AN</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forced self to break rigid diet rules</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slow self-recovery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bulimia—eating and vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very restrictive over eating (rigid) - not to clinical level</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-monitoring/recovery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX G: TIMELINE – COLLETTE

− Started to get overwhelmed during high school
− Finding life stressful
− Feeling out of control
− Reduction in hunger—not getting hungry
− Reduced food intake
− Increased exercise

− Increased pressure to perform well
− Increased parental and family conflict
− Weight decreasing
− Doctor suggested AN—treatment denied
− Saw counsellor—bad experience

− Returned to treatment for AN (specialised)
− Monitoring treatment commenced
− Continued to work on recovery herself

− Severely underweight—hospitalised
− Treatment for AN (specialised)
− Discharged from treatment
− Relapse of AN

Early factors 15 17 18 19 20

Approximate age (years)
APPENDIX H: TIMELINE – EVA

- Begun high school—lack of existing friends
- Lonely and socially isolated
- Unsure how to solve/cope
- Restricted food intake
- Family concern (active interference)
- Disappointment with lack of significant weight loss

Early factors 13 16 18

- Miscarried baby—partner left
- Isolated/lonely
- Distress
- Unable to cope with negative emotions
- Unconscious reduction in food intake
- Family concern (active—family therapy) - perceived as unhelpful

(Approximate age (years)

- Separated from partner
- Socially isolated and lonely
- Sad
- Independent from family
- Lack of monitoring around food
- Active restricting of food intake
- Gradually more severe restricting
- Family concern (passive)

(Approximate age (years)

- Significant weight decline over long period of time

- Becomes aware of extreme thinness from seeing image of self (previously unaware due to distorted body image)
- Self-refers for treatment
- Accepted for treatment for AN (specialised)

(Approximate age (years)

- Discharged from treatment

225
APPENDIX I: TIMELINE – KATE

- Started reducing food intake
- Gradually lost substantial amount of weight (approximately 6 months)
- Parental concern—denied restricting
- Hospitalisation
- Made decision to recover

Early factors | 10-11 | 12 | 16—18

- Increased pressure at high school
- Felt out of control - not achieving as I wanted to
- Increased control over food intake
- Reduced weight (e.g., visible bones)

Approximate age (years)

- Counselling for AN (child)
- Did not find useful (may have been resistant)
- Perceived it as surface-level and not focusing on relevant strategies

Approximate age (years)

- Started with new therapist
- Working on issues of control and obsession

Approximate age (years)

22
### APPENDIX J: TIMELINE – MALIHA

<table>
<thead>
<tr>
<th>Early factors</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Started to diet</td>
<td>Actively restricted diet to lose weight</td>
<td>Considered dieting ‘cool’ - open with friends</td>
<td>Others not concerned/dismissive (i.e., not seen as serious, funny).</td>
<td>\begin{itemize} \item Restricting used as a coping mechanism but not to full syndrome \item Other mental health intensifies \end{itemize}</td>
</tr>
<tr>
<td></td>
<td>Severely underweight</td>
<td>Declining mental health (severe anxiety and depression)</td>
<td>Overdose and hospitalisation</td>
<td>Diagnosed with AN</td>
<td>Treatment for AN</td>
</tr>
<tr>
<td></td>
<td>Overdose and hospitalisation</td>
<td>Treatment for other mental health</td>
<td>\begin{itemize} \item Restricting used as a coping mechanism but not to full syndrome \item Other mental health intensifies \end{itemize}</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Becoming progressively more underweight</td>
<td>Others starting to become concerned (e.g., family, friends, doctor)</td>
<td>Becoming secretive — concealing, no longer open with others</td>
<td>Mental health stable (i.e. period of being ‘fine’)</td>
<td>\begin{itemize} \item Restricting used as a coping mechanism but not to full syndrome \item Other mental health intensifies \end{itemize}</td>
</tr>
</tbody>
</table>

Approximate age (years): 227
APPENDIX J: TIMELINE – KORA

- Nephew born—forced to care for him
- Recurring sexual abuse
- Feeling a lack of control over life—distressed ↓
- Restricting food intake
- Increased exercise/energy expenditure

14–15
- Nephew turned 5 years old—returned care to parents
- Loosening of food restriction rules—eating fruits and vegetables
- Greater focus on self-building own life, better influences in life

<table>
<thead>
<tr>
<th>Early factors</th>
<th>14–15</th>
<th>15–16</th>
<th>19–20</th>
<th>21</th>
</tr>
</thead>
</table>
| - Amenorrhea—saw doctor—diagnosed with AN
  - Referred for treatment ↓
  - Did not want to admit problem or receive help
  - No known follow-up for referral—no known contact with family about the issue |
- Inpatient treatment (general mental health)
  - Reduced autonomy and control over life/treatment
  - Relapsed into self-starvation (2+ months)
  - Staff noticed—forced food
  - Began eating to be released |
- 'Broke' long-term food restriction—ate ice-cream
- Lost control and binged on many ice-creams following breaking this rule
- Distraught and upset at having lost control
- Onset of vomiting after eating—maintained strict rules, no subsequent binges

- Vomiting after eating gets progressively worse—more severe tools needed to induce vomiting
- Diet extended—includes healthy foods (e.g., whole grains) - vomit after eating anything
- No excessive binging

20–22
- Drank corrosive/poisonous substance to induce vomiting—hospitalised
- Liquid diet for a long time
- Non-restrictive diet pursued after this (range of foods, little purging/restricting/excessive exercise)

22–23

Approximate age (years)
APPENDIX L: TIMELINE – SCARLET

- Started dieting – lost some weight (non-threatening amount)
- Gained weight back
- Made a resolution: lose more weight and keep it off
- Rapid decline in weight
- Continued restricted food intake
- Hospitalised
- Treatment (brief, general)
- Slow relapse into restriction
- Returned to treatment
- Struggling with weight after recovering—ambivalent
- Pattern of restrictive and non-restrictive eating
- Thought: ‘could just not do this [AN]’ - recovery perspective
- Triggered: change and pressure
- Relapsed
- Weight recovered

<table>
<thead>
<tr>
<th>Early factors</th>
<th>13–14</th>
<th>15</th>
<th>16</th>
<th>17</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Approximate age (years)
## APPENDIX M: TIMELINE – ANABELLE

<table>
<thead>
<tr>
<th>Early factors</th>
<th>12</th>
<th>14–15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19–20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Restricting heavily—only eating two foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Diagnosed with OCD—medicated</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Treatment (general)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Continued dietary restriction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Accessed services (underweight) - no action taken</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approximate age (years)</th>
<th>12–15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19–20</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Returned to New Zealand</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Treatment (specialised)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Hospitalised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Treatment (inpatient, another city)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Hospitalised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approximate age (years)</th>
<th>14–15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19–20</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Returned to New Zealand</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Hospitalised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Treatment (specialised, inpatient)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approximate age (years)</th>
<th>12</th>
<th>15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19–20</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Treatment (specialised, outpatient) - ‘good period’</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approximate age (years)</th>
<th>21</th>
<th>22</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Hospitalised</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Treatment (inpatient, another city)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>