An investigation of uncertainty and intolerance of uncertainty and associated factors in anorexia nervosa

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An Investigation of Intolerance of Uncertainty and Associated Factors in Anorexia Nervosa

By

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Abstract

Anorexia nervosa is a serious and complex mental illness, where little is known of factors implicated in its maintenance. Current effective treatments for adolescent anorexia nervosa have shown promising outcomes, however a significant group of patients still remain unwell. One factor that contributes to a poor treatment outcome is comorbid anxiety. However, there is a lack of knowledge of anxiety related vulnerability factors in individuals with anorexia nervosa. A potentially useful anxiety related factor is intolerance of uncertainty (IU). Theoretically and clinically IU could be associated with eating disorder psychopathology and the need for control, often found in individuals with anorexia nervosa.

This thesis comprises of a conceptual model of IU in anorexia nervosa, four studies that empirically examine IU and associated factors in relation to anorexia nervosa and a proposed future study. The first quantitative study investigates anxiety related factors in adults with anorexia nervosa and healthy controls. The two subsequent qualitative studies explore the meaning of uncertainty for adolescents with anorexia nervosa and their parents. The fourth study examines anxiety related factors in adolescents with anorexia nervosa, similar to study 1, and further investigates whether such factors along with beliefs about having an eating disorder and parental distress moderate/mediate response to treatment.

Findings, suggest that IU and anxiety related factors are elevated in adults and adolescents with anorexia nervosa compared to the normal population and are positively associated with eating disorder psychopathology. Personal accounts from adolescents further reveal that IU is predominately a negative experience, while parents find uncertainty in relation to their child’s illness excessive and a source of distress. Results from the fourth study indicate that ambivalence in adolescents at the beginning of therapy predicts response to treatment. This thesis has brought to the forefront the construct of IU as a possible maintenance factor of anorexia nervosa. Data are discussed in relation to the proposed model of IU in anorexia nervosa and both theoretical and clinical implications are discussed.
Statement of Contribution and publications

The present candidate proposed the idea of examining the construct of IU in anorexia nervosa to her first supervisor and was accepted after the necessary procedures for a PhD at the IoP, King’s College London. Interest in the area stemmed out of the candidate’s previous research, as part of her MSc in 2006 (Konstantellou & Reynolds 2010) and a continuous interest in anxiety and in particular IU in the field of eating disorders. The candidate’s previous research and clinical experience suggested this to be a promising area to further pursue that will advance our knowledge of maintenance factors for anorexia nervosa with possible important clinical implications.

The candidate’s contribution to the conceptual model, the four studies and a proposed future study is as follows. Theory and model development (Chapter 2): The maintenance cycle of IU at the individual patient level was proposed by the candidate. The family level was worked on following discussions with her first supervisor. Study 1 (Chapter 3): Examining anxiety related vulnerability factors based on the Dugas model was proposed by the candidate and further elaborated with her second supervisor. Study 2 (Chapter 4): This was proposed by the candidate after collaborating with the adult eating disorder team and acting as a facilitator in running focus groups on uncertainty with adults with anorexia nervosa. The candidate thought it was important to compliment her two quantitative studies with qualitative work. Since little is known of IU in relation to eating disorders this would help understand better the mechanisms that take place between IU and anorexia nervosa by hearing patients’ own thoughts of how uncertainty is like for them. Furthermore, adolescents with anorexia nervosa may experience uncertainty differently to adults with the same disorder due to developmental factors. Study 3 (Chapter 5): This was suggested by the candidate and discussed with her first supervisor. Study 4 (Chapter 6): The cross sectional part of study 6 was the candidate’s initial proposal for her PhD. That is examining anxiety related vulnerability factors based on the Dugas model in individuals with anorexia nervosa and comparing their responses to a healthy control group. The candidate further wanted to examine anxiety, worry and beliefs about having an eating disorder in accordance with the conceptual model. Discussions with her first supervisor resulted in examining both patient and parental factors over the first three months of therapy as potential moderators/mediators of response to therapy. Finally, the candidate has outlined a possible future research project in Chapter 8 following findings reported in studies 1 to 4.

A number of papers (Konstantellou, Campbell, Eisler, Simic, & Treasure, 2011; Konstantellou, Hale, Sternheim, Simic, & Eisler, 2013; Konstantellou, Nowotny, Sternheim, Hale, Treasure, & Simic, 2013 Konstantellou, Payne, Espie, Eisler, & Simic, 2013) are associated with the present thesis. The candidate has also presented findings from study 4 at the first IU symposium part of the European Association for Behavioural and Cognitive Therapies (EABCT) conference (Geneva, 2012).
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Common Abbreviations used throughout this thesis

- BMI = Body Mass Index
- CAQ = Cognitive Avoidance Questionnaire
- EDNOS-R = Eating Disorders Not Otherwise Specified - Restrictive Subtype
- HC = Healthy Controls
- IU = Intolerance of Uncertainty
- M = Mean
- NPOQ = Negative Problem Orientation
- PSWQ = Penn State Worry Questionnaire
- SD = Standard Deviation
- RCT – Randomised Controlled Trial
- WWII = Why Worry Questionnaire
- W/H = Weight for Height
Chapter 1

Introduction

Anorexia nervosa is a serious psychological disorder afflicting mostly young females. The need to increase both our understanding of factors influencing anorexia nervosa psychopathology and treatment effectiveness is of vital importance. Frequently individuals with anorexia nervosa also have comorbid states of anxiety, which can contribute to a poorer treatment outcome. Despite this, very little is known of the role of anxiety related vulnerability factors in the eating disorders. The main aim of this thesis is to empirically examine known vulnerability factors of Generalised Anxiety Disorder (GAD), with a particular interest and emphasis on one anxiety related factor, namely intolerance of uncertainty (IU). IU could be an important factor maintaining comorbid states of anxiety and also influencing anorexia nervosa psychopathology and the need for control, characteristic of individuals with anorexia nervosa.

Eight chapters comprise the present thesis. Chapter 1 introduces the topic of the thesis providing extensive information of the relevant literature which forms the backbone of the thesis. Chapter 2 presents a conceptual model of IU in anorexia nervosa. This essentially proposes a number of possible pathways through which IU could be affecting adults, as well as, adolescents with anorexia nervosa and their parents and its possible role in relation to treatment. This theoretical chapter is used for guidance for the following Chapters. Chapter 3 consists of the first of four studies that empirically examines anxiety related vulnerability factors, including IU, in adults with anorexia nervosa and healthy controls. Chapter 4 and Chapter 5 consist of two qualitative studies that explore how adolescents with anorexia nervosa and their parents experience and cope with uncertainty. These complement the quantitative studies in this thesis and allow for a deeper understanding of how uncertainty is like for adolescents with anorexia nervosa and their parents. Chapter 6 comprises of a similar study to that carried out with adults, presented in Chapter 3, examining anxiety related vulnerability factors in adolescents with anorexia nervosa. In addition this study examines the extent to which these factors, beliefs about having an eating disorder and parental mood may moderate and/or mediate response to treatment. Findings from all studies are brought together in Chapter 7, which puts them in context in terms of previous literature and the conceptual model that was presented and discusses both theoretical and clinical implications. The final Chapter of the thesis outlines a potential future project that follows on from findings reported in studies 1-4, particularly from study 4.

1.1 Overview of chapter

The present chapter begins with an introduction to the eating disorders, their presentation and seriousness. Emphasis is then placed on comorbidity, particularly anxiety in relation to anorexia nervosa. IU is then introduced with an up-to-date review of the available literature. Finally, an outline of the
treatments available for anorexia nervosa is provided, mostly focusing on family therapy for adolescent anorexia nervosa and current knowledge on moderators and mediators of treatment. The chapter comes to an end outlining three main gaps in the literature. These include a lack of examination of IU in relation to anorexia nervosa, despite its clear theoretical and clinical relevance, a lack of knowledge of underlying anxiety related vulnerability factors in anorexia nervosa and a lack of knowledge of patient and parental related moderators and mediators of response to therapy for adolescent anorexia nervosa.

1.2 Overview of eating disorders

1.2.1 Diagnostic categories

Eating disorders are considered a disturbance in eating habits, weight control behaviours and thoughts about food, weight and shape. Evidence suggests that eating disorders are considered a serious mental illness (Klump, Bulik, Kaye, Treasure, & Tyson, 2009). Patients with an eating disorder hold the view that thinness is of great value, exhibit a persistent quest to be thin (Bruch, 1978) and tend to evaluate their self in terms of their weight and shape (Fairburn & Harrison, 2003; Vitousek & Hollon, 1990). Currently according to the Diagnostic and Statistical Manual of Mental Illness Text Revision from the American Psychological Association (DSM-IV-TR) (APA, 2000) eating disorders are classified into three categories: anorexia nervosa, bulimia nervosa and Eating Disorders Not Otherwise Specified (EDNOS). See Box 1 and Appendix 1 for detailed information on the current diagnostic criteria of all three categories.

The first eating disorder diagnostic category is anorexia nervosa, which is recognised by its severe restriction to food intake and refusal to maintain a minimal normal weight for age and height that is less than 85% of that expected (See Box 1 for DSM-IV-TR criteria for anorexia nervosa). Other key diagnostic criteria include an intense fear of becoming fat even when considerably underweight, a range of disturbed thoughts regarding one’s weight and shape and the absence of at least three consecutive menstrual cycles. There are two subtypes for anorexia nervosa. The restrictive subtype is characterised by the use of dietary restriction as the main method to maintain a low body weight and people in this category rarely engage in binge eating or purging behaviours. People in the binge/purge subtype regularly engage in binge eating or purging behaviours, such as, self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

The second category is bulimia nervosa. Bulimia and anorexia nervosa share the overvaluation of weight and body shape on the sense of self. In contrast to anorexia nervosa, the person with bulimia nervosa will generally be in the normal weight range and will eat large amounts of food compared to what one would usually be expected to eat. Feelings of loss of control will often be present and such binges are accompanied by guilt and compensatory behaviours to prevent any weight gain in the form of self-induced vomiting, misuse of laxatives, diuretics, enemas, or other medications, fasting, or excessive exercise. This category is also divided into two subtypes. The purging subtype, which involves regular compensatory behaviours during an episode of bulimia nervosa, such as self-induced vomiting or the
misuse of laxatives, diuretics, or enemas and the non purging subtype whereby other compensatory behaviours are used to achieve a low weight such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics or enemas.

The third category is called EDNOS or atypical eating disorders and refers to individuals who do not meet the full diagnostic criteria for anorexia nervosa nor bulimia nervosa. That is, they may meet most of the criteria for anorexia nervosa but have regular menses or may show many of the symptoms for bulimia nervosa but the frequency of binges and compensatory behaviours is less often that what is required for a diagnosis of bulimia nervosa, that is it occurs at a frequency of less than twice a week or a duration of less than 3 months.

Box 1:
DSM-IV-TR criteria for anorexia nervosa (APA, 2000)

Anorexia Nervosa
A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
B. Intense fear of gaining weight or becoming fat, even though underweight.
C. 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 denial of the seriousness of the current low body weight.
D. In post-menarcheal females, amenorrhea, i.e., the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., estrogen, administration.)

Specify type:
Restricting Type: during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)
Binge-Eating/Purging Type: during the current episode of Anorexia Nervosa, the person has regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

1.2.2 Diagnostic utility

More often than not patients with an eating disorder often cross over from one diagnostic category to another, particularly from anorexia nervosa to bulimia nervosa (Peat, Mitchell, Hoek, & Wonderlich, 2009; Råstam, Gillberg, & Gillberg, 1995; Strober, Freeman, & Morrell, 1997; van der Ham, van Strien, & van Engeland, 1994). This creates some concern regarding the diagnostic categories. Peat, and colleagues (2009) point out that there is a lack of strength in using the different subtypes of anorexia nervosa-restrictive subtype and bulimia nervosa subtype. For instance, patients switch from one subtype to the other and it is not always clear what is required for one to be considered to have moved to another subtype, as well as, difficulty determining what constitutes a binge by someone who has anorexia nervosa, as it could be overestimated (Peat et al., 2009).

One further main area of concern and debate regarding the current diagnostic system lies in the third diagnostic category, that of EDNOS. EDNOS is the most common diagnosis that is given to those seeking treatment for an eating disorder, ironically more so than a diagnosis of anorexia nervosa or bulimia.
nervosa (Turner & Bryant-Waugh, 2004). For instance, the average prevalence rate for an EDNOS diagnosis for treatment seeking individuals is 60% for adults (Button, Benson, Nollett, & Palmer, 2005; Fairburn & Bohn, 2005; Fairburn, et al., 2007; Turner & Bryant-Waugh, 2004) and similar rates have been found for adolescents (Eddy, Doyle, Hoste, Herzog, & Le Grange, 2008). Most importantly this category comprises of individuals who although do not meet the diagnostic criteria of neither anorexia nervosa nor bulimia nervosa, usually due to missing certain physical requirements as opposed to core eating disorder psychopathology (Fairburn & Bohn, 2005; Turner & Bryant-Waugh, 2004), they nonetheless are similar in many respects to individuals with a diagnosis of anorexia nervosa or bulimia nervosa. For instance, an extensive meta-analysis of 125 papers found that individuals with an EDNOS diagnosis did not differ in any substantial way between those with a recognised eating disorder classification, such as anorexia nervosa, in terms of their eating psychopathology, overall psychopathology and general health (Thomas, Vartanian, & Brownell, 2009). In other words, individuals with EDNOS have symptoms of similar clinical severity (Button, Benson, Nollett, & Palmer, 2005; Fairburn, et al., 2007; Thomas, et al., 2009; Turner & Bryant-Waugh, 2004) duration of illness, secondary psychosocial problems (Fairburn, et al., 2007) and require the same amount of therapy sessions to those with anorexia nervosa or bulimia nervosa (Button, et al., 2005).

A number of ways have been proposed to help tackle issues with the current diagnostic system and the EDNOS category which is a poorly defined group making up the majority of diagnostic cases (Fairburn & Bohn, 2005). One proposition has been to adopt a transdiagnostic approach of the eating disorders, which emphasises the fact that there are much more common features uniting the categories than separating them (Fairburn, et al., 2009; Fairburn, Cooper, & Shafran, 2003). However caution has been placed on this view on the grounds that it does not meet all the basic criteria for a transdiagnostic model (Birmingham, Touyz, & Harbottle, 2009). Other propositions include expanding the diagnostic criteria for anorexia nervosa and bulimia nervosa (Knoll, Bulik, & Hebebrand, 2011) to a broad system of categories for eating disorders (Walsh & Sysko, 2009), which would reduce the number of cases in the EDNOS category or including positive diagnostic criteria for an EDNOS diagnosis (Fairburn & Bohn, 2005). Currently, no specific features are required to be present for an individual to be given an EDNOS diagnosis apart from showing clinical levels of eating psychopathology and not meeting all the necessary criteria for either anorexia nervosa or bulimia nervosa (Fairburn & Bohn, 2005).

With the preparation and arrival of the 5th edition of the DSM, due to be published in May 2013, the diagnostic categories of eating disorders are currently being extensively reviewed and discussed resolving some of the issues raised concerning diagnostic utility. For instance, criteria involving menstruation for anorexia nervosa will be removed. Furthermore, criteria regarding weight loss that leads to a body weight of less than 85% of that expected for one’s age and height is now recognised as being somewhat arbitrary and no specific weight figures will be included in the DSM-V. As for bulimia nervosa frequency of the binge/purge cycle will be reduced from twice a week for the past 3 months to
once a week for the past three months. A key implication of these changes is a significant reduction of the EDNOS category.

1.2.3 Aetiology of anorexia nervosa

The nature of anorexia nervosa is complex and its aetiology multi-factorial (Garner & Garfinkel, 1980). Many research studies have attempted to understand the origins of anorexia nervosa by identifying specific risk factors that contribute to its development, including psychosocial/cultural factors (Striegel-Moore & Cachelin, 2001) and genetic/biological factors (Kipman, Gorwood, Mouren-Siméoni, & Adès, 1999).

Anorexia nervosa has previously been considered as a culture bound syndrome arising in Caucasian individuals living in Westernised countries due to being exposed to ideals about weight and shape and the importance of being thin (Leslie, 1985). Such views have been recently challenged, for instance, a meta analysis concluded that there is no sufficient evidence that anorexia nervosa is a culture bound syndrome (Keel & Klump, 2003) in fact anorexia nervosa is present in different cultures across the world (Miller & Pumariega, 2001). A number of individual and environmental factors from birth to onset have been considered as potential risk factors implicated in the development of anorexia nervosa. For instance, a recent review of the evidence looked at both longitudinal and cross-sectional studies and found that female gender, early childhood eating problems, elevated weight and shape concerns, low self esteem, sexual abuse, other adverse experiences, high parental concern, excessive exercise, perfectionism and psychiatric comorbidity such as OCPT/OCD are potential risk factors for anorexia nervosa (Jacobi, Hayward, de Zwaan, Kraemer, & Agras, 2004). An area of concern is that it is often difficult to distinguish between factors present prior to the onset of the disorder, particularly in cross sectional studies, and factors that are perpetuating the illness.

More recently attention has shifted from examining psychosocial factors to examining biological/genetic risk factors for anorexia nervosa (Bulik, Slof-Op’t Landt, van Furth, & Sullivan, 2007). There are two lines of evidence family studies and twin studies that give support to the importance of genetics in the development of anorexia nervosa. It is well documented from family studies that eating disorders co-segregate run in families (Strober, 2000). However, family studies do not control for environmental components while twin studies do (Fairburn, Cowen, & Harrison, 1999). One of the largest twin studies has examined the heritability of anorexia nervosa, using a strict definition of the illness, and found additive genetic effects of 0.56 (Bulik, et al., 2006). Overall there is the need to understand better how potential risk factors come together to cause anorexia nervosa and the interplay between genetics and environment is difficult to determine (Treasure & Kanakam, 2011).
1.2.4 Incidence and prevalence of anorexia nervosa

Epidemiological studies have looked at the rate of the occurrence of new cases of anorexia nervosa per 100,000 (i.e., incidence) and how common anorexia nervosa is in a population at a specific point in time (i.e., prevalence). The majority of epidemiological studies have been carried out in Western Europe and North America (Hoek & van Hoeken, 2003). What is challenging in interpreting epidemiological research is that different studies use different methods to detect cases, different types and number of data sources, and different criteria to define cases (i.e., what diagnosis criteria is used and how strict that criteria is carried out). All of which will influence findings and at times underestimate the true incidence of eating disorders.

Overall, anorexia nervosa is a rare illness in the general population but much more common in females than males with a female-to-male ratio of approximately 10:1 (Currin, Schmidt, Treasure, & Jick, 2005; Joergensen, 1992; Lucas, Beard, O’Fallon, & Kurland, 1991) and adolescent girls, for instance 15-19 year olds are reported to comprise 40% of identified cases (Hoek, 2006; Hoek & van Hoeken, 2003; Lewinsohn, Striegel-Moore, & Seeley, 2000; Theander, 1996). A review of the literature on incidence of anorexia nervosa found an average incidence of 8 per 100,000 per year (Hoek & van Hoeken, 2003). One of the most comprehensive studies that used information from medical case files from three sources, including health care providers, general practitioners, and specialist services in Rochester, a particular city in Minneapolis, USA, found incidence rates of anorexia nervosa of 8.3 per 100,000 between the period of 1935-1984 with an increase for females aged 15-19 years old 43.5 per 100,000 (69.4 per 100,000 for females and 7.3 per 100,000 for males) (Lucas et al., 1991).

In terms of time trends, there is support from a review for a small increase in the incidence of anorexia nervosa in the 20th century (Keel & Klump, 2003) with more stable trends in the past few decades (Hoek, 2006). For instance, annual incidence rates for anorexia nervosa for individuals aged 10-39 years of age have been found to remain stable from 1988 (18.5 per 100,000) to 2000 (20.1 in 100,000), with the highest incidence of 34.5 per 100,000 for females 10-19 years of age (Currin, et al., 2005). A nationwide study based in the Netherlands used the recordings of general practitioners to identify cases of anorexia nervosa (van Son, van Hoeken, Bartelds, van Furth, & Hoek, 2006) during two set of periods: 1985-1989 and 1995-1999. Findings confirmed that overall age and sex adjusted incidence for anorexia nervosa shows a stable trend (from 7.4 to 7.7 per 100,000) however when looking at specific age defined groups, female adolescents, aged 15-19 years old, showed significant increase in number of incidents from 56.4 to 109.2 per 100,000 (van Son et al., 2006).

The average lifetime prevalence rate of anorexia nervosa across a range of epidemiological studies for young females is 0.3% (Hoek & van Hoeken, 2003). In adolescents girls these rates are higher. For instance, one study found a prevalence rate of adolescent girls with anorexia nervosa of 0.6%, with higher rates detected for sub-threshold levels of anorexia nervosa (3.5%) (Touchette, et al., 2011). Age
and sex adjusted prevalence rate for anorexia nervosa is 0.15 % using information from medical case files from health care providers, general practitioners, and specialists (Lucas et al., 1991).

1.2.5 Prognosis

**Mortality and morbidity**

Anorexia nervosa is a life-threatening illness with high rates of mortality (Harris & Barraclough, 1998; Hoek, 2006; Papadopoulos, et al., 2009). The most recent review of the evidence found standardized mortality ratios (i.e., the ratio of observed deaths in a population with anorexia nervosa compared to the ratio of expected any-cause deaths in an age- and sex-matched population) of 5.86 for anorexia nervosa and 1.92 for EDNOS (Arcelus, Mitchell, Wales, & Nielsen, 2011). The standard mortality ratio of 6009 females with one or more inpatient treatment(s) from 1973-2003 was 6.2, including both natural and unnatural causes of death (Papadopoulos, et al., 2009). Crude mortality (i.e., the number of deaths in a population, scaled to the size of that population at a specific time) rates have also been reported. A recent review of the evidence identified 36 studies and found weighted annual crude mortality rates of 5.1% for anorexia nervosa and 3.3% for EDNOS, (Arcelus, Mitchell, Wales, & Nielsen, 2011). Despite the overall high rates of mortality in individuals with anorexia nervosa, when looking specifically at mortality during adolescent years these rates are lower, for instance one study found crude mortality rate of a Spanish sample of adolescents to be 2%, (Pla & Toro, 1999) while another study found no mortality rates in adolescents with anorexia nervosa that were followed up for 10 years (Råstam, Gillberg, & Wentz, 2003). Differences in mortality rates found between studies could reflect differences in methodology, follow-up period, as well as, increased recognition of anorexia nervosa, better access to services and improvement of available treatments over the years.

Along with the threat of death that plagues anorexia nervosa, individuals with this illness also experience high levels of morbidity. This is of particular concern since time of onset is usually at adolescence when one is rapidly developing both physically and psychologically. One’s natural development then can become severely compromised, with psychological, biological and psychosocial functioning becoming severely impaired (Bollen & Wojciechowski, 2004; Katzman, 2005; Lewinsohn, et al., 2000). Individuals with anorexia nervosa also exhibit high levels of emotional distress when compared to healthy controls (Bollen & Wojciechowski, 2004). Personal accounts from patients with anorexia nervosa further emphasise the extent to which the illness has intruded into their lives, even more so than patients with a serious physical or another psychiatric disorder (Carter, Bewell, & Devins, 2008). This is also reflected in research that has found decreased levels of quality of life of individuals with an eating disorder, including health related and quality of life when compared to healthy controls (Mond, Owen, Hay, Rodgers, & Beumont, 2005). Finally, the impact of the illness can also negatively affect the family, producing great amounts of stress and burden on parents (Gilbert, Shaw, & Notar, 2000; Sim, et al., 2009).
Prognostic factors, chronicity and recovery of anorexia nervosa

The course of anorexia nervosa is variable, ranging from patients successfully recovering from the illness to patients having a more poorer and chronic course. Many studies have endeavoured to examine the course of anorexia nervosa. A review of 22 studies looking at different factors that may influence the course of anorexia nervosa, including psychological factors, eating related and genetic factors, concludes that the evidence is moderate in strength (Berkman, Lohr, & Bulik, 2007).

One of the more consistent finding is that a younger age of onset predicts a better outcome. A review of 119 studies found that 57% of adolescents with an adolescent onset of anorexia nervosa recovered while 44% with both an illness onset at adolescent and adulthood (Steinhausen, et al., 2008). Adolescents with anorexia nervosa tend to have a more favourable outcome than adults, with approximately 70% of adolescents recovering at eight (Casper & Jabine, 1996; Pla & Toro, 1999), five (Martin, 1985) and up to 15 year follow-ups (Strober, Freeman, & Morrell, 1997) and 59% of adolescents with anorexia nervosa do not show any eating disorder psychopathology at 6 years follow-up (Fichter & Quadflieg, 1999). Other studies have found slightly lower levels of approximately 50% at 4 and 10 year follow-ups, respectively, in terms of eating psychopathology and psychiatric comorbidity (Råstam, et al., 2003; van der Ham, van Strien, & van Engeland, 1994). While in adults, rates are slightly lower with 55.4% of 101 female adults with an initial anorexia nervosa diagnosis showed no major eating disorder symptoms at 6 years post treatment follow-up (Ficchter & Quadflieg, 1999), while at 8 and 10 year follow-ups, respectively, 40% of adult patients have recovered (Casper & Jabine, 1996; Råstam, et al., 2003). Poorer outcome at 20 year follow-up was associated with a later age of onset, neurotic symptoms, personality difficulties, disturbed relationships in the family and a longer duration of illness (Ratnasuriya, et al., 1991).

Although the above findings are promising for adolescent with anorexia nervosa, there are still a subgroup of adolescents who become chronic (Herpertz-Dahlmann, et al., 2001; Strober, et al., 1997) particularly those with restrictive anorexia nervosa may continue for an extended period of time to experience subclinical levels of anorexia nervosa psychopathology (Berkman, et al., 2007) or develop bulimia symptomatology (Milos, Spindler, Schnyder, & Fairburn, 2005).

There is some evidence that comorbid psychopathology, family behaviours and early response to therapy predict dropout and remission in family therapy for adolescent anorexia nervosa (Lock, et al., 2006). Other factors that have been examined include, insight into one’s illness (Greenfeld, Anyan, Hobart, Quinlan, & Plantes, 1991) and better decision making abilities (Cavedini, et al., 2006), which have been found to contribute to a better outcome, while inability to ignore, high levels of anxiety, eating related obsessionality, low BMI, comorbid psychopathology and social problems have been found to contribute to a poorer prognosis (Dickson, et al., 2008; Yackobovitch-Gavan, et al., 2009; Lowe, et al.,
Another study found chronically ill patients show more harm avoidance, lower self-directedness and low cooperativeness (Bulik, Sullivan, Fear, & Pickering, 2000).

1.2.6 Personality disorders and eating disorders

A number of personality related traits and disorders have consistently been found to be prominent in individuals with an eating disorder. A meta-analysis of the evidence looking at personality traits and eating disorders in the past decade found that individuals with anorexia nervosa and bulimia nervosa are characterized by perfectionism, obsessive compulsive traits, neuroticism, harm avoidance and obsessive compulsive traits (Cassin & von Ranson, 2005). Perfectionist, anxious and harm avoidant tendencies seem to persistent even after one has recovered from an eating disorder (Kaye, et al., 2004).

In adults some personality traits appear to differentiate between individuals with anorexia nervosa and those with bulimia nervosa. For instance, a rigid personality, high levels of neuroticism (Bollen & Wojciechowsk, 2004) and low novelty seeking, with a need for structure, order and symmetry is often found in individuals with anorexia nervosa (Zucker & Losh, 2008), while in individuals with bulimia nervosa raised levels of impulsivity and sensation seeking are more prominent (Cassin & von Ranson, 2005). Adolescents with an eating disorder also show similar patterns of personality traits and disorders to adults, including perfectionist tendencies, obsessive compulsive rigid traits, emotion regulation problems and avoidant traits (Cassidy, Allsopp, & Williams, 1999; Thompson-Brenner, et al., 2008). However, the evidence is less clear in adolescents whether personality related traits differ across eating disorder diagnostic categories (Råstam, et al., 2003).

The relationship between different personality traits and eating disorders can be conceptualised in different ways. A recent comprehensive review of the literature has weighed up the evidence of four conceptual models when considering this relationship (Lilenfeld, Wonderlich, Riso, Crosby, Mitchell, 2006). For instance, evidence supporting a predisposition model comes from prospective studies that have identified negative affect, perfectionism, drive for thinness, poor interoceptive awareness, ineffectiveness and obsessive compulsive personality traits as risk factors for the development of an eating disorder (Lilenfeld, et al., 2006). In contrast, a complication model does not assume that personality traits precede or increase the risk of developing an eating disorder but does argue that variation in personality characteristics can produce complication in the eating disorders. There is however, little available evidence to clearly differentiate a complication model from other models. Another way of understanding the relationship between personality traits and eating disorders is through a common pathway model, which suggests that personality disorders and eating disorders are distinct disorders caused by the same underlying factor(s). Evidence from a few family studies suggest that obsessive compulsive personality disorder and anorexia nervosa share common family diathesis, however, it is difficult to distinguish whether this is due to a genetic predisposition or environmental factors. Finally, a pathoplasty model does not make any inferences regarding causality, but does suggest that once personality traits and eating disorders are present in an individual, they may interact in a way...
that modifies the presentation and course of each condition. Support for this model comes from a number of studies that have found that certain personality traits can influence outcome for eating disorders. In particular, cluster B personality disorders for people with an eating disorder, and obsessive compulsive personality disorder traits, high levels of harm avoidance and fears related to maturing (Steinhausen, 2002) can have negative effects on outcome for patients with anorexia nervosa, while histrionic personality and increased levels of self-directedness can have positive effects on outcome for eating disorder patients, for anorexia nervosa (Lilenfeld, et al., 2006).

It has further been suggested that people with an eating disorder have an identity impairment and suffer from a disturbance in one’s sense of self. One study, for instance, found that compared to healthy controls individuals with an eating disorder view themselves in a much less positive light and assign much more negative attributes to themselves (Stein & Corte, 2007). It has also been suggested that young adult women with an eating disorder have a personality profile that resembles more adolescent girls, whereby they see themselves as being special and different, with unrealistic views of physical harm and are more prone to psychological distress (Fox, Harrop, Trower, & Leung, 2009).

1.2.7 Control and eating disorders

Control is a complex construct. Issues related to having a sense of control or need for control have been considered in relation to psychological distress. For instance, a feeling of loss of control is thought an important factor contributing to psychological distress, while feeling in control of one’s internal states and environment are important for one’s psychological well-being (Declerck, Boone, & De Brabander, 2006; Shapiro, Schwartz, & Astin, 1996). Healthy individuals have an increased sense of control, possibly due to an overestimation of the amount of control that they actually have, when compared to individuals with a psychological disorder (Shapiro, et al., 1996). Overall, psychological distress can be conceptualised as arising due to a fear of loss of control (Mansell, 2005), which then increases the need to gain a sense of control (Friedland, Keinan, & Regev, 1992). In the anxiety literature, past experiences in one’s life where one was not in control can predispose someone to develop a cognitive bias whereby future events are seen as out of one’s control and subsequently develop an anxiety disorder (Chorpita & Barlow, 1998).

Within the eating disorder field, individuals with anorexia nervosa have long been recognized as having various issues with control expressed by themselves (Espindola, & Blay, 2009) and identified by clinicians as well (Jarman, Smith, & Walsh, 1997). In particular, Individuals with anorexia nervosa often mention that they feel a lack of control over their feelings, external events and life in general (Sassaroli, et al., 2008), which seems to fuel a strong need for control (Bruch, 1978). Controlling then one’s body through anorexia nervosa related behaviours has been at least partly understood as a way of dealing with the need to regain a sense of control in one’s life (Bruch, 1978; Fairburn, Shafran, & Cooper, 1999). For instance, in one qualitative study patients described how anorexia nervosa is interpreted in terms of their identity and a need for control (Espindola, et al., 2009). Unfortunately the feeling of gaining control
through one’s illness is only temporary successful and patients end up feeling out of control and paradoxically controlled by their illness. Although control issues are seen by many as being at the centre of eating disorder psychopathology, little is known of what underlies these issues of control, in particular this lack of control and strong need to restore control (Surgenor, Horn, Plumridge, & Hudson, 2002).

Control has been to some extent overlooked and not empirically examined despite long held conceptualisations of its importance in anorexia nervosa dating back to the work of Hilde Bruch (1973, 1982) and Fairburn, Shafran and Cooper (1999). Recently, Sassaroli and Ruggiero, (2011) have brought to the forefront the importance of need for control in eating disorders. They define control as “a coping belief regarding the need to obsessively control the unpredictable events and the threats of external world” (Sassaroli & Ruggiero, 2011, p: 20). According to this model, eating psychopathology is understood through elevated levels of perfectionism, low self esteem and need for control, which result in negative thought processes. The authors argue that this preoccupation and need for control in individuals with an eating disorder is not only limited to eating, weight and shape concerns but also extends to external events and internal feelings and states linked to their life in general (Sassaroli & Ruggiero, 2011). It is through dieting that a sense of control is attained and consequently eating disorder maintained (Sassaroli & Ruggiero, 2011). A need for control reveals an anxiety about threatening future events. Having a sense of control of a threatening situation would suggest one can predict the situation and is confident in managing it, while feeling out of control suggests the opposite (Sassaroli & Ruggiero, 2011). In light of their theoretical suggestions Sassaroli and Ruggiero have developed the control and worry focused treatment of eating disorders (CWT-ED; Sassaroli & Ruggiero, 2011), which targets biases beliefs and processes regarding control and worry (Sassaroli & Ruggiero, 2011).

1.2.8 Psychiatric comorbidity and eating disorders
More often than not individuals seeking treatment for an eating disorder also show symptoms of other disorders, particularly anxiety (Blinder, Cumella, & Sanathara, 2006; Spindler & Milos, 2007) and depression (O’Brien & Vincent, 2003). Research suggests that up to two thirds of individuals with eating disorders meet diagnostic criteria for at least one lifetime anxiety disorder (Jordan et al., 2008; Kaye, et al., 2004). One study found a lifetime prevalence of anxiety, particularly social phobia and obsessive compulsive disorder (OCD) (65%) (Halmi, Eckert, Marchi, Sampugnaro, & et al., 1991; Kaye, Bulik, Thornton, Barbarich, & Masters, 2004) while other studies have found rates of social phobia in more than half of those with an eating disorder (Hinrichsen, Wright, Waller, & Meyer, 2003; Peñas-Lledó, et al., 2010). These findings have also been replicated in Japanese (Iwasaki, Matsunaga, Kiriike, Tanaka, & Matsui, 2000) and French samples (Godart, Flament, Lecrubier, & Jeammet, 2000). Similar findings come from a number of other studies (Bulik, Sullivan, Fear, & Joyce, 1997; Godart, Flament, Perdereau, & Jeammet, 2002; Raney, et al., 2008).
Similar patterns of comorbid anxiety and depression seen in adults have also been found in children and adolescents with an eating disorder (Herpertz-Dahlmann, Wewetzer, Schulz, & Remschmidt, 1996; McDermott, Forbes, Harris, McCormack, & Gibbon, 2006; Salbach-Andrae, et al., 2008), in girls with subclinical levels of eating disorders (Touchette, et al., 2011) and in young individuals with partial syndromes of eating disorders (Lewinsohn, et al., 2000; Patton, Coffey, Carlin, Sanci, & Sawyer, 2008). High levels of anxiety and depression are also positively associated with more severe symptoms, poorer outcome and a longer duration of illness (AN) (Herpertz-Dahlmann, et al., 1996; McDermott, et al., 2006). Of interest, adolescents with EDNOS show more comorbidity, including anxiety, depression, OCD and substance misuse, than adolescents with bulimia nervosa (Schmidt, et al., 2008).

Out of all the anxiety disorders OCD has been the most researched anxiety disorder in relation to eating disorder. A number of reviews of the literature conclude that there is a definite association between eating disorders and OCD and obsessive compulsive personality traits, particularly with anorexia nervosa (Altman & Shankman, 2009; O’Brien & Vincent, 2003; Serpell, Livingstone, Neiderman, & Lask, 2002; Swinbourne & Touyz, 2007). Research has consistently found elevated levels of OCD and obsessive compulsive symptoms in adults (Blinder, et al., 2006; Wentz, Gillberg, Gillberg, & Råstam, 2001) and adolescents (Anderluh, Tchanturia, Rabe-Hesketh, & Treasure, 2003; Serpell, Hirani, Willoughby, Neiderman, & Lask, 2006; Wentz, et al., 2001) with anorexia nervosa in particular but also bulimia nervosa (Fornari, Kaplan, Sandberg, Matthews, & et al., 1992), with OCD symptoms in individuals with an eating disorder reaching comparative levels to patients with an OCD (Halmi, et al., 2003; Matsunaga, et al., 1999). However, one study found current comorbidity of anxiety disorders without OCD (25.7%) to be higher than comorbidity with OCD (16%) in 103 female adolescent in-patients with anorexia nervosa (Salbach-Andrae, et al., 2008). OCD and eating disorders seem to share similar personality traits (e.g. obsessionality) particularly with anorexia nervosa (Jiménez-Murcia, et al., 2007) even after 6 years of initial illness onset (Råstam, Gillberg, & Gillberg, 1996). In individuals with an early onset of an eating disorder, obsessive compulsive personality disorder and anxiety disorders are the most common disorders that remained after 10 years (Herpertz-Dahlmann, et al., 2001).

Less is known about the specificity of comorbidity in the eating disorders. That is whether anxiety disorders, such as OCD, are elevated in anorexia nervosa because of the specific disorder or due to general levels of psychopathology. One study that sought to answer this found very similar levels of comorbidity in anorexia nervosa, bulimia nervosa and major depression disorder (MDD), with some evidence of specificity for certain comorbid states, including OCD for anorexia nervosa while non specific states included anxiety and cluster C personality disorders (Jordan, et al., 2008).

When looking at the temporal relationship between anxiety disorders and anorexia nervosa, one of the largest comorbidity studies found anxiety disorders, such as OCD, GAD, social phobia and specific phobia to precede onset of an eating disorder (Kaye, et al., 2004) similarly, obsessive compulsive problems also

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tend to exist prior to the onset of the anorexia nervosa (Wentz, et al., 2001), providing some support of anxiety being a risk factor for developing later eating difficulties (Wentz, et al., 2001). Indeed, anxiety is believed to be implicated in both the aetiology and maintenance of eating disorders (Bulik, 1995; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003).

Whether high rates of comorbidity in anorexia nervosa are due to the effects of starvation and subsequent weight loss is an area of debate, as not much is known about fluctuations of comorbidity at different phases of the illness. There is some evidence that depression, anxiety and obsessionality are at their highest when individuals are in their more severe phase of the illness and most underweight (Pollice, Kaye, Greeno, & Weltzin, 1997). Once weight has been restored and the individual has recovered, symptoms of depression reach normal levels (Wentz, et al., 2001) similar to those seen before the onset of the eating disorder (Råstam, et al., 1996). A quite different picture emerges for anxiety and obsessive compulsive behaviours, as there is only a slight decrease in their severity and symptoms remain elevated compared to healthy controls (Holtkamp, Muller, Heussen, Remschmidt, & Herpertz-Dahlmann, 2005; Pollice, et al., 1997; Råstam, et al., 1996; Råstam, et al., 2003), even after long term recovery has taken place (Pollice, et al., 1997; Yackobovitch-Gavan, et al., 2009). One study for instance found high levels of anxiety psychopathology in currently treatment seeking eating disorder patients, slightly lower levels in partially remitted individuals and fully recovered, but still remaining significantly higher when compared to a healthy control group (Bardone-Cone, et al., 2010).

### Methodological issues of comorbidty studies

A number of methodological considerations need to be mentioned when reviewing research on comorbidity and eating disorders. It has been noted that different studies use different sample populations ranging from outpatient settings, inpatient settings or from the community. A further limitation includes very small numbers in different groups. For example, when looking at variations of comorbidity at different stages of anorexia nervosa, group sizes ranged from 22-26 (Pollice, et al., 1997). Older studies have also used a different set of diagnostic criteria to determine the presence of an eating disorder and anxiety disorders (Halmi, Kleifield, Braun, & Sunday, 1999), this may have affected rates of comorbidity (Swinbourne & Touyz, 2007). Many studies also lack any comparison groups. It is much more informative knowing whether rates found are significantly different from the normal population and other clinical groups, as opposed to just reporting prevalence rates. Retrospective studies also seem to be the norm rather than the exception for gaining information on comorbid anxiety in the eating disorders as noted by Pallister & Waller (2008). Finally, there is danger for a sampling bias, when using clinical samples, as there is research showing that individuals with more than one diagnosis are more likely to be referred for treatment than if they had a single diagnosis, also known as Berkson’s bias (Du Fort, Newman, & Bland, 1993).
Despite these methodological shortcomings, one can safely say that there is a clear picture emerging from the majority of the research that anxiety disorders are more often present before illness onset and to a large extent after recovery in individuals with an eating disorder compared to healthy individuals, and appear to run across eating disorder categories (Blinder, et al., 2006; Godart, et al., 2006; Hinrichsen, et al., 2003; Kaye, et al., 2004).

**Comorbidity and treatment outcome**

The majority of studies, as previously seen, have looked at comorbidity in terms of prevalence. The few studies that have examined the possible effects of comorbid states on treatment outcome and recovery have consistently shown that comorbid psychopathology particularly anxiety, in individuals with an eating disorder often severely compromises their illness prognosis (Herpertz-Dahlmann, et al., 1996; Steinhausen, 2002) and leads to poorer treatment outcome (Berkman, et al., 2007; Pallister & Waller, 2008). OCD symptoms in particular have been found to contribute to poorer treatment outcome in both adults (Milos, Spindler, Ruggiero, Klaghofer, & Schnyder, 2002) and adolescents (Lock et al 2005). What remains unclear is whether comorbidity has a direct effect on the eating disorder and/or on the general functioning of the individual (Grilo, 2002).

**Understanding the relationship between anxiety and eating disorders**

Despite the large amount of research showing a close relationship between anxiety and eating disorders many gaps still exist in our understanding of the nature of this relationship (Godart, et al., 2002). A number of propositions have been put forward that attempt to identify possible pathways and mechanisms that may explain why anxiety and eating disorders so often co-exist. One way of understanding this relationship is through a predisposing model whereby anxiety acts as a risk factor for the development of an eating disorder. Some support for this model comes from studies that find anxiety disorders, including OCD, GAD, specific and social phobia to more often than not precede the onset of an eating disorder (Kaye, et al., 2004; Wentz, et al., 2001). Another way of understanding the overlap is by considering eating disorders being in essence part of the anxiety disorder spectrum (Fairburn, et al., 2003; Pallister & Waller, 2008) or an OCD (Holden, 1990). For instance, anorexia nervosa related behaviours, such as restricting, could be considered as safety behaviours that function as a means of avoiding processing more difficult emotions (Pallister & Waller, 2008). Such safety behaviours may temporarily relieve one from anxiety but in the long term they maintain the anxiety (Lovibond, Mitchell, Minard, Brady, & Menzies, 2009; Waller, 2008).

Anxiety disorders and eating disorders could also be understood as part of a common causal model whereby they are both an expression of the same underlying vulnerability factors that are manifested at different times in different ways (Altman & Shankman, 2009). Evidence from family studies suggests that anxiety and eating disorders share common family diathesis (Keel, Klump, Miller, McGue, & Iacono, 2005) which supports such a model. Pallister and Waller (2008) propose a model of shared vulnerability.
factors between the eating disorders and anxiety disorders that encourage targeting such factors in treatments for eating disorders, including harm avoidance tendencies and safety behaviours (Pallister & Waller, 2008). Strober (2004) has further highlighted the strong overlap between fear of weight and fear seen in anxiety disorders. An over expression of neural circuitry has been identified in women with anorexia nervosa similar to that seen under fear conditions, someone then who is more prone for quick ‘fear conditioning’ maybe more prone to develop anorexia nervosa that those with a more slow fear conditioning mode (Strober, 2004). On a similar note, future directed thinking and fear about the future have been identified in individuals with anorexia nervosa. For instance, individuals with anorexia nervosa show no differences in the level of positive thoughts that they hold about the future, but they do tend to have significantly more negative future oriented thinking when compared to healthy controls, with particular concerns placed around their health and social situations (Godley, Tchanturia, MacLeod, & Schmidt, 2001).

Another way of understanding the relationship between anorexia nervosa and anxiety is through a complication model whereby different levels of anxiety can produce complications in the eating disorders but anxiety is not thought to increase the risk for the development of an eating disorders. The effect of anorexia nervosa related behaviours on levels of anxiety also need to be considered. For instance, food restriction and starvation could be affecting anxiety and reinforcing the maintenance of anorexia nervosa behaviours through their anxiolytic effects (Dellava, et al., 2010; Kaye, 2003). Excessive exercise which may arise for varied reasons may have a dual effect of both lowering anxiety and reducing weight also due to its anxiolytic effects (Thornton, et al., 2011). Such effects could be reinforcing anorexia related behaviours in order to relieve oneself from anxiety, providing at least partial explanation as to why individuals continue starving themselves even when they have reached a very low weight. Higher levels of pre-morbid anxiety would then mean a higher risk to engage in restricting behaviours and use them to deal with underlying anxiety. In fact it has been found that individuals with GAD engage in excessive exercise and restricting behaviours more so than healthy individuals (Thornton, Dellava, Root, Lichtenstein, & Bulik, 2011). Patients then with both anorexia nervosa and GAD would be even more prone to engage in excessive exercise and restricting behaviours than patients showing just an eating disorder without any comorbidity (Thornton, et al., 2011).

Finally, according to a pathoplasty model, which is agnostic in terms of causality, when anxiety and anorexia nervosa are both present they can interact with one another and this interaction may affect the course of both the anxiety disorder and the eating disorder. Some support for this comes from studies where presence of anxiety affects the outcome of the eating disorder (Berkman, et al., 2007; Herpertz-Dahlmann, et al., 1996; Steinhausen, 2002; Pallister & Waller, 2008). Although the relationship between anxiety and eating disorders can be conceptualised through the above models, each of which propose distinct mechanisms in understanding the link between anxiety and eating disorders they may not be mutually exclusive from each other. Further research is needed to understand better the
relationship between eating disorders and anxiety and whether more than one of these mechanisms may be operating.

1.3 Overview of Intolerance of uncertainty

1.3.1 How is intolerance of uncertainty defined?

People face uncertainty everyday in all kinds of shapes and forms. As there are levels of uncertainty in different situations there are also individual differences in how individuals experience, tolerate, control and manage uncertainty. Avoiding uncertainties altogether is unrealistic as we live in a world full of uncertainties and unpredictable events. Krohne (1989) was the first to coin the term intolerance of uncertainty (IU) arguing that people who are easily anxious are more prone to feel threatened by uncertainty and emotional arousal. In the past 20 years the construct of IU has been refined within the anxiety literature and a number of definitions have been put forward (Dugas, Gosselin, & Ladouceur, 2001; Freeston, Rhéaume, Letarte, Dugas, & Ladouceur, 1994). The more recent definition conceptualises IU as a personality trait that is future orientated and results in a cognitive bias regarding uncertainty and its implications (Dugas & Robichaud, 2007) found both in males and females (Robichaud, Dugas, & Conway, 2003) and across different ethnicities (Norton, 2005). One way of accounting for differences in tolerating uncertainty is through past exposure to an uncontrollable situation which brings elevated levels of uncertainty that cannot be diminished, this failed attempt to reduce uncertainty may determine how one responds to uncontrollable events in the future (Kofta & Sedek, 1999). IU has mostly been considered and examined as a personality trait. However, more recently it has been recognised that IU can also be considered as a state variable (Mahoney & McEvoy, 2012b). For instance, someone may have a general positive predisposition towards uncertainty but also show a different disposition towards uncertainty when in a specific situation. For instance, a patient may show high levels of IU in situations that are related to ones illness while show a more positive attitude towards uncertainty in other life situations. There is thus the need to consider disorder specific IU, which may not be captured when examined IU as a trait (Mahoney & McEvoy, 2012b).

IU shares theoretical resemblance to a number of factors, the closest one being intolerance of ambiguity (IA) (Frenkel-Brunswik, 1949) defined as a predisposition to interpret an ambiguous situation as a threat or a source of discomfort (Budner, 1962; Frenkel-Brunswik, 1949). IU and IA show a number of similarities along the lines that both use the term ‘intolerance’ to capture one’s tendency to view or appraise a situation as threatening causing distress and anxiety when faced with ambiguity or uncertainty (Dugas, Gagnon, Ladouceur, & Freeston, 1998; Frenkel-Brunswik, 1949; Ladouceur, Gosselin, & Dugas, 2000) and both concepts suggest a negative reaction on a cognitive, emotional and behavioural level when confronted with an uncertain or an ambiguous situation (Grenier, Barrette, & Ladouceur, 2005). What differentiates the two constructs is that IU is future orientated, while IA is concerned with an ambiguous situation in the present (Grenier, et al., 2005). This is a temporal issue,
which also explains why IU has mostly been examined in anxiety disorders, which are known to be related to worries about future events (Grenier, et al., 2005). Other theoretical concepts similar but distinct from IU include desire for predictability and need for cognitive closure (Berenbaum, Bredemeier, & Thompson, 2008).

IU and anxiety

The empirical examination of IU took place in the 1990s, particularly with the development of the IU model (IUM) of GAD by Dugas and colleagues (Dugas, et al., 1998). According to this model, excessive worry, the main feature of GAD defined as a cognitive thought activity tailored towards a fear of future threatening events (Borkovec, Ray, & Stober, 1998), is maintained by four factors: IU, positive beliefs about worry, poor problem orientation and cognitive avoidance (Dugas, et al., 1998; Dugas, et al., 2007). An extensive amount of research has shown a strong positive relationship between IU and the defining feature of GAD, that of worry in both non clinical (Dugas, et al., 1998) and clinical adult populations (Dugas & Ladouceur, 2000). IU has also been found to differentiate GAD patients from worriers in the normal population (Ladouceur, Blais, Freeston, & Dugas, 1998) and predict severity of GAD (Dugas, et al., 2007). Both IU and worry in individuals with GAD are also positively linked to elevated levels of distress and avoidance when faced with difficult emotions (Lee, Orsillo, Roemer, & Allen, 2010). IU is considered a risk factor for worry and has been found a good predictor of worry levels (Buhr & Dugas, 2006; Dugas, Freeston, & Ladouceur, 1997; Dugas, et al., 1998; Grenier & Ladouceur, 2004; Ladouceur, Gosselin, et al., 2000). Evidence for a causal relationship between IU and worry further comes from a number of experimental studies showing that participants whose IU was experimentally increased reported higher levels of worry and significantly needed more time to make a decision compared to those whose IU was decreased (Krain, et al., 2008; Ladouceur, et al., 1998; Ladouceur, Gosselin, et al., 2000; Ladouceur, Talbot, & Dugas, 1997) Indeed IU is considered implicated in a number of decision making deficits, particularly, deficits in the amount of information and time required to make a decision when confronted with an ambiguous situation (Krain et al., 2008). The need for information in order to reduce uncertainty in highly anxious individuals surpasses that of whether their decision is correct (Bensi & Giusberti, 2007). How one approaches uncertain situations influences their decision making style (Lipshitz & Strauss, 1997). Individuals high in trait anxiety will favour a “jumping to conclusions strategy” when faced with a reasoning task under levels of uncertainty as a means to reduce uncertainty and levels of discomfort (Bensi & Guisberti, 2007).

There is some support to the notion that similar underlying vulnerability factors for worry in adults are also relevant in adolescent worry. For instance, a handful of studies have found IU (Barahmand, 2008; Boelen, Vrinssen, van Tulder, 2010; Comer, et al., 2009; Dugas, Laugesen, & Bukowsi, 2012; Fialko, Bolton & Perrin, 2012; Laugesen, Dugas, & Bukowski, 2003) avoidance strategies and beliefs about worry (Gosselin et al., 2007) to be associated with worry in adolescent samples. Similar to the adult literature IU is the best predictor out of other variables such as, positive beliefs about worry, negative problem orientation, and thought suppression in distinguishing between moderate and high worriers in 528
adolescents (Laugesen et al. 2003). IU also shares positive correlations with worry, social anxiety and depression in both boys and girls, however when controlling for the shared variance between these variables, as well as, negative affect, age and gender, IU was not related to depression (Boelen et al., 2010). The only longitudinal study to examine IU in 336 adolescents found that IU and worry share a bi-directional relationship whereby both IU mediates change in worry by 53%, but worry too mediates change in IU by 60%. Fear of anxiety was found to mediate less (29%) change in worry compared to IU, while worry nearly fully mediated change in fear of anxiety (97%) (Dugas et al., 2012). The applicability of the IU model to adolescents has also been recently examined by Fialko and colleagues (2012). The original model suggests the IU is a higher order vulnerability factors for cognitive avoidance, problem orientation and worry, with worry mediating the relationship between these cognitive vulnerability factors and anxiety (Fialko, et al., 2012). When looking at the model in 515 children and adolescents, the best fit model for adolescents is in many ways similar to that proposed for adults, with IU acting as a higher order factor to cognitive avoidance and positive beliefs about worry and the strongest predictor of worry. In contrast to the adult model, the relationship between IU, cognitive avoidance and positive beliefs about worry and anxiety was not mediated by worry. IU had a direct effect on anxiety, as did cognitive avoidance but to a lesser extent. In children, the best fit did not resemble much of the original pathway model for adults nor for adolescents, with positive beliefs about worry having no independent effect on worry and anxiety.

Mechanisms through which IU affects worry and anxiety

A number of pathways have been put forward explaining the mechanisms through which IU may affect worry and anxiety. IU is thought to increase worry first by increasing positive beliefs about worry, negative problem orientation and cognitive avoidance, and second, by affecting one’s perception and sensitivity to threat, triggering ‘what if questions’ (Dugas, et al., 1998). In other words, high levels of IU produce “what if” questions, which subsequently increase worry (Dugas, et al., 1998). Individuals with elevated levels of IU have further been indentified to have a number of information processing biases which are thought to at least partly explain the dislike towards uncertainty and the subsequent high levels of worry and anxiety. For instance, positive associations have been indentified between IU and a tendency to anticipate a negative outcome (Grupe & Nitschke, 2011) as well as, an information processing bias towards threatening stimuli (Dugas, Hedayati, et al., 2005). Perceived threat has also been found to partially mediate the relationship between IU and worry, which provides support for such a mechanism (Bredemeier & Berenbaum, 2008). Several studies have also found a link between IU and cognitive bias in interpreting ambiguous information as threatening (Koerner & Dugas, 2008; Rassin & Muris, 2005). Anxious individuals also tend to evaluate ambiguous and uncertain outcomes negatively (Gu, Ge, Jiang, & Luo, 2010) and excessive worry is related to increased processing of threatening information (Verkuil, Brosschot, Putman, & Thayer, 2009). It has also been found that making a threatening event such as an anticipated panic attack, more predictable helps in reducing chronic anxiety (Fonteyne, Vervliet, Hermans, Baeysens, & Vansteenwegen, 2009). Such biases seen in individuals with high levels of IU are thought to arise due to a malfunctioning in one’s danger and safety signals that
is knowing whether to avoid certain situations and whether a threatening situation has ended or it is unlikely that it will take place (Lohr, Olatunji, & Sawchuk, 2007). An over-activation of danger signals and under-activation of safety signals then can result in the presence of an anxiety disorder (Lohr, et al., 2007).

**IU and treatment outcome**

A few clinical trials have been carried out testing the efficacy of targeting IU that is, helping individuals with anxiety manage uncertainty better within a cognitive behavioural therapy (CBT) framework for GAD. For instance, one study found that targeting IU is superior to a waiting list control group of patients on all treatment outcome factors, including worry, somatic anxiety, general anxiety and depression, with positive outcomes being maintained at 6 and 12 month follow-ups (Dugas, et al., 2003). Targeting IU within a CBT framework has also been found superior to nondirective therapy (Gosselin, Ladouceur, Morin, Dugas, & Baillargeon, 2006) and active therapy, such as applied relaxation, particularly in maintaining positive outcomes and symptom remission from pre-treatment to post-treatment (Dugas, et al., 2010). A small open trial with 4 adults with a primary diagnosis of GAD showed positive changes in anxiety and depression at post treatment and 6 months follow-up (Dugas & Ladouceur, 2000). Hewitt and colleagues (2009) have examined the effects of targeting only IU without attending to other anxiety symptoms in one patient with an anxiety disorder. Results were promising in improving levels of IU during the intervention and 4 week follow-up with noticeable improvements in symptoms of social anxiety at post-treatment and at follow-up but with no substantial improvement in levels of general anxiety (Hewitt, Egan, & Rees, 2009). Much less is known of the effects of targeting IU in adolescents with GAD compared to the adult literature. The only study looking at this in 7 adolescents with GAD found that 3 adolescents showed clinically significant improvements after the intervention at 6 and 12 month follow-ups, while the rest showed moderate to minor improvements (Léger, et al., 2003).

1.3.2. IU as a generic factor of psychological distress

**IU, depression and other anxiety disorders**

IU was originally considered to be a specific construct to worry and GAD. A number of studies showed that IU and worry were positively associated independently of anxiety and depression (Freeston et al., 1994) or due to the shared variance of related concepts such as perfectionism and IA (Buhr & Dugas, 2006; Dugas, Gosselin, et al., 2001; Dugas, Marchand, & Ladouceur, 2005; Dugas, Schwartz, & Francis, 2004). IU was also found to share a weak associations with obsessions and compulsions or panic sensations, in a non-clinical sample (Dugas, Gosselin, et al., 2001). A further study found IU positively associated with anxiety and worry but not depression when controlling for mood, age and gender in adolescents (Boelen & Reijntjes, 2009). Specificity of IU to GAD was also argued as IU was found higher in GAD patients than those with other anxiety disorders (Ladouceur, et al., 1999).
The view that IU is specific to worry and GAD however, has been recently challenged. A growing number of studies suggest that IU is in fact a transdiagnostic construct for a number of psychological disorders (Brown & Naragon-Gainey, 2012; Carleton, Mulvogue, et al., 2012; McEvoy & Mahoney, 2012) and this is supported by a recent meta-analysis of 58 studies, which concludes that IU is a shared cognitive vulnerability factor for GAD, depression and OCD, with no sufficient evidence for narrow specificity of IU to GAD (Gentes & Ruscio, 2011). Indeed IU is present in other anxiety disorder apart from GAD (Starcevic & Berle, 2006), such as, social anxiety disorder (Boelen & Reijntjes, 2009; Carleton, Collimore, & Asmundson, 2010). post-traumatic stress disorder (PTSD, Boelen, 2010) and OCD, particularly linked to checking and repeating compulsions, possibly due to their connection with doubt (Lind & Boschen, 2009; Overton & Menzies, 2005; Tolin, Abramowitz, Brigidi, & Foa, 2003). When controlling for other related factors, such as, negative problem orientation and perfectionism in both GAD and OCD, IU was a strong predictor of both GAD and OCD symptoms (Fergus & Wu, 2010). Obsessive compulsive personality traits have also been linked to an increased need for information regarding threatening events and IU (Gallagher, South, & Oltmanns, 2003). Holaway, and colleagues (2006) found strong positive correlations between IU and symptoms related to GAD and OCD, while less so for depression, when controlling for other related factors in both GAD and OCD only IU could still predict GAD and OCD symptoms (Fergus & Wu, 2010). There is further evidence that IU is a cognitive construct related to psychological disorders, such as depression (Dugas, et al., 2004; Norton, Sexton, Walker, & Norton, 2005; Yook, Kim, Suh, & Lee, 2010) and psychosis (Broome, et al., 2007; White & Gumley, 2010). For instance, IU has been found as a good predictor of variance in symptoms associated with social phobia, panic disorder, agoraphobia, OCD, GAD, and depression when levels of neuroticism were accounted for (McEvoy & Mahoney, 2012). Indeed evidence suggests that levels of IU do not differ between individuals with various anxiety disorders (e.g. GAD, panic disorder, social anxiety disorder, OCD) and depression (Carleton, Mulvogue, et al., 2012; McEvoy & Mahoney, 2012) apart from individuals with social anxiety disorder scoring higher than those with panic disorder (Carleton, Mulvogue, et al., 2012), with all clinical groups scoring higher on IU when compared to student and community samples (Carleton, Mulvogue, et al., 2012; McEvoy & Mahoney, 2012). A taxometric analysis, that is a statistical approach related to classification of entities and used to evaluate whether the latent structure of a construct is continuous or dichotomous (Waller & Meehl, 1998), suggests that IU is a continuous construct across populations and differs only in degree from individual to individual, which in accordance with the notion of IU as a transdiagnostic construct (Carleton, Weeks, et al., 2012).

There have been a couple of studies that suggest IU to be a specific risk factor for depression (Miranda, Fontes, & Marroquin, 2008; Norton, et al., 2005). However, findings are at times inconsistent, mostly because some studies fail to control for worry or anxiety. One study for instance, found that the link between IU and depression disappeared when worry was controlled for (Yook, et al., 2010). Another recent study found that IU strongly correlated more to OCD and GAD related symptoms than depressive symptoms in a non clinical population (Fergus & Wu, 2010). Similarly, Boelen and Reijntjes (2009) found IU to be related to GAD, OCD and social anxiety but not depression when controlling for the shared
variance among these symptoms. Compared to the anxiety disorder literature there is a lack of understanding of the nature of the relationship between IU and depression. One group of researchers proposed that if the direction of the “what if” question is at the self, the outcome will be depression and hopelessness, while, if it is directed at an unwanted event in the future, the outcome will be anxiety (Ciarrochi, Said, & Deane, 2005).

The notion that IU could be an indicator of general levels of psychological distress and not exclusive to anxiety comes from a number of studies that show that levels of IU are proportional to the number of comorbid psychological disorders, that is higher levels of IU are found in individuals with a higher number of comorbid disorders (Holaway, et al., 2006; Mahoney & McEvoy, 2012a; Yook et al., 2010). For instance, one study used a non-clinical sample of 560 participants with obsessive-compulsive and general anxiety symptoms and found that participants who scored high on both set of symptoms showed higher levels of IU than those who scored high only in one set of symptoms (Holaway, et al., 2006). Similar findings come from clinical studies showing that individuals with a single disorder such as GAD tend to have lower levels of IU than those with comorbid disorders, such as depression (Dupuy & Ladouceur, 2008; Yook, et al., 2010).

IU and eating disorders

IU has only very recently received attention within the eating disorder field. There is some evidence that IU is elevated in females with problematic eating attitudes when compared to healthy controls in a non-clinical sample (Konstantellou & Reynolds, 2010) and also in clinical populations of individuals with an eating disorder (Frank, et al., 2012; Sternheim, Startup, & Schmidt, 2011; Stewart, 2009). For instance, Stewart (2009) examined IU in a mixed non-clinical, subclinical and clinical eating disorder sample. Results showed that IU was a significant predictor of drive for thinness and positively related to eating psychopathology, even after controlling for anxiety and depression. Similar elevated levels of IU have been found in individuals with anorexia nervosa and bulimia nervosa when compared to healthy controls, with IU positively correlating with harm avoidance and depression in both diagnostic groups (Frank et al., 2012). A further group of researchers found elevated levels of IU in adults with an eating disorder when compared to healthy controls (Sternheim et al., 2011). Personal accounts of adults with anorexia nervosa reveal that uncertainty is viewed as a negative experience that can cause a lot of anxiety and stress, and should be avoided at all costs (Sternheim, Konstantellou, Startup, & Schmidt, 2011). Being uncertain about oneself, the world and/or how others viewed them were strongly associated with being out of control and the need to regain a sense of certainty which was to some extent managed by adopting rigid tendencies and trying to predict the future (Sternheim, Konstantellou, et al., 2011).
1.4 Current treatments for adolescent anorexia nervosa

At present there is a wide range of treatments that have been advocated for anorexia nervosa including inpatient treatment, psychodynamic psychotherapy, family therapy, cognitive behavioural therapy (CBT) and many others (Robin, Gilroy, & Dennis, 1998). One of the most recognised treatments which the present thesis focuses on is the Maudsley family therapy approach for anorexia nervosa, which dates back to the mid 1980s (Dare, Eisler, Colahan, Crowther, & et al., 1995). This treatment approach considers families as playing a crucial role in contributing to the effectiveness of therapy and aims to focus more constructively in empowering and enhancing the families’ own adaptive mechanisms to challenge the eating disorder (Eisler, 2005). Rather than trying to find what has gone wrong within the family unit that may have caused the illness, focus is placed on understanding how the family becomes reorganized around the illness (Dare, 1985; Eisler, 2005; Le Grange, 1999). This treatment approach has been manualised (Lock, le Grange, Agras, Dare, 2001; Lock & le Grange, 2013). A number of key components have been described in the manual including, parents taking control of their ill child’s eating disorder, adopting a consistent attitude when managing their child’s eating behaviours, externalizing the illness as a means of separating the illness from the child which helps adopt a non-blaming stance towards their child, increasing family resources through restructuring, and encouraging sibling support.

More recently, an alternative form to family therapy is available for patients and their families called Multiple Family Group Therapy (MFGT). This treatment approach involves a number of families coming together for a specific period of time to receive therapy and take part in group sessions, which is thought to increase positive outcome for more families, reducing at the same time costs and minimising resources (Dare & Eisler, 2000). This type of family therapy has received very positive feedback from both adolescents and their families (Colahan & Robinson, 2002; Dare & Eisler, 2000; Scholz & Asen, 2001).

1.4.1 How effective are current treatments for anorexia nervosa

Empirical evidence from a large scale randomized control trial (RCT) with 121 adolescents suggests that family based therapy has superior long lasting effects at 6 and 12 month follow-ups compared to an adolescent focused individual therapy (Lock, et al., 2010). Smaller scale studies have also found that family therapy is superior to individual therapy for adolescents with a short duration of illness and younger than 19 years of age (Robin, et al., 1999; Russell, Szmukler, Dare, & Eisler, 1987) with benefits maintained at one year (Robin, Siegel, & Moye, 1995) and five years after termination of treatment (Eisler, et al., 1997). Family therapy has also been shown superior to individual therapy in terms of increasing weight gain and showing faster results (Robin, Siegel, Koeppke, Moye, & et al., 1994; Robin, Siegel, Moye, Gilroy, Dennis, & Sikand, 1999). A small RCT found both family therapy and cognitive behavioural therapy to show good outcomes for adolescents with anorexia nervosa including significantly improvements in eating psychopathology, self esteem, depression and anxiety at end of
treatment and 6 months follow-up (Ball & Mitchell, 2004). Both family therapy and psychoanalytic therapy have also been found superior in increasing weight gain compared to cognitive analytic therapy and low contact treatment (Dare, Eisler, Russell, Treasure, & Dodge, 2001). Other studies suggest that family and individual therapy along with a group family therapy and inpatient treatment showed similar positive effects at one year follow-up compared to no treatment (Crisp, Norton, Gowers, Halek, & et al., 1991) with clinical improvements maintained for the outpatient treatments at two years as well (Gowers, Norton, Halek, & Crisp, 1994).

Differences in effectiveness between different forms of family therapy have been examined by a set of studies which have tried to identify conditions under which one form of family therapy could be superior to another. The majority of studies have shown no major differences between two forms of family therapy, that of conjoint family therapy and separated family therapy with patients receiving either one form of family therapy showing similar benefits at end of therapy in symptoms, psychological functioning and family functioning (Eisler, et al., 2000; Le Grange, Eisler, Dare, & Russell, 1992) and such positive outcomes remaining at 5 years follow-up with more than 75% of patients reaching full recovery (Eisler, et al., 2007). One important difference that has been identified is that families high on maternal criticism benefited more from separated family therapy than conjoint family therapy (Eisler, et al., 2000; Le Grange, et al., 1992). Different lengths of treatment have also been looked at in terms of differentiating effectiveness and it has been found that patients with anorexia nervosa receiving either short or long term family therapy do not show any differences in treatment outcome, apart from those with more severe obsessive eating related thinking and from separated parents benefited more from long term treatment (Lock, et al., 2005).

Further support for the effectiveness of family therapy for adolescent anorexia nervosa comes from one recent study that looked at whether the key components of the Maudsley Manual of family therapy for adolescent anorexia nervosa can predict treatment outcome (Ellison et al., 2012). Fifty nine adolescents with anorexia nervosa took part in this study and received 20 family therapy sessions following the Maudsley family therapy approach by trained therapists upon discharge from an inpatient unit. Results confirm that factors such as parental control, parents coming across as unified, externalising their child’s illness, adopting a non blaming attitude towards their child, are all good predictors of weight gain and overall treatment outcome, with parental control being the best predictor of outcome above anorexia related behaviours (Ellison et al., 2012). The only factor that did not predict treatment outcome was siblings’ support of patient. In addition to the key components of the manualised family based treatment, authors also examined therapeutic alliance and found that both maternal and paternal therapeutic alliance predicted treatment outcome (Ellison et al., 2012). This study provides further support to the effectiveness of family based therapy by showing how the key components that make up this treatment are actively contributing to a positive treatment outcome.
The main focus of the present thesis is on children and adolescents with anorexia nervosa. A full detailed review of adults is beyond the scope of the present thesis but main findings of the adult literature are presented here. Research into the effectiveness of family based treatments for adults with an eating disorder is sparse. In contrast to family based treatments of adolescents where parents are encouraged to take control, adult treatment usually take the form of individual treatments, with full responsibility given to the patients and little involvement of family members. One recent small RCT with 48 in-patients and their family members compared the effectiveness and acceptability of a skills based family day workshop where families received group treatment and psycho-education to a more traditional individual family therapy (Whitney, Murphy et al., 2012). Both treatments were successful in reducing patients’ BMI and carer distress, with no differences between groups detected (Whitney, Murphy et al., 2012). One key limitation of this study is that it is difficult to isolate the contribution of the family interventions to outcome as patients had been admitted in an inpatient unit, which means that outcome could be due to the treatment they receive as inpatients. Another RCT recruited 84 adult patients who were randomised to one of four treatment conditions, 1 year of psychoanalytic psychotherapy, 7 months of cognitive analytic therapy, 1 year of family therapy and 1 year of low impact treatment that acted as the control condition (Dare, Eisler, Russell, Treasure, Dodge, 2001). After one year patients in all conditions showed a modest improvement in their symptoms. Both family therapy and psychoanalytic therapy were found superior in increasing weight gain compared to the control treatment (Dare, et al., 2001). Authors conclude that patients receiving specialist treatment contributes to less chances being admitted into hospital than if they received routine low impact treatment (Dare, et al., 2001). Three studies have used both adolescent and adult samples in their studies (Crisp et al 1991; Gowers, Norton, Halek & Crisp, 1994; Russell et al., 1987). Russell et al (1987) compared family therapy to individual supportive therapy at one year post assessment. Results suggest that family therapy is an effective treatment intervention particularly for those with a young age of onset and shorter illness, while individual supportive therapy was more promising with patients who had an older age of onset (Russell et al 1987). Family therapy was also found to have similar effects with inpatient treatment; outpatient individual and out-patient group therapy at 1 year follow-up, with all three active treatments showed superior effects when compared to a one-off assessment session that acted as the control condition (Crisp et al., 1991). Positive effects in terms of social, psychosexual adjustment and physical state of the outpatient treatments were further maintained at two years follow up (Gowers, et al., 1994).

Support for the effectiveness of family therapy for anorexia nervosa further comes from two meta-analyses (Fisher, Hetrick, & Rushford, 2010; Couturier, Kimber, & Szatmari 2013), particularly from the most recent The first meta-analysis (Fisher, et al., 2010) adopted a broad approach and included in their analysis 13 RCT comparing any type of family based treatment with any other type of intervention for both adolescent and adult samples. The authors conclude that there is some evidence that family therapy is superior to treatment as usual in the short term but not enough evidence to support that it is superior to other psychological intervention, particularly since this evidence stems from small scale RCTs.
and much larger trials are needed to make any firmer conclusions. A second more recent meta-analysis has been conducted that focused only on studies that administered family therapy based on the Maudsley family therapy approach with adolescents (Couturier, Kimber, & Szatmari 2013). Three high quality RCT studies were included in their meta-analysis and results suggested that at end of treatment family therapy did not significantly differ from individual therapy but did show superior effects at 6 and 12 months follow up for adolescents with an eating disorder. The same pattern of results emerged when including 6 studies in the analysis (Couturier, et al., 2013). These more positive conclusions of the effectiveness of family therapy compared to the Fisher review could be due to a number of factors. The Fisher review did not include the largest RCT that became available since then (Lock et al 2010), which was included in the Couturier review. Couturier and colleagues also used more strict inclusion criteria and included high quality studies that followed the Maudsley model of family therapy and not other variants of family therapy. They also only included studies carried out with adolescents not adults.

Overall, family based therapies, in particular the Maudsley family therapy approach for adolescents, is the best available treatment for adolescents with anorexia nervosa (Lock, 2011) and has been consistently shown to be effective by a series of controlled and uncontrolled studies (Ball, 1999; Eisler, et al., 1997; Le Grange, et al., 1992; Lock, et al., 2010; Martin, 1985; Robin, et al., 1994; Robin, et al., 1995) particularly for patients with a short duration of illness (le Grange & Lock 2005) As a result, both the National Institute for Health and Clinical Excellence (NICE, 2004) guidelines and the APA strongly advocate family based treatment as the gold standard intervention for children and adolescents with an anorexia nervosa during acute illness and after weight restoration. There still however remains a subgroup of patients who receive family therapy and still remain unwell, especially those of chronic conditions (Russell et al., 1987). In other words, family based treatments are not effective with all families, with about half of patients fully recover and 80% significantly improve in symptoms (Lock, 2011; Lock, le Grange, Agras, Moye, Bryson, & Jo, 2010). More research studies are thus needed that seek to examine and understand why there is still a subgroup of patients that don’t get better despite advances in treatment and evidence of effectiveness, as well as, identify factors that enhance treatment effectiveness and contribute to bigger recovery rates. In other words, research is needed into identifying moderators and mediators of treatment effectiveness.

1.4.2 Moderators and mediators of treatment for anorexia nervosa

At present, our knowledge about effective treatments for anorexia nervosa, such as, the Maudsley approach is limited in that little examination of factors that differentiate treatment response (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007). In other words, effective treatments are not yet well understood from the point of view of mediators and moderators of treatment outcome (Eisler, 2005). The term mediator refers to factors that “identify possible mechanisms through which a treatment might achieve its effects” (Kraemer, Wilson, Fairburn, & Agras, 2002). The term moderator refers to factors that “specify for whom and under what conditions the treatment works” (Kraemer et al., 2002, p. 878). Even if the majority of patients treated with family therapy for anorexia nervosa do have a
positive outcome, there still remains a subgroup of patients that do not respond well to treatment and have poor outcomes.

A recent study investigated moderators and mediators of treatment outcome for anorexia nervosa using data from a large RCT comparing family based treatment to adolescent focused individual therapy (Lock et al., 2010). At end of treatment eating disorder related psychopathology and eating related obsesionality were identified as moderators of treatment outcome. Patients with a more severe eating related psychopathology and obsesionality did better when in family based treatment than in individual therapy (Le Grange et al., 2012). A study looking at moderators for adolescents with bulimia nervosa also found eating psychopathology to moderate outcome, but this time it was found that patients with a less severe eating psychopathology were more likely to be recovered if they were in the family based treatment condition than if they were in the individual treatment condition (Le Grange and colleagues, 2008). A number of individual, family and therapy related factors have been identified as non-specific predictors of treatment outcome, these are factors that affect treatment outcome irrespective of treatment condition. Individual factors that have been found to predict poorer treatment outcome include psychiatric comorbidity (Casper & Jabine, 1996; Herpertz-Dahlmann, et al., 2001; Pla & Toro, 1999), OCPD, autistic traits (Wentz, et al., 2009), severity of illness (Casper & Jabine, 1996; Eisler, et al., 2000; Lock, et al., 2005) previous treatment, hospitalisation (Eisler, et al., 2000; Le Grange, et al., 2012) low age of anorexia nervosa onset (Wentz, et al., 2009), older age and longer duration of illness (Le Grange, et al., 2012). Research has also shown that readiness to change can mediate the impact of eating disorder psychopathology (Bewell & Carter, 2008). Another study found that greater levels of psychopathology predicted speed of weight gain over 10 weeks into therapy (Lockwood, Serpell, & Waller, 2012).

Parental and family factors that have been looked at in relation to treatment outcome include expressed emotion in the relatives such as maternal criticism (Eisler, et al., 2000; Eisler, et al., 2007; Moulds, et al., 2000; van Furth, et al., 1996) and family intactness (Lock, et al., 2005). A family history of anorexia nervosa and paternal alcoholism has also been found to predict poorer outcome (Steinhausen, et al., 2008), while parental warmth has been identified as a predictor of positive outcome for family based treatment (Le Grange, Hoste, Lock & Bryson, 2011). Finally, in relation to therapy, alliance and engagement in therapy has been shown to be important in determining treatment outcome (Pereira, Lock, & Oggins, 2006). Overall, when looking at moderators and mediators of treatment outcome, there is strong need to identify parental and family variables, particularly when treating children and adolescents, as such variables can play a pivotal role in the treatment process (Eisler, 2005).

Research on mediators is even sparser when compared to moderators. No mediators were identified in patients with anorexia nervosa taking part in a RCT comparing family based treatment and adolescent focused individual therapy (Le Grange et al., 2012). Family based treatment was more effective than supportive psychotherapy in the treatment of adolescent bulimia nervosa and this was found to be
mediated by changes in eating disorder psychopathology (Lock, Le Grange, & Crosby, 2008). The few studies that have looked at mediators in adults with bulimia nervosa have yielded mixed results (Spangler, Baldwin, & Agras, 2004; Wilson, Fairburn, Agras, Walsh, & Kraemer, 2002).

Research examining mediators during treatment has identified certain time points to be important during treatment. These are 4 weeks into treatment, which is considered a time where most change takes place (Fairburn, Agras, Walsh, Wilson, & Stice, 2004). Examining potential mediators at this time point in treatment may provide insight as to why subgroups of patients get stuck and whether that may contribute to overall poorer treatment outcome. Changes made six to ten weeks into therapy have also been considered to be indicative of overall treatment response (Fairburn, et al., 2004; Gowers, et al., 1994), changes at 3 months psychological and family functioning (Eisler, et al., 2000). One study that has examined initial response to therapy for anorexia nervosa found greater levels of psychopathology predicted speed of weight gain over 10 weeks into therapy (Lockwood, et al., 2012). This limited knowledge on moderators and mediations of treatment response is due to the fact that most RCTs to date have either not included such questions in their design and/or have not had sufficient power in their analysis. In addition in order to detect behaviour change there is a need for studies to examine factors during treatment at theoretically important points, (Eddy, Dishion, & Stoolmiller, 1998). Increasing our understanding of mediating and moderating factors allows for the identification of the active ingredients of therapy and creates the opportunity to increase overall treatment effectiveness (Kraemer, et al., 2002; Murphy, Cooper, Hollon, & Fairburn, 2009).

1.5 Gap in the literature and rationale of thesis

The rationale behind the present thesis was based on three gaps in the literature that were identified, these can be summarised as follows:

1. **Limited empirical examination of IU in the eating disorders despite theoretical and clinical relevance**

The current literature shows that individuals with anorexia nervosa tend to be characterised as having rigid, compulsive and obsessional traits (Cassidy, et al., 1999; Schmidt, & Treasure, 2006) with low levels of novelty seeking (Cassin & von Ranson, 2005; Fassino, et al., 2002) and high levels of need for control (Reid, Burr, Williams, & Hammersley, 2008; Sassaroli, et al., 2008). Despite this there is a lack of research examining possible factors contributing to such traits, particularly the need for control. Conceptually, IU could be contributing to the occurrence and maintenance of such traits found in individuals with anorexia nervosa. We further know that individuals with anorexia nervosa often assign a positive value to their illness due to a perceived function of the illness providing them with a sense of control, structure and security (Nordbø, et al., 2008; Serpell, Treasure, Teasdale, & Sullivan, 1999). Examining IU may thus help explain the positive value eating disorder patients often place on their illness (Agras, et al., 2004; Serpell, et al., 1999; Vitousek & Hollon, 1990). Overall, both theory and clinical observations point towards the need to empirically examine IU in relation to anorexia nervosa.

2. **Limited knowledge of anxiety related vulnerability factors in eating disorders**
Comorbid states of anxiety and worry are often found in individuals with an eating disorder and contribute to poorer treatment outcome. We also know that these states tend to precede the eating disorder and to a large extent remain even after remission of eating disorder symptoms. In spite of this relatively little investigation has taken place identifying known vulnerability factors for anxiety in individuals with an eating disorder. This can help understand better the mechanisms through which anxiety and worry operate in eating disorders and the way they may need to be addressed in treatment to improve long term outcomes.

3. Limited knowledge of individual and family factors that moderate and mediate response to effective treatments for adolescent anorexia nervosa

Effective treatments, such as eating disorder focussed family therapy for adolescent anorexia nervosa, are not well understood in terms of factors that moderate and mediate treatment response. There is a strong need to identify factors in both patients and the family that may explain different responses of patients to otherwise effective treatments. A better understanding of the role of anxiety and anxiety related factors might allow existing evidence based treatments such as family therapy to be tailored to the specific needs of individual families or adjunctive treatments such as CBT addressing anxiety problems to be added for those who might need them.

1.6 What are the aims of the thesis?

The present thesis is original and makes a distinct contribution to our current knowledge of eating disorders in the following ways:

- It proposes a conceptual model of IU in relation to anorexia nervosa psychopathology and treatment, which has not been conceptualised in the past. This prepares the ground for the empirical investigation of IU in eating disorders. It also brings together theoretical concepts and possible pathways through which IU could be influencing anorexia nervosa.

- It aims to investigate anxiety related vulnerability factors, including IU, in both adults and adolescents with anorexia nervosa compared to healthy control groups.

- It aims to investigate for the first time the experience of uncertainty for adolescents with anorexia nervosa and their parents. This has not been previously examined, and will increase our understanding of the possible role of IU in relation to eating psychopathology.

- It aims to empirically examine for the first time IU and associated factors in adolescents with anorexia nervosa and anxiety related factors in parents in terms of symptom maintenance and treatment response. This will contribute to our knowledge of possible moderators and mediators of therapy for anorexia nervosa.

- Taken together the thesis provides valuable information for the improvement of current therapies and the development of new interventions for anorexia nervosa.
Chapter 2

A multi-dimensional conceptual model of IU in anorexia nervosa

2.1 Overview of chapter
The literature review in Chapter 1 has highlighted a number of gaps in our understanding of the relationship between anxiety and eating disorder psychopathology, as well as the link between IU, need for control and eating disorders. Prior to any examination of IU in relation to eating disorders and in particular anorexia nervosa, a conceptual model of the possible role of IU in anorexia nervosa is presented in this chapter. The model draws on relevant theories on GAD and highlights possible pathways where IU can play a part in maintaining symptoms and blocking treatment effectiveness. The present chapter provides the theoretical background and conceptual framework for the studies reported in this thesis.

2.2 An IU model for anorexia nervosa
Taking into account previous literature, research evidence suggests that individuals with high levels of IU will show elevated levels of worry (Freeston et al., 1994) and anxiety (Dugas, et al., 1998) compared to individuals with low levels of IU. Individuals with high IU will further show a cognitive bias in interpreting in a threatening way ambiguous/uncertain situations and anticipating a negative outcome when faced with an uncertain situation (Dugas et al., 2005). Research has also shown that IU is implicated in the amount of information one needs to reach a decision, otherwise known as elevated evidence requirement (Berenbaum et al., 2008). Theoretically, one can speculate that high IU may also contribute to a fear of change, rigidity and aversion to novelty. IU could also affect one’s time orientation, in that individuals with a dislike of uncertainty will favour the "present" which seems relatively less uncertain, over the "future" which is likely to be uncertain. Fig 2.1 summarises the above traits.
IU within the present theoretical framework is considered a transdiagnostic cognitive vulnerability factor for a number of disorders, including anxiety, OCD, depression and eating disorders. Disorders that tend to co-exist are likely to share common vulnerability factors (Harvey, et al., 2004). At present we do not know much about such factors between eating disorders and anxiety disorders. Drawing on work by Harvey and colleagues a number of cognitive processes meet definite transdiagnostic criteria and these are shared by a number of disorders and contribute to psychological distress (Harvey, Watkins, Mansell, & Shafran, 2004). For instance, processes that meet a definite transdiagnostic criteria include attention processes (e.g. selective attention to internal and external stimuli), memory processes (e.g., explicit and recurrent memory), biases in reasoning (e.g., biases in one’s interpretation, reasoning expectation and emotional reasoning), thinking patterns (e.g. recurrent thinking and positive and negative metacognitive beliefs) and behavioural process (e.g., avoidance behaviours, safety behaviours and experiential avoidance). Even though different psychological disorders may share similar vulnerability factors, different psychological disorders can be accounted for by the following three reasons (Harvey et al., 2004). First, a person’s current concerns can influence what kind of cognitive processes get activated. In other words, current concerns determine where attention is given.

<table>
<thead>
<tr>
<th>High IU</th>
<th>Low IU</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Need for control /certainty.</td>
<td>• Tolerate uncertainty /less need for control</td>
</tr>
<tr>
<td>• Rigidity/inflexibility</td>
<td>• Flexibility.</td>
</tr>
<tr>
<td>• Worry/anxiety</td>
<td>• Less worry/anxiety.</td>
</tr>
<tr>
<td>• Fear of change/low novelty seeking.</td>
<td>• Accept change/ high novelty seeking.</td>
</tr>
<tr>
<td>• Unbalanced time orientation/stuck in the present</td>
<td>• Time orientation balanced</td>
</tr>
<tr>
<td>• Cognitive bias: interpreting uncertain situations as threatening</td>
<td>• Equally interpret an uncertain situation as positive or negative</td>
</tr>
<tr>
<td>• Anticipating a negative outcome when faced with an uncertain situation</td>
<td>• Equally anticipate a positive/negative outcome</td>
</tr>
<tr>
<td>• Elevated evidence requirement/impaired decision making</td>
<td>• Less need for information</td>
</tr>
<tr>
<td>• Low levels of evidence requirement prior making a decision</td>
<td>• Low levels of evidence requirement prior making a decision</td>
</tr>
</tbody>
</table>
Individual, environmental and biological factors will determine which cognitive processes are more activated in an individual. If for instance, someone is concerned about their weight and shape their attention will become biased and exclusively focused on relevant stimuli. Second, cognitive processes exist on a continuum in the population. People with a psychological disturbance can have different levels of disturbance in different cognitive processes. Depending on the balance of different processes different psychological disorder can arise and this accounts for which disorder is more dominant (Harvey et al., 2004). Thirdly, the presence of a specific cognitive process or processes may be accounting for the presence of differences between psychological disorders (Harvey et al., 2004).

Currently, therapy focuses on treating a specific disorder and targeting specific maintenance factors for that disorder. This however can be problematic for patients with comorbid states. According to Harvey et al (2004) comorbid states are present in most patients because they share similar maintenance processes. Such transdiagnostic processes might be maintaining more than one disorder or one transdiagnostic process may increase the likelihood of the presence of another disorder. At any given time then although there may be a primary diagnosis of a psychological disorder, symptoms of another disorder may also be present, as the underlying vulnerability factor will also be influencing these secondary symptoms (Harvey et al, 2004). Attending then to both the specific disorder but also to the underlying shared vulnerability factors will guarantee a more effective recovery as the individual will not resort to other symptoms in order to express and cope with underlying distress (Harvey et al, 2004). Whether this is actually the case has not been empirically examined. Therapy may directly or indirectly influence a number of transdiagnostic processes, which may also account for a better treatment outcome. These authors propose a “process-focused approach” where importance is placed on attending transdiagnostic processes that may be partly accountable for a poorer treatment response and act as a barrier to change (Harvey et al., 2004).

In terms of IU, individuals with different psychological disorders may have similar elevated levels of IU. How IU is expressed and dealt with may be due to differences in individuals’ past experiences, and biological and psychological make-up. For instance, one person may engage in excessive worry and obsessive compulsive behaviours while someone else may find their restricting food and losing weight gives them a sense of certainty. In other words, the same vulnerability factor may be dealt with and managed in different ways. Fig 2.2 illustrates these points and takes into account that not all individuals with a psychological disorder have high levels of IU. Low levels can also exist whereby other factors, (e.g. low self-esteem, perfectionism) which are beyond the scope of the present chapter, contribute also to psychological distress.
2.2.1 The role of IU at the patient/ individual level

In the following paragraphs a specific model of the role of IU in anorexia nervosa is presented. According to the present model IU can affect anorexia nervosa symptoms and treatment effectiveness through 2 pathways. Fig 3 shows the two pathways described below whereby IU can affect anorexia nervosa symptoms and prolong treatment effectiveness.

The first pathway involves IU accounting for the presence of factors not specific to the anorexia nervosa, such as worry, which will be contributing to comorbid states of anxiety and thus indirectly affecting treatment outcome, since comorbidity is known to contribute to a poorer treatment outcome. The second pathway involves IU affecting factors more specific to the anorexia nervosa, such as restricting behaviours, need for control and positive beliefs attached to the illness (See figure 2.3). Individuals who
have a strong dislike and fear of uncertainty will be particularly attracted to the certainty, safety, security and control that the anorexia nervosa is supposedly providing them with because there is an implicit goal to reduce uncertainty. This then may reinforce positive beliefs attached to the illness. If high levels of IU trigger a sense of loss of control and certainty, one would predict that individuals with high IU will behave in ways that will help them to regain a sense of being in control. The anorexia nervosa world is full of rigid rules, which in a way provide the patient with the perfect place to hide away from all the uncertainties, possible threats and unpredictable events that surround the world outside the illness. In other words, when there is high IU, anorexia nervosa will take up an additional function, as the consequences of the illness will feed into the need for certainty and control and symptoms will be valued and maintained. This may take place from the initial onset of the illness or later.

It is often said that individuals with anorexia nervosa are ambivalent about change, however this general belief could be understood better if it was shown that IU was a key factor leading to such ambivalence. This could also explain differences in levels of ambivalence between patients with anorexia nervosa. Furthermore, if change is seen as a threat and recovery from the illness is perceived as leading to a future that is uncertain and potentially threatening, high levels of IU could encourage patients to stay in a locked and constant environment dominated by anorexia nervosa rules making any change difficult to take place. Issues surrounding IU would need to be addressed in therapy and replaced with more helpful coping strategies.

Figure 2.3 Outline of two pathways that IU can affect anorexia nervosa

![Diagram of two pathways affecting anorexia nervosa](attachment:figure23.png)

Figure 2.4 examines closer the second pathway by which IU can maintain anorexia nervosa symptoms and block treatment effectiveness. According to the proposed theoretical model, high levels of IU in individuals with anorexia nervosa symptoms reinforce a need for control, which will be expressed by controlling one’s weight and shape. Eating disorder related behaviours such as restricting will be
positively reinforced due to the sense of control and certainty obtained, as well as, the potential anxiolytic effects that food restriction may achieve. This is likely to lead to the development of positive beliefs about the eating disorder (Schmidt & Treasure, 2006), which will contribute to low motivation to change and ambivalence about treatment and recovery. This creates a positive feedback cycle whereby symptoms will be maintained and treatment blocked. It is acknowledged that not all patients with high levels of IU will have a poor treatment outcome other factors will also play a role, as well as, the individual’s own personality and resources.

Figure 2.4 A maintenance cycle of the effect of IU in anorexia nervosa

2.2.2 A developmental perspective of IU

The concept of IU throughout the life span can be best understood in relation to a developmental model which suggests that human behaviour is largely driven by physical needs but also by four basic psychological needs (Langmeier, & Matějček, 1975). Langmeier and Matějček (1975) within the context of examining psychological deprivation in children discuss what they refer to as four ‘basic psychological needs’ that humans have throughout their life and which govern behaviour. These psychological needs have also been discussed within a family context (Eisler, 1993). The first is the need for variability, which involves the need for a level of variability and stimulation when interacting with the outside world from infancy to old age. The second is the need for stability, that is, a need for a predictable and structured external world. The third is the need for dependence, this refers to the need to be attached to a specific object of affection and form a close and stable relationship. Finally, the fourth is the need for independence, which refers to a child’s autonomy and search for identity and independence as an individual. Figure 2.5 shows the four psychological needs depicted on two broad axis. The need for stability and variability are considered primarily to influence a person’s cognitive development while the
need for dependence and independence are thought to mainly influence one’s emotional development (Eisler, 1993).

Figure 2. 5 Four basic psychological needs

![Diagram of four basic psychological needs](image)

Adapted from Eisler, 1993 ‘Psychological needs’

Although the need for stability and the need for change are at one level polar opposites they are also complementary best seen in the fact that when the need for stability is met it leads to an increase in exploratory behaviour and vice versa (Eisler, 1993). The way in which the balance between these two needs is met changes over the life cycle, as well as, the way in which these needs are met changes. Dependence and independence are better thought of as separate dimensions again reflecting two basic psychological needs that are both opposites and dynamically connected. Both dimensions (Variability-Structure & Dependence-Independence) can be linked to attachment and uncertainty and provide a good basis for offering a developmental perspective across the life span from infancy to old age. Furthermore, psychological needs of each member of the family are influence by the wider family cycle dynamic and change over time with the family playing a key part in whether these psychological needs are met in each of its members (Eisler, 1993).

In relation to the above psychological needs, uncertainty is mostly experienced when attending to the need for independence and variability, while it is at its lowest when attending to the need for dependence and structure. How these four needs are moulded together from a young age, as well as, one’s parental attachment style will influence how uncertainty is experienced. If fear of uncertainty prevails then this will lead to a need for structure and dependence rather than independent and change.
In terms of attachment, if a child has an insecure/ambivalent attachment style with their parent they may be more likely to fear uncertainty than a child who has a secure or avoidant attachment style. As previously mentioned when discussing the four psychological needs, when one need is met that triggers the search for the opposite need. However, if there is a fear of uncertainty and an excessive need for certainty then the need for security and stability will not have been met, which may dampen the search for variability or independence. Furthermore, the child moves from a world that is usually a place of security and certainty provided by their parents to a time of turmoil and uncertainty characteristic of adolescence whereby many psychological and physical transformations take place. Independence from parents also takes place and life becomes more unpredictable. This is a time when one becomes more cognitively conscious of uncertainty. A healthy relationship with uncertainty would involve accepting uncertainty as part of life that could lead to both positive and negative outcomes and which one is able to manage and cope with whichever the outcome. A healthy relationship with uncertainty would also involve a healthy balance between the four psychological needs. However, depending on past experiences, one’s attachment style, individual characteristic, and biological predispositions one may with time grow up with a cognitive bias towards viewing uncertainty as negative on an emotional, behavioural and cognitive level. The more one takes up this view and lives one’s life with a fear of uncertainty the more engrained the fear of uncertainty will become part of one’s personality.

2.2.3 The role of IU at the parent/family level

The present model also takes into account the effect of IU at the family level, in particular in parents of adolescents with anorexia nervosa. The model attempts to explain possible pathways that IU may impact on parents and the family unit as a whole in dealing with the illness and responding to treatment. IU at a family level may be due to 2 separate factors: 1. a predisposition in the parent(s) to IU pre-dating the development of anorexia nervosa and 2. The response to the threatening/anxiety provoking nature of anorexia nervosa and repeated (unsuccessful) attempts to deal with the problem which lead the family to respond in ways that “at least will not make things worse” Subsequently the presence of IU due to the above factors could affect how anorexia nervosa is managed through these two interlinked pathways (See Fig. 2.6).
The first pathway that is proposed in figure 2.6 involves IU being present in parents as a personality trait prior to their child’s illness (i.e. factor 1) and affecting parent’s overall confidence and self-efficacy in their parental skills. Parent self efficacy, defined as the parental ability to take primary responsibility of being in control of their child’s eating in the home environment with the aim to help their child recover (Rhodes, Baillee, Brown, & Madden 2005) has been found to increase during the course of family therapy for anorexia nervosa (Robinson, Strahan, Girz, Wilson & Boachie, 2012). Most importantly both maternal and paternal self efficacy has been found to predict adolescent outcome in terms of eating psychopathology and depressed mood and paternal self efficacy has also been found to predict anxiety levels (Robinson, et al., 2012). This highlights the key role that parents play in the recovery of their child’s illness. In family therapy for anorexia nervosa parents are encouraged as a first step in treatment to take responsibility for their child managing their meals. Early on, particularly if the illness is severe, when the anorexia nervosa has taken over most of the young person’s thinking, the ability of the parents to step in is dependent on their confidence in their parenting ability. A predisposition to find uncertainty distressing and a tendency to avoid uncertain situations can undermine parents’ ability to be
persistent and firm. It is likely that the potential mediating role that IU might have in determining how
well the parents can challenge the anorexia nervosa and stay firm towards their child is determined by
pre-existing attachment patterns which determine whether the child (and indeed the parent)
experiences parental firmness as caring or punitive. Parents frequently comment that they have to
revert to acting like parents of a much younger child, setting limits, giving reassurance and giving more
time to their child than they would expect at this stage of the family life-cycle (Whitney & Eisler, 2005).

A second pathway involves IU being present due to the severity of the illness (figure 2.6; factor 2). This
suggests that a parent may not necessarily be intolerant of uncertainty but become intolerant in the
face of their child’s illness. Through this pathway IU affects how the family accommodates to the illness
and the extent to which the family becomes a less flexible system that holds onto certainty instead of
being open to change. In other words the more IU is present in the family the more the family will re-
arrange itself in order to achieve certainty and a sense of control. In the face of uncertainty certainty
and control will be favoured against other more uncertain alternative options but which could in the
long run have more beneficial options.

At the family level then when uncertainty is not tolerated the family system can become closed and
static where there is no space for change, possibly negatively affecting the treatment processes (Eisler,
2005; Whitney & Eisler, 2005). The model proposes that a fear of uncertainty can keep parents in
unhealthy patterns of seeking certainty instead of opening up to the process of change and using their
own resources to challenge their child’s illness. Uncertainty surrounding what the young person may do
if they are made to eat could be distressing as well. ‘What if’ questions tailored towards the future along
with a cognitive bias towards fearing negative outcomes in the face of uncertainty are characteristic of
individuals with IU. If parents are pre-occupied then with ‘what if’ questions about their decisions and
their child’s illness this will both increase their distress as carers and add to the difficulty of managing
their child’s illness. Parents with high IU may be biased to stick to what feels familiar and safe when
managing their child’s illness rather than challenge the illness and try out different approaches. When
parents are confronted then with their child’s illness this involves uncertainty on many levels including
how the young person will respond, the course of the illness and treatment. A parent who in general
finds uncertainty distressing may find it even more difficult to deal with the uncertainties related to
their child’s illness. For instance, a mother with high IU, may be predisposed to stick to short term
achievements in the here and now, instead of challenging and supporting her daughter for instance to
eat more, as this may pose bigger threats and uncertainties. This illustrates the important interaction of
time orientation and tolerating uncertainty, leading to a predisposition towards adopting present time
focus, which has been suggested, is a function of family re-organization around the anorexia nervosa
(Eisler, 2005). In terms of successful treatment it is important that parents have a strong sense of
parental control and confidence. As previously discussed in the introductory chapter, parental control is
a key component described in the manual for family therapy based on the Maudsley approach and
strong predictor of treatment outcome for adolescents with anorexia nervosa. How uncertainty in
parents relates to their child’s illness and treatment process can be an important factor in the course of the illness.

As discussed earlier, when one psychological need is met within the individual the opposite need is triggered, and this pattern can also be seen within the family. For example, if there is a need for certainty in one member of the family this can either activate the need for uncertainty in another member of the family (based on the psychological needs model) or it could further intensify the need for certainty. However, what is expressed within the family may not represent all family members’ needs. One need may dominate family life and end up taking over the way the family operates. This can be seen in families with an adolescent with anorexia nervosa where there may be the need for unpredictability in one member of the family but this usually gets overshadowed by the need for certainty found in the ill adolescent where the need for predictability prevails. Another reason why the need for certainty may overshadow the need for uncertainty is that the presence itself of a life threatening illness in the family can intensify the need for certainty as any uncertainty may be seen a threatening situation that leaves room for a negative outcome, such as the deterioration of the ill child becoming worse. This further illustrates the complexity of the interaction between parent IU and child IU. Psychological needs can also be looked at in relation to parent-child attachment and the nature of the family-therapist therapeutic alliance. The type of attachment style and balance between one’s four basic psychological needs may influence how parents and their ill child respond to treatment. The type of parent-child attachment can influence whether the child accepts the support and firmness of their parents, and similarly if there is a fear of uncertainty and insecure attachment style then the family may not feel ready to accept the directedness of the therapist. A strong relationship and tolerance of uncertainty is needed for people to trust and receive advice and directedness. A good therapeutic alliance and a good parental attachment style then can mediate the effect of directedness from the therapist to the family and from the parent to the child.

In order to be open to the future a degree of tolerance for uncertainty is needed. The future requires an element of openness and change otherwise the future would be stagnant and pre-determined. Encouraging parents to take charge of their child’s eating behaviours is shown to be part of effective treatments (Eisler, et al., 2000). The initial part of the intervention of encouraging parents to take charge may create a context were a sense of certainty and control is maintained but comes from parental behaviour rather than from the child. In order for the child to accept this, there needs to be a shift in perception of such behaviour so that it is experienced as nurturing/caring rather than punitive or controlling. Arguably this can be perhaps seen as a temporary developmental regression with the family functioning for a time as they would have done during an earlier stage of the family life cycle. It is during later stages of therapy that there needs to be a shift to a more appropriate life cycle stage of functioning which also requires an increase in the tolerance of uncertainty.
According to Mason, (1993) therapy should provide an environment that welcomes uncertainty and allows families to explore different options and perspectives. Different people can experience uncertainty to different degrees and have different levels of tolerating and accepting uncertainty. Mason (1993) identified four combinations of levels of certainty (certainty/uncertainty) with levels of tolerating uncertainty (safe/unsafe) (see Fig 2.5). For instance, in condition 1 uncertainty is experienced as unsafe, which implies high levels of IU and distress. In condition 3, although there is a degree of certainty, it is albeit at a cost. It is where individuals and families end up in attempting to move away from condition 1 and trying to achieve condition 4. Condition 4 is an unrealistic condition, as we are always faced with some kind of uncertainty. Overall, conditions 1, 3 & 4 can lead to distress and psychological problems for different reasons. Individuals that seek therapy are usually in a state of unsafe certainty (Condition 3; fixed solutions this has to be done to fix the problem) or unsafe uncertainty (Condition 1). This state is characterised by a dynamic process were things are not fixed but space is left for change. Condition 2 is the most optimal condition to be in, where one feels safe with uncertainty and there is a dynamic rather than static element to this condition. “Safe uncertainty is not a technique but an evolving state of being” (Mason, 1993, p: 198). The aim of therapy is to help clients and families reach a state of safe uncertainty (Condition 2) or in other words tolerance uncertainty better.

**Figure 2. 7 Different conditions of safe and unsafe uncertainty**

- **Condition 1**
  - Unsafe/Uncertainty
  - Unsafe
  - Uncertain

- **Condition 2**
  - Safe/Uncertainty
  - Safe
  - Uncertain

- **Condition 3**
  - Unsafe/Certainty
  - Unsafe
  - Certain

- **Condition 4**
  - Safe/Certainty
  - Safe
  - Certain

Based on Mason (1993) “Towards positions of safe uncertainty”

In summary, the two pathways outlined in Fig. 2.6 are not mutually exclusive from each other and depending on whether parents are IU to start off with this will affect how IU is managed within the family in relation to the illness. The interaction between parental IU and family IU in relation to anorexia nervosa can also have implications on both how the family is accommodating and managing the illness and how they respond to treatment. The relevance of this is in particular to the conceptualization of family therapy initially engaging the family on the one hand by emphasizing the dangers of anorexia nervosa aiming to capitalize on parental anxiety while at the same time encouraging the parents to respond in a way that at first reduces uncertainty for the adolescent (and maybe also for the parents by...
the therapy team owning a high level of expertise in dealing with the problem. At later stages of therapy
the aim is the opposite i.e. to increase tolerance of uncertainty.

2.2.4 Summary of the conceptualisations of IU and the proposed model of IU for anorexia nervosa
IU involves a fear of uncertainty propelled by “what if...” questions about the future. High levels of IU
are likely to be the result of a cognitive interpretation bias whereby uncertainty is associated with
expecting the worst case scenario happening and the fear of lacking the resources to cope with a
negative outcome. Past experiences along with biological, environmental and individual factors come
together to determine how well one tolerates and manages uncertainty. IU is here conceptualised as a
personality trait but one that can also show state like properties. That is, uncertainty may be tolerated
differently in specific situations or areas in one’s life that could be different from their overall more
stable trait like disposition towards uncertainty. For instance, someone may enjoy uncertainty in general
but may show high levels of IU when it comes to a specific situation, such as their health.

IU is further conceptualised within the present thesis as a transdiagnostic factor that can act as a risk
and maintenance factor for a number of psychological disorders and not exclusive to worry and GAD.
Within a specific psychological disorder, such as anorexia nervosa, IU can account for comorbid states of
worry and anxiety but can also share a more close relationship with the primary diagnosis and
associated symptoms. How IU is expressed and managed can thus take up different forms in different
psychological disorders and at different phases of one’s illness.

Attending to high levels of IU in patients with anorexia nervosa could benefit them in the following
ways:

- Decrease the need for certainty and control
- Decrease levels of worry and anxiety
- Encourage healthy ways of relating to and managing uncertainty rather than
unhealthy ways such as relying on restricting behaviours as sources of certainty
and control
- Decrease positive value attached to one’s eating disorder for providing a sense of
security and certainty
- Increase flexibility in one’s thoughts and behaviours
- Increase resilience in the face of uncertainty and confidence in being able to
manage future uncertainty situations.
- Increase one’s acceptance of change both in treatment and outside.

Finally, IU has predominately been examined on an individual and patient level. According to the
proposed conceptual model should also be considered at a more dynamic and family level, particularly
for families with an adolescent with an eating disorder. There are two main reasons for this. First,
anorexia nervosa is a serious illness with many physical and psychological complications that are likely to
create many uncertainty situations for the parents and the whole family. Understanding how the family respond to these situations may inform treatment. Second, if families are to be actively involved in treatment (as is increasingly recommended in the treatment of adolescents with anorexia nervosa), how parents approach and tolerate uncertainty and how they are supported in this by the therapist may interact and influence the treatment process and their child’s recovery.

In summary the present model makes the following assumptions:

1. IU accounts for the presence and maintenance of both comorbid states of anxiety found in individuals with anorexia nervosa and eating disorder related psychopathology.
2. IU will interfere with parents’ sense of ability to help and challenge their child’s illness. The family will re-arrange itself into a closed system instead of open, which can make treatment effectiveness difficult.
3. IU will promote stability despite expression of desire to change.
Chapter 3

Generalised Anxiety Disorder and Anorexia Nervosa: An examination of shared vulnerability factors (Study 1)

3.1. Overview of chapter

Chapter 1 and Chapter 2 provided the theoretical foundations for the present thesis and highlighted important gaps in the literature regarding anxiety and associated factors, in particular IU in relation to anorexia nervosa. The present chapter seeks to address the need to understand further the relationship between anxiety and anorexia nervosa by reporting results from a quantitative study that examines known vulnerability factors for GAD in adults with anorexia nervosa.

3.2. Introduction

3.2.1 What is GAD and worry?

GAD is characterised by excessive, uncontrollable and long lasting worry and anxiety which significantly impacts a range of different life domains (Borkovec, et al., 1998; see Appendix 2 for detailed information on the current diagnostic criteria for GAD). For a formal diagnosis of GAD along with worry other symptoms are also required, such as physical responses to anxiety including, restlessness, muscle tension or difficulty concentrating (Ayelet Meron, 2002). Worry is also not mutually exclusive to GAD as it can also be present in other anxiety disorders as well (Olatunji, Wolitzky-Taylor, Sawchuk, & Ciesielski, 2011).

Worry itself has been conceptualised as a cognitive thought activity usually tailored towards a fear of future threatening events (Borkovec, et al., 1998). While some have been critical of the distinction between worry and anxiety (O’Neill, 1985) there is now evidence that worry is a distinct construct from anxiety (Ayelet Meron, 2002; Davey, Hampton, Farrell, & Davidson, 1992; Gana, Martin, & Canouet, 2001) and differentiated from anxiety as a positive problem solving strategy used to prevent a potential threatening event from happening (Gladstone & Parker, 2003; Mathews, 1990) while anxiety is independently linked to low confidence in one’s problem solving abilities (Davey, et al., 1992). One study further looked at the causal relationship between worry and anxiety and found that such a relationship is not bidirectional, that is, worry has a significant effect on anxiety but not the other way round (Gana, et al., 2001). Research supports a dimensional structure of worry over a categorical one, which means that the act of worrying itself is present to greater or lesser degree in everyone (Olatunji, et al., 2011). In terms of why people worry, common reasons for both anxious and non anxious individuals include worrying in order to gain motivation, to get things done, to avoid negative events from happening and to be prepared for the worst, if it cannot be prevented (Borkovec & Roemer, 1995; Gladstone & Parker, 2003). However, individuals with GAD also worry in order to distract themselves from more emotionally
distressing issues (Borkovec, et al., 1998; Borkovec & Roemer, 1995). Indeed fear or negative emotions, as well as, feeling out of control with one’s emotions have all been found to predict excessive worry and GAD (Hazlett-Stevens & Craske, 2003). Worrying thus can become problematic when it is excessive, uncontrollable (Borkovec, et al., 1998) and maintained by “What if...?” questions, described as catastrophic worrying (or “catastrophising”) (Davey, et al., 1992). Such catastrophising worrying is thought to be linked with a cognitive bias of indentifying and categorising events as threatening when there is no need to (Davey, et al., 1992). Indeed this “threat related attention bias” is present in anxious people but not found in healthy individuals (Bar-Haim, Lamy, Pergamin, Bakermans-Kranenburg, & van Ijzendoorn, 2007). Supporting this view one study found that high worriers tend to interpret ambiguous information as more threatening than healthy individuals and those who have recovered from an anxiety disorder (Eysenck, Mogg, May, Richards, & Mathews, 1991). This information processing bias can be explained due to a tendency to store threatening information more so than non threatening information, when faced with ambiguous stimuli (Hock & Krohne, 2004). Altering the interpretation bias in GAD patients has also been found to play a role in reducing negative thought intrusions (Hayes, Hirsch, Krebs, & Mathews, 2010). Overall, individuals with GAD are characterised by excessive worry, tend to interpret ambiguous information as threatening, expect a higher likelihood of a negative event happening in the future and are oversensitive to threatening cues in the environment (Borkovec, et al., 1998).

3.2.2 What are the different GAD models?
Different authors have emphasized the importance of different cognitive, emotional and behavioural processes in explaining GAD and this has resulted in a number of models that have been put forward for GAD. For instance, the avoidance model (Borkovec, 1994; Borkovec, Alcaine, & Behar, 2004), one of the most influential and long held GAD models, which we briefly touched upon in the previous section, emphasises that worry is a thought based activity, which when used as a strategy to dampen and avoid more upsetting negative emotions and associated negative outcomes results in anxiety. A more recent GAD model, with clearly defined components and increasing recognition and empirical evidence, is the Intolerance of uncertainty model (Dugas, et al., 1998). According to this model worry is maintained by four components: IU, positive beliefs about worry, poor problem orientation and cognitive avoidance. IU has been previously described in detail in Chapter 1. Positive beliefs about worry refer to a set of beliefs that promote worry as a useful strategy. These include the belief that worry aids problem solving, motivates the individual to do things, prevents negative outcomes, protects one from negative emotions in the event of a negative outcome and is thought of as a positive personality trait (Freeston, et al., 1994). Negative problem orientation refers to a set of negative beliefs about one’s cognitive approach towards solving problems, such as, doubting one’s problem-solving abilities, finding problems threatening and having a pessimistic view about the outcome of a problem (Davey, 1994; Dugas, Letarte, Rheaume, Freeston, & et al., 1995). Whether one actually has the skills to solve problems is independent to worry and one’s beliefs about solving problems, while how one approaches problems (i.e. problem orientation) has been found to predict worry (Dugas, et al., 1997). Indeed, high worriers do
not lack the skills to solve problems, what they do lack is the confidence and positive approach when confronted with a problem (Davey, 1994). Finally, cognitive avoidance consists of an individual’s tendency to use avoidance strategies to manage worry, such as suppressing threatening intrusive thoughts or unpleasant emotions (Dugas & Robichaud, 2007).

A further influential model is the metacognitive model (Wells, 2000). In this model GAD is understood as the result of a set of maladaptive metacognitive beliefs associated with worry. According to Wells, what is important in maintaining psychopathology is how one approaches one’s thoughts and the style of thinking that is adopted as opposed to the content of the thoughts (Wells, 2005). A number of metacognitive strategies have been identified that are believed to maintain psychopathology. These include cognitive confidence, positive beliefs about worry, which are not grounded on any evidence and maintain worry as a positive coping strategy, cognitive self consciousness, uncontrollability and danger of thoughts and need to control thoughts. According to the Self-Regulatory Executive Function (S-REF) model of emotional disorders, psychological distress arises due to a cognitive-attentional syndrome, characterised by high levels of self-focused attention, preservative forms of processing (worry/rumination), activation of negative self-beliefs, attentional strategies of threat monitoring, and coping behaviours that interfere with more adaptive processing, which would otherwise return the individual to normal mental functioning (Wells, 2000; Wells & Matthews, 1994).

Other proposed models of GAD have focused more on emotional and behavioural processes rather than cognitive processes. For instance, the acceptance based model (Roemer & Orsillo, 2002; Roemer, Salters, Raffa, & Orsillo, 2005) suggests that GAD result from avoiding internal experiences and limiting behaviours and activities that would be helpful, such as seeing friends. Difficulties in monitoring, accepting and interpreting emotions are at the centre of understanding worry and GAD (Roemer et al., 2005). Individuals with GAD have been found to show an elevated fear of allowing themselves to process their emotions and feel less in control of their feelings (Stapinski, Abbott, & Rapee, 2010). This results in maladaptive emotion regulation strategies that increase worry and the development of GAD (Olatunji, et al., 2011).

Despite apparent differences between the above GAD models, all share the notion that anxiety arises due to avoidance of one’s internal states (Behar et al., 2009). Other overlaps are also apparent between models. For instance, both the IU model and Well’s metacognitive model recognizing positive beliefs about worry as crucial in maintaining worry. For a detailed summery of current GAD models please see an integrated review by Behar and colleagues (2009).

3.3 Aims of study 1

From Chapter 1 we know that anxiety, including GAD is one of the most frequent comorbid anxiety disorders present in individuals with anorexia nervosa, alongside social anxiety and OCD. However,
compared to OCD and social anxiety disorder, GAD and particular anxiety related vulnerability factors have received little attention in the eating disorders. Identifying shared vulnerability factors between different psychological disorders is considered important for attending to comorbidity and for patients that do not do well to otherwise effective treatments (Harvey et al., 2004).

The aim of the present quantitative study is to investigate anxiety related vulnerability factors in adults with anorexia nervosa and a group of healthy controls. The choice of the anxiety related vulnerability factors was driven by the overall aim of the present thesis to investigate the cognitive construct of IU. Two main lines of reasoning guided the present study. First, there is a need to understand, beyond comorbidity the overlap between GAD and anorexia nervosa by investigating anxiety related vulnerability factors. Second, there is little empirical examination of IU in relation to eating psychopathology.

3.4 Hypotheses

1. Participants with anorexia nervosa will show significantly elevated anxiety related vulnerability factors, including, IU, negative problem orientation, positive beliefs about worry and cognitive avoidance when compared to a healthy control group (H1).

2. Differences between participants with anorexia nervosa compared to a healthy control group will remain for the anxiety related vulnerability factors, particularly for IU, when anxiety levels are controlled for (H2).

3. The anxiety related vulnerability factors will predict eating disorder psychopathology (H3).

3.5 Method

3.5.1 Design

A cross sectional design was chosen for the present study. The independent variable was whether participants were in the clinical or control group and the dependent variables were, positive beliefs about worry, IU, negative problem orientation and cognitive avoidance.

3.5.2 Participants and recruitment procedure

The recruitment procedure and sample size of each of the two groups is described below.

Clinical group (N= 39)

200 individuals from the volunteer database at the Institute of Psychiatry, Eating Disorders Research Unit were invited to complete the questionnaires as part of their monthly newsletter that they received from the adult eating disorder service.. Potential participants received information sheets (see Appendix 3) and questionnaire packs containing the self-report measures detailed below along with the eating
disorder newsletter. Reply envelops were also provided for those who agreed to take part to return the completed questionnaires via post. In the information sheet it was highlighted that returning the questionnaires would suggest that one consented to take part in the study, as was agreed with the research ethics committee. The clinical group with anorexia nervosa eating disorder psychopathology consisted of 39 adult females, with a mean age was 33.38 (SD = 11.57) and a BMI of 16.21 (SD = 1.49). Fourteen participants at time of completing the study were receiving treatment for anorexia nervosa, 19 were not in treatment at time of completing the study and 6 did not specify. At time of participating in the study the clinical group were not formally re-diagnosed. BMI and responses on the EAT-26 were used as indicative of their level of eating psychopathology.

Control group (N = 73)

For the recruitment of healthy controls, questionnaires were transferred onto the commercial program Question Pro (http://www.questionpro.com/) and an online link that included information about the study and the questionnaires was created. The control group was recruited through two sources. First, emails containing information about the study (see Appendix 3), consent and the online link to complete the questionnaires online were circulated to students from the Institute of Psychiatry, Kings College London. Second, similar emails were sent to friends, of the present author, who were asked to forward the email to family and friends. Potential participants were initially screened for an eating disorder using the using the Eating Attitudes Test (EAT-26) (Garner & Garfinkel, 1979; Garner, Olmsted, Bohr, & Garfinkel, 1982). If they scored a total of 20 or more on items 1-26 of the EAT-26 or if they answered YES to any of the eating disordered behavior questions (e.g., In the past 6 months have you gone on eating binges where you feel that you may not be able to stop?) they were not included in the study. The control group was further screened for GAD using the Worry and Anxiety Questionnaire (Dugas, Freeston, et al., 2001). In total, 73 participants made up the control group, these consisted of both students and non student adults with a mean age of 31.64 years (SD = 9.68).

3.5.3 Measures

Assessing eating psychopathology

1. **Eating Attitudes Test** (EAT-26; (Garner & Garfinkel, 1979; Garner, et al., 1982). The EAT-26 is a 26-item self-report questionnaire designed to measure problematic eating attitudes and behaviours. Responses are made on a six-point Likert scale and a total score is comprised by adding up all the items (items 1-26) of the EAT-26. A total score of 20 or greater, and/or a positive response in one or more of the four behavioural questions is indicative of problematic eating attitudes and behaviours. The EAT-26 shows good to excellent internal consistency ($\alpha = .70 - .88$). Convergent and discriminant validity have also been established (Doninger, Enders, & Burnett, 2005; Mintz & O'Halloran, 2000). The EAT-26 was also used to screen potential control participants for eating psychopathology.
Participants with a total score of over 20 or a “YES” response to one of the behavioural questions were excluded from the study. The EAT-26 takes no more than 10 minutes to complete.

Assessing anxiety

2. Worry and Anxiety Questionnaire (WAQ; Dugas, Freeston, et al., 2001). The WAQ assesses the presence and the severity of the GAD diagnostic criteria, as they appear in the DSM-IV (American Psychological Association, 1994). It is an 11-item self-report measure rated on a nine-point Likert scale. The first item of this instrument asks about the most frequent worry topics and the subsequent items assess the presence and severity of GAD diagnostic criteria. The WAQ is scored by adding up the responses for all of the items. The WAQ has good validity and shows satisfactory test–retest reliability (Dugas, Freeston, et al., 2001). The WAQ takes on average 5 minutes to complete.

Measuring anxiety related vulnerability factors

3. Intolerance of Uncertainty Index (IUI, See Appendix 4) (Gosselin, et al., 2008); English version: (Carleton, Gosselin, & Asmundson, 2010). The IUI is a 45-item self-report questionnaire that measures an individuals’ tendency to find uncertainty distressing and unacceptable. The IUI is made up of two parts; Part A, which comprises of 15-items assessing the level of dislike and unacceptability towards uncertainty and Part B, which comprises of 30 items assessing different manifestations of intolerance of uncertainty. Part A is made up of 3 subscales: Intolerance of uncertainty and uncertain situations; Intolerance of the unexpected; Difficulty waiting in an uncertain situation. Part B is made up of six subscales: Overestimation of the probability that a negative event will occur, Control, Reassurance, Avoidance, Worry, and Doubt. The IUI is scored by summing up all the items of part A and part B. Subscales can also be calculated by summing up all the items for each subscale for part A and separately for part B. The IUI shows excellent psychometric properties (Carleton, et al., 2010; Gosselin et al., 2008). The IUI was chosen over the popular IUS (Buhr & Dugas, 2002) as a more appropriate measure of IU for this clinical group as it differentiates between dislike towards uncertainty per se and responses to uncertainty.

4. Why Worry Questionnaire (WW-II; Gosselin, et al., 2003); English version: Holowka, Dugas, Francis, & Laugesen, 2000). The WW-II is a 25-item self report revised measure of the Why Worry Questionnaire (WW-I; Freeston et al., 1994). It is designed to assess positive beliefs about worry and has five subscales assessing different aspects of this construct (i.e., worry aids in problem solving, worry helps to motivate, worrying protects one from negative emotions in the event of a negative outcome, the act of worrying itself prevents negative outcomes, and worry is a positive personality trait). Participants rate the extent to which a
statement best describes them along a 5-point Likert scale from “Not at all” = 1 to “Very much” = 5. It can be both used as a unifactorial and multifactorial measure. The WW-II has high internal consistency (α = .93), adequate test-retest reliability (r = .81) and shows evidence of convergent, divergent, and criterion validity (Gosselin et al., 2003). It takes on average 5 minutes to complete.

5. **Negative Problem Orientation Questionnaire (NPOQ)** (Robichaud, Dugas, Robichaud, & Dugas, 2005). The NPOQ is a 12-item self-reported measure assessing an individual’s cognitive approach towards problems (e.g., finding problems threatening, doubting one’s problem-solving ability and having a pessimistic view about the outcome of a problem). Participants rate the extent to which a statement best describes them along a 5-point Likert scale from “Not at all” = 1 to “Very much” = 5. An initial psychometric evaluation suggested that the NPOQ is unifactorial, with excellent internal consistency (α = .92), high test–retest reliability (r = .80), and good convergent and discriminant validity (Robichaud & Dugas, 2005). The NPOQ takes no more than 5 minutes to complete.

6. **Cognitive Avoidance Questionnaire (CAQ)** (Gosselin, et al., 2002), English translation: (Sexton & Dugas, 2008). The CAQ is a self report measure that consists of 25 items assessing an individual’s tendency to use cognitive avoidance strategies. The CAQ has five theoretically derived subscales: Thought substitution, transformation of images into thoughts, distraction, avoidance of threatening stimuli, and thought suppression. Participants rate the extent to which a statement best describes them along a 5-point Likert scale from “Not at all” = 1 to “Very much” = 5. It can be both used as a unifactorial and multifactorial measure. The CAQ total scale has excellent internal consistency (α = .95) and high test-re test reliability (r = .85) (Sexton & Dugas, 2008). On average it takes 5 minutes to complete the CAQ.

### 3.6 Ethical approval

Ethical approval was granted by the Kings College London Research Ethics Committee.

### 3.7 Data storage

All hard copies of the completed questionnaires are stored at the Institute of Psychiatry, Kings College London in a locked cabinet in a locked office. Questionnaires completed online were printed and locked in the same location as the hard copy questionnaires.

### 3.8 Initial assumption testing

Testing for normality

In order to assess whether parametric or non-parametric tests would be most appropriate for the data set a number of assumptions were tested. Normality of data was assessed by running tests for normality (Kolmogorov-Smirnov tests) and visually examining histograms for continuous variables separately for
the clinical group and control group. Data of the clinical group showed no violations of normality ($p>.05$) for the following variables: eating psychopathology (EAT-26; total score, subscales: dieting, bulimia, oral control), IU part A of the IUI; positive beliefs about worry (WWII), negative problem orientation (NPOQ) and cognitive avoidance (CAQ). The only variable that showed deviation from normality was Part B of the IUI. Data from the control group showed no violations from normality apart from some deviations for negative problem orientation (NPOQ) and positive beliefs about worry (WWII). Parametric tests were selected for the present data set.

Homogeneity of variance
Tests for homogeneity of variance are presented under results for hypothesis 1 and hypothesis 2.

3.9 Data Analyses

Data were analysed using the Statistics Package for the Social Sciences: Version 17 (SPSS Chicago, 2007).
The following analyses were conducted.

Preliminary Analyses

1. A one-way analysis of variance (ANOVA) was conducted to examine differences in eating disorder symptoms and anxiety related factors between participants in the eating disorder group currently being treated and participants not in treatment.

2. Pearson product moment correlations were conducted to explore the relationship between BMI, eating psychopathology and anxiety related factors in the clinical group.

Main analyses

1. A series of one way between group analyses of variance (ANOVA) were conducted to examine differences on the anxiety related vulnerability factors between the clinical group and the healthy control group (H1).

2. A series of one way between groups analyses of covariance (ANCOVA) were conducted to examine whether differences on the anxiety related vulnerability factors between the clinical group and the healthy control group remained when levels of anxiety were accounted for (H2).

3. Multiple regression analysis was conducted to examine whether anxiety related vulnerability factors could predict variance in eating disorder psychopathology (H3).

3.10 Results
3.10.1 Examining differences on BMI, eating psychopathology and anxiety related factors in terms of treatment status

Preliminary assumption testing was carried out which indicated that there were no violations of the assumptions of homogeneity of variance after carrying out a Levene’s test of equality of error variances. A series of one-way between-groups analysis of variance (ANOVAS) were conducted to explore differences on BMI, eating psychopathology, IU, positive beliefs about worry, cognitive avoidance and negative problem orientation between participants in treatment at time of completing the study and participants not in treatment. A statistically significant difference was found for eating disorder psychopathology with the currently in treatment group scoring higher on the total EAT score compared to the not in treatment group (see Table 3.1). There was no statistically significant difference of the remaining factors between the two groups (see Table 3.1). For the remaining of the analyses the whole clinical group sample will be used.

Table 3.1 Differences between participants in treatment and participants not in treatment on eating psychopathology and anxiety related factors

<table>
<thead>
<tr>
<th>DVs</th>
<th>In treatment (N = 14)</th>
<th>Not in treatment (N = 19)</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI</td>
<td>16.23</td>
<td>16.31</td>
<td>0.01</td>
<td>ns</td>
</tr>
<tr>
<td>EAT-TS</td>
<td>47.21</td>
<td>33.00</td>
<td>7.26</td>
<td>**</td>
</tr>
<tr>
<td>WWII</td>
<td>58.57</td>
<td>67.94</td>
<td>2.13</td>
<td>ns</td>
</tr>
<tr>
<td>IUI-A</td>
<td>56.78</td>
<td>67.94</td>
<td>0.10</td>
<td>ns</td>
</tr>
<tr>
<td>IUI-B</td>
<td>113.14</td>
<td>115.84</td>
<td>0.10</td>
<td>ns</td>
</tr>
<tr>
<td>NPOQ</td>
<td>42.07</td>
<td>39.79</td>
<td>0.32</td>
<td>ns</td>
</tr>
<tr>
<td>CAQ</td>
<td>72.85</td>
<td>81.26</td>
<td>1.30</td>
<td>ns</td>
</tr>
</tbody>
</table>

Note: DVs = Dependent variables; BMI = Body Mass Index; EAT-TS = Eating Attitudes Test; WWII = Why Worry Questionnaire; IUI-A = Intolerance of Uncertainty Inventory part A; IUI-B = Intolerance of Uncertainty Inventory part B; CAQ = Cognitive Avoidance Questionnaire; NPOQ = Negative Problem Orientation Questionnaire.

** Significant at the \( p \leq .01 \) level

ns = non significant

3.10.2 Examining associations between BMI, eating psychopathology and anxiety related factors

The relationship between BMI, eating psychopathology and anxiety related factors was investigated using Pearson product-moment correlation coefficient. There were moderate to strong positive correlations between most of the examined variable. A number of variables however did not correlate with each other. For instance, BMI did not correlate with any of the examined variables, while positive beliefs about worry and cognitive avoidance did not correlate with eating psychopathology or part A of the IUI (see Table 3.2).
Table 3.2 Pearson product moments correlations between BMI, eating psychopathology and anxiety related factors (clinical group N =39)

<table>
<thead>
<tr>
<th>Variables</th>
<th>EAT-TS</th>
<th>BMI</th>
<th>WWII</th>
<th>IUI-A</th>
<th>IUI-B</th>
<th>NPOQ</th>
<th>CAQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>EAT-TS</td>
<td>-</td>
<td>-0.09*</td>
<td>0.07ns</td>
<td>0.53**</td>
<td>0.38*</td>
<td>0.44**</td>
<td>0.28ns</td>
</tr>
<tr>
<td>BMI</td>
<td>-</td>
<td>0.23</td>
<td>-0.06ns</td>
<td>-0.16ns</td>
<td>0.07ns</td>
<td>0.07ns</td>
<td></td>
</tr>
<tr>
<td>WWII</td>
<td>-</td>
<td>0.24ns</td>
<td>0.45**</td>
<td>0.35*</td>
<td>0.42**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IUI-A</td>
<td>-</td>
<td>0.78**</td>
<td>0.52**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IUI-B</td>
<td>-</td>
<td></td>
<td>0.72**</td>
<td>0.56**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPOQ</td>
<td>-</td>
<td></td>
<td></td>
<td>0.69**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CAQ</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: EAT-TS = Eating Attitudes Test Total Score; BMI = Body Mass Index; WWII = Why Worry Questionnaire; IUI-A = Intolerance of Uncertainty Inventory part A; IUI-B = Intolerance of Uncertainty Inventory part B; CAQ = Cognitive Avoidance Questionnaire; NPOQ = Negative Problem Orientation Questionnaire.

ns = non significant
* Correlation is significant at the .05 level (two-tailed).
** Correlation is significant at the .01 level (two-tailed).

3.10.3 Examining differences between groups on the examined anxiety related vulnerability factors (H1)

Initial assumption testing showed that data did not violate the assumption of homogeneity of variances after carrying out a Levene’s test of equality of error variances, apart from WWII, for which a stricter alpha level will be used to determine significance following a Bonferroni adjustment, α = 05/5 = .01.

A series of ANOVAs were conducted to examine differences on anxiety related factors between participants in the anorexia nervosa group and participants in the healthy control group. Statistically significant differences were detected between the two groups for all of the examined anxiety related factors at the p < .001 level (see Table 3.3). All of the anxiety related factors showed large effect sizes calculated using eta squared, based on Cohen’s criteria (1988), with the largest effect size for part A and B of the IUI. Figure 3.1 illustrates these differences between the two groups.
Table 3. Differences between the two groups on the anxiety related factors

<table>
<thead>
<tr>
<th>Groups</th>
<th>AN (N = 39)</th>
<th>HC (N = 73)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>WWII</td>
<td>64.84</td>
<td>18.63</td>
</tr>
<tr>
<td>IUI-A</td>
<td>57.00</td>
<td>13.52</td>
</tr>
<tr>
<td>IUI-B</td>
<td>115.82</td>
<td>21.86</td>
</tr>
<tr>
<td>NPOQ</td>
<td>40.92</td>
<td>11.14</td>
</tr>
<tr>
<td>CAQ</td>
<td>77.07</td>
<td>20.70</td>
</tr>
</tbody>
</table>

Note: DVs = Dependent Variables; AN = anorexia nervosa; HC = Healthy Controls; M = mean; SD = standard deviation; F = statistical test; (η2) = eta squared (effect size); WWII: Why Worry Questionnaire; NPOQ: Negative Problem Orientation Questionnaire; CAQ: Cognitive Avoidance Questionnaire; IUI-A: Intolerance of Uncertainty Inventory part A; IUI-B: Intolerance of Uncertainty Inventory part B.

*** Significant at the p < .001 level

Figure 3. Mean scores on anxiety factors for participants in the clinical and control group

3.10.4 Do differences between the two groups remain even when anxiety levels are controlled for? (H2)

No violations of homogeneity of variances were detected after carrying out a Levene’s test of equality of error variances, apart for positive beliefs about worry (WWII), for which a Bonferroni adjusted alpha level (α = .01) was used to determine significance levels. A series of one-way between-groups analysis of covariance (ANCOVA) were carried out in order to examine whether differences between participants in the anorexia nervosa group and those in the healthy control group remained for the anxiety related vulnerability factors even when anxiety levels were controlled for. After adjusting for anxiety scores (WAQ) significant differences between the two groups remained for part A of the IUI [F(1, 109) = 14.32, p<.0001, partial eta squared = .12]; part B of the IUI [(F(1, 109) = 21.10, p<.0001, partial eta squared =
negative problem orientation \([F(1, 109) = 8.96, p<.01, \text{partial eta squared }=.08]\) and positive beliefs about worry \([F(1, 109) = 11.59, p<.01, \text{partial eta squared }=.09]\), with part A and part B of the IUI showing a large effect size, calculated using eta squared, while they disappeared for cognitive avoidance \([F(1, 109) = 3.72, p>.05, \text{partial eta squared }=.03]\).

### 3.10.5 Examining whether anxiety related factors predict eating disorder psychopathology (H3)

A standard multiple regression analysis was carried out examining the predictive ability of the examined anxiety related factors on EAT-26 scores across the clinical group. Using the enter method a significant model emerged \(F(5, 33) = 3.79, p < .01\). The model explains 36.5% (R-squared) of the variance in EAT-26 scores. When examining which of the predictor variables included in the model contributed to the prediction of the dependent variable it was found that IU part A of the IUI made the strongest significant contribution in explaining the dependent variable, when the variance explained by the rest of the predictor variables was controlled for (see Table 3.4).

#### Table 3.4 Summary of multiple regression analysis for the predictor variables

<table>
<thead>
<tr>
<th>Predictor variable (EAT-26)</th>
<th>(\beta)</th>
<th>SE (\beta)</th>
<th>(\beta)</th>
<th>(t)</th>
<th>(P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>8.41</td>
<td>11.92</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>WWII</td>
<td>-.06</td>
<td>.13</td>
<td>-.07</td>
<td>-.44</td>
<td>.66</td>
</tr>
<tr>
<td>IUI-A</td>
<td>.73</td>
<td>.26</td>
<td>.64</td>
<td>2.75</td>
<td>.01**</td>
</tr>
<tr>
<td>IUI-B</td>
<td>-.27</td>
<td>.21</td>
<td>-.39</td>
<td>1.33</td>
<td>.19</td>
</tr>
<tr>
<td>NPOQ</td>
<td>.47</td>
<td>.32</td>
<td>.35</td>
<td>1.50</td>
<td>.14</td>
</tr>
<tr>
<td>CAQ</td>
<td>.07</td>
<td>.15</td>
<td>.09</td>
<td>.45</td>
<td>.65</td>
</tr>
</tbody>
</table>

Note: \(\beta\) = unstandardized coefficients; SE \(\beta\) = standard error; \(\beta\) = standardized beta coefficient; \(t\) = t-test statistic; \(P\) = significance value; WWII = Why Worry Questionnaire; IUI-A = Intolerance of Uncertainty Index part A; IUI-B = Intolerance of Uncertainty Index part B; NPOQ = Negative Problem Orientation Questionnaire; CAQ = Cognitive Avoidance Questionnaire.

** Significant at the \(p \leq .01\) level

### 3.11 Discussion

#### 3.11.1 Summary of results

The present study extends our understanding of the relationship between anxiety disorders and eating disorders, moving beyond comorbidity and looking at specific vulnerability factors of GAD in individuals with anorexia nervosa.

Initial explorations of the clinical group revealed that participants in treatment and participants not in treatment at time of completing the study did not significantly differ on the anxiety related factors that
were examined. In terms of physical state, both groups had a low BMI. The only difference detected was that the not in treatment group scored significantly lower on eating disorder psychopathology compared to the in treatment group but well above the cut off score on the EAT-26. It is thus difficult to know whether the not in treatment group were at all recovered. Further explorations of the clinical group (i.e. both the not in treatment and in treatment group) indicated that most examined factors showed positive correlations with eating psychopathology, apart from positive beliefs about worry, cognitive avoidance and BMI. In fact BMI did not correlate with any of the examined factors. This suggests that physical state of the individual can be independent of anxiety related cognitive processes. Positive beliefs about worry and cognitive avoidance were also not associated with eating related psychopathology while IU and poor problem orientations were. One interpretation of this is that some anxiety related vulnerability factors are independent of eating psychopathology and are closely related to worry and anxiety, while other anxiety related vulnerability factors share a more close relationship with eating disorder psychopathology. Part A of the IUI also did not correlate with positive beliefs about worry and cognitive avoidance. The latter is unexpected as IU and positive beliefs about worry are known to share a close relationship and play a key role in maintaining worry. However, part A of the IUI, as described in the methods section (3.5.3), is part of the IUI questionnaire that directly measures IU without making any links to worry and anxiety or responses to uncertainty. In other words, part A of the IUI is a disorder free measure of IU. Lack of significant findings then could be due to part A of the IUI measuring an aspect of IU that is independent of anxiety. Although part A of the IUI was not associated part B of the IUI was found associated with positive beliefs about worry. This could mean that part B of the IUI touches upon IU that is associated with worry and thus also positive beliefs about worry, while, part A of the IUI touches upon a dislike towards uncertainty per se, which may not be associated with worry.

Results overall supported the three main hypotheses of the present study. The first hypothesis was fully supported. Findings confirmed that individuals with anorexia nervosa scored significantly higher than healthy controls on IU, positive beliefs about worry, negative problem orientation, and cognitive avoidance. The second main hypothesis of the present study was partly supported. Results showed that differences between the clinical group and the control group on the examined anxiety factors remained elevated even when anxiety levels were accounted for, apart from cognitive avoidance. Out of all the examined factors, IU (IUIA +IUIB) showed the largest effect sizes when levels of anxiety were accounted for. This finding is consistent with the idea that IU may share a more specific relationship with eating psychopathology, irrespective of anxiety. Such findings further suggest that the examined anxiety related factors could be both playing a role in maintaining comorbid levels of GAD in individuals with anorexia nervosa, but also some anxiety factors such as IU may be maintain levels of anorexia nervosa psychopathology as well. Finally, the third hypothesis was supported showing that the examined anxiety related factors were able to predict eating disorder psychopathology. However, only part A of the IUI uniquely provided a significant contribution to the variance in eating symptoms compared to all of the
other variables. This means that when the variance for all the other variables was controlled for, part A of the IUI was the sole variable to significantly explain the variance in EAT-26 scores.

Taken together present findings indicate that anxiety related factors are relevant in adults with anorexia nervosa and most of them remain elevated irrespective of anxiety levels. In line with the present thesis predictions, IU (part A of the IUI), was found to share a close relationship with eating psychopathology and was a strong predictor of eating psychopathology. This indicates that IU may share a more specific relationship with eating psychopathology irrespective of anxiety. For instance, IU may be related to dieting behaviours or particular characteristics of individuals with an eating disorder such as need for control (Fairburn, Shafran, et al., 1999; Sassaroli, et al., 2008) and low novelty seeking (Dalle Grave, et al., 2008; Fassino, et al., 2002). In other words, high levels of IU may be increasing the need for predictability and certainty and reinforcing a tendency to avoid uncertain and new situations.

3.11.2 Limitations of study 1

A number of limitations need to be taken into account when considering the present results. Firstly, the cross-sectional nature of the study does not allow for any causal inferences to be made about the relationship between the anxiety related factors and eating psychopathology. Secondly, there was limited background information on the clinical group, such as length of illness and overall previous psychopathology which would have been informative. Thirdly, the healthy control group was not screened for depression nor past psychopathology.
Chapter 4

A qualitative examination of IU in adolescents with anorexia nervosa (Study 2)

4.1 Overview of chapter

In the present thesis, IU is considered as a potential important factor involved in the maintenance of anorexia nervosa. Both quantitative and qualitative research is required particularly when examining new concepts. Chapter 4 presents results from a qualitative study that looks at how adolescents with anorexia nervosa currently in treatment experience and manage uncertainty. Research in the present Chapter not only complements the quantitative study in Chapter 6, but also contributes in refining the proposed model of IU and anorexia nervosa, presented in Chapter 2. The present Chapter also puts in context the rationale for the chosen design and selection of data analysis as it is the first of two qualitative studies (Chapter 4 & Chapter 5).

4.2 Introduction

Qualitative research seeks to understand meanings, experiences and views of people, while quantitative research examines the world through hypothesis testing and investigating the relationship between different variables providing quantified answers to research questions (Pope and Mays, 1995). Emphasis, in qualitative research is placed in reaching a deep understanding of an experience and how people relate to a given phenomenon (Willig, 2001). Qualitative and quantitative research designs have often been viewed as conflicting with one another. Strong opinions often develop favouring either one approach over the other. In the past, qualitative research has received a lot of criticism and was viewed as a more weak methodology compared to quantitative research. This can partly be explained due to the tendency to favour hypothesis testing rather than hypotheses generating, measurement rather than explanations and generalisability rather than understanding (Jones, 1995). A number of advances have been made to bridge qualitative and quantitative research, stressing the important contribution to knowledge both types of research can offer (Pope & Mays, 1995). There is indeed a need to gain an understanding of how best the two research approaches can complement each other rather than compete with each other. Human behaviour is complex and both quantitative and qualitative methods can provide important insights. Depending on the research question, quantitative or qualitative research methods can be adopted and at times a mixed methods design may be more appropriate (Pope and Mays, 1995). Pope and Mays (1995) outline three ways quantitative and qualitative research designs can work well together. These include using qualitative research as a first step in understanding a phenomenon and guiding quantitative research, such as constructing a survey based on individuals’ own words and experiences yielded from qualitative research. Qualitative research can also be used to complement quantitative research to validate findings and enrich our knowledge. Finally qualitative research can be adopted as an extension of quantitative research when exploring complex phenomena, where quantitative research cannot reach.
IU is a relatively new cognitive construct that has been extensively examined in the anxiety literature however with little knowledge of its role in the eating disorders. At present only a handful of quantitative studies (Frank et al., 2012; Konstantellou & Reynolds, 2010; Sternheim, et al., 2011; Stewart, 2009) and one recent qualitative study have directly linked IU with eating disorder psychopathology (Sternheim, Konstantellou, et al., 2011). In order to understand in depth the nature of the relationship between IU and eating disorders both quantitative and qualitative research is needed. On the one hand, quantitative research for instance can tell us about possible elevated levels of IU in individuals with an eating disorder and associations with other variables, as well as, its relationship with eating disorder psychopathology. On the other hand, qualitative research can inform us of how uncertainty is like for individuals with anorexia nervosa, which will shed light into understanding better the possible role of IU in anorexia nervosa. Finally, examining personal accounts of individuals with anorexia nervosa of how they experience and manage uncertainty will both inform theory and clinical practise.

4.3 Aim of Study 2

The aim of study 2 is to explore how adolescents currently in treatment for anorexia nervosa experience and manage uncertainty in their lives. In other words, what kind of meanings and experiences this particular age and clinical group hold when thinking of uncertainty. One important aspect of the study was to refrain from inflicting any previous beliefs and assumptions of how adolescents with anorexia nervosa may experience uncertainty.

4.4 Ethical considerations

This study was reviewed and granted ethical approval by the Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee. Three main ethical concerns were raised by the committee: confidentiality, consent and accessing notes.

1. First, there was concern regarding participants being provided with clear information regarding confidentiality and conditions whereby confidentiality may be breached. This was dealt with by explaining in the information sheets (see Appendix 5) what confidentiality meant and conditions under which it may be breached, as well as, asking participants to consent that they understood when confidentiality may be broken (see Appendix 6).

2. Second, it was thought important to inform participants that permission would be sought from them to use non-identifiable direct quotes. This was dealt with by explaining to participants that for research purposes it may be needed to use some direct quotes from the discussion and that we would contact them to gain permission before this was done. This was included in the consent forms as well. When potential quotes for the results section were identified, adolescents and parents with an adolescent under 16 years of age whose quotes belonged to
were contacted by the present author. A letter was sent asking for permission to use non
identifiable quotes from them to illustrate themes that were generated in the analysis of the
research that they took part. Sufficient time was available for participants and parents to
express any concerns. No concerns were raised and all non-identified quotes were used in the
results section.

3. Thirdly, there was concern from the committee regarding accessing clinical notes. The present
author explained how accessing background information and contact details was necessary for
the study in order to be able to get in touch with participants regarding gaining permission to
use quotes and gaining background clinical information, like their illness duration. This matter
was further dealt with by seeking written consent from participants giving permission for the
chief researcher to access their clinical notes only for research purposes.

Written consent was further sought for discussions within the groups to be audio-taped and used for
these purposes (See Appendix 6). Parental consent was also sought for adolescents under the age of 16
(see Appendix 7). To ensure anonymity all real names were replaced during the transcribing process
with anonymous codes. Overall, all participants gave written consent to take part in the study.

4.5 Method

4.5.1 Participants: sampling and recruitment (N =13)
Participants were recruited from pre-existing groups as part of three consecutive Multi Family Therapy
(MFT) groups (Dare & Eisler, 2000) provided by the Child and Adolescent Eating Disorders Service, South
London and Maudsley NHS Foundation Trust. MFT runs for five full days followed by three follow-ups.
The group of patients that were screened were at the point of taking part in their second follow-up.

The inclusion criteria for the study were:

1. A diagnosis of Anorexia Nervosa or Eating Disorder Not Otherwise Specified Restrictive type
(EDNOS AN- R; DSM-IV; ICD-10) determined at the initial clinical assessment prior therapy by
the clinical team.

2. Individuals had to be aged between 12 and 18.

Only one of the potential participants, from the third MFT group (FG3) did not want her responses to be
part of research and her contribution to the discussion was not transcribed or analysed. All remaining
adolescents agreed to take part in the study. A total number of 13 participants gave written consent
and took part in the study. Participants were predominantly female with the exception of one male.
Twelve of the 13 participants came from a white British background, and one from a mixed race. See
Table 4.1 for demographic characteristics of each participant, including length of illness, treatment and
comorbidity at time of initial clinical assessment. Comorbidity was determined based on patient scores
on the MFQ to assess depression and the SCARED to assess anxiety. Both measures were administered
at patients’ initial assessment as part of routine clinical practise. If the total score on the MFQ was 29 or above this was considered indicative of presence of a comorbid depressive disorder (Daviss et al., 2006). If the total score on the SCARED was 25 or above this was considered indicative of a possible comorbid anxiety disorder (Birmaher et al, 1999). Comorbidity at time of participation in the focus groups was not re-assessed.

Table 4.1 Participant Demographics and Clinical Characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Group</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Length of illness (months)</th>
<th>Length of Treatment (M)</th>
<th>Comorbidity at assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>P1</td>
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<td>FG1</td>
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<td>Female</td>
<td>AN-R</td>
<td>8</td>
<td>4</td>
<td>V V</td>
</tr>
<tr>
<td>P5</td>
<td>FG1</td>
<td>17</td>
<td>Female</td>
<td>AN-R</td>
<td>26</td>
<td>2</td>
<td>V V</td>
</tr>
<tr>
<td>P6</td>
<td>FG2</td>
<td>15</td>
<td>Male</td>
<td>EDNOS-R</td>
<td>13</td>
<td>6</td>
<td>V V</td>
</tr>
<tr>
<td>P7</td>
<td>FG2</td>
<td>16</td>
<td>Female</td>
<td>AN-R</td>
<td>16</td>
<td>10</td>
<td>X V</td>
</tr>
<tr>
<td>P8</td>
<td>FG2</td>
<td>15</td>
<td>Female</td>
<td>EDNOS-R</td>
<td>8</td>
<td>2</td>
<td>X V</td>
</tr>
<tr>
<td>P9</td>
<td>FG2</td>
<td>18</td>
<td>Female</td>
<td>AN-R</td>
<td>14</td>
<td>2</td>
<td>V V</td>
</tr>
<tr>
<td>P10</td>
<td>FG2</td>
<td>17</td>
<td>Female</td>
<td>EDNOS-R</td>
<td>14</td>
<td>2</td>
<td>X X</td>
</tr>
<tr>
<td>P11</td>
<td>FG3</td>
<td>16</td>
<td>Female</td>
<td>AN-R</td>
<td>8</td>
<td>2</td>
<td>V V</td>
</tr>
<tr>
<td>P12</td>
<td>FG3</td>
<td>12</td>
<td>Female</td>
<td>AN-R</td>
<td>24</td>
<td>3</td>
<td>X X</td>
</tr>
<tr>
<td>P13</td>
<td>FG3</td>
<td>15</td>
<td>Female</td>
<td>AN-R</td>
<td>14</td>
<td>10</td>
<td>X V</td>
</tr>
</tbody>
</table>

Note: AN-R = anorexia nervosa restrictive type, EDNOS-R = Eating Disorders Not Otherwise Specified Restrictive Type, X = not present, V = present.

4.5.2 Design

A focus group design was chosen as the most appropriate for the purpose of the present study. Focus groups, like individual interviews, allow researchers to see the world from the participants’ perspectives (Heary & Hennessy, 2002) but further encourage and facilitate openness in participants’ responses and engagement in discussions, even more so than individual interviews (Kyriacou, Easter, & Tchanturia, 2009; Lewis, 1992, Wilkinson, 2009). Focus groups are often used in studies that examine peoples’ opinions and attitudes (Wilkinson, 2008), which fits the aims of the present study, and are considered as a more appropriate design for young individuals as they perhaps reduce any power imbalances between the young participant and the moderator (Hennessy & Heary, 2004). The topic of uncertainty was not viewed as too sensitive for adolescents to discuss in a group setting. It is also important to stress that participants in each focus group already knew each other from attending the MFT group. Using already established groups is thought to have positive effects encouraging engagement in discussions (Palmer,
Finally, previous research has successfully run focus groups with individuals with anorexia nervosa (Kyriacou, et al., 2009). Past experiences of the present author of running focus groups on uncertainty with adults with anorexia nervosa further suggests that focus groups on this topic are received very positively by this clinical group (Stenrheim, Konstantellou, et al., 2010).

4.5.3 Focus Groups

In the present study three focus groups on uncertainty were run, with the first 2 groups consisting of 5 participants and the third group of three participants. In general less than 3 is not considered a group and more than six participants there is the risk of the group breaking into sub groups (Breakwell, 1990). A small number of participants in each group further allowed time for each participant to express their opinions and obtain more rich and in depth data (Smith & Osborn, 2008). The composition of participants in all three focus groups was similar in terms of their age range and illness duration.

4.5.4 Moderator and facilitators: background information

All three focus groups were run by the current author, who acted as the moderator, and one other researcher, who acted as a facilitator. The moderator was responsible for introducing the study to the participants and leading the group discussion using the focus group schedule as guidance. The facilitator was introduced to participants as a researcher that would be helping with the groups and making notes during the discussion. In essence, the facilitator was responsible for taking notes on non verbal behaviour of participants making also sure that all participants were given the chance to express their own experiences and views. The chosen method of analysis places emphasis on the interpretative role of the moderator, and the potential of the moderator to influencing the analysis process. It is seen as helpful to provide some background information and research interests of the individuals who run the groups and analysed the data. Both moderator and facilitators were female in their mid to late 20s holding a research oriented post with previous training and experience in running focus groups in general and with adults with anorexia nervosa. Both researchers had an interest in the concept of IU and its relationship to eating disorders.

4.5.5 Focus group schedule

The focus group schedule was the same as the one used in a recent study exploring uncertainty in adults with anorexia nervosa (Sternheim, et al., 2011). Originally the focus group schedule was formed following a review of the relevant literature on anxiety related processes, in particular IU and discussions with clinicians. It was then piloted and appropriately revised. Learning from the previous study, the focus group schedule used in the present study had one alteration whereby a final question was added addressing participants’ experience of uncertainty prior to the onset of their illness. This was thought to provide stimulus for a more global understanding of participants’ experience with uncertainty. See Appendix 8 for the focus group schedule used.
4.5.6 Procedure

Participants met the moderator along with the facilitator in one of the rooms in the Michael Rutter Centre. The moderator used the focus group schedule to stimulate discussion. Discussion was facilitated with both verbal (e.g., “OK”; “Can you tell me more about that?”) and non-verbal cues (e.g., nodding), ensuring not to prime participants towards particular answers, following guidelines from (Smith, 1996). Appropriate time was left for each participant to have a chance to voice their opinions and experiences, whilst at the same time ensuring that all questions were raised for discussion (Smith, 1996). The second researcher made notes on non-verbal information and group dynamics. Each focus group lasted approximately 45 minutes.

4.5.7 Choice of analysis: IPA

Interpretative Phenomenological Analysis (IPA; Smith, 1996) was chosen as the method of analysis for the present study as it was in accordance with the study aims of understanding participants’ psychological world in terms of uncertainty and thought more suitable than thematic analysis. IPA is concerned with in depth explorations of individuals’ subjective experience on a given phenomena, how they make sense of it and what meaning they attach to it (Smith & Osborn, 2008; Willing, 2009). IPA has its roots in phenomenology which is concerned with how things appear to us as perceivers, setting aside or bracketing, that which we (think) we already know about them (Smith & Osborn, 2008). IPA can be contrasted with other qualitative approaches that are relatively theoretical, such as thematic analysis. On the one hand IPA focuses on understanding subjective meaning of a given phenomena instead of aiming to objectify it (Smith & Osborn, 2008), on the other hand IPA acknowledges that total access to someone else’s subjective experience is not possible. The interpretative role of the researcher is acknowledged as the analysis is very much dependent on the researcher’s pre-existing beliefs and expectations. In other words, when a researcher attempts to access a participant’s internal world through IPA, inevitably the researcher’s own characteristics, relationship with the participant and his/her own internal world will influence the interpretation (Willing, 2009). Thematic analysis as the name implies aims to identify themes in the data by organizing and describing the data (Braun & Clarke, 2006). The essence of IPA lies in understanding a persons’ lived experience. In other words, how people themselves make sense of a given phenomenon and what meanings they attach to it.

A number of steps were in place from the beginning to the end of the analysis that were consistent with an IPA framework. Questions that made up the topic guide involved open ended neutral questions that broadly asked participants about their experiences of uncertainty with little prompting. When running all focus groups the facilitator took notes on group dynamics, including non verbal behaviours, group atmosphere, silences, tone of discussions and language used. A separate section has been included commenting on moderator and facilitators’ background and the possible effect of this on the group and interpretation of the data, capturing the interpretative aspect of IPA, that is how our own experiences and values could influence the interpretations we give. In terms of the analysis process, transcripts were read a few times by the author to familiarise herself with the data, themes on a subordinate and super
ordinate level were identified, looking at what the experience of uncertainty means to participants exploring the function of statements made by participants to understand in depth their experiences. Finally, shared themes between groups and differences were identified. At different stages of the analysis process, themes were checked that they related with the data.

4.5.8 IPA and focus group design

Although IPA was not initially designed for focus group research, studies are accumulating that have successfully applied IPA within a focus group framework (Dunne & Quayle, 2001; Flowers, Knussen, & Duncan, 2001; Jordan, Eccleston, & Osborn, 2007; Palmer, et al., 2010) and IPA is increasingly being recognition as a suitable method for analysing focus group research (Palmer et al., 2010). Initial concerns regarding the pairing up of focus groups and IPA (Tomkins & Eatough, 2010), involved concerns about the loss of accessing personal experiences at the expense of the whole group (Smith, 2004). In fact recent research has found that when examining a naturally occurring group of carers experiences of mental health services, participants seemed to engage with discussions and disclose personal experiences not despite the group setting but because of being within a group (Palmer, et al., 2010). The authors conclude that there are clear positive effects, such as encouraging engagement, when working with pre-existing groups (Palmer, et al., 2010).

4.6 Data Storage

The recordings of the focus groups along with the transcripts, focus group schedule and notes of the analysis process are stored at the Institute of Psychiatry, Kings College London and are available for external review.

4.7 The analysis process

Focus group recordings were transcribed verbatim by the moderator and cross-checked by another researcher involved in the research project and the analysis process. What followed was a bottom up process of analysis guided by recommendations made by Smith and Osborn (2008). For each of the three transcripts the following stages of analysis occurred.

- In the first stage, both the moderator and the facilitator independently read the transcripts a few times to familiarise themselves with the data, noting down initial impressions.

- In the second stage, the first line of coding occurred, whereby both moderator and facilitator independently read the transcript noting down themes on the left hand side of the margin for each sentence on a descriptive level mostly paraphrasing what participants said.
In the third stage, transcripts were read again and this time on the right hand side of the margin more interpretative themes were written down, on a more psychological level. These were then listed on a piece of paper. These second level themes were then clustered together in different subordinate themes and illustrated in boxes. Researchers then went back to the transcript to cross check the validity of these sub-ordinate themes.

In the fourth stage of the analysis links were made between sub-ordinate themes which were clustered together accordingly into super ordinate themes. This was illustrated by a set of boxes which contained subordinate themes inside and were titled accordingly with a super-ordinate theme.

In the final fifth stage sub-ordinate and super-ordinate themes for all three groups were looked at together by both researchers identifying overlaps across themes and differences. An overarching consensus was made between the two researchers on subordinate and super-ordinate themes that run across all three groups. Notes were made of differences across the three groups regarding both sub-ordinate and super-ordinate themes. Finally, quotes were selected that best described each theme subordinate and super-ordinate theme.

At each stage of the analysis, both moderator and facilitator met and discussed how they had coded the transcripts. Any differences were discussed and a joint decision of what themes to keep was made. Analyses were also reviewed by a third researcher who was part of the research project and familiar with the data.

4.8 Initial reflections

Prior to any analysis initial moderator reactions were recorded. Moderators were quite impressed by the reflective ability of the adolescents to discuss the topic of uncertainty. Overall, all three focus groups generated interesting discussions and ran smoothly. Participants were able to discuss uncertainty both on a more abstract but also personal level, giving examples of their own experiences, usually associated with their illness.

From the present results and experience in running the focus groups, young people came across as able to express personal feelings in relation to uncertainty in different contexts. The fact that participants previously knew each other could have contributed to this and seemed to have worked for the best providing what came across as a safe environment for participants to talk about their experiences. The young age of adolescents did not seem to restrict their ability to express themselves. However, the choice of language was less complex than that of adults.

4.9 Group dynamics

Group dynamics were monitored in each group. The moderator ensured in each group that when a question was asked every adolescent was given the opportunity to share their thoughts. Of note, in FG1 everyone contributed equally in discussions. Furthermore, a friendly atmosphere dominated the group,
with young people referring to each other by their first names either agreeing or disagreeing with one another. In FG2 the dynamics were perceived as slightly different, whereby one female participant clearly dominated group discussions and another female participant contributed very little to the discussions even when encouraged to share her views. In FG3 contributions by each participant were overall equally distributed.

4.10 Results

Five super-ordinate themes were identified across all three focus groups, with a number of sub-ordinate themes for each. See Table 4.2 for an overview of the super-ordinate and sub-ordinate themes indicating which sub-ordinate themes were present in each focus group. Each theme is described below and illustrated with the most relevant quotes from participants.

Table 4.2 Super-ordinate and subordinate themes across all three focus groups

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Subordinate themes</th>
<th>FG1</th>
<th>FG2</th>
<th>FG3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Experiences of Uncertainty</td>
<td>1.1. Negative experiences of uncertainty</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>1.2. Positive experiences of uncertainty</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>1.3. Uncertainty experienced by everyone</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>1.4. Cognitive bias and uncertainty</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>2. Responses to Uncertainty</td>
<td>2.1. Negative responses to uncertainty</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>2.2. Positive responses to uncertainty</td>
<td>√</td>
<td>√</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>2.3. Before and after experiences of uncertainty</td>
<td>√</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>3. Anorexia and Uncertainty</td>
<td>3.1. Function of anorexia nervosa</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>3.2. Uncertainty and presence of anorexia nervosa</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>3.3. Uncertainty and recovery</td>
<td>√</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>4. Control</td>
<td>4.1. Need for control</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>4.2. Total control is unfeasible</td>
<td>√</td>
<td>√</td>
<td>√</td>
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<tr>
<td></td>
<td>4.3. Change and control</td>
<td>√</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>5. Coping with Uncertainty</td>
<td>5.1. Effective coping</td>
<td>√</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>5.2. Maladaptive coping</td>
<td>√</td>
<td>V</td>
<td>√</td>
</tr>
</tbody>
</table>

Note: √ = present in the group; X = not present in the group
1. Experiences of uncertainty

Overall, participants could easily identify situations in their lives that were uncertain both in the context of the illness and outside.

1.1 Negative experiences of uncertainty

Uncertainty was predominantly experienced as something negative, not a pleasant experience across all three groups. This was expressed in a number of ways. Explicitly stating that uncertainty is not nice and uncertain situations are distressing. Examples were given that were both related and unrelated to the eating disorder. Some participants in FG2 found the more serious situations to cause the most uncertainty and distress, while for others it was small situations that they weren’t sure about that seemed more troubling.

“...well uncertainty kind of scares me ...” (FG1, P4, 82).

“I get much less anxious about big situations. When it is like tiny situations like yeah like choosing what shoes...tiny little things that you are not sure about, I find them much more anxiety provoking than the big ones” (FG2, P7, lines: 24-27).

“The bigger the decision can impact your life the bigger the worry it’s going to be... But also at the same time when food is concerned is just as big...” (FG2, P8, Lines: 124-125).

“I think I’ve found uncertainty quite hard and stuff...” (FG3, P12, 334-335).

“... around your weight and stuff that is always uncertain and then like mood changes and the way that I feel is uncertain, I don’t know how I am going to feel from day-to-day and what my thought processes are going to be like so that’s kind of uncertain...” (FG3, P11, lines: 21-24).

Participants further talked about “bad uncertainty” and “good uncertainty”. Bad uncertainty was distinguished from good uncertainty in that participants felt that something bad was going to happen.

"With the bad uncertainty it is like you feel there is a worst case scenario that could happen and you are always focussing on that, what’s the bad thing that can happen... “ (FG3, P13, lines 248-249).

Uncertainty was also more troubling when it was related to oneself. In other words, it was expressed that uncertainty was a negative experience when directly influencing oneself versus an external event that was not threatening one’s self-esteem.

“ I think that also when it is more affecting you, like ... something that is going to happen ... in a football match... is much less anxiety provoking than when you are uncertain about what others think of you... “ (FG2, P7, lines: 41-44).
“what is going to happen in the holiday or what you are going to learn at school or like the football match, or lottery that can be really exciting but when it is affecting how you think people view you like with the marks or meeting people or like what you are going to wear, all that kind of stuff, is much more difficult to cope with” (FG2, P7, lines: 296-300).

1.2. Positive experiences of uncertainty

Even though uncertainty was predominantly experienced as a negative experience, participants could identify that there were good sides to uncertainty as well. Particularly P1 from FG1 talked about the exciting and fun side of uncertainty. It was also suggested that if there wasn’t any uncertainty in life you would not benefit from not knowing when something bad was going to happen and uncertainty could help you keep an open mind. Some participants although they did not themselves describe uncertainty as a pleasant experience they could acknowledge the potential positive aspects of uncertainty and expressed a yearning to be able to like uncertainty more.

“...well I really like uncertainty and I’ve just moved school and yeah I just... it’s quite fun for me” (FG1, P1, line: 14-15).

“I think uncertain things are always going to happen in life and I think it is good that uncertain things happen in life... but the thing is the hard thing is trying to grasp the fact that not everything is in your hands and grasp the fact that you can’t really plan everything because you don’t actually know what is actually going to happen...” (FG1, P3, Lines 402-406).

“Like when I am uncertain... I always think to myself why can’t I just let things be... so when I feel uncertain I just sometimes feel a bit like why can’t I just let it go but it’s hard to sort of let go and let things happen” (FG1, P3, lines: 153-158).

“Life is full of uncertain things and like if you just plan life it will be a bit boring...” (FG1, P1, lines: 162-163)

“If there wasn’t any uncertainty and you knew what was going to happen there would be bad bits along the way ... you wouldn’t want to know about them! That is a good part” (FG2, P8, lines: 310-312).

“I think it has also to do with being open minded... if you just sort of sit back and sort of discuss what could be your options and stuff and not panic about it ...” (FG2, P9, lines: 333-336).

“I think that the good uncertainty... it can keep you with an open mind, coz if you are going somewhere and you are uncertain about what is going to happen there, then you can’t decide that it is going to be bad, so it’s not making it worse than it is” (FG3, P12, lines: 271-274).

Good uncertainty was further conceptualised by some participants as knowing that the outcome would likely be good and one would benefit from it. Lastly, good uncertainty was defined by being instigated by yourself rather than by someone else, as that meant you had a measure of control over the situation.
“...uncertainty can be good but it’s primarily when you kind of instigates it yourself...it’s like OK to not be certain about something when it is you who has kind of changed it because that way you still have a measure of control over it...” (FG1, P4, lines: 440-444).

“...when it is good uncertainty it’s like you know that something good is going to happen, and it is not going to result in something bad, it is going result in you benefiting in some way, and so that is what makes it good, coz you don’t know what it is going to be, but you know that it is going to be good...” (FG3, P13, lines: 250-253).

1.3. Uncertainty experienced by everyone
There was a unanimous voice across groups that uncertainty is ubiquitous in the population. Uncertainty was acknowledged as an essential part of life, experienced across the life span although not thought about much when young.

“I think it’s inevitable that everyone experiences uncertainty at some point, it just depends on the degree and how people cope with it as to how it affects them” (FG1, P4, lines: 438-440).

“I think everyone experiences it (uncertainty) and even from like young children to adults...” (FG3, P13, line: 257).

Even though a number of participants mentioned that everyone experiences uncertainty only when you reach adolescence you think about it.

“...when I was younger, I’d never really thought about uncertainty...” (FG3, P11, line: 459).

“When you go through adolescence you kind of think more about these things...” (FG2, P7, line: 463)

1.4. Cognitive bias and uncertainty
Across all three groups there was strong consensus that when confronted with uncertainty the first expectation generally is for something negative to happen. Participants referred to this as “‘worst case scenario”. This was believed to be due to past life events which have shaped one’s personality and one’s responses to uncertainty. Furthermore, the worst case scenario event seemed particularly relevant in relation to participants’ body weight. This sub-ordinate theme links to what was previously mentioned about the experience of “bad uncertainty” and the theme of control which will be discussed further on in this thesis.

“...you are just so fixated on all of the bad possibilities that you kind of lose your mind to what could possibly be really helpful...” (FG1, P2, lines: 197-199).

“but I think that yeah, I guess it is also events not so much the illness affects how you perceive uncertainty but like events in your life coz everyone has events in their life (FG2,P7, lines: 442).

“...in the case where it is your weight you should try and have an impact on it, it is like if it does come to the worse and I have lost weight, it’s like I have the impact that I can change that...”
because I am the one influencing my weight, because I am the one who has the problem, that if I want to overcome the anxiety, I should be the one that does my best to stop the worst from happening” (FG3, P13, 141-146).

“I don’t know a lot of my worst case scenarios are things like death, being alone and dying, things like that” (FG3, P11, lines: 108-109).

“I can’t think of anything else, I just think about what could happen and how bad it could be...” (FG3, P12, lines: 120-121).

2. Responses to Uncertainty

In the first theme we saw how participants discussed both negative and positive experiences of uncertainty, giving different examples and stressing how uncertainty is part of life that everyone experiences. It was also discussed under what conditions uncertainty was perceived as negative and when was it a pleasant experience. The theme of responses of uncertainty picks up on the more direct cognitive and emotional responses of participants when exposed to an uncertainty situation. When participants were prompted to discuss their initial feelings and thoughts when confronted with uncertainty they described strong negative reactions and to a much lesser extent positive reactions. Only P1 from FG1 talked about positive reactions to uncertainty, without any pre-conditions.

2.1. Negative responses

When prompted to talk about thoughts and feelings that arise when confronted with uncertainty all three groups expressed strong negative reactions towards uncertainty. These negative reactions were expressed both at a physical level (e.g., panic attacks) but also on a more cognitive level (e.g., increased worrying). One participant in fact talked about how anxiety was always present in the face of uncertainty up until the uncertain situation became certain. Negative reactions where understood in the context of a fear of a negative outcome happening when things are uncertain, which links to a previous sub-ordinate theme that was discussed earlier (see section 1.4. “cognitive bias and uncertainty”).

“... just like panic, just fear... quite overwhelming” (FG1, P5, lines: 302).

“Stress” (FG2, P8, line: 86).

“Mine’s more thoughts, worry” (FG2, P6, line: 93).

“...obsessive thoughts as well” (FG2, P7, line: 98).

“I get quite worked up I guess” (FG2, P8, line: 61).

“...but like with me it is like panic attacks, obviously there is still anxiety but just in a different form for me, and like when I get anxious I just go through all the possibilities and the I just get stressed...” (FG3, P11, line 78).
“I get anxious and get really stressed can’t concentrate or focus my mind on anything else” (FG3, P12, lines: 114-115).

“A lot of anxiety and a bit of fear that it could be our worst possibility...” (FG3, P12, line: 63).

“...like panic attacks...” (FG3, P11, line: 78).

“A lot of anxiety and a bit of fear that it could be your worst possibility” (FG3, P12, line: 63).

Negative responses to uncertainty also involved adopting certain safety behaviours that were thought to prevent a negative outcome from happening. This seemed to be stemming out of an initial cognitive bias of expecting a bad outcome when faced with uncertainty, which we have previously talked about under the super-ordinate theme of experiences of uncertainty (see section 1).

“Like I remember when my grandmother was in hospital I’d always sort of think if I don’t cross the road at that certain point or something, like something very bad would happen you know the kind of obsessive stuff...” (FG2, P7, lines: 98-101).

2.2. Positive responses

Although participants did acknowledge uncertainty to be important in life, with the potential for positive sides to it, only two participants across the three groups explicitly talked about having a positive response to uncertainty, however P7 in FG2 stressed that she can experience uncertainty as positive only when it was not directly impacting on herself.

“I get the sort of like quite excited feeling in my stomach when something different happens...” (FG1, P1, lines: 234-235).

“I quite like it at times it gives you an adrenaline boost at times and you don’t know what is going to happen at a party and you get all excited there is a good point to it too, it’s just when it’s like how people view you I think that is really like bad...” (FG2, P7, line: 289).

2.3. Before and after experiences of uncertainty

In both FG1 and FG3 participants expressed a difference in feelings prior to the uncertain situation occurring and afterwards. Participants indicated that the negative reactions mentioned in section 2.1. such as heightened levels of anxiety and worry were present when anticipating the uncertain situation but once the uncertain situation was over there was relief and reduction of anxiety.

“...that’s the thing after the uncertain thing happens... you feel a whole lot better...and kind of... well I feel better...and I kind of feel better than I did before uncertainty” (FG1, P3 lines: 224-226).

“...my anxiety went up even more and then went down...” (FG3, P11, lines: 167-169).

3. Anorexia nervosa and uncertainty
A close link between the anorexia nervosa and uncertainty was captured by this third theme. Eating related symptoms were not only mentioned as examples of uncertain situations but specific patterns of the relationship between uncertainty and anorexia nervosa were discussed. These included, a function of the illness as a way of dealing with uncertainty, uncertainty being more prominent with the presence of the illness and uncertainty being very much present when it come to recovery. Overall, uncertainty was an integral part of the anorexia nervosa.

3.1. Function of anorexia nervosa
All three groups discussed anorexia nervosa as a function of reducing uncertainty, anxiety and increasing control. This mainly was conceptualised due to the perception of control. The illness was thought to allow a better management of anxiety, as well as, a sense of safety and security.

“I think it is a part of anorexia that is so into the controlling, if one of the things that I think sort of you get anorexia is from sort of not being in control of your life and you want something to be able, you are able to control, and food is one of those aspects” (FG1, P1, lines: 464-468).

“... and I think ... like the illness tries to hold on to a lot of control around that and that is when you end up getting stuck when you are having the same thing every day and you are calculating calories exactly... everything... erm,... but I think it’s really difficult to try and let go of that when you are faced with that sort of uncertainty it’s the hardest thing” (FG1, P5, lines: 290-297).

“... I felt more safe and secure like you said you can kind of you feel more in control and not eating made it easier coz I wasn’t as anxious” (FG3, P12, lines: 390-392).

3.2. Uncertainty and presence of anorexia nervosa
Differences in one’s experiences of uncertainty prior and after the onset of the illness were discussed in all groups but most prominently in FG3. For instance, many participants strongly expressed how anorexia nervosa amplified and maintained one’s original dislike towards uncertainty.

“sometimes you have like a predisposition to get things like anorexia just because of your personality or what you are like but then increases it (uncertainty) to a whole new level, and just takes it to the kind of extreme so though you may already have had a difficulty with facing change and things, it just magnifies it and makes it worse” (FG1, P2, lines: 487-491).

“I think now it (uncertainty) is worse, now with the illness” (FG2, P8, line: 408).

“I’ve always had uncertainty like before I had the eating disorder....” (FG3, P11, line: 320).

“ I think I have always been quite of an anxious person...now coming here and stuff is so much uncertainty that has definitely gone bigger since I have had problems”(FG3, P12, lines: 334-336).

“I can’t remember when I haven’t experienced uncertainty...” (FG3, P13, line: 292).
“I’ve always had uncertainty, like before I had the eating disorder.... But I think you know the eating disorder has just really highlighted how much uncertainty was in my life... but I don’t think it has changed I just think it has highlighted it more...” (FG3, P11, lines: 320-325).

3.3. Uncertainty and recovery

FG1 and FG3 expressed a lot of uncertainty in relation to treatment and the recovery process, particularly linked to one’s own reaction to treatment and recovery, what kind of feelings will arise and how they will respond to them.

“I think the thing I’m most like uncertain about is when am I going to be in normal weight... that’s the kind of ... like when, like I just don’t know when it will happen, ...I don’t know how I will feel about it when it does...” (FG1, P3, line: 71-74).

“I think another example of uncertainty is where are you going to be in like two years time will you still be here or will you be trying to get on with your life...yea so that is just a big uncertainty for me what is going to happen, in the future” (FG3, P13, lines: 29-32).

“...you would come here and you would be weighed and it was like that is the biggest part of the uncertainty and then the comments you get, is it bad is it good, and from day to day you are like uncertain whether you are going to get ill or not, whether that is going to affect your weight when you come back...The whole every day what’s uncertain what it is going to come next is it going to be bad, if worst come to worst what is going to happen to me...will I still be in treatment?...”  (FG3, P13, lines: 305-311).

Some participants also discussed the challenges of getting better and facing uncertainty when one is in a difficult place.

“...I think the biggest thing for all of us....probably when you are in hospital and you are facing uncertainty and you don’t know what the food is, what is in it, who has prepared it... and I think ... like the illness tries to hold on to a lot of control around that and that is when you end up getting stuck when you are having the same thing every day and you are calculating calories exactly... everything... but I think it’s really difficult to try and let go of that when you are faced with that sort of uncertainty it’s the hardest thing” (FG1: P5 lines: 290-297).

“Coz there would be a time when I would not be able to make any decision for myself because I was just so absorbed in it (the illness), whereas now being in a better place you can take a moment and say ‘hang on there is a bigger picture here, you know life goes on’, but it takes a lot of time to get to that place and it is not necessarily easy to just change” (FG1, P2, lines: 374-378).

4. Control

Control was a prominent theme across all three groups discussed in different ways by participants. In particular a strong need for control was expressed in the presence of uncertainty and change in FG1. Despite the need for complete control over situations it was acknowledged that that would be unfeasible.
4.1. Need for control
A need for control was a prominent topic in FG1, but also discussed in FG2 and FG3. Two different aspects of need for control were identified. Firstly participants indicated needing to control one’s weight, and wanting to be certain about other peoples’ judgements. This included wanting to control how others perceive oneself and being able to prevent a negative outcome. Again this seems linked to the worst case scenario theme mentioned in section 2.1. Secondly, participants expressed a strong need to be in the know regarding all aspects of their life. For example, needing to know what will happen in the future and what other people think of them. What seems to increase participants’ stress is the combination of high uncertainty related to others’ thoughts, and the perceived low control over a situation.

“I don’t know like what teachers are going to do what pupils are going to say how everything is going to pan out…” (FG1, P2, line: 61-63).

“I like to kind of be in control of what I do” (FG1; P2, line: 44).

“I always need to have kind of a plan…” (FG1, P4, lines: 82-83).

“I have this compulsive urge to kind of know, kind of everything and if it doesn’t work your way then it’s quite distressing if you’ve gone to the trouble of like planning it” (FG1, P2, lines: 116-119).

“I’m very anxious of what everyone else is thinking about” (FG2 P6, line: 184).

“Like today when I was here with my dad I had thoughts what is going to happen and everything” (FG2, P6 line: 202-203).


4.2. Change and control
This sub-ordinate theme was present only in FG1 and covers participants’ expression of distress when confronted with change, such as change of plans/change of school. Change appeared to be an unsettling situation whereby participants’ need to know and need for control increased dramatically. When change was perceived as inevitable, participants felt it more preferable to instigate it themselves, rather than wait and see what happens. However although this was the case for all four participants in FG1, one participant did not reveal a need to know what will happen. This is the same participant who talked about having positive experiences when it came down to uncertainty.

“…I tend to kind of get quite upset when situations present themselves to me that I had not expected... sometimes it is kind of worse when somebody tries to kind of make it how it was because it’s already been changed and situations have already happened and ... I tend to get quite angry with whoever has kind of instigated the change…” (FG1, P4, lines 279-289)
“I like not knowing what is going to happen next, I don’t like to have a plan in life (FG1, P1, lines: 19-20).

“like if something like did change, I’d prefer it if like if like on the spur of the moment it was me doing the change not like someone else telling me like this is the change you’re going to do it. It’s easy to suddenly say oh yeah I might go and do that now, or I might go and do that to make the decision yourself” (FG1, P3, lines: 315-319).

“…but it’s when someone else kind of springs it on you like you want to take control of your kind of life, and your own situation, whereas when somebody kind of springs on you, it’s kind of like the shock kind of throws you off a little bit...” (FG1, P2, lines: 324-327).

4.3. Total control is unfeasible
Participants in FG1 acknowledged that one can’t control everything and that certain things are out of one’s control. However, food and one’s weight seemed to be an exception as participants believed they could have absolute control over, and if controlled, can help prevent a bad outcome from happening.

“I think uncertain things are always going to happen in life and I think it’s good that uncertain things happen, but the thing is, the hard thing is trying to grasp the fact that not everything is in your hands and grasp the fact that you can’t really plan everything because you don’t actually know what is actually going to happen” (FG1, P3, lines: 402-408).

5. Coping with uncertainty
When participants were prompted to discuss how they dealt with uncertainty that was distressing some strategies were mentioned that made such situations more manageable while other participants stressed how they did not know of any effective coping strategies and just did not manage well with uncertainty.

5.1. Effective coping
Participants were not able to think of many positive and helpful ways of coping with uncertainty but did mention that being around people, friends and family was helpful. Accepting the situation and getting on with it was also mentioned.

“So, you just have to try and keep things balanced and keep everything kind of where it should be, and just remember that if it happens and you don’t like it, it’s only one day of your life that’s been like that there are going to be other days that are good. So, I think you just have to get on with it, because otherwise you are going to spend your whole life worrying, that’s no life really” (FG1, P2, 454-459).

“Keep yourself busy doing stuff...” (FG2, P8, lines: 348).

“I just have to be around people” (FG3, P11, Line: 197).

“If I have my family around me showing support and stuff, then I feel better.”(FG3, P12, lines: 211-212).
“Just try and just look past it when you are faced with it, it is like if the worst happens, it is not that is it your fault... in the case where it is your weight you should try and have an impact on it... if it does come to the worse and I have lost weight it’s like I have the impact that I can change that because I am the one influencing my weight ...” (FG3, P13, lines: 140-145).

“If it is something I can’t change, I just have to move past it but not like it, it’s hard to, you just have to try and get on with it.” (FG3, P13, lines: 150-151).

5.2. Maladaptive coping
Unhealthy strategies to manage uncertainty were also discussed by participants across the three groups. These involved avoidant behaviours, such as, blocking certain emotions and thoughts, as well as, trying to cope by increasing control in other areas of their life. Anorexia nervosa related behaviours were mentioned to ameliorate distress associated with uncertainty in the short term. This can be linked back to participants’ view of the function of anorexia nervosa earlier on in this paper (see section 3.1). Some participants expressed feeling unable to cope and did not know how they should cope with uncertainty.

“...coz I think you can end up having quite negative coping strategies that don’t actually deal with it, they just steer it on to something else, like to deal with the uncertainty to try and get control in other areas or something” (FG1, P5, lines: 418-421).

“I don’t think I cope very well, don’t know how to or what ways...” (FG2, P8, line: 210).

“I don’t know it would never go away until I knew what was going to happen in an uncertain situation, uncertainty until I was sure what is going to happen it won’t go away” (FG3, P11, line 157-159).

4.11 Discussion
4.11.1 Summary of results
Five super-ordinate themes were identified including experiences of uncertainty, responses to uncertainty, anorexia nervosa and uncertainty, control and coping with uncertainty. Overall, participants acknowledged uncertainty as a relevant concept in their lives and were able to identify a number of uncertain situations. Most of these were illness related, as one might expect given the centrality of anorexia nervosa in their lives. Uncertainty was predominantly experienced as something bad and scary, evoking a number of negative responses such as increased anxiety, worry and stress. Participants often mentioned anxiety and worry when thinking of feelings and thoughts linked to uncertainty.

Situations that involved some element of change, and so some level of uncertainty, were also mentioned as frustrating and sources of bad uncertainty. Knowing more about the change, and being in control of the change would allow for these situations to become less distressing according to participants. A heightened fear of being judged by others expressed by participants was also associated
with bad uncertainty. Participants placed great importance on how other people viewed them and thought of them, as this was perceived as a potential threat to oneself. The fear of threat to oneself and the uncertainty in terms of not being able to predict and control what others were thinking of them was experienced with a lot of frustration. Positive experiences and sides to uncertainty were also discussed by participants, but to a lesser extent than negative experiences. Only one participant across all three focus groups explicitly discussed how she enjoyed uncertainty. Otherwise, what was discussed and understood as ‘good uncertainty’ was usually when one knew that the outcome was going to be positive, when it did not have a direct impact on one’s self, or when the uncertain situation was instigated by oneself rather than someone else, having thus some level of control over the situation.

The theme on experiences of uncertainty that captures some patients more positive attitudes towards uncertainty and particularly the one patient who explicitly stated that she liked and enjoyed uncertainty highlights that not all patients with anorexia nervosa will necessarily show high levels of IU. As previously stated in the proposed model, Chapter 2, IU is one potential pathway that can play a role in the development of anorexia nervosa and its maintenance. Other factors and pathways will also have contributed to the emergence and maintenance of the eating disorder, as well as, certain protective factors may play a role. Section 2.2.2 in Chapter 2 also outlines developmental aspects of IU and how previous experiences, biological and psychological variables can influence whether one develops an aversion to uncertainty or not and to what degree.

One way of understanding these predominately negative responses to uncertainty is within the context of a cognitive bias towards expecting and fearing the worst case scenario from happening, which could be fuelled by high levels of IU. In other words, when there is uncertainty regarding how something is going to turn out and you are predisposed to fear uncertainty and expect that something bad will happen it is very likely that you will experience a number of negative reactions. Indeed IU is known to produce “what if” questions, which subsequently increase worry (Ladouceur, Gosselin, et al., 2000). Such a cognitive bias seen in the present findings also goes along with previous research that has found individuals with anorexia nervosa to have significantly elevated levels of negative future oriented thinking when compared to controls, with particular concern regarding their health and social situations (Godley, et al., 2001). Excessive worry has also been linked to an increased processing of threatening information (Verkuil, et al., 2009). This could be due to a malfunction to one’s safety and danger signals, which could also be the source of such a cognitive bias, in fact anxiety is thought to be the result of an over activation of danger cues and possible under activation of safety cues (Lohr, et al., 2007). Whether someone has a cognitive bias in expecting a negative outcome as opposed to a positive or neutral outcome was thought to be influenced by one’s personality, past life events but also of the stage of the illness the individual is in. In other words, IU may have state like properties as well as, trait in relation to anorexia nervosa.

Although a number of examples were given when thinking of uncertainty both related and unrelated to the illness, uncertainty was discussed in many ways being an integral part of the anorexia nervosa. For
instance, anorexia nervosa was given the role of providing a sense of certainty and safety. This is consistent with previous findings, whereby patients with anorexia nervosa are known to place a positive function to their illness as providing them with security and control (Espindola, et al., 2009; Fox, Larkin, & Leung, 2011; Nordbø, et al., 2008; Schmidt, et al., 2006; Serpell, et al., 1999). Uncertainty was further perceived to be very much present in relation to recovery. Participants were plagued by concerns and fears of whether they will get better, what will happen to them, how will they feel if they start getting better and reach a healthier weight. Of particular interest, some participants believed that anorexia nervosa amplified uncertainty. However, it was not clear in what way it amplified it and why.

The present findings highlight the link between uncertainty and the need for control. The need for control was a prominent theme that emerged in a number of ways in relation to uncertainty and is in line with the long held notion of the importance of need for control in individuals with anorexia nervosa (Sassaroli et al., 2008; Schmidt & Treasure, 2006). Although, need for control and uncertainty have been theoretically linked, empirically this relationship has not been examined within the eating disorder field. Present findings show that one possible reason why uncertainty is troubling is because it is associated with an increased sense of lack of control and a need to restore this. The need for control could also be fuelled by a cognitive bias of fearing the worst case scenario which would lead to distress and fuel the need to control the situation.

When prompted to share their thoughts on ways of coping with uncertainty and accompanied distress, some adolescents talked about how in order to prevent a negative event from happening, when faced with an uncertain situation, they engaged in ritualistic compulsive behaviours, such as rehearsing all of the possible worst case scenarios. This is consistent with findings of increased levels of rigid personality traits, obsessionality and anxiety in this population reported in both adults and adolescents with anorexia nervosa (Cassidy, et al., 1999; Cassin & von Ranson, 2005; Schmidt, et al., 2006). Other participants mentioned how keeping busy and being around friends and families helped. The anorexia nervosa itself was also seen as a way of dealing with uncertainty in one’s life, in fact it was also mentioned that having a lot of uncertainty in one’s life and a lack of control was thought to have played a role in the development of the illness.

Present findings also support recent quantitative research that has found elevated levels of IU in both clinical and non clinical populations with eating disorder psychopathology (Frank et al., 2012; Konstantellou & Reynolds, 2010; Sternheim, et al., 2011). It is also of interest to compare the current findings with a study that used the same focus group schedule on uncertainty with adults with anorexia nervosa (Sternheim, Konstantellou, et al., 2011). Themes across the two studies shared many resemblances. For instance, in both studies there was a strong tendency for participants to experience uncertainty negatively and show strong negative reactions to it, as well as, express a need for control. Participants in both studies further placed great importance on how others viewed them and uncertainty was intertwined with their illness. Anorexia nervosa was seen across studies as a possible coping mechanisms for anxiety and uncertainty. Despite these evident resemblances in themes between
adults and adolescents a number interesting differences emerge when looking closer at the themes between the two studies. For example, in Sterheim’s and colleagues study one prominent theme was “identity” and the extent to which participants identified themselves with their illness. This was not present in adolescents, which could be because of a shorter duration of the illness compared to adults. A further difference involved the positive experiences of uncertainty and coping with uncertainty. Unlike adults, adolescents acknowledged more positives side to uncertainty and showed a maturity in thinking about ways to deal with uncertainty that was distressing. Adolescents were more flexible in their thinking, giving more hope and encouragement to let things go and move on with life. Furthermore, adolescents discussed the benefits of being less rigid and more able to see things from different perspectives. It is important to note that in Sterheim and colleagues study participants were either in an inpatient facility, day care centre or receiving out patient care, while in the present study adolescents were receiving only outpatient care. This means that duration of illness and severity varied across the studies and could have influenced discussions. Developmental issues however could also be held accountable for such differences. Overall, findings of study 2 suggest a possible role of IU as a maintaining factor in anorexia nervosa as part of a cognitive process underpinning the need for control but also perhaps the positive value attached by patients to anorexia nervosa (Serpell, et al., 1999; Schmidt, & Treasure, 2006). It is also possible that certain safety behaviours seen in individuals with anorexia nervosa could be functioning as a means to cope with high levels of IU, particularly for those individuals where there is a strong link with high levels of anxiety (Waller, 2008).

4.11.2 Group differences in themes

A number of issues need to be discussed when considering results between groups. Although there was strong congruence across groups on all the super-ordinate themes, a few differences were identified between groups on the sub-ordinate themes that are worth mentioning (see Table 2). For example, participants in FG1 did not talk about uncertainty in relation to different stages of the illness (3.2). In FG2 there was no discussion about differences in experiences before and after an uncertain event nor did they talk about uncertainty in relation to the recovery process. Change (4.2) was a prominent theme in FG1 but not in FG2 or FG3. Finally, FG2 and FG3 failed to bring up any positive responses towards uncertainty or any positive ways of coping with uncertainty. FG1 and FG3 straight away could think of examples regarding uncertainty, while FG2 there was a need to clarify a bit what was meant with uncertainty. It is unclear whether these differences are a reflection of the differences in participant characteristics or a chance variation due to the dynamic of the evolving conversation in each group.

4.11.3 Moderator and facilitator influences

All groups were run by the same moderator who had previous experience in running focus groups in clinical settings and was familiar with the focus group schedule. Having the same moderator run all three groups was further thought to reduce the impact of possible moderator factors on participants’ responses. In other words all participants in each group were exposed to the same people running the groups and thus subject to similar influences. One such potential influence was the fact that the present
author had extensive knowledge on the area of eating disorders and IU. On the positive side, the moderator is engaged with the focus group schedule and the aims of the study on a possible more negative side this could have unconsciously directed participants to answer in certain ways that re-affirmed the present authors’ assumptions about how adolescents with anorexia nervosa may experience uncertainty. In order to control for this, the present author stuck to the focus group schedule and involve in the analysis process a second researcher. The fact that the current author is female in her mid 20s could also have influenced responses. This could have encouraged young people to open up, and possibly feel less of a power imbalance.

4.11.4 Strengths of study 2
The present study has a number of strengths. The focus group design was positively accepted by participants and was thought successful in allowing for in depth access to the subjective experiences of participants on the topic of uncertainty. The group setting was further thought to encourage discussions with participants bouncing off experiences from another. Further strengths include having a relatively good homogeneous sample of participants across groups, which is important when analysing a number of focus groups together (Palmer, et al., 2010). An additional question regarding participants’ experiences prior to the illness was added to the original focus group schedule used by Sternheim and colleagues (2011). This was thought of as a strength as it allowed to obtain a more global understanding of the experience of uncertainty and how the onset of the illness may have affected this.

4.11.5 Rigor in the results
Qualitative rigor is particularly important in order to establish confidence in findings. A number of steps were taken to establish rigor in the results, these included reaching credibility, transferability, and dependability (Thomas & Magilvy, 2011). Credibility was established through reflexivity which involves being aware of the potential conscious or unconscious biases brought forward by the researcher during the research and the analysis process and how this may have influenced findings. Both moderator and facilitator discussed thoroughly their initial reactions after the focus groups and how their own ideas and assumptions could have influenced the direction of discussions. Another way of reaching credibility is through triangulation, which refers to the use of one or more sources to reach credibility in the results. In the present study each major step of the analysis which was carried out by the moderator was further cross validated by the facilitator and supervised by a third researcher who was familiar with carrying out IPA within a focus group framework. This ensured that a number of levels of triangulation were reached. However, the results were not cross validated with participants themselves which did not enable to check whether the interpretations reached by researchers were accurately representing participants’ views. Due to practical reasons this did not take place and could be considered as a limitation of the study. The second criteria refer to the levels of transferability of results to other situations and participants (Thomas & Magilvy, 2011). Finally, dependency was achieved through describing each step of the analysis process with two fellow researchers and outlining in detail all the steps that were taken to set up and carry out the study. Repeating the study with a different sample is
also considered to increase dependency of findings (Thomas & Magilvy, 2011). Three focus groups were on uncertainty using similar samples with the same age range and clinical presentations. Overarching themes were identified across the three focus groups, which added to the dependency of findings.

4.11.6 Limitations of study 2

One limitation involved the absence of any background information on participant’s comorbid states of anxiety, prohibiting the possibility to see how responses may have been influenced by levels of anxiety. Furthermore, as with all small qualitative studies, caution needs to be taken regarding the transferability of the current findings. Finally, although after each group there was time set aside for participants to express off the record what they thought of the groups they took part in, no written feedback forms were given. This would have increased our knowledge of their experience being in a group discussing the topic of uncertainty and allowed for participants to freely express their views which may have been restricted when in front of others.
Chapter 5

A qualitative examination of IU in parents of adolescents with anorexia nervosa 
(Study 3)

5.1 Overview of chapter
The present chapter essentially follows on from study 2, Chapter 4 and reports results from a similar qualitative study but this time examining how parents of adolescents with anorexia nervosa experience and manage uncertainty in their lives.

5.2 Introduction
Taking into account the life threatening nature of the illness, its psychological and physical complications (Arcelus, et al., 2011; Harris & Barraclough, 1998), as discussed in Chapter 1, it is evident that great amounts of strain and demands will be placed on those caring for someone with anorexia nervosa. For instance, research shows that caring for someone with an eating disorder is associated with elevated levels of psychological distress, anxiety, depression and burden, which consists of care giving strains, overload, loss of self and a sense of captivity (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004; Kyriacou, Treasure, & Schmidt, 2008; Whitney & Eisler, 2005; Whitney, Haigh, Weinman, & Treasure, 2007; Zabala, Macdonald, & Treasure, 2009). Parents caring for adolescents with anorexia nervosa show higher levels of guilt, shame and distress than parents taking care of adolescents with psychosis (Treasure, et al., 2001) and caring for someone with anorexia nervosa can produce as much stress and emotional strain and burden on the family as caring for someone with a physical illness (Gilbert, et al., 2000; Sim, et al., 2009). Personal accounts of caring for someone with an eating disorder further reveal feelings of physical and psychological burden (Cottee-Lane, et al., 2004; Kamerling & Smith, 2010). There is also evidence that female carers experience more psychological distress, including anxiety and depression, compared to male carers (Kyriacou, et al., 2008). Family relationships are very likely to be affected by the presence of anorexia nervosa and can take different forms, either uniting the family or dividing them (Hilleg, Beale, & McMaster, 2006). Support for this alternative pathway comes from a longitudinal study that found a direct effect of the ill person on the relationship between mother and daughter, while support for the reverse pathway was not found (Archibald, Linver, Graber, & Brooks-Gunn, 2002). Furthermore, parents copying abilities are likely to be diminished due to experiencing high levels of emotional burden and lack of appropriate support from friends and health professionals, as well as, financial strains (Hilleg et al. 2006).

Unfortunately, quite often carers of those with anorexia nervosa all too easily can feel that they are blamed for their child’s illness and their distress gets neglected, with little practical and emotional support available for them (Haigh & Treasure, 2003). There is thus a need for much greater understanding of factors contributing to carer distress. A number of factors that have been identified
include the level of dependency of the individual with the eating disorder, the stigma associated with the illness, the lack of sufficient information concerning anorexia nervosa and treatment, as well as, inadequate support from friends and family (Whitney, et al., 2007). Finally, carers’ personal views and interpretations of the illness play a key role in determining their own reactions and coping strategies (Treasure, Gavan, Todd, & Schmidt, 2003). One unexamined factor in carers of those with an eating disorder is IU. At present IU has exclusively been researched in clinical and non-clinical populations with different forms of psychopathology, as opposed to populations caring for someone with a psychological disorder.

A small amount of research has looked at the concept of illness uncertainty in parents, based on Mishel’s model of perceived illness uncertainty (Mishel, 1983), which refers to elevated levels of uncertainty and stress in parents regarding their child’s illness and course of treatment. According to Mishel’s model, uncertainty plays a prominent role in how parents perceive and manage their child’s illness. The model proposes that the more parents experience ambiguity, lack of clarity, lack of information, and unpredictability concerning their offspring’s illness and treatment outcome, the greater their distress (Mishel, 1983). In fact parental distress that results from uncertainty when caring for a child with a serious illness has been found to resemble post-traumatic stress disorder symptoms, such as avoidance and hyper vigilance when having experienced a traumatic event (Santacroce, 2003). A number of studies have also found that reducing uncertainty for parents results in reduced levels of distress. For instance, reducing uncertainty for parents with a newly diagnosed child with diabetes was found to significantly decrease levels of distress in both mothers and fathers when compared to treatment as usual (Hoff, et al., 2005). Helping parents manage uncertainty when their child is returning home after intensive care has also been found helpful (Mitchell & Courtney, 2004; Mitchell, Courtney, & Coye, 2003).

5.3 Aim of study 3
The aim of the present study was to examine how parents of adolescents with an eating disorder experience and manage uncertainty.

5.4 Ethical considerations
The research project was reviewed and granted ethical approval by the Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee. The study reported in Chapter 4 and the study in the present chapter, were presented as one research project to the above research ethics committee. The same ethical issues apply for the present reported study. Please see Chapter 4 (under section 4.4 Ethical considerations) for details.
5.5. Method
The methodology for the present study reported in this chapter mirrors the one described in Chapter 4. In order to avoid any unnecessary repetitions only information that is specific to the methodology of the present study is described in the following sections.

5.5.1 Participants and recruitment (N = 17)
Clinicians initially screened parents taking part in three consecutive Multi Family Therapy (MFT) groups for anorexia nervosa (Dare & Eisler, 2000; Eisler, Lock, & le Grange, 2010) at the Child and Adolescent Eating Disorders Service at the South London and Maudsley NHS Foundation Trust in London. MFT runs for five full days followed by three follow-ups. The groups of parents that were screened were at the point of taking part in their second follow-up. The inclusion criteria consisted of:

1. Having a 12-18 year old adolescent with a diagnosis of anorexia nervosa or Eating Disorders Not Otherwise Specified, Restrictive Type (EDNOS; DSM-IV or ICD-10).

Information sheets (see Appendix 9) were handed out by the present author to parents and time was allocated for any questions to be answered. All 17 parents part of the three consecutive MFT groups that were present for the follow ups were invited to take part in the study and all consented and were recruited into the study. Nine of which were mothers and 8 fathers from a predominately White British background. See Table 5.2 for demographic characteristics of parents in each of the focus groups, while Table 5.3 shows basic demographic information of adolescents that parents in each focus group were caring for. Of note, the parents that took part in the present study are those of the adolescents that took part in the focus groups reported in Chapter 4. That is FG1 (mothers group) and FG2 (fathers group) were the parents of the first focus group with adolescents. FG3 (fathers group) and FG4 (mothers groups) were the parents of adolescents in the second focus group with adolescents. Finally, FG5 were the mothers of the third focus groups with adolescents. Fathers of the three adolescents that made up the third focus group were not present for the follow-ups and thus not available to be approached and recruited into the study. Altogether there were six families were the young person (three from YP-FG1 and three from YP-FG2), the mum (three from M-FG1 & three from M-FG4) and the dad (three from F-FG2 & three from F-FG3) took part in separate FG groups. In three occasions only the young person (three from YP-FG3) and the mum (three from M-FG5) were present and for two young people (one in YP-FG1 and one in YP-FG2) neither of their parents were present and did not take part in any of the focus groups. Finally, two young people (one in YP-FG1 and one in YP-FG2) only had their dads take part (one in F-FG2 and one in F-FG3). Please see Table 5.1 for a detailed description of how parents match up with the young people in Chapter 4.
Table 5.1 Matching parent focus groups with young people focus groups

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<tr>
<th>YP Groups</th>
<th>Mother Groups</th>
<th>Father Groups</th>
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<tr>
<td>YP-FG1 (N =5)</td>
<td>M-FG1 (N=3)</td>
<td>F-FG2 (N=4)</td>
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<tr>
<td>YP-FG2 (N =5)</td>
<td>M-FG4 (N=3)</td>
<td>F-FG3 (N=4)</td>
</tr>
<tr>
<td>YP-FG3 (N =3)</td>
<td>M-FG5 (N=3)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

All parents gave written consent to take part in the study (see Appendix 10 for the consent forms).

Table 5.2 Demographic characteristics of parents

<table>
<thead>
<tr>
<th>ID</th>
<th>Group</th>
<th>Age</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>FG1 (mothers)</td>
<td>47</td>
<td>White/British</td>
</tr>
<tr>
<td>P2</td>
<td>FG1 (mothers)</td>
<td>53</td>
<td>White/British</td>
</tr>
<tr>
<td>P3</td>
<td>FG1 (mothers)</td>
<td>42</td>
<td>White/British</td>
</tr>
<tr>
<td>P4</td>
<td>FG2 (fathers)</td>
<td>43</td>
<td>White/British</td>
</tr>
<tr>
<td>P5</td>
<td>FG2 (fathers)</td>
<td>54</td>
<td>White/British</td>
</tr>
<tr>
<td>P6</td>
<td>FG2 (fathers)</td>
<td>48</td>
<td>White/British</td>
</tr>
<tr>
<td>P7</td>
<td>FG2 (fathers)</td>
<td>69</td>
<td>White/British</td>
</tr>
<tr>
<td>P8</td>
<td>FG3 (fathers)</td>
<td>53</td>
<td>White/British</td>
</tr>
<tr>
<td>P9</td>
<td>FG3 (fathers)</td>
<td>49</td>
<td>White/British</td>
</tr>
<tr>
<td>P10</td>
<td>FG3 (fathers)</td>
<td>45</td>
<td>Asian</td>
</tr>
<tr>
<td>P11</td>
<td>FG3 (fathers)</td>
<td>60</td>
<td>White/British</td>
</tr>
<tr>
<td>P12</td>
<td>FG4 (mothers)</td>
<td>45</td>
<td>White/British</td>
</tr>
<tr>
<td>P13</td>
<td>FG4 (mothers)</td>
<td>54</td>
<td>White/Other</td>
</tr>
<tr>
<td>P14</td>
<td>FG4 (mothers)</td>
<td>45</td>
<td>White/British</td>
</tr>
<tr>
<td>P15</td>
<td>FG5 (mothers)</td>
<td>48</td>
<td>White/British</td>
</tr>
<tr>
<td>P16</td>
<td>FG5 (mothers)</td>
<td>45</td>
<td>Mixed Race/White Caribbean</td>
</tr>
<tr>
<td>P17</td>
<td>FG5 (mothers)</td>
<td>49</td>
<td>White British</td>
</tr>
</tbody>
</table>

Note: FG1 & FG2 were mothers and fathers from the same families and the same was true of FG3 & FG4. While FG5 were mothers from a separate group.
Table 5. Demographic and clinical characteristics of adolescents parents were caring for

<table>
<thead>
<tr>
<th>Focus group</th>
<th>FG1</th>
<th>FG2</th>
<th>FG3</th>
<th>FG4</th>
<th>FG5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>AN-R</td>
<td>AN-R</td>
<td>AN-R (2); EDNOS-R (3)</td>
<td>AN-R (2); EDNOS-R (3)</td>
<td>AN-R (3)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>(N)</td>
<td>(5)</td>
<td>(5)</td>
<td>(3)</td>
<td>(3)</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>14.80 (1.78)</td>
<td>14.80 (1.78)</td>
<td>14.80 (1.78)</td>
<td>14.80 (1.78)</td>
<td>14.80 (1.78)</td>
</tr>
<tr>
<td>Illness Duration (months)</td>
<td>8-27</td>
<td>8-27</td>
<td>8-27</td>
<td>8-27</td>
<td>8-27</td>
</tr>
</tbody>
</table>

Note: N = Number of Participants; SD = standard deviation; AN-R = anorexia nervosa restrictive type, EDNOS-R = Eating Disorders Not Otherwise Specified Restrictive Type.

5.5.2 Design

For the purpose of the present study a focus group design was chosen as the most appropriate. To avoid any repetitions, for a description of focus groups please see Chapter 4 (under the section 4.5.2 Design). The topic of uncertainty was not considered too sensitive for parents to discuss and the fact that parents in each group already knew each other is thought to contribute to engagement in discussions (Palmer, et al., 2010).

5.5.3 Focus groups

Five focus groups on uncertainty were run. Having focus groups made up of only mothers or fathers was favoured for a number of reasons. Firstly, increasing homogeneity can help with the analysis and can add to the credibility of the findings. Secondly, having mothers and fathers in separate groups meant that partners caring for the same young person would not be in the same groups. This was important as it gave the opportunity for parents to disclose their thoughts and feelings on uncertainty, their life and their child, without being at all compromised by possibly thoughts of what their partner may say or think. Having mixed groups that included couples may have influenced how parents whose partner was not present contributed to the group and may have induced feelings of being excluded from the group. Finally, being able to examine any potential gender differences on themes also informed the decision to separate mothers and fathers.

In particular, three groups consisted of mothers (FG1, FG4 & FG5) and two groups consisted of fathers (FG2 & FG3). FG1 and FG2 consisted of mothers and fathers who were part of the same MFT (in other words fathers and mothers from the same families), similarly FG3 and FG4 consisted of fathers and mothers who were part of another MFT group that run at a different time to the previous one. FG5 was a group of mothers from a third MFT group. In this MFT group none of the fathers were able to attend on the day of the focus group. Having separate focus groups for mothers and fathers was done to
increase homogeneity and avoid possible confounding dynamics between members of the same family in one group.

5.5.5 Focus group schedule
The focus group schedule used for the present focus groups was the same as the one used in Chapter 4, with one difference a final question was added and tailored for parents, examining their experiences of uncertainty across different times in their lives that is before and after the onset of their child’s eating disorder. See Appendix 11 for the focus group schedule.

5.5.6 Moderator and facilitator: background information
Groups were run by the present author, who acted as the moderator, along with either a researcher or a clinician part of the research project, who acted either as the moderator or the facilitator. The same researchers who co-facilitated the three focus groups with the adolescents, seen in Chapter 4, also contributed in running most of the focus groups with parents. Due to running focus groups at parallel sessions as it was not convenient for parents to come at different times, researchers or clinicians part of the research also helped run focus groups, one of which was the present author’s first supervisor. The clinicians involved in the focus groups were also the ones running the MFT with extensive experience in running groups and familiar with the aims of the study. Ideally the same moderator and facilitator would have run all focus groups and not someone involved in treatment, however this was not practically possible as groups run in parallel.

5.5.7 Procedure
Parents met with the allocated moderator and facilitator in one of the rooms at the Maudsley Hospital. The moderator used the selected focus group schedule to stimulate discussion. Discussion was facilitated with both verbal (e.g., “OK”; “Can you tell me more about that”) and non-verbal cues (e.g., nodding), ensuring not to prime participants towards particular answers, following guidelines from Smith (1996). Appropriate time was left for each participant to have a chance to voice their opinions and experiences, whilst at the same time ensuring that all questions were raised for discussion (Smith, 1996). The second researcher made notes on non-verbal information and group dynamics. Once discussions ended and the researcher stopped the recorder the parents were given the chance to express how they experienced the groups.

5.6 Data Storage
The recordings of the focus groups along with the transcripts, focus group schedule and notes of the analysis process are stored at the Institute of Psychiatry, Kings College London and are available for external review.

5.7 Choice of analysis
Interpretative Phenomenological Analysis (IPA; Smith, 1996; Smith & Osborn, 2008) was chosen as the most appropriate method of analysis and in accordance with the aims of the study. To avoid any
repetitions please see Chapter 4 (under section 4.5.7/4.5.8) for a description of IPA and the rationale of analysing focus group data with IPA.

5.7.1 The analysis process

Once focus group recordings were transcribed verbatim by the present author and cross-checked by another researcher involved in the research project a bottom up process of analysis took place (Smith & Osborn, 2008). Essentially, the analysis process involved the same steps that were described in detail in chapter 4. Please see Chapter 4 (under section 4.7).

5.7.2 Initial reflections and group dynamics

Prior to any analysis initial reflections from the moderator and facilitator of the groups were noted. Overall, the environment across the five groups was experienced by those running the group as comfortable, warm and friendly. This positive and supportive atmosphere was likely to be due to the fact that the participants in each group already knew one another from the MFT group and had previous experience taking part in group activities. It may also be the case that parents were able to identify with each others’ experiences and the struggles they faced, which could have promoted bonding and understanding, particularly when discussing uncertainty in relation to their child’s illness. One reflection from one of the clinicians running one of the mothers groups was that it was difficult to get a more clear understanding of their experience of uncertainty in general as conversations would instinctively turn to their children, their children’s illness and the uncertainty that accompanied it.

5.8 Results

Seven super-ordinate themes and a number of sub-ordinate themes were identified across all five groups following IPA guidelines (Smith, 1996; Smith & Osborn, 2008). Both sub-ordinate and super-ordinate themes are presented below and illustrated with relevant quotes. See Table 5.4 for a summary of the presence and absence of each theme for each focus group.
### Table 5.4 Super-ordinate and sub-ordinate themes across all five groups

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Sub-ordinate themes</th>
<th>FG1</th>
<th>FG2</th>
<th>FG3</th>
<th>FG4</th>
<th>FG5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Anorexia nervosa and uncertainty</td>
<td>No sub-ordinate themes</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>2. Experiences of uncertainty and AN</td>
<td>2.1. Negative experiences of uncertainty</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>2.2. Positive experiences of uncertainty</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>3. Coping with uncertainty</td>
<td>3.1. Helpful coping</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>3.2. Difficulties in coping</td>
<td>√</td>
<td>X</td>
<td>√</td>
<td>√</td>
<td>X</td>
</tr>
<tr>
<td>4. Parents’ roles and abilities</td>
<td>No sub-ordinate themes</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>5. Parents’ needs</td>
<td>5.1. Need to take care of young person and understand the illness</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>5.2. Need for professional advice and guidance</td>
<td>√</td>
<td>√</td>
<td>X</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>5.3. Need for support and understanding</td>
<td>√</td>
<td>√</td>
<td>X</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>5.4. Need to resume normal life</td>
<td>√</td>
<td>X</td>
<td>X</td>
<td>√</td>
<td>X</td>
</tr>
<tr>
<td>6. Adolescents and uncertainty</td>
<td>No sub-ordinate themes</td>
<td>√</td>
<td>X</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>7. Impact of uncertainty in a family context</td>
<td>7.1. Impact of anorexia nervosa and uncertainty on the family</td>
<td>X</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>7.2. Impact of uncertainty on family relationships</td>
<td>√</td>
<td>√</td>
<td>X</td>
<td>√</td>
<td>X</td>
</tr>
</tbody>
</table>

*Note: AN = Anorexia nervosa; √ = present in group; X = not present in group*

1. Anorexia nervosa and uncertainty

When parents were prompted to talk about uncertainty, discussion in the mothers’ groups (FG1, FG4, & FG5) quickly turned to uncertainty in relation to their child’s illness, while in the fathers’ groups (FG2 & FG3) discussions generally turned to uncertainty in relation to employment. Parents across all five groups stressed how much uncertainty was an integral part of the anorexia and that it was the source of intolerable amounts of uncertainty and distress. Anorexia nervosa was further perceived as a very serious illness with the threat of death, and thought different from physical illnesses, where you could follow a doctors’ prescription. Finally, the uncertain course of the illness and lack of clear guidance from previous experience of health care professionals also contributed to great amounts of distress. Adding to this uncertainty was the unpredictability of the young people themselves. In FG4 for instance, parents talked about how they were in constant doubt to what extent their child was driven by their illness or independent of it.
“...the most challenging thing is the uncertainty of the anorexia it’s so painful.” (FG1, P2 line: 44).

“...this anorexia has created a completely uncertain world where you just don’t know what next week is going to be like...” (FG2, P7, lines: 67-68).

“...this (illness) with (name of young person), is uncertainty I’ve never experienced before, I can’t be laid back about it, I panic about it whereas with my job it’s irrelevant but this is something very close to our hearts, totally different type of uncertainty.” (FG3, P8 lines: 130-133).

“...I am never sure, I’m never certain whether it’s (name of young person) talking or whether the anorexia talking...” (FG4, P13, lines: 191-192).

“...anorexia is so uncertain the recovery is so uncertain there is no guarantee that full recovery will take place...” (FG5, P16, lines: 21-22).

2. Experiences of uncertainty

Parents could identify both negative and positive situations in which they had experienced uncertainty.

2.1. Negative experiences of uncertainty

All parents across the groups were able to explicitly talk about negative experiences of uncertainty much more often than positive experiences. Some, negative experiences were mentioned related to their own lives, for example, employment but more often than not they discussed negative experiences in relation to their child’s illness. This type of uncertainty was one they had never experienced before and it was perceived as substantially different to uncertainty in everyday life, which was much more manageable. Some participants talked about the characteristics that made uncertainty negative, such as the threat of a worst case scenario happening, having little control over the situation and not knowing the outcome of an uncertain situation. When faced with this type of negative uncertainty, particularly in the context of their child’s illness, parents expressed strong negative reactions, on both a cognitive and emotional level, such as anxiety, frustration, fear, and despair.

“I think the unpleasantness (of uncertainty) is not feeling you have any control. I think one of the key things is no possible control but also what is the worst that can happen.” (FG3, P10, lines: 306-313).

“I would say out of all the uncertainties I had in my life, which have been a huge amount, this (uncertainty linked with AN) is probably the most severe...” (FG5, P15 lines: 409-412).

Moderator: how do you feel when you don’t know what will happen?
“Terrifying... it is fear a really strong kind of like gut fear I think its coz it is your child coz you would do anything...” (FG1, P2, lines: 129-130).

“Frustration” (FG3, P8 &10; lines: 182, 184).

“...more than sad actually complete utter black despair...” (FG4, P13, line: 286).
2.2. Positive experiences of uncertainty

A number of parents across all five groups described uncertainty as a positive and an essential part of life, without which life would be boring. Uncertainty, and more specifically tolerating uncertainty, was further seen as a positive character trait since it prepared one for life, which simply is unpredictable. Other parents discussed positive feelings that uncertainty evoked, such as enjoyment and excitement. It is important to note that the positive perceptions of uncertainty were never in the context of their child’s illness.

“...if everything was absolutely certain I think I would be really bored to death...So I think uncertainty can actually be very positive and energizing...” (FG1, P2, lines: 437-439).

“I find uncertainty quite liberating...” (FG2, P4, Line: 358).

“I think uncertainty is quite exciting not knowing what is going to happen...”(FG3, P10, lines: 258-259).

“I like a bit of uncertainty...” (FG4, P13, line: 492).

“It (tolerating uncertainty) is character building in the long term” (FG5, P15, line: 379).

3. Coping with Uncertainty

Parents discussed both helpful and unhelpful coping strategies when faced with uncertainty.

3.1. Helpful coping

When prompted to discuss how one copes with uncertainty, parents in all groups identified various strategies, including trying to gain control of the situation, looking at possible positive outcomes of the uncertain situation, or taking time out from the situation. In FG3 it was conceptualised that personality and social factors determined one’s resilience to uncertain situations.

“I suppose talking to other people helps...” (FG1, P1, line: 249).

“...I kind of hold on to certain things, I simply don’t worry about things a lot of people worry about...” (FG2, P11, lines: 82-85).

“...in a work situation how I tend to deal with uncertainty is what can I control, what can I not control, if I can’t control it how can I influence it... and how actually can I get what I need...” (FG3, P10, lines: 69-71).

“... time out is a very important thing...” (FG5, P17, line: 366).

3.2. Difficulties in coping
Parents in FG1, FG3, & FG4 discussed that they found coping with uncertainty difficult and how certain things were unhelpful. Furthermore, techniques that were thought useful in dealing with uncertainty in life in general were felt inappropriate for the uncertainty that related to their child’s illness.

“... and then you get more and more exhausted and less and less able to cope so it’s like a vicious cycle...” (FG1, P3, lines: 139-140).

“So its weighing up those risks somehow is far more difficult than my future job sort of thing, you are far more emotionally involved...” (FG3, P10, lines: 172-174).

Moderator: how do you manage the uncertainty?
“I don’t really I get in a panic...” (FG4, P14, line: 498).

4. Parents’ roles and abilities
This theme was prominent across all groups. Parents talked about how they felt under-skilled when faced with their child’s illness and the accompanied uncertainty was something they had never dealt with in the past. They expressed that their parental abilities were constantly under scrutiny, which they believed was more so than if their child would not have been ill. A number of parents discussed how the uncertainty associated with the anorexia nervosa negatively affected their confidence as parents, feeling often guilty, and their decision making skills. For instance, one dilemma they mentioned was whether as parents they should help their children to tolerate more uncertainty instead of protecting them from it. They further talked about feeling frustrated and that they couldn’t rely on things that worked in the past to guide their judgment and decisions in the present as their child’s responses were very unpredictable. Despite these criticisms and worries, a few parents did acknowledge that having such feelings was not helpful and that one needed to learn to allow oneself to make mistakes.

“I’ve always been quite a confident parent... so all of that kind of confidence that you have built up of your parenting kind of like completely gets scrapped and you suddenly become incredibly kind of well I don’t know what I am doing...” (FG1, P3, lines: 67-68; 71-73).

“I think uncertainty can be imprisoning, it makes you feel indecisive...” (FG2, P11, 332-333).

“...one of the most difficult things is the fact that it (anorexia nervosa) changes, you are constantly on shifting sand...” (FG2, P6, lines: 188-192).

“I think I have doubted my judgment when uncertain... particularly when it is to do with the illness...” (FG3, P10, lines: 155-156).

“...I think it is very scary, makes you very lonely... uncertainty takes away your confidence...” (FG4, P14, lines: 349-350).

“...you start thinking have I been an OK parent, our children are feeling judged and you feel judged... that uncertainty it is quite a hard place to be...” (FG5, P16, lines: 340-342).
5. Parents’ needs
A number of needs were discussed by most parents. These ranged from a need to understand their
children and their illness to a need for clear professional advice regarding the illness and treatment.
Parents also expressed a strong need to be supported and understood by their social environment.

5.1. Need to take care of adolescent and understand the illness
Parents in all five groups expressed that the most important thing in their lives was their children’s
health and to see them recovering. Everything else, such as holidays, their child’s education, and their
own needs, came second. Anorexia nervosa was experienced as a paradox and difficult coming into grips
with, resulting in a strong need to understand the nature of their child’s illness.

“I think its coz it is your child coz you would do anything, it is such a deep instinct to protect your
child...” (FG1, P2, lines: 129-130).

“... you want to say ‘this is how I understand the illness’ you know, why hasn’t someone told me
it has been around for a while...It has been very difficult to get used to the fact that this
probably can’t happen...” (FG2, P4, lines: 113-116).

“I mean I do find it quite difficult to understand the actual problem because it is just completely
alien to me. I can’t see how someone would not want to eat you know...” (FG3, P9, lines: 191-193).

“...all I want is for you (child) to be healthy enough to have a clear mind to make a clear
decision...” (FG4, P14, lines: 175-176).

“...I feel bad to think of my own needs...” (FG5, P16, line: 94).

5.2. Need for professional advice and guidance
This was particularly present in FG1 but also in FG2 and FG5. The course of their child’s illness and
treatment were plagued by great amounts of uncertainty which was reason for much frustration.
Parents expressed disappointment with the care and professional guidance that they had received in the
past and indicated a need for clear, concrete professional advice and treatment plans.

“I would just love for somebody to say to me ‘your daughter has anorexia, just do this, or give
her this pill and she will be fine’, that’d be fantastic...” (FG1, P2, lines: 398-340).

“...we had a lot of conflicting information...” (FG2, P4, line: 98).

“Consistency of opinions you don’t expect professionals to have all the answers but some
consistency...” (FG5, P16, lines: 37-38).

5.3. Need for social support and understanding
Parents in FG1, FG2 and FG5 expressed the need for more emotional support and understanding from
friends and family. Although friends and family were a source of comfort, parents felt that they were not
understood as much as they would have needed and that meeting other people going through a similar situation was considered helpful.

“I suppose talking to other people helps, coming into a forum like this helps where people can identify. I mean my friends in my ‘normal’ life don’t identify it is very hard to describe to people the illness who have not experienced it.” (FG1, P1, lines: 249-251).

“... very rewarding the fact that there is someone there to share it with someone you can sign off, someone who is on your side.” (FG2, P5, lines: 319-320).

“Yes I think you know having support if people understood a bit more would make a huge difference” (FG5, P15, lines: 335-336).

5.4. Need to resume normal life

A need for normality in one’s life was mentioned in FG1 and FG4. Amongst all the uncertainty, stress, concern and unpredictable nature of the anorexia holding on to something normal or doing something normal such as going on a holiday was something parents longed for and was thought of as having therapeutic abilities.

“So I do kind of quite like it when I do something normal” (FG1, P3, line: 279).

“I would really like to go back to my work and hoping that is sort of what I am going to do...” (FG4, P14, lines: 84-85).

6. Adolescents and uncertainty

Across FG1, FG3, FG4 and FG5, parents discussed that adolescents have a lot of uncertainty in their lives. They further talked about young people being distressed in the face of uncertainty and change, as well as, a having a strong need to know the future, need for structure and control. Anorexia nervosa was thought to function as a means of dealing with a fear of uncertainty and a lack of control. Some parents in FG1 expressed how this IU seen in their children was frustrating for them.

“... I think (name young person) gets quite frightened about change and uncertainty and she gets consumed in the fear and that is what I can’t bear I wish she could let a bit more in of uncertainty without getting so much frightened about it and I think she has to try to lock everything down in a sense and the eating in a way is to do with that...” (FG1, P3, lines: 378-383).

“I think (name young person) is very worried about uncertainty, she is worried about the future.” (FG3, P10, line: 512).

“I think she can’t let go of the anorexia because of the uncertainty that awaits her beyond anorexia, anorexia is something to do almost or certainly protecting her so there is a lot of uncertainty in her life at the moment...” (FG4, P12, lines: 16-19).
“Thinking about other things that have happened last week and the week before that sort of tipped her over the edge where all things that were quite uncertain...” (FG5, P15, lines: 175-177).

7. Impact of uncertainty in a family context
Parents discussed a number of ways in which anorexia-related uncertainty affected their family life and relationships.

7.1. Impact of anorexia nervosa and uncertainty on the family
Parents in all groups apart from FG1 identified a number of ways in which the presence of the anorexia nervosa, as well as the uncertainty associated with it, affected family life. For instance, the family as a whole was thought to have re-arranged itself in order to accommodate the presence of the illness. This included allowing space for things not to go according to plan, avoiding any uncertain situations and becoming very rigid as a family. Planning and taking decisions regarding the future became much more difficult than usual. Parents further talked about an overall disruption to family life and how they felt they were stuck in the present not being able to plan ahead or look into the future with hope.

“We all have the same illness in our families but we are getting dealt different set of cards.” (FG3, P5, line: 216-217).

“...like this summer holiday we have just haven’t planned anything, we can’t go away, can’t really do any of that...” (FG3, P10, lines: 210-211).

“...so basically you begin avoiding situations that have an uncertain outcome that is what we do so our lives become very very predictable and very very safe...” (FG4, P12, lines: 109-111).

“I kind of almost feel that I have surrendered myself to uncertainty, the days where nice happy family and how quickly it changed from that and since that time it has been very painful and nothing has been certain...” (FG5, P16, lines: 209-212).

7.2. Impact of the anorexia on family relationships
A number of relationship dynamics were discussed by parents in FG1, FG2 and FG4 as being disrupted due to the presence of the anorexia nervosa. For example, in FG4, one carer felt that her child was using her illness as a way to stay close to her. On the other hand parents talked how much they were at the mercy of their children. Overall, parents felt that they had to be constantly available for their children.

“...because they never seem to want it when you are offering it, it has to be at their beck and call to offer support at your time scale it doesn’t really work, they need to come to you when they need it....” (FG1, P1, lines: 240-242).

“...which particular hoop they are going to have you jumping through which particular week...” (FG2, P5, lines: 161-162).
“...you know she feels she has to be by my side and the way to do that is to be an anorexic you know and it’s so so draining...” (FG4, P14, lines: 97-98).

5.9 Discussion

5.9.1 Summary of results

Seven super-ordinate themes and 10 subordinate themes were identified following IPA. Overall, parents easily identified uncertain experiences in their lives. These were predominately in relation to their children and their illness but not exclusively. Employment and other life situations were mentioned when thinking of uncertainty but to a much lesser extent. While some parents expressed an intolerance and dislike towards uncertainty in all domains of life, others were intolerant only in the context of their child’s illness. One of the strongest themes in fact that came up was the view that uncertainty is an integral part of their child’s anorexia nervosa. The fact that participants were not directly prompted to talk about uncertainty in relation to their ill offspring further strengthens the importance of this link. However, it is also important to keep in mind that these are parents who were very likely to be pre-occupied with their child’s illness and when asked to think of uncertain situations would easily mention situations that were the most relevant to them at that point in time.

The results illustrate that some parents tolerated and enjoyed uncertainty in their lives, while others disliked uncertainty, highlighting differences between parents on IU as a personality trait. As a group all 17 parents did not show any bias towards disliking uncertainty although they did express a dislike towards uncertainty at specific times in their lives or in relation to specific situations. For instance, although most parents agreed that uncertainty could have positive sides and evoke feelings of excitement, this was never the case with uncertainty that was in the context of their child’s illness, which was described as “negative uncertainty” that was extreme and something they had never experienced before. It seems that IU can show both trait and state like properties. The lack of information about the illness and the unpredictability of the course of the illness and treatment were further sources of “negative uncertainty”. This is in line with previous research that has found that insufficient information in the context of an eating disorder and the treatment process increases carer distress (Whitney, et al., 2007), as well as, illness in general (Mishel, 1983). When little is known about the cause, course, and consequences of the illness and there is a perceived lack of control regarding a situation, parents’ behaviours and coping can be negatively affected (Treasure, et al., 2003). A number of factors were discussed by parents as playing a role in determining whether uncertainty would be negative. These included the severity of the consequences associated with the situation, the likelihood of a worst case scenario happening and the level of control one had over the situation. Negative experiences of uncertainty were often accompanied by feelings of anxiety, stress, frustration, fear, and despair. Finally, parents perceived adolescents with anorexia nervosa as a source of uncertainty. In other words, their reactions and behaviours were described as more unpredictable than your average teenager. Parents also expressed worry and uncertainty whether it was their child talking or the illness,
which seemed to make matters more confusing for parents and in trusting their judgment. Adolescents were not only sources of uncertainty but were also perceived by their parents as being very rigid and intolerant of uncertainty themselves. This parental perception is in accordance with study 3, whereby adolescents with anorexia nervosa expressed a dislike towards uncertainty (see Chapter 4).

When prompted to discuss ways of coping when faced with “negative uncertainty” both helpful and unhelpful coping strategies were identified. A need for more helpful ways of coping was expressed particularly with uncertainty in the context of the anorexia nervosa. Interestingly, a few differences were noted in styles of coping between groups of mothers and fathers. One notable difference, which was also mentioned by participants themselves, was that mothers tended to worry more and cope less effectively when faced with uncertainty in relation to their child’s illness, while fathers opted for more pragmatic ways of dealing with “negative uncertainty”. These included identifying factors that they could change that would improve a situation, keeping in mind things that were certain while not worrying about things that were out of one’s control and taking time out to return to a situation with a clearer mindset.

The seriousness of the illness and the uncertainty associated with it were seen to negatively affect both individual family members and the family as a whole. Both mothers and fathers felt that their parental abilities and confidence were undermined and that their decision making abilities and judgment became impaired. For example, parents felt unable to make any decisions for the future, such as plan holidays. They also questioned the extent to which they should make their children’s lives predictable and safe, with the danger of providing them with a “fake security blanket” instead of letting them be exposed to uncertainty and learn to tolerate it better. Finally, parents felt stuck in the present and described how their lives ended up being organised around the illness with strains placed on family relationships. Overall, such findings are in line with previous research (Cottee-Lane, et al., 2004) and with current models that argue that families taking care of an adolescent suffering from anorexia nervosa become “re-organised” around the illness and immobilised in the “here and now”, with their own strengths and resources being overlooked (Eisler, 2005; Whitney & Eisler, 2005). How families respond to the illness is of vital importance in increasing our understanding of factors that maintain the illness (Eisler, 2005; Whitney & Eisler, 2005).

Parents further expressed a need to take care of their child and see them get better, as well as, a need for normality, support and understanding by friends and professionals echoing previous research findings (Whitney et al., 2007). A need for understanding and support by friends comes as no surprise given the difficulties and stress associated with this illness. Previous research has also found that not enough support from friends and family can add to the distress (Whitney et al., 2007). A number of parents further mentioned how sharing their experiences with other families going through similar difficulties was very helpful, which is in line with earlier research (Cottee-Lane, et al., 2004).
The identified themes are in accordance with the proposed model presented in Chapter 2. IU at the family level is considered to affect how parents and the family as a whole adapt and manage the illness. The more uncertainty is not accepted in the family the less flexible the family system will become, making change and progress in terms of overcoming the illness difficult. Indeed we see that one of the themes that emerged in study 3 was the impact of uncertainty on the family (super-ordinate theme 7). Parents described how they favoured familiar routines and uncertain situations were stressful, like going on holidays finding it difficult to think about the future and preferring to focus on the present. Some parents discussed how they always disliked uncertainty while others found uncertainty distressing only in relation to their child’s illness. This taps into what is illustrated in the model proposed in Chapter 2 of IU being either the result of a personality trait, present before their child got ill or as a consequence of the threatening and unpredictable nature of the illness and the likelihood of a negative outcome being feared. The unpredictable and threatening nature of the anorexia nervosa can increase thinking in the lines of ‘what if we challenge the anorexia nervosa and things get worse’, such as the ill young person stops eating altogether. Given that a strong parental role in the management of eating is essential in the treatment process, especially in the first phase of family therapy if such thinking predominates in the family this can delay treatment progress. The proposed model predicts that parents will find uncertainty distressing and prefer to respond to their child and their illness in such a way that would be most secure in order to avoid any unwanted outcomes. This links to the theme of parental roles and abilities especially how parental confidence and decision-making abilities are diminished in the face of the illness and the accompanied uncertainty.

5.9.2 Gender differences and groups
Moderator perceptions and notes from facilitators revealed a few differences between the mothers groups and the fathers groups. For instance, fathers usually talked in more ‘mechanical terms’ and dealt with uncertainty associated with anorexia nervosa with a problem solving style, which was not seen in mothers, who were more emotional. Previous research (Whitney & Eisler, 2005) has found mothers showing a more emotional response to their child’s illness while fathers “a more cognitive detached response”, which goes along with findings from the present study. Furthermore, a few fathers more easily blamed the young person with the illness and found it difficult to understand the nature of the illness and why the adolescent ‘just can’t eat’, which supports previous research (Treasure et al., 2003). Mothers on the other hand, expressed more worries, which was also commented on by fathers. Such gender differences are consistent with previous findings (Kyriakou et al., 2008). Differences in coping styles detected between mothers and fathers, is likely to reflect differences in coping with stress between males and females. For instance, a review of 30 research studies (Yee & Schulz, 2000) found that women caregivers are more likely to have psychiatric morbidity compared to men because they respond differently to stress. Female carers are more distressed than male carers which could be down to males engaging less with their emotions and thus report less distress. Another theory is that women are encouraged to use coping mechanisms that are actually less effective (Lutzky & Knight, 1994).
Matud (2004) looked at gender differences in coping styles between males and females and found that females worry more about the little things and use more emotional and avoidance coping styles while opting less for rational and detached styles, while males show the reverse (Matud, 2004). Whilst most themes run across all five groups one difference between presence and absence of themes between groups of mothers and fathers is worth mentioning. This involves the need to resume a normal life, which was only present in two of the groups made up of mothers and none of the fathers groups. This might indicate that mothers’ life is more disturbed than fathers’ life and thus mothers miss more doing normal things and have a higher need to hold on to something normal. Fathers may also get more time off from caring for their ill child compared to mothers, as one mother commented on, and so have kept a sense of normality at least in one part of their life.

5.9.3 Differences in themes between groups.

All super-ordinate themes run across groups apart from the theme on young people and uncertainty that wasn’t present in FG2. While most sub-ordinate themes were also present in each focus group, a number of sub-ordinate themes did not run throughout. These included difficulties in coping that was not present in FG2 and FG5; need for professional advice, guidance, support and understanding were not present in FG3 and FG4; need for normal life was not present in FG2 and FG5; while anorexia nervosa and uncertainty in the family was not present in FG1 and impact of uncertainty on family relationships was not present in FG3 and FG5. It may seem surprising that these themes were not present in all groups, particularly the need for professional guidance, support and understanding and the impact of anorexia nervosa and uncertainty on family relationships, as they were dominant in the rest of the groups. It is, however, difficult to know whether such differences are a reflection of the differences in parents’ characteristics, group dynamics or a chance variation due to the dynamic of the evolving conversation in each group. In accordance with IPA there is the need to acknowledge possible influences due to the dynamic process of analysis and the interpretative nature of the researchers (Smith, 1996). Moderator characteristics including previous beliefs and assumptions, as well as, the fact that participants had undergone MFT, could also have influenced how results were interpreted and what themes emerged.

5.9.4 Strengths of the study

The present study used a good sample size of 17 carers, with no more than four in each group. Usually small sample sizes are favoured when carrying out IPA (Smith & Osborn, 2008). Both mothers and fathers were included in the study but were seen in separate focus groups which allowed for more homogeneous samples to exist in each focus group, which also permitted for the exploration of potential differences between mothers and fathers on how they experience uncertainty. Being in a same-sex group and not in the same group as their spouse may have also facilitated disclosure for both mothers and fathers to openly share their experiences on uncertainty. A final strength of the study was that the focus group schedule was tailored to broadly explore uncertainty in general, as well as, before
the presence of their child’s illness, which allowed the exploration of parental experiences of uncertainty more globally and not restricted to one time of their life.

5.9.5 Rigor in the results

A number of steps were taken in study 3 that would assess levels of credibility transferability and dependability of the findings. These steps are the same as the ones outlined in Chapter 4 (section 4.11.5 titled rigor in the results) and to avoid any repetitions will not be outlined in this section.

5.9.6 Limitations of the study

The present study shows similar limitations to those reported in study 2 (see Chapter 4). For instance, the transferability of current results could be compromised as parents were part of a specific MFT setting and themes were also not cross validated by parents themselves. More specific to study 3, not all focus groups were run by the same moderator and facilitator. That is two of the mothers groups were run by the present author and two researchers that were also involved in the focus groups run by adolescents, while the rest of the groups were run by a clinician part of the research study. This means that not all groups were exposed to the same moderator influences and this in turn may have influenced the dynamics within those groups and the context of what parents chose to discuss compared to groups that were run by the present author. In addition participants already knew the clinician while they had only briefly met the present author. This may have influenced the extent to which participants disclosed in the discussion. Participants may have wanted to please the clinician or wanted to respond in a way that they thought their clinician would expect them too. This however was not picked up by the moderators or facilitators. When listening to the discussions and analysing the transcripts groups discussions from groups run by clinicians did not seem to differ in engagement and openness compared to those run by the researchers. Furthermore, clinicians running the groups strictly followed the focus group schedule and were familiar with the aims of the study. It seems likely that having a clinician as the moderator could have fostered feelings of familiarity and trust which could have stimulated discussion and openness.
Chapter 6

A quantitative examination of anxiety factors in adolescents with anorexia nervosa and their parents in a family therapy context (Study 4)

6.1 Overview of chapter

The present thesis so far has shown that anxiety related vulnerability factors (i.e., positive beliefs about worry; IU; negative problem orientation; and cognitive avoidance) are elevated in adults with anorexia nervosa (see Chapter 3). IU is further confirmed by adolescents themselves and by their parents as a relevant factor that is related to the anorexia nervosa, (Chapters 4 & 5).

Parents themselves also express uncertainty as distressing, particularly uncertainty in the context of their child’s illness (see Chapter 5). The present chapter reports a quantitative study (study 4) that complements studies 1-3 and seeks to examine anxiety related vulnerability factors in adolescents with anorexia nervosa compared to a healthy control group, similarly to Study 1 (see Chapter 3). Study 4 further examines whether certain factors in adolescents currently seeking treatment for anorexia nervosa and certain parental factors moderate and/or mediate response to treatment.

6.2 Introduction

Adolescent anorexia nervosa can have a favourable course if treated with effective treatments, particularly early on in the course of the illness. Individual factors that contribute to a poor treatment outcome include levels of comorbid anxiety. At present we know very little of underlying vulnerability factors of one of the most frequent comorbid anxiety disorders, that of GAD, in individuals with anorexia nervosa. There is thus a need to understand in depth the role of anxiety related vulnerability factors, such as IU, and how best to manage them in treatment. Little is also known of positive and negative beliefs about having an eating disorder in adolescents, and the possible role of IU in the maintenance of such beliefs. In particular examining such beliefs and levels of ambivalence in the context of having an eating disorder has received little attention in adolescents compared to the adult literature. Finally, little is known of whether parental distress in the first few months of therapy could influence response to treatment.

6.2.1 Anxiety related vulnerability factors and worry in anorexia nervosa

Adolescence in particular is a transitional period usually characterised by change and uncertainty and thus anxiety related issues can be more prominent during this time. Indeed, anxiety disorders are one of the most prevalent forms of psychopathology in children and adolescents (Curry, March, & Hervey, 2004). Although anxiety disorders can be found across the lifespan onset of the disorder is usually at a young age (Kessler, et al., 2005). Taking into account that anorexia nervosa often occurs at a young age we would expect anxiety related issues to be prominent at this age and client group. The few existing
studies that have looked at anxiety in adolescents with anorexia nervosa have found high prevalence of a number of anxiety disorders, including GAD (Herpertz-Dahlmann, et al., 1996; McDermott, et al., 2006; Salbach-Andrae, et al., 2008). Other anxiety related factors, such as worry however have not been examined in adolescents with an eating disorder, neither have underlying anxiety related vulnerability factors.

In the adult literature, excessive worry which is the cardinal feature of GAD has been found elevated in individuals with an eating disorder compared to healthy controls (Kerkhof, et al., 2000; Sassaroli, et al., 2005) and has also been positively associated with dietary restraint (Scattoloni & Nicki, 1995). More recently Startup and colleagues (2012) found elevated levels of worry in adults with anorexia nervosa when compared to healthy controls with worry levels reaching even higher levels of those found in other anxiety populations, such as panic disorder and comparable levels to those seeking treatment for GAD and a diagnosis of OCD, though slightly lower levels of worry when compared to those meeting a strict GAD criteria. Overall, there is a clear need to further explore worry and anxiety related vulnerability factors in adolescents with anorexia nervosa.

6.2.2 Ambivalence about having an eating disorder: positive and negative beliefs

Individuals with anorexia nervosa are faced with a very serious psychological illness, despite this they often deny that they have an illness altogether (Espindola, et al., 2009; Vandereycken, 2006) and often feel unique and immune to any of the negative effects of having an eating disorder, resulting in patients having low motivation to change (Fox, et al., 2009).

One of the most challenging aspects of treating adolescents with anorexia nervosa is the amount of ambivalence and low motivation to change that is exhibited in terms of their illness and the prospect of getting better. Unlike other psychological disorders whereby patients want to recover and overcome their debilitating symptoms, patients with anorexia nervosa are undecided and plagued by mixed feelings regarding recovery. One qualitative study for instance, found that women with anorexia nervosa, although were verbally able to express a wish to recover, they found it difficult to take action and make behavioural changes (Nordbø et al., 2008). A number of factors were mentioned as influencing their level of motivating to get better, including thinking of the things that they can gain from not having an eating disorder, such as feeling energetic and being able to do the things that make them happy, as well as, thinking of all the negative physical, social and psychological consequences that can result from their illness. Intrinsically taking the decision to recover rather than someone else taking it for them was also mentioned as an important factor in terms of motivation (Nordbø et al., 2008).

Ambivalence towards treatment is important as willingness to change has been found to predict treatment outcome for eating disorders above and beyond initial eating disorder symptoms in adults with anorexia nervosa (Bewell & Carter, 2008). Reaching a better understanding of ambivalence towards treatment and one’s illness can partly be understood due to the positive and negative beliefs individuals
with anorexia nervosa often hold about their illness (Serpell et al., 1999; Schmidt & Treasure, 2006). For instance, anorexia nervosa often becomes an integral part of one’s identity and takes up additional functions in terms of providing patients with a sense of safety, control, and security, and as a means of coping with negative emotions and anxiety (Schmidt & Treasure, 2006). These positive functional roles attached to the illness can contribute to the development of positive beliefs about the illness, which in turn may play a crucial role in one’s motivations to change.

6.2.3 Parental factors and eating disorders

Parents of adolescents with an eating disorder have received a lot of attention in terms of the cause and course of their child’s illness. Initially, this interest was predominately negative, as parents were strictly excluded from the treatment process and considered to do more harm than good (Hoste, Doyle, & Le Grange, 2011). Later on attention was directed to parents based on clinical accounts that tried to identify certain characteristics of “anorexic families” (Minuchin, Rosman, & Baker, 1978), such as that families were rigid, had poor communication and parents who were over involved with their children’s lives all of which were considered as causal factors of the eating disorder (Yager, 1982). Parents were then included in therapy in order to target the identified areas that supposedly contributed to the onset or maintenance of the illness. Claims of the ‘anorexic family’ however are not supported by empirical research as documented by a number of reviews of the literature (Eisler, 1995; Konstantellou, Cambell, & Eisler, 2011). Research that focuses on identifying family related aetiological factors of eating disorders is methodologically weak, dominated by small cross sectional studies from which few firm conclusions or generalisations can be made (Eisler, 1995; Konstantellou et al., 2011). Methodological shortcomings further include a lack of prospective data and comparison groups, small sample sizes that are mainly made up of chronically ill patients who are treated in specialist services and lack of control for third variables that may be mediating a relationship between parental factors and eating disorder psychopathology (Eisler, 1995; Konstantellou, et al., 2011).

Studies looking at parental influences on eating disorder behaviour are further limited as they are unidirectional and run the risk of oversimplifying more dynamic family processes and failing to take into account how the presence of the illness could have contributed to certain family characteristics and parental distress (Eisler, 2005; Konstantellou, et al., 2011). For instance, it is important to take into account that the burden, stress and presence of the eating disorder itself could have contributed to elevated levels of psychopathology often found in carers (Eisler, 2005; Konstantellou, et al., 2011). Parents of adolescents with an eating disorder show increased levels of overall psychopathology and particular personality characteristics when compared to parents of healthy individuals (Fassino, Amianto, & Abbate-Daga, 2009; Lilenfeld, et al., 1998; Steiger, Stotland, Trottier, & Ghadirian, 1996) including perfectionism (de Amusquibar & De Simone, 2003; Lilenfeld, et al., 2000); anxiety (Strober, Freeman, Lampert, & Diamond, 2007), eating disorders, depression, OCD (de Amusquibar & De Simone 2003 Lilenfeld et al., 1998) and alexithymia (i.e., the inability to identify and process emotions; (Espina, 2003)). However, little is actually known of the relationship between parental psychopathology and
eating disorder psychopathology and how parental psychopathology may affect response to treatment (Konstantellou, et al, 2011). One study used a cross sectional design and measured parental psychopathology including anxiety, depression, hostility, interpersonal sensitivity, obsessive compulsive symptoms, paranoid ideation, phobic anxiety, psychoticism and somatisation at initial clinical assessment and eating disorder psychopathology in adolescents with anorexia nervosa (Ravi, Forsberg, Fitzpatrick, & Lock, 2009). Results showed that parents of adolescents with anorexia nervosa showed subclinical and clinical levels of psychopathology, including depression, anxiety, obsessive compulsive traits and hostility more so than what one would find in the normal population, but less than individuals receiving outpatient psychiatric treatment (Ravi, et al., 2009). Of interest, only hostility in mothers and fathers was found positively associated with eating disorder psychopathology and duration of illness respectively (Ravi, et al., 2009).

Overall, focus on families within the eating disorder literature has shifted from an aetiological stance that aims to explain the occurrence of the eating disorder in a particular family to one where parents’ distress is recognised and parents are considered an important resource in the treatment process. Research would be more valuable if focus was placed on understanding better how parental factors can affect treatment outcome and how best to manage this, as well as, the positive role parents can have in the treatment process of their children (Eisler, 1995; Le Grange et al. 2010).

6.2.4 Moderators and mediators of family therapy for eating disorders
We have so far highlighted the need to understand better how anxiety related vulnerability factors and positive and negative beliefs about having an eating disorder in adolescents with anorexia nervosa and factors in parents such as anxiety and stress, may affect response to treatment. One way of examining this is by testing whether such factors in adolescents and in parents moderate and or mediate response to therapy. In fact, in Chapter 1, when reviewing the literature on moderators and mediators of treatment outcome for patients with an eating disorder, there was a lack of substantial research on factors that moderate and mediate response to effective therapies for adolescent anorexia nervosa (Bulik, Berkman, et al., 2007; Eisler, 2005).

6.3 Aims of study 4
The main purposes of the present study were threefold. The first aim involved examining whether anxiety related vulnerability factors and worry are elevated in adolescents with anorexia nervosa when compared to a healthy adolescent. The second aim involved examining whether anxiety related vulnerability factors, worry, positive and negative beliefs of having an eating disorder and levels of ambivalence in adolescents currently seeking treatment for anorexia nervosa are associated with eating disorder psychopathology and whether they moderate and/or mediate response to treatment. A final third aim was to examine parental factors in relation to eating disorder psychopathology and whether they moderate and/or mediate response to treatment.

6.4. Hypotheses of study 4
6.4.1 Adolescent hypotheses

Between groups hypotheses

- Adolescents with anorexia nervosa will score significantly higher on anxiety related vulnerability factors (i.e. IU, positive beliefs about worry, cognitive avoidance & poor problem orientation) and worry when compared to a healthy control group (H1).

- Differences on the anxiety related vulnerability factors, particularly for IU, will remain between adolescents with anorexia nervosa and healthy adolescents even when levels of anxiety are accounted for (H2).

Baseline hypothesis (T1)

- Positive associations will be detected between anxiety related vulnerability factors; worry, anxiety, positive and negative beliefs about having an eating disorder; ambivalence, depression and eating psychopathology in adolescents with anorexia nervosa (H3).

- IU out of anxiety, worry and depression will be the strongest predictor of eating psychopathology and weight for height. In other words the higher the levels of IU the higher the need for certainty and structure that will result in more anorexia nervosa related behaviours such as restricting and weight loss. This is one mechanism through which IU might be affecting weight. (H4).

Moderator/mediator hypotheses (T1-T3)

- Anxiety related vulnerability factors, worry and positive and negative beliefs about having an eating disorder in adolescents at T1 will moderate response to treatment, determined by patients' weight for height and eating related cognitions and behaviours at T3 (three months) (H5).

- If change occurs during the first three months of therapy in the anxiety related vulnerability factors, worry, and beliefs about the pros and cons of having an eating disorder this will precede symptom change and mediate treatment response (H6).

6.4.2 Parental hypotheses

Moderator/mediator hypotheses (T1-T3)

- Anxiety related vulnerability factors, worry, anxiety, depression and stress in parents will predict/moderate response to treatment, determined by patients' weight for height and eating related cognitions and behaviours at three months (H7).
If change occurs during the first three months of therapy in anxiety related vulnerability factors, worry, anxiety, depression and stress in parents this will precede symptoms change and mediate adolescents’ response to treatment (H8).

6.5 Ethical approval
Ethical approval was granted for the present study by the Camden and Islington Community Research Ethics Committee.

6.6 Method

6.6.1 Inclusion and exclusion criteria

Inclusion criteria for the adolescent clinical group

DSM-IV and ICD-10 diagnosis of anorexia nervosa both restrictive and binge/purge type or eating disorder not otherwise specified restrictive type (EDNOS-R). Although there is no formal subtype of EDNOS, EDNOS-R was determined within the clinical team as part of clinical practice patients are given a diagnosis of EDNOS and are described as to whether they resemble more with a restrictive clinical presentation or a binge-purge clinical presentation. The present researcher liaised with clinicians to determine whether patients with an EDNOS diagnosis resembled more with anorexia nervosa or bulimia nervosa.

- 13-18 years of age

Inclusion criteria for the adolescent healthy control group

- Female
- 13-18 years of age

Exclusion criteria for adolescent controls

- Current eating related problems indicative of an eating disorder.
- Current elevated levels of anxiety indicative of GAD.

Exclusion criteria for all groups

Participants were excluded from the study if they did not have an adequate understanding of English, which was determined at initial clinical assessment.6.6.2 Design
The present study involves a cross sectional and longitudinal repeated measures design. A cross sectional design was adopted to examine differences between adolescents with anorexia nervosa and healthy adolescents on anxiety related factors. A longitudinal design was chosen to examine possible changes over the first three months of treatment in the selected adolescent and parental factors and
whether such factors moderated and mediated response to therapy. Three specific time points were selected where measurement of factors took place for both adolescents and parents. These included at pre treatment (T1), after one month of therapy (T2) and at three months into therapy (T3).

6.6.3 Sample size calculations
The main aims of the present study and estimation of required sample size after consultation with a statistician are presented below:

1. A power calculation was carried out taking into account the effect size of a study (Frank et al., 2012; which was first published online in 2011) that used the IUS in an eating disorder population. A G*Power calculation showed that a sample size of 10 adolescents with anorexia nervosa and an equal number of healthy adolescent will have 99 % power to detect an effect size of 2.14 using a groups t-test with a .05 two tailed sig. level.

2. The second main aim of study 4 is to examine whether certain factors in adolescents with anorexia nervosa and in their parents moderate and or mediate response to therapy. Based on guidelines by Frazier and colleagues regression analysis is considered the most appropriate method (Frazier, Tix, & Baron, 2004). Following advice from a statistician the four strongest predictor variables for each of the regression analysis would be entered into a multiple regression analyses. Using the rule of 10 cases for each predictor variable entered in the analysis a sample of 40 families would be required.

6.6.4 Measures

Measures for the clinical group of adolescents

Measuring anxiety

1. Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999). The SCARED is a 38-item self-report screening measure on the DSM-IV symptom criteria for a number of anxiety disorders including, separation anxiety, generalized anxiety disorder, phobias (social and simple), and panic disorder. The SCARED is appropriate for children aged 9-18 years. The measure has high internal consistency (total scale $\alpha = .93$) and high test–retest reliability (total scale $r = .86$; subscales range from .70 to .90) (Silverman & Ollendick, 2005). A total score of 25 or more is indicative of the presence of an anxiety disorder. More specifically, a score of 7 or more on certain items is indicative of panic disorder, a score of 9 or more on certain items indicative of GAD, a score of 5 or more on certain items indicative of separation anxiety disorder, a score of 8 or more for certain items indicative of social anxiety disorder, and a score of 3 or more on certain items indicative of significant school avoidance. The SCARED takes approximately 5 minutes to complete.
Measuring worry

2. *Penn State Worry Questionnaire for Children* (PSWQ-C; Chorpita, Tracey, Brown, Collica, & Barlow, 1997). The PSWQ-C is an adaptation of the PSWQ, which was designed to assess severity and level of trait worry in adults (Penn State Worry Questionnaire; Meyer, Miller, Metzger, & Borkovec, 1990) and suitable for children and adolescents aged 6-18 years of age. The PSWQ-C is a 14-item self report measure that can be completed within 5 minutes. The PSWQ-C shows respectable psychometric properties with good internal consistency $\alpha = .89$ and high convergent and discriminant ability in a community sample of children and adolescents (Chorpita et al., 1997). A cut off score of 45 has been identified as indicative of clinical significance (Behar, Alcaine, Zuellig, & Borkovec, 2003).

Measuring anxiety related vulnerability factors

3. *Intolerance of Uncertainty Scale for Children* (IUS-C, see Appendix 12 (Comer, et al., 2009)). The IUS-C investigates children’s tendency to react negatively on an emotional, cognitive, and behavioural level to uncertain situations and events. The young person version of this measure was adapted from the 27-item English version of the adult IUS (Buhr & Dugas, 2002; Freeston et al., 1994) and is suitable for children and adolescents aged 7-17. For the child-report form, items were reworded to enhance child compatibility. Participants rate the extent to which a statement best describes them along a 5-point Likert scale from “Not at all”= 1 to “Very much” = 5. It is completed on average in five minutes and has demonstrated excellent to good internal consistency ($\alpha = .92$) and convergent validity in young people (Comer et al., 2009). The IUSC takes on average 5 minutes to complete. Although the IUI (Gosselin et al., 2008; English version: Carleton, Gosselin, & Asmundson, 2010) was used to measure IU in study 1 and would have been a more “disorder-neutral measure” compared to the IUS-C, the IUS-C was chosen for study 4 for two main reasons. First, the IUI is much longer than the IUS-C. Taking into account the young age, patient group and not to overload participants with questionnaires a shorter measure like the IUS-C was considered more appropriate. Second and most importantly the IUI is a relatively new measure that has not been previously used nor validated in a child/adolescent sample. Taking into account the young age of participants and the relatively abstract construct of IU, it would be imperative that adolescents could understand the statements included in the questionnaire. For these reasons the well established IUS-C was chosen for the adolescent sample.

4. *Why Worry Questionnaire* (WW-II; Gosselin et al., 2003; English version: Holowka, Dugas, Francis & Laugesen, 2000). [Please see Chapter 3 section 3.5.3 for a detailed description].Although this measure has not been formally adapted for children it has been used in adolescent populations. *Negative Problem Orientation Questionnaire* (NPOQ; Gosselin, Pelletier, & Ladouceur, 2001; English translation: Robichaud & Dugas, 2005). [Please see
Chapter 3 section 3.5.3 for a detailed description] Although this measure has not been formally adapted for children it has been used in adolescent populations.

5. **Cognitive Avoidance Questionnaire** (CAQ; Gosselin et al., 2002; English translation: Sexton & Dugas, 2008). [Please see Chapter 3 section 3.5.3 for a detailed description] Although this measure has not been formally adapted for children it has been used in adolescent populations.

Measuring positive and negative beliefs about having an eating disorder

6. **Pros and Cons of Eating Disorders** (PCED; Gale, Holliday, Troop, Serpell, & Treasure, 2006). The PCED was developed to measure the pros and cons of having an eating disorder and is based on a former measure the pros and cons of anorexia nervosa (PCAN; Serpell et al., 1999), which has been shown suitable for adolescents aged 13 to 18 (Serpell, Neiderman, Haworth, Emmanueli, & Lask, 2003). The PCED is a self report measure which consists of 67 items rated on a 5 point Likert scale from ‘agree strongly’ scored 2, to ‘disagree strongly’ scored -2. It comprises of 8 pro subscales (i.e. safe/structured; appearance; fertility/sexuality; special skis; fitness; communicate emotions; eat but stay slim; boredom) and 6 con subscales (i.e. trapped; guilt; hatred; stifled emotions; negative self image; weight and shape). The PCED has an additional two questions to measure attitudinal ambivalence which can be calculated using Griffin’s calculation (Thompson, Zanna, Griffin, 1995). This formula essentially looks at the relationship between the intensity and the similarity of the unipolar questions. The greater the intensity or the greater the similarity the higher the ambivalence score. Answers are made on a 7-point Likert scale from 1 = “not at all positive” to 7 = “extremely positive”. Scores range from -2 to 7, with higher scores indicating higher ambivalence in other words that the individual is experiencing their eating disorder both positively and negatively, while lower scores indicate that the individual is either experiencing mainly positives from the disorder or mainly negatives. The PCED takes on average 10 minutes to complete.

Measuring depression

7. **Mood and Feelings Questionnaire** (MFQ; Angold, Costello, Pickels & Winder, 1987; Costello & Angola, 1988) The MFQ is a 33-item self report measure specifically designed for children and adolescents (8-18 years old) assessing symptoms of major depression disorder according to DSM-III-R criteria. Participants are asked to indicate “how much they have felt or acted this way in the past two weeks” and responses are made on a three point scale from “True” = 2, “Sometimes” = 1 to “Not True” = 0, with total scores ranging from 0-68. The measure has shown acceptable psychometric properties, with high internal consistency ($\alpha = .94$) (Wood, Kroll, Moore, & Harrington, 1995); ($\alpha = .91$) (Sund, Larsson, & Wichstrøm, 2001), good convergent validity with the Beck Depression Inventory ($r = .91$) (Sund, et al., 2001) and test re-
test reliability, for a three week period \( r = .84 \) (Sund, et al., 2001). The MFQ takes approximately 5 minutes to complete.

Measuring eating psychopathology

8. *The Eating Disorder Examination Questionnaire: Version 6* (EDE-Q; 6.0 Fairburn & Beglin, 2008). The EDEQ: 6.0 is a 28 item self report alternative measure to the original EDEQ (Fairburn & Beglin, 1994), which is based on the widely used interview based eating disorder examination (EDE; Fairburn & Cooper, 1993). The EDEQ 6.0 assesses eating disorder psychopathology focusing on the past 28 days. Good internal consistency has been found for the EDEQ subscales (restraint \( \alpha = .70 \); eating concern \( \alpha = .73 \); shape concern \( \alpha = .83 \); weight concern \( \alpha = .82 \)) and EDEQ total scale (\( \alpha = .90 \)) (Mond, Hay, Rodgers, Owen, & Beumont, 2004; Peterson, et al., 2007) and EDEQ subscales show excellent test-retest reliability: restraint \( r = .81 \), shape concern \( r = .94 \), weight concern \( r = .92 \) and eating concern \( r = .87 \) (Luce & Crowther, 1999). The EDEQ has widely used with adolescent populations (Passi, Bryson & Lock, 2003). Community norms are available for adults (Mond, et al., 2004 (Mond, Hay, Rodgers, & Owen, 2006), and adolescents (Carter, Stewart, & Fairburn, 2001). A global score of 4 or higher is considered clinically significant and indicative of an eating disorder (Carter, et al., 2001). Approximately 10 minutes are required to complete the EDEQ 6.0.

9. *Weight for height %.* Weight for height for adolescents was obtained from clinical notes and the electronic patient journey system (EPJS).

**Measures for the healthy control group of adolescents**

These were the same measures as the ones administered to the clinical group of adolescents.

**Measuring anxiety related vulnerability factors**

1. *Intolerance of Uncertainty Scale for Children* (IUSC; Comer et al., 2009).
Measuring worry

5. *Penn State Worry Questionnaire for Children* (PSWQ-C; Chorpita, Tracey, Brown, Collica, & Barlow, 1997).

Screening for eating psychopathology

6. *The Eating Disorder Examination Questionnaire* (EDE-Q; Fairburn & Beglin, 2008). The EDEQ has been found a suitable self-report measure for screening for eating disorders in a community setting (Mond, Hay, Rodgers, Owen, & Beaumont, 2004). EDEQ global and subscale means and standard deviations in the normal population of adolescent girls are as follows: Restraint 1.4(1.5); eating concern 1.0(1.0); shape concern 2.2(1.7); weight concern 1.8(1.7) and global EDEQ score 1.6(1.4) (Carter, et al., 2001). A global score on the EDEQ of 4 or higher is considered indicative of an eating disorder (Carter et al., 2001). Any participants that scored higher than the cut off score were excluded. In the present sample one adolescent was excluded.

Screening for anxiety

7. Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999). The SCARED has also been found a reliable measure screening for childhood anxiety disorder in non-referred individuals in the community (Muris, Meesters, & Gobel, 2001). In particular the SCARED was found to be sensitive in detecting GAD and separation anxiety disorder (Muris et al., 2001). For the present study, healthy control adolescents were screened for GAD. If participants scored higher than the cut off point for GAD, which is 9, they were excluded from the study. In the present sample two were excluded.

Measures for parents

Measuring anxiety related vulnerability factors

1. *Intolerance of Uncertainty Scale* (IUS; see Appendix 13; Freeston et al., 1994; English translation: Buhr & Dugas, 2002) consists of 27 items and measures one’s level of intolerance of uncertainty, that is, beliefs that intolerance of uncertainty is distressing, unacceptable, reflects badly on a person, and makes a person unable to take action. Participants make their responses on a five-point Likert scale ranging from 1 = ‘not at all characteristic of me’ to 5 = ‘entirely characteristic of me’. Examples of items include ‘uncertainty makes life intolerable’, ‘my mind can’t be relaxed if I do not know what will happen tomorrow’, and ‘when I am uncertain I can’t go forward’. The IUS has excellent internal consistency, $\alpha = .91$ (Freeston, et al., 1994) and good test-retest reliability over a period of five-weeks ($r = .74$, Freeston, et al., 1994) ($r = .78$, Dugas, Freeston & Ladouceur, 1997). Similar results have been found for the English Version of the IUS
(Buhr & Dugas, 2002). No differences in scores on the IUS have been found between gender (Robichaud, et al., 2003) and ethnic groups (Norton, 2005) The IUS takes approximately 5 minutes to complete.

2. **Intolerance of Uncertainty Scale for Children- Parent Report** (IUS-C; see Appendix 14, Comer et al., 2009). This measure is completed by the parents for the young person asking the parent to rate their child’s tendency to react negatively to uncertain situations and events. It comprises of 27 items rated on a 5-point scale, which takes on average 5 minutes to complete (Comer et al., 2009) Psychometric properties have been shown to be good with excellent internal consistency ($\alpha = .96$; Comer et al., 2009). The IUS-C takes approximately 5 minutes to complete.

10. **Negative Problem Orientation Questionnaire** (NPOQ; Gosselin, Pelletier, & Ladouceur, 2001; English translation: Robichaud & Dugas, 2005). [[Please see Chapter 3 section 3.5.3 for a detailed description].

11. **Cognitive Avoidance Questionnaire** (CAQ; Gosselin et al., 2002; English translation: Sexton & Dugas, 2008). [Please see Chapter 3 section 3.5.3 for a detailed description]. [ 

12. **Why Worry Questionnaire** (WW-II; Gosselin et al., 2003; English version: Holowka, Dugas, Francis & Laugesen, 2000). [Please see Chapter 3 section 3.5.3 for a detailed description].

**Measuring worry**

3. **The Penn State Worry Questionnaire** (PSWQ; Meyer et al., 1990) is a 16–item self-report measure designed to assess the pathological worry characteristic of generalized anxiety disorder (GAD) in individuals aged 18 and over. The PSWQ has good internal consistency in a large sample with various anxiety disorders $\alpha = .93$; and a community sample $\alpha = .91, .94, .95$; test-retest reliability with a two week interval $r = .75$; 4 weeks $r = .74$; 8-10 weeks $r = .92$ and one month $r =.93$, as well as, satisfactory convergent and discriminant validity (Meyer et al., 1990). A number of studies have identified optimal cut off scores for detecting high levels of worry indicative of an anxiety disorder. For instance, A cut off score of 62 has been identified to have the optimal levels of sensitivity and specificity to differentiate between a student population with analogue GAD and healthy individuals. Such a cut off score is a good indicator of a possible GAD disorder Behar et al., 2003. A simila r cut off score of 65 was found to distinguish GAD patients from patients with another anxiety disorder (Fresco, Heimberg, Mennin, & Turk, 2002). The PSWQ takes no more than 5 minutes to complete.

**Measuring depression, anxiety and stress**

4. **Depression and Anxiety Stress Scale** (DASS-21; Henry & Crawford, 2005). The DASS-21 is a shortened self report measure of the original DASS (DASS; Lovibond & Lovibond, 1995). The DASS-21 consists of 21 items assessing mood, anxiety and stress. The DASS-21 can be
administered to adults and adolescents down to the age of 14 years. Participants are asked to indicate to what extent a number of statements apply to them over the past week using a four point Likert scale from 0 = “Did not apply to me at all” to 3 = “applied to me very much, or most of the time”. The DASS-21 has been found to be a valid and reliable measure of anxiety and depression in primary care (Henry & Crawford, 2005) and has been found to be a valid and reliable measure of anxiety and depression in non-clinical samples (Crawford & Henry, 2003). The DASS-21 has shown good psychometric properties in clinical and non clinical populations, including good internal consistency measured by Cronbach’s alpha for the subscales, depression: $\alpha = .88-.94$; anxiety: $\alpha = .82-.87$; stress: $\alpha = .90-.91$ and for the total scale $\alpha = .93$, as well as, good convergent and discriminant ability when compared to established measures of anxiety and depression (Henry & Crawford, 2005). Norms of the DASS-21 are available and means and standard deviations are as follows for the three subscales, depression 2.83(3.87); anxiety 1.88(2.95) stress 4.73(4.20) and total scale 9.43 (9.66) (Henry & Crawford, 2005). The DASS takes on average 5 minutes to complete.

6.6.5 Available options for participants completing measures

Questionnaires for all participants were available either as hard copy paper versions or following an online link where questionnaires were available to be completed online. Online links were created using the commercial programme: Question Pro: http://www.questionpro.com/. Three online links were created one for adolescents with anorexia nervosa/EDNOS-R, one for parents of adolescents with anorexia nervosa/EDNOS-R and one for healthy adolescents. Each online link contained information sheets, demographic sheets and questionnaires forming the same hard copy pack that was handed out to participants. Potential participants when entering the online link to complete questionnaires were prompted to enter an ID that was previously provided to them and responses appeared under the present authors account when logging into the question pro site. The online option of completing questionnaires was thought to increase response rate and particularly helpful for healthy adolescents completing the questionnaires.

6.6.6 Location for completing measures

Adolescents with anorexia nervosa and their parents completed questionnaires at home. T1 questionnaires for the majority of adolescents with anorexia nervosa and for their parents were part of the initial clinical assessment measures that families were required to complete as part of routine practise. T1 questionnaires then were already completed at home or were completed as close as possible to their initial assessment and returned to the researcher at their next therapy appointment. For T2 and T3 questionnaires the present researcher met with families either prior or after their pre-arranged therapy appointment one week prior to when the questionnaires had to be completed and handed out T2 and T3 questionnaires that needed to be brought back at their next therapy session. Reminder letters with freepost envelopes were also sent out when there was a long gap between therapy sessions for families to post back completed questionnaires. There was also the option that
some families chose to complete T2 and T3 questionnaires online. An email in that case was sent out containing the link to the questionnaires. If families had forgotten to bring back questionnaires two reminders were thought appropriate as to not pressure or cause any distress to the families. If they had not returned the questionnaires by then they were considered as missing data. Overall time of completion of adolescent questionnaires was approximately 1 hour while time of completion of parental measures was approximately 30 minutes.

Healthy adolescents completed questionnaires either at home or at an allocated computer room at their school. The online option although available to all participants was predominantly used by the healthy adolescents. Overall time of completion of measures was approximately 20 minutes.

6.6.7 Sites for the recruitment of adolescents with anorexia nervosa and their parents
Participants were recruited from two NHS sites. The first one was the main site of recruitment where the researcher was based at. The second site was added later on in order to increase recruitment rates. Recruitment in the first site spanned approximately 1 year while in the second site a few months.
Sites:
1. Michael Rutter Centre, Maudsley Hospital London or Eating Disorder Service at the North East London Foundation Trust.
2. Richmond Royal Hospital, South West London and St George’s NHS Foundation Trust.

6.6.8 Procedure for the recruitment of adolescents with anorexia nervosa and their parents
A number of steps took place according to ethical protocol for the recruitment of adolescents with anorexia nervosa and their parents.

1. The present author at each new assessment consulted the lead clinician and the clinical team involved in the new assessment, who normally has access to patient records without explicit consent, to determine whether the adolescent met the inclusion criteria for the research study.
2. If the adolescent met the inclusion criteria the lead clinician consulted with the family and the present author was introduced and briefly described what the study involved. At that point the present author handed a plastic wallet with information sheets (see Appendices 15 & 16), and consent forms (see Appendices 18, 19 & 20) and depending whether that had already completed the questionnaires as part of the clinical assessment or not they were handed out the questionnaires as well. Families were also informed that at their next appointment the researcher would be available to answer any questions and they would be asked whether they agreed to take part and sign the consent forms provided if they did.
3. At the next appointment along with the clinician providing therapy to the family, the present author asked the family whether they had a chance to read the information sheets, whether they had any questions about the study and whether they were interested in taking part. If the family were happy and all of their questions were answered consent forms were signed and collected and they were recruited in the study.
Fig 6.1 illustrates the overall number of suitable families, the number of families who either did not want to take part or dropped out and the final total number of families who provided written consent and took part in the study. The main reasons for not taking part in the study included time restrictions, that they had other priorities and that the adolescent had to focus on getting better and her studies. This was expressed either at times by the mother or the adolescent themselves. The design of the study required recruiting adolescents and their parents at the beginning of therapy. This is a particularly difficult time for the family. Another reason given by the adolescent was that they strongly felt that there was nothing wrong with them and they did not want to complete any questionnaires. The latter reason given by some adolescents reflects difficulties in engagement and motivation to get better and this in turn seemed to reflect their decision whether to get involved in research or not. One family, had a previous negative experience in taking part in research, and both the parent and young person strongly felt that they did not want to take part in any kind of research. Families that dropped out of research involved families who had initially agreed to take part in the study, seemed quite keen and happy to take part but for a number of reasons were not able to sign the consent forms and/or complete the questionnaires. For instance, some families after their initial assessment were transferred to another service and could not take part in the research. Other families after receiving the first set of questionnaires, changed their minds, the young person got upset and refused to complete the questionnaires. For other families the adolescent got better and left the service, even though they would have wanted to have taken part they did want to be reminded of a time when the young person was not well. Finally, no tangible incentives were provided to the family as part of thanking them in taking part in research for their time and effort, which could have increased recruitment rates.

Figure 6. 1 Flow chart illustrating the recruitment of the clinical group across sites
6.6.9 Schools for the recruitment of healthy controls

A number of schools with similar socioeconomic background as adolescents seen at the clinic were approached via email and telephone by the present author as sources of healthy adolescents to act as a control group. Two schools, a selective state girls school and a mixed sex private school positively responded and collaborated with the present author.

6.6.10 Procedure for the recruitment of healthy adolescents

Two slightly different recruitment strategies were used to recruit adolescents at the two schools.

- At the first school, the head teacher informed pupils that a psychology related research study would be available to take part and whoever would be interested were informed to attend brief informative sessions at specific school times. The present author briefly presented the research and handed out information sheets (see Appendix 17), consent forms (see Appendices 21 & 22) and IDs for pupils to enter if they decided to complete the questionnaires online. The present author visited the school a couple of times to answer any questions that pupils had and collect consent forms. Spare consent forms were also available.

At the second school a circular email was sent by the teacher collaborating with the present author inviting pupils to take part in a psychology research project, containing information about the study (see Appendix 17) and consent forms (see Appendices 21 & 22). Consent forms were also available to be collected from their allocated teachers. The email was sent out to approximately 100 female pupils aged 13-18 years of age and to parents, as consent would be sought for individuals under 16 years of age (see Appendix 19). Two sets of time were allocated whereby the present author was present at the school and pupils could ask any questions about the study, return or sign at that time the consent form and collect their ID to complete the online questionnaires. A computer room was also booked for one whole afternoon for pupils to complete questionnaires there if they wished.

Figure 6. 2 Flow chart illustrating stages of recruitment of the healthy adolescents across schools

![Flow chart](image-url)

- **N = 51**
  Number of potential participants who started the questionnaire or opened the link

- **N = 25**
  Number of participants who fully completed the online questionnaires

- **N = 22**
  Number of participants who took part in the study as healthy adolescents

- **N = 3**
  Number of participants excluded from the study
6.7 Missing data
Missing data consisted of two types. The first type involved one or more missing responses from a questionnaires that either the young person or the parent had completed. The second type of missing data involved data that was missing for most of or a whole questionnaire for any of the three time points. Missing data were handled in two different ways following advice from a statistician. The first type of missing data, when only a few responses were missing in one questionnaire a mean of either the total score or a mean of the subscale that the question belonged to was calculated and inserted into the database. The second type of missing data (i.e. when most items of a questionnaire were left blank or a whole questionnaire was not completed responses) was left as missing data in the SPSS database. An electronic dataset was kept recording all of the type one missing data for adolescents with and without an eating disorder and parents and the values which were calculated and inserted into the SPSS database.

6.8 Data storage
Consent forms and questionnaires are stored at the Institute of Psychiatry, Kings College London in a locked cabinet in a locked office and are available for external review.

6.9 Analyses
Data were analysed using the Statistics Package for the Social Sciences: Version 17 (SPSS, Chicago, Illinois, USA).

6.9.1 Initial assumption testing and selection of statistical tests

Testing for normality
In order to assess whether parametric or non-parametric tests would be most appropriate for the data set a number of assumptions were tested. Normality of data was assessed by running tests for normality (Kolmogorov-Smirnov tests) and visually examining histograms for continuous variables separately for the adolescent clinical group, the adolescents healthy control group and parents. Some of the variables were normally distributed others less so but with no major violations. Tests of Parametric tests were selected for the analysis of the present study.

Testing for homogeneity of variance
Tests for homogeneity of variance are presented under each of the results that examine differences between two groups.
6.10 Demographic characteristics of participants

6.10.1 Demographic and clinical characteristics of the adolescent clinical group and healthy control group

Table 6.1 shows basic demographic characteristics of the clinical sample of adolescents that took part in the study and the sample of adolescents that made up the healthy control group, including gender, age and ethnicity.

Table 6.1 Demographic characteristics of adolescents with anorexia nervosa and healthy controls

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Age (years)</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AN</td>
<td>43</td>
<td>Female = 93 %; Male = 7 %</td>
<td>AN = 74.4%; EDNOR-R = 25.6%</td>
<td>Mean = 14.93 (SD = 1.28)</td>
<td>White British = 86 %; Mixed Race = 9.4 %; Asian = 4.7 %</td>
</tr>
<tr>
<td>HC</td>
<td>22</td>
<td>Female= 100%</td>
<td>N/A</td>
<td>Mean = 15.82 (SD = 1.43)</td>
<td>White British = 63.6 %; White Other = 4.5 %; Mixed Race = 18.2 %; Asian = 4.5 %; Other = 4.5 %</td>
</tr>
</tbody>
</table>

Note: AN = Anorexia Nervosa group; HC = Healthy Controls; EDNOS-R = Eating Disorders Not Otherwise Specified-Restrictive subtype; SD = Standard Deviation; % = Frequency.

Table 6.2 displays clinical characteristics of the adolescent group with anorexia nervosa including eating disorder psychopathology, weight for height, duration of symptoms and comorbid states of anxiety and depression at T1 that is, before therapy begun at initial clinical assessment. Reports on comorbidity are not formal diagnoses but indicative of a possible depression or anxiety disorder using established cut off scores. If the total score on the MFQ was 29 or above this was considered indicative of presence of a comorbid depressive disorder (Daviss et al., 2006). If the total score on the SCARED was 25 or above this was considered indicative of a possible comorbid anxiety disorder (Birmaher et al, 1999). Previous duration of symptoms was calculated at the point in time where significant change in one’s cognitions, behaviours and habits related to food weight and shape occurred that would have been of significant clinical concern and could have otherwise yielded a diagnosis of an eating disorder. This information was obtained from clinical notes found on the EPJ system as was information about the duration of symptoms, prior to the initial assessment. In the present sample, 26.2 % had eating disorder symptoms of less than 3 months, 42.9% between 3 and 12 months and 31% more than 12 months. It is worth mentioning that the sample that took part in the study was largely representative of the patients seen at the clinic in terms of age, ethnicity and eating psychopathology.
Table 6.2 Clinical related characteristics of adolescents with anorexia nervosa

| ED -TS | EDEQ-Restraint | EDEQ-Weight | EDEQ-Shape | EDEQ-Eating | W/H % | DS | Comorbidity
<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>M (SD)</td>
<td>3.58 (1.71)</td>
<td>3.30 (1.93)</td>
<td>2.99 (1.76)</td>
<td>4.21 (1.81)</td>
<td>3.78 (1.86)</td>
<td>83.29 (9.48)</td>
<td>13.97 (17.28)</td>
</tr>
</tbody>
</table>

Note: ED = Eating Disorder Psychopathology; M = Mean; W/H % = weight for height percentage; SD = standard deviation; EDEQ-TS = Eating Disorder Examination Questionnaire Total Score. DS = Duration of Symptoms; % = Frequency.

6.10.2 Demographic characteristics of parents of adolescents with anorexia nervosa

Table 6.3 shows the demographic characteristics of the parents that took part in the study.

Table 6.3 Basic demographic characteristics of parents

<table>
<thead>
<tr>
<th>N</th>
<th>Parent</th>
<th>Age (years)</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>59</td>
<td>Mothers = 66.9%</td>
<td>Mean = 47.98 (SD = 5.59)</td>
<td>White British = 83.1%</td>
</tr>
<tr>
<td>59</td>
<td>Fathers = 33.9%</td>
<td></td>
<td>White Other = 5.1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mixed Race = 5.1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Asian = 6.8%</td>
</tr>
</tbody>
</table>

Note: N = Number of participants; SD = Standard Deviation.

6.11 Results

The first set of results looks at hypotheses 1 and 2, that is exploring differences between adolescents with anorexia nervosa and healthy adolescents on anxiety related factors

6.11.1 A comparison of anxiety related vulnerability factors and worry between adolescents with anorexia nervosa and healthy adolescents (H1)

Initial assumption testing showed that some data did violate the assumption of homogeneity of variances after carrying out a Levene’s test of equality of error variances. These included IU (IUS-C), positive beliefs and worry (WWII) and negative problem orientation (NPOQ) for which a stricter alpha level will be used to determine significance following a Bonferroni adjustment (a = 05/5 = .01). A series of one way univariate analyses of variances (ANOVA) were conducted to explore differences between adolescents with anorexia nervosa and healthy adolescents on IU, cognitive avoidance, poor problem orientation, positive beliefs about worry, and worry. There were statistically significant differences detected for all of the anxiety related vulnerability factors between the two groups (see Table 6.4). The effect sizes calculated using eta squared ranged from medium for positive beliefs about worry and large
for all of the remaining variables based on Cohen’s criteria (1988). Findings reported in table 6.4 are illustrated in figure 6.3.

Table 6.4 Group differences between the clinical and control group on anxiety related factors

<table>
<thead>
<tr>
<th>DVs</th>
<th>Groups</th>
<th>N</th>
<th>M(SD)</th>
<th>F</th>
<th>(η2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>WWII</td>
<td>AN</td>
<td>39</td>
<td>57.58(22.91)</td>
<td>8.61**</td>
<td>0.13</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>41.00(17.42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IUS-C</td>
<td>AN</td>
<td>40</td>
<td>75.78(27.21)</td>
<td>29.72***</td>
<td>0.33</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>42.50(11.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPOQ</td>
<td>AN</td>
<td>41</td>
<td>33.37(12.10)</td>
<td>33.23***</td>
<td>0.36</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>17.77(5.20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CAQ</td>
<td>AN</td>
<td>38</td>
<td>62.93(22.12)</td>
<td>10.74**</td>
<td>0.15</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>45.00(17.68)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSWQ</td>
<td>AN</td>
<td>41</td>
<td>27.28(8.85)</td>
<td>28.35***</td>
<td>0.32</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>15.27(7.70)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: DVs = Dependent Variables; AN = anorexia nervosa group; F = statistical value; (η2) partial eta squared: effect size; WWII = positive beliefs about worry; IUS-C = Intolerance of Uncertainty Scale; NPOQ = Negative Problem Orientation; CAQ = Cognitive Avoidance Questionnaire; PSWQ = Penn State Worry Questionnaire.

** Significant at the p ≤.01 level

*** Significant at the p <.001 level
6.11.2 Do differences between groups remain when anxiety levels are controlled for? (H2)

Further analysis of covariance (ANCOVA) was carried out in order to examine whether differences between the two groups (i.e. adolescents with anorexia nervosa and healthy adolescents) remained even when anxiety levels were controlled for. This will provide some indication as to whether IU and other variables are elevated in adolescents with anorexia nervosa independent of anxiety. Initial assumption testing showed that only negative problem orientation violated the assumption of homogeneity of variances after carrying out a Levene’s test of equality of error variances, for which a stricter alpha level will be used to determine significance following a Bonferroni adjustment ($\alpha = 0.05/5 = .01$).

A series of one way between groups analysis of covariance (ANCOVA) were conducted. The independent variable was the group participants belonged to, the dependent variables were the examined anxiety related factors, while participants’ scores on anxiety as measured using the SCARED were used as the covariate in this analysis. After adjusting for anxiety scores, significant differences still remained between the two groups for IU; negative problem orientation and worry while this disappeared for positive beliefs about worry and cognitive avoidance (See Table 6.5). Effect size was calculated using eta squared. According to Cohen’s criteria (1988) IU showed a moderate effect size, negative problem orientation showed a large effect size and worry showed a small effect size (See Table, 6.5).
Table 6.5 Group differences between the clinical and control group after adjusting for anxiety levels

<table>
<thead>
<tr>
<th>DVs</th>
<th>Groups</th>
<th>N</th>
<th>M(SD)</th>
<th>F</th>
<th>(η²)</th>
</tr>
</thead>
<tbody>
<tr>
<td>WWII</td>
<td>AN</td>
<td>38</td>
<td>57.57(22.90)</td>
<td>.07ns</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>41.00(17.42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IUS-C</td>
<td>AN</td>
<td>38</td>
<td>76.47(27.17)</td>
<td>5.88**</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>42.50(11.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPOQ</td>
<td>AN</td>
<td>37</td>
<td>33.49(11.79)</td>
<td>9.21**</td>
<td>0.14</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>17.77(5.19 )</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CAQ</td>
<td>AN</td>
<td>38</td>
<td>63.16(21.88)</td>
<td>0.61ns</td>
<td>0.01</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>45.00(17.68)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSWQ-C</td>
<td>AN</td>
<td>37</td>
<td>26.82(8.75 )</td>
<td>4.23*</td>
<td>0.07</td>
</tr>
<tr>
<td></td>
<td>HC</td>
<td>22</td>
<td>15.27(10.04)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: DVs = Dependent Variables; AN = anorexia nervosa group; F = statistical value; (η²) partial eta squared: effect size; WWII = positive beliefs about worry; IUS-C = Intolerance of Uncertainty Scale; NPOQ = Negative Problem Orientation; CAQ = Cognitive Avoidance Questionnaire; PSWQ-C = Penn State Worry Questionnaire child version.

* Significant at the $p < .05$ level

** Significant at the $p \leq .01$ level

ns = non significant

These next sets of findings examine different associations between factors in adolescents and parents at T1, that is, prior to commencement of treatment. Firstly, the relationship between parental and child reports on IU is examined. Secondly, potential differences are explored on the examined factors between mothers and fathers. Thirdly, associations between anxiety related factors, depression, beliefs about having an eating disorder, ambivalence and eating psychopathology in adolescent are examined. Finally, which adolescent and parental factors best predict eating disorder psychopathology is explored.

6.11.3 Agreement between adolescents and parents on IU

Both adolescents with anorexia nervosa and their parents completed the IUS-C, with adolescents responding for themselves and parents reporting on their child. Adolescents scored themselves higher on IU than what their parents reported, as seen by the means in Table 6.6. Correlation analysis revealed a strong positive correlation between adolescent and parent responses on the IUS-C.
Table 6. 6 Parent-child agreement on the IUS-C (Pearson Product Moment Correlation Coefficient)

<table>
<thead>
<tr>
<th>IUSC -Child report (N= 41)</th>
<th>IUSC - Parent report (N= 37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>75.78 (27.21)</td>
</tr>
<tr>
<td>IUSC-Child report</td>
<td>542 ***</td>
</tr>
</tbody>
</table>

Note: SD = Standard deviation; N = Number of participants; IUS-C = Intolerance of Uncertainty Scale Child Version.

*** Significant at the p ≤ 0.001 level.

6.11.4 Examining differences between mothers and fathers responses on the examined factors

Initial assumption testing showed that data only on worry violated the assumption of homogeneity of variances after carrying out a Levene’s test of equality of error variances, for which a stricter alpha level will be used to determine significance following a Bonferroni adjustment (α = 05/6 = .008).

A series of ANOVAs were carried out. No significant differences were detected between mothers and fathers on worry, IU, negative problem orientation, cognitive avoidance, positive beliefs about worry and a global score of depression, anxiety and stress (See Table 6.7). Mothers and fathers responses will be grouped together for the remaining of the analyses.

Table 6. 7 Differences between mothers and fathers on the examined factors (T1)

<table>
<thead>
<tr>
<th>DVs</th>
<th>Parent (N)</th>
<th>Mean(SD)</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>DASS-TS</td>
<td>Mother (35)</td>
<td>14.37(8.51)</td>
<td>0.35**</td>
</tr>
<tr>
<td></td>
<td>Father (16)</td>
<td>12.81(9.32)</td>
<td></td>
</tr>
<tr>
<td>PSWQ</td>
<td>Mother (34)</td>
<td>48.03(12.96)</td>
<td>4.60**</td>
</tr>
<tr>
<td></td>
<td>Father (16)</td>
<td>40.50(7.75)</td>
<td></td>
</tr>
<tr>
<td>NPOQ</td>
<td>Mother (34)</td>
<td>24.12(10.56)</td>
<td>3.61**</td>
</tr>
<tr>
<td></td>
<td>Father (16)</td>
<td>18.56(7.22)</td>
<td></td>
</tr>
<tr>
<td>CAQ</td>
<td>Mother (34)</td>
<td>43.59(13.66)</td>
<td>0.07ns</td>
</tr>
<tr>
<td></td>
<td>Father (15)</td>
<td>42.40(16.12)</td>
<td></td>
</tr>
<tr>
<td>WWII</td>
<td>Mother (33)</td>
<td>45.24(17.13)</td>
<td>0.00ns</td>
</tr>
<tr>
<td></td>
<td>Father (16)</td>
<td>44.94(17.75)</td>
<td></td>
</tr>
<tr>
<td>IUS</td>
<td>Mother (34)</td>
<td>51.73(15.57)</td>
<td>0.00ns</td>
</tr>
<tr>
<td></td>
<td>Father (16)</td>
<td>51.62(17.54)</td>
<td></td>
</tr>
</tbody>
</table>

Note: DVs = Dependent Variables; N = Number of participants; SD = Standard Deviation; Sig. = Significance; F = statistic value; DASS-TS = Depression and Anxiety Stress Scale; PSWQ = Penn State Worry Questionnaire; NPOQ = Negative Problem Orientation; CAQ = Cognitive Avoidance Questionnaire; WWII = Positive Beliefs about Worry; IUS = Intolerance of Uncertainty Scale.

ns = non significant
6.11.5 Relationship between anxiety related vulnerability factors, worry, depression, beliefs about having an eating disorder and eating psychopathology (H3)

Pearson product moment correlations were carried out to examine the relationship between anxiety related vulnerability factors, worry, positive and negative beliefs about having an eating disorder, weight for height and eating psychopathology at T1 in adolescents. Medium to strong positive correlations were detected for anxiety related vulnerability factors, worry, eating psychopathology and both positive and negative beliefs about having an eating disorder. This was not the case for weight for height which did not correlate with any of the remaining variables. Depression positively correlated with most of the examined variables apart from IU and positive beliefs about worry, while, ambivalence only moderately positively correlated with depression (see Table 6.8).

Table 6.8 Pearson product moment correlation coefficient between examined factors (T1)

<table>
<thead>
<tr>
<th>Vs</th>
<th>IUS-C</th>
<th>WWII</th>
<th>NPOQ</th>
<th>CAQ</th>
<th>PSWQ</th>
<th>MFQ</th>
<th>PCED-P</th>
<th>PCED-C</th>
<th>AMB</th>
<th>EDEQ-TS</th>
<th>W/H %</th>
</tr>
</thead>
<tbody>
<tr>
<td>IUS-C</td>
<td>-</td>
<td>.72**</td>
<td>.91**</td>
<td>.76**</td>
<td>.75**</td>
<td>.32**</td>
<td>.53**</td>
<td>.57**</td>
<td>.12**</td>
<td>.79**</td>
<td>.02**</td>
</tr>
<tr>
<td>WWII</td>
<td>-</td>
<td>.70**</td>
<td>.60**</td>
<td>.56**</td>
<td>.33**</td>
<td>.43**</td>
<td>.36**</td>
<td>.05**</td>
<td>.61**</td>
<td>- .03**</td>
<td></td>
</tr>
<tr>
<td>NPOQ</td>
<td>-</td>
<td></td>
<td>.77**</td>
<td>.75**</td>
<td>.48**</td>
<td>.55**</td>
<td>.64**</td>
<td>.09**</td>
<td>.78**</td>
<td>.09**</td>
<td></td>
</tr>
<tr>
<td>CAQ</td>
<td>-</td>
<td></td>
<td></td>
<td>.66**</td>
<td>.36**</td>
<td>.55**</td>
<td>.50**</td>
<td>.04**</td>
<td>.71**</td>
<td>.06**</td>
<td></td>
</tr>
<tr>
<td>PSWQ</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td>.38*</td>
<td>.46**</td>
<td>.65**</td>
<td>.22**</td>
<td>.65**</td>
<td>- .07**</td>
<td></td>
</tr>
<tr>
<td>MFQ</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.35*</td>
<td>.38*</td>
<td>.37*</td>
<td>.48**</td>
<td>.11**</td>
<td></td>
</tr>
<tr>
<td>PCED-P</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.50**</td>
<td>.28**</td>
<td>.69**</td>
<td>.00**</td>
<td></td>
</tr>
<tr>
<td>PCED-C</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- .01**</td>
<td>.65**</td>
<td>- .07**</td>
</tr>
<tr>
<td>AMB</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.24**</td>
<td>.06**</td>
</tr>
<tr>
<td>EDEQ-TS</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.13**</td>
</tr>
<tr>
<td>W/H %</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Vs = Variables; WWII = Positive Beliefs about Worry; IUS-C = Intolerance of Uncertainty Scale Child Version; NPOQ = Negative Problem Orientation; CAQ = Cognitive Avoidance Questionnaire; PSWQ = Penn State Worry Questionnaire; MFQ = Mood and Feelings Questionnaire; PCED-P = Pros and Cons of Eating Disorders Pros Total Subscale; PCED-C = Pros and Cons of Eating Disorders Cons Total Subscale; AMB = Ambivalence; EDEQ-TS = Eating Disorder Examination Questionnaire – Total score; W/H = Weight for Height.

** Significant at the .01 level (2-tailed)

ns = non significant

Similar Pearson product moment correlations were carried out examining the relationship between anxiety factors and eating psychopathology controlling for potential confounding variables such as, duration of symptoms, age, weight for height and depression. Results remained the same as in Table 6.8
apart from the relationship between positive beliefs about worry and negative beliefs about having an eating disorder which yielded non-significant from significant.

6.11.6 Examining in more detail positive and negative beliefs about having an eating disorder with IU and eating disorder psychopathology (T1)

Pearson product moment correlations were carried out to examine the relationship between different positive and negative beliefs about having an eating disorder with IU, weight for height, and eating psychopathology. Strong positive correlations were found between IU and most of the pro subscales, including safe/structure, apart from the subscale on appearance, fertility/sexuality and fitness. Positive associations were also detected for most of the con subscales apart from hatred. Moderate to strong positive correlations were also found between eating psychopathology and both positive and negative subscales, apart from the pro subscale of appearance and the con subscale of hatred. In terms of weight for height there were no significant correlations detected with any of the PCED subscales (See Table 6.9).

Table 6.9 Pearson product moment correlation for PCED IU and eating psychopathology (T1)

<table>
<thead>
<tr>
<th>PCED</th>
<th>IU</th>
<th>W/H%</th>
<th>EDEQ-TS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pro-Safe/Structure</td>
<td>.61**</td>
<td>.10ns</td>
<td>.72**</td>
</tr>
<tr>
<td>Pro-Appearance</td>
<td>.07ns</td>
<td>-.11ns</td>
<td>.26ns</td>
</tr>
<tr>
<td>Pro-Fertility/Sexuality</td>
<td>.15ns</td>
<td>-.15ns</td>
<td>.18ns</td>
</tr>
<tr>
<td>Pro-Special Skill</td>
<td>.46**</td>
<td>-.11ns</td>
<td>.48**</td>
</tr>
<tr>
<td>Pro-Fitness</td>
<td>.18ns</td>
<td>.16ns</td>
<td>.38*</td>
</tr>
<tr>
<td>Pro-Communicate emotions</td>
<td>.47**</td>
<td>.05ns</td>
<td>.66**</td>
</tr>
<tr>
<td>Pro-Eat but stay slim</td>
<td>.35*</td>
<td>-.19ns</td>
<td>.37*</td>
</tr>
<tr>
<td>Pro-Boredom</td>
<td>.55**</td>
<td>.29ns</td>
<td>.62**</td>
</tr>
<tr>
<td>Con-Trapped</td>
<td>.45**</td>
<td>.02ns</td>
<td>.60**</td>
</tr>
<tr>
<td>Con-Guilt</td>
<td>.45**</td>
<td>-.06ns</td>
<td>.58**</td>
</tr>
<tr>
<td>Con-Hatred</td>
<td>.11ns</td>
<td>.24ns</td>
<td>.05ns</td>
</tr>
<tr>
<td>Con-Stifles emotions</td>
<td>.43**</td>
<td>.16ns</td>
<td>.46**</td>
</tr>
<tr>
<td>Con-negative self image</td>
<td>.53**</td>
<td>.04ns</td>
<td>.61**</td>
</tr>
<tr>
<td>Con-Weight and shape</td>
<td>.54**</td>
<td>-.11ns</td>
<td>.67**</td>
</tr>
</tbody>
</table>

*Correlation is significant at the .05 level (2-tailed)
**Correlation is significant at the .01 level (2-tailed)
ns = non significant

6.11.7 Do adolescent factors predict eating disorder pathology at T1 (H4).

Initial single regression analyses were carried out for all of the adolescent examined factors examining whether they predict eating disorder psychopathology (EDEQ) and W/H. The four strongest predictor
variables those of IU, worry, positive beliefs about having an eating disorder and negative beliefs about having an eating disorder were selected and a standard multiple regression analysis was carried out. Worry, IU, positive beliefs about having an eating disorder and negative beliefs about having an eating disorder were entered as the predictor variables and EDEQ global score as the outcome variable. Using the enter method a significant model emerged $F(4, 31) = 16.19, p < .0005$. The model explains 67.6% of the variance in EDEQ scores. When examining which of the predictor variables included in the model contributed to the variance in scores of the dependent variable it was found that positive beliefs about having an eating disorder and IU were the only variables to significantly contribute to the variance of EDEQ score when the remaining examined variables were accounted for (See table 6.10).

Table 6.10 Multiple regression analysis of adolescent factors predicting variance in eating disorder psychopathology (T1)

<table>
<thead>
<tr>
<th>Predictor variables (EDEQ-T1)</th>
<th>B</th>
<th>SE</th>
<th>B</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>1.62</td>
<td>.73</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>IU</td>
<td>.02</td>
<td>.01</td>
<td>.37</td>
<td>2.38</td>
<td>.02*</td>
</tr>
<tr>
<td>Worry</td>
<td>-.003</td>
<td>.03</td>
<td>-.01</td>
<td>-.11</td>
<td>.91 ns</td>
</tr>
<tr>
<td>PCED-Pros</td>
<td>.91</td>
<td>.31</td>
<td>.37</td>
<td>2.94</td>
<td>.01*</td>
</tr>
<tr>
<td>PCED-Cons</td>
<td>.64</td>
<td>.33</td>
<td>.26</td>
<td>1.96</td>
<td>.06*</td>
</tr>
</tbody>
</table>

Note: B = unstandardized coefficients; SE B = Standard Error; $\beta$ = standardized beta coefficient; $t$ = t-test value; P = significance value.

*significant at the $p < .05$ level

ns = non significant

A similar regression analysis was conducted but this time examining whether worry, IU, positive beliefs about having an eating disorder and negative beliefs about having an eating disorders can predict variance in weight for height at T1. Using the enter method the model did not yield significant $F(4, 31) = .28, p > .05$ (See Table 6.11).

Table 6.11 Multiple regression analysis of adolescent factors predicting variance in weight for height (T1)

<table>
<thead>
<tr>
<th>Predictor variables (W/H-T1)</th>
<th>B</th>
<th>SE</th>
<th>B</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>85.53</td>
<td>6.97</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>IU</td>
<td>.07</td>
<td>.09</td>
<td>.20</td>
<td>.74</td>
<td>.46 ns</td>
</tr>
<tr>
<td>Worry</td>
<td>-.25</td>
<td>.28</td>
<td>-.23</td>
<td>-.90</td>
<td>.38 ns</td>
</tr>
<tr>
<td>PCED-Pros</td>
<td>.49</td>
<td>2.96</td>
<td>.03</td>
<td>.17</td>
<td>.87 ns</td>
</tr>
<tr>
<td>PCED-Cons</td>
<td>-.84</td>
<td>3.14</td>
<td>-.06</td>
<td>-.27</td>
<td>.79 ns</td>
</tr>
</tbody>
</table>
The next set of findings look at temporal changes in adolescents who completed all three time points on eating psychopathology, anxiety related factors, beliefs about having an eating disorder and ambivalence in the first three months of therapy, as well as, changes in the examined factors in parents.

It is important to mention that attrition rates were high for T2 and T3. Reasons for this included participants having left the service early on, other participants had improved in terms of their illness and did not want to be reminded when they were unwell, or they did not have the time to complete the questionnaires as they had school exams coming up or other family issues. Finally others would forget to return the questionnaires after being reminded a couple of times.

6.11.8 Type and amount of therapy received over three months (T1-T3)

Twenty adolescents completed T1 and T3 questionnaires. On average they received an average of 11.6 therapy sessions (SD = 2.82) within that time frame. Sixty five percent (N = 13) received a combination of individual therapy (IT) and family therapy (FT); 15% (N = 3) IT+FT with multi family therapy (MFT), 15% (N = 3) IT+FT with intensive programme therapy (ITP) and 5% (N = 1) and IT+FT with both ITP and MFT.

6.11.9 Eating disorder psychopathology at all three time points for adolescents (T1-T3)

Table 6.12 and Figure 6.4/Figure 6.5 show weight for height and scores on the EDEQ at all three time points for the clinical adolescent group.

Table 6.12 Means and standards deviations of scores on the EDEQ and weight for height at all three time points

<table>
<thead>
<tr>
<th>Variable</th>
<th>EDEQ-TS</th>
<th>W/H %</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 N</td>
<td>3.51(1.45)</td>
<td>79.80(1.59)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>3.15(1.49)</td>
<td>83.16(2.25)</td>
</tr>
<tr>
<td>T3 N</td>
<td>3.44(1.26)</td>
<td>83.93(1.98)</td>
</tr>
</tbody>
</table>

Note: EDEQ-TS = eating disorder examination questionnaire-total score; SD = standard deviation; W/H = weight for height.
Figure 6.4 Mean scores on W/H for adolescents at all three time points

Figure 6.5 Mean scores on EDEQ for adolescents at all three time points
6.11.10 Positive and negative beliefs about having an eating disorder for adolescents with anorexia nervosa

Table 6.13 shows the strength of agreement and disagreement on total positive subscales of the PCED and negative subscales of the PCED at all three time points

Table 6.13 Means and standard deviations of the total PCED at all three time points

<table>
<thead>
<tr>
<th>Time point</th>
<th>N</th>
<th>PCED Total Pros Scale M(SD)</th>
<th>N</th>
<th>PCED Total Cons Scale M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>19</td>
<td>-.18(.75)</td>
<td>18</td>
<td>.72(.65)</td>
</tr>
<tr>
<td>T2</td>
<td>8</td>
<td>-.32(.63)</td>
<td>7</td>
<td>1.06(1.03)</td>
</tr>
<tr>
<td>T3</td>
<td>19</td>
<td>-.086(.76)</td>
<td>18</td>
<td>.77(.53)</td>
</tr>
</tbody>
</table>

Note: M = Mean; SD = Standard Deviation; T1 = Start of therapy; T2 = one month into therapy; T3 = three months into therapy.

6.11.11 Ambivalence in adolescents with anorexia nervosa

Table 6.14 shows mean attitudinal ambivalence scores for all three time points. These are illustrated in figure 6.6. As one can see scores are fluctuating around 2 indicating some level of ambivalence, with highest ambivalence at T3 compared to T1 and T2.

Table 6.14 Means and standard deviations of ambivalence across all time points

<table>
<thead>
<tr>
<th>N</th>
<th>AMB M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>18</td>
</tr>
<tr>
<td>T2</td>
<td>8</td>
</tr>
<tr>
<td>T3</td>
<td>18</td>
</tr>
</tbody>
</table>

Note: AMB = attitudinal ambivalence; M = Mean; SD = Standard Deviation
6.11.12 Anxiety related factors at all three time points for adolescents (T1-T3)

Table 6.15 levels of anxiety related vulnerability factors in adolescents with anorexia nervosa at T1, after one month of therapy (T2) and at three months into therapy (T3).

<table>
<thead>
<tr>
<th>Variable</th>
<th>PSWQ</th>
<th>NPOQ</th>
<th>CAQ</th>
<th>WWII</th>
<th>IUS-C</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 - N</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>M (SD)</td>
<td>27.00(9.22)</td>
<td>34.83(9.91)</td>
<td>65.27(22.43)</td>
<td>56.42(21.39)</td>
<td>76.94(26.08)</td>
</tr>
<tr>
<td>T2 - N</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>M (SD)</td>
<td>24.87(11.26)</td>
<td>27.62(9.02)</td>
<td>60.87(24.42)</td>
<td>46.28(12.54)</td>
<td>68.33(19.07)</td>
</tr>
<tr>
<td>T3 - N</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>M (SD)</td>
<td>24.61(9.58)</td>
<td>30.61(13.33)</td>
<td>66.22(20.05)</td>
<td>55.05(18.49)</td>
<td>72.29(26.28)</td>
</tr>
</tbody>
</table>

Note: PSWQ = Penn State Worry Questionnaire; NPOQ = Negative Problem Orientation Questionnaire; CAQ = Cognitive Avoidance Questionnaire; WWII = Positive Beliefs about worry; IUS = Intolerance of Uncertainty Scale; DASS-TS = Depression Anxiety and Stress Scale Total Score; M = Mean; SD = Standard Deviation.

Table 6.16 shows descriptive information for parents of adolescents with anorexia nervosa on anxiety related vulnerability factors, worry, anxiety, stress and depression at all three time points.
Table 6. 16 Parental factors for all three time points

<table>
<thead>
<tr>
<th>Variable</th>
<th>NPOQ</th>
<th>CAQ</th>
<th>WWII</th>
<th>IUS</th>
<th>PSWQ</th>
<th>DASS-TS</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 - N</td>
<td>22</td>
<td>22</td>
<td>21</td>
<td>20</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>M (SD)</td>
<td>22.13(9.94)</td>
<td>44.50(14.82)</td>
<td>45.33(19.07)</td>
<td>52.85(16.23)</td>
<td>46.31(12.71)</td>
<td>15.72(7.67)</td>
</tr>
<tr>
<td>T2 - N</td>
<td>12</td>
<td>12</td>
<td>12</td>
<td>12</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>M(SD)</td>
<td>19.58(9.71)</td>
<td>43.58(16.50)</td>
<td>44.08(20.36)</td>
<td>52.00(19.46)</td>
<td>43.17(14.73)</td>
<td>15.25(15.81)</td>
</tr>
<tr>
<td>T3 - N</td>
<td>22</td>
<td>22</td>
<td>21</td>
<td>20</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>M (SD)</td>
<td>22.83(9.98)</td>
<td>46.09(13.55)</td>
<td>48.28(25.09)</td>
<td>50.60(17.63)</td>
<td>47.72(13.29)</td>
<td>12.90(9.48)</td>
</tr>
</tbody>
</table>

Note: NPOQ = Negative Problem Orientation Questionnaire; CAQ = Cognitive Avoidance Questionnaire; WWII = Positive Beliefs about worry; IUS = Intolerance of Uncertainty Scale; PSWQ = Penn State Worry Questionnaire; DASS-TS = Depression Anxiety and Stress Scale Total Score; M = Mean; SD = Standard Deviation.

6.11.13 Examining potential differences on examined factors in adolescents and parents from T1 to T3

A set of paired samples t-tests were conducted to evaluate any significant differences on factors in adolescents and parents from T1 to T3. There was a statistically significant increase in weight for height in adolescents from T1 (M= 79.80, SD=7.14) to T3 (M=83.93, SD=8.85; t (19) = -2.70 p <.05. The eta squared statistic (.27) indicates a large effect size. All other factors in adolescents and parents did not show any significant fluctuations from T1 to T3.

This next set of findings look in more detail whether examined factors in adolescents moderate eating psychopathology at T3. In terms of mediation effect all of the examined adolescents and parental factors did not show any statistically significant changes. This restricts the examination of possible mediators of response to therapy.

6.11.14 Do adolescent factors moderate eating disorder psychopathology at T3 (H5).

A series of single regression analyses were carried out separately for all of the examined adolescent factors. Only two factors were found as significant predictors of eating disorder psychopathology at T3, those of eating disorder psychopathology and ambivalence at T1. A standard multiple regression analysis was carried out to examine whether ambivalence and eating disorder psychopathology predict variance in eating disorder psychopathology at T3. Using the enter method the model yielded significant, $F (2, 15) = 9.34$, p <.01. The model explains 55.5% of the variance in EDEQ scores. However only ambivalence remained a significant predictor while eating psychopathology did not (see Table 6.17).
Table 6.17 Multiple regression analyses of adolescent factors predicting variance in eating disorder psychopathology (T3)

<table>
<thead>
<tr>
<th>Predictor variables (EDEQ-T3)</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>2.19</td>
<td>.58</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>AMB</td>
<td>.30</td>
<td>.08</td>
<td>.64</td>
<td>3.45</td>
<td>.004**</td>
</tr>
<tr>
<td>EDEQ-T1</td>
<td>1.86</td>
<td>.16</td>
<td>.21</td>
<td>1.15</td>
<td>.26ns</td>
</tr>
</tbody>
</table>

Note: B = unstandardized coefficients; SE B = Standard Error; β = standardized beta coefficient; t = t-test value; P = significance value; AMB = Ambivalence; EDEQ = Eating Disorder Examination Questionnaire.

**significant at the p < .01 level

ns = non significant

A similar standard multiple regression analysis was conducted to explore whether ambivalence and eating psychopathology at T1 could predict weight for height at T3. Using the enter method the model did not yield significant $F (2, 14) = 1.08, p > .05$ (See Table 6.18).

Table 6. 18 Multiple regression analysis of adolescent factors predicting variance weight for height (T3)

<table>
<thead>
<tr>
<th>Predictor variables (W/H-T1)</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>85.97</td>
<td>4.43</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>AMB</td>
<td>-.97</td>
<td>.68</td>
<td>-.36</td>
<td>-1.44</td>
<td>.17ns</td>
</tr>
<tr>
<td>EDEQ-T1</td>
<td>-.04</td>
<td>1.20</td>
<td>-.01</td>
<td>-.03</td>
<td>.97ns</td>
</tr>
</tbody>
</table>

Note: B = unstandardized coefficients; SE B = Standard Error; β = standardized beta coefficient; t = t-test value; P = significance value; AMB = Ambivalence; EDEQ = Eating Disorder Examination Questionnaire.

ns = non significant

This next set of findings look in more detail whether the examined parental factors moderate eating disorder psychopathology at beginning of therapy three months into family therapy.

6.11.15 Do parental factors moderate eating psychopathology at T3 (H6).

A standard multiple regression analysis was carried out using the enter method examining whether IU, worry, as well as, depression anxiety and stress could predict eating psychopathology at T3. The model did not yield significant $F (3, 19) = .87, p > .05$.

A similar standard multiple regression analysis was also carried out using the enter method examining this time whether IU, worry, as well as, depression anxiety and stress at T1 predicted weight for height variability at T3, the model did not yield significant $F (5, 17) = 3.45, p > .05$. 

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6.12 Discussion

6.12.1 Summary of results

Differences between adolescents in the clinical group and adolescents in the healthy control group

Comorbid states of anxiety are the norm rather than the exception in individuals with anorexia nervosa. Indeed in the present sample of adolescents more than half showed current comorbid anxiety and depression. This study further found that known anxiety related vulnerability factors are significantly elevated in adolescents with anorexia nervosa compared to a healthy adolescent control group, which fully supports the first hypothesis of the study. Such results suggests that adolescents with anorexia nervosa compared to adolescents in the normal population hold more positive beliefs about worry, approach problems with a more negative stance, with little confidence in their problem solving abilities, are intolerant of uncertainty and use more avoidance cognitive strategies when faced with difficult thoughts. Worry was also found significantly elevated in adolescents with anorexia nervosa compared to healthy adolescents. This is in line with previous research that has found elevated levels of worry in adults with an eating disorder (Kerkhof et al., 2000; Sassaroli et al., 2005) and extends such findings to adolescents.

Current findings further mirror results from study 1 reported in Chapter 3, whereby adults with anorexia nervosa showed significantly higher levels of anxiety related vulnerability factors compared to a healthy control group. Comparisons of results reported in study 1 and results reported in the present Chapter are restricted as participants across the two groups were at different stages of treatment and different questionnaires were used to measure IU. However, for positive beliefs about worry, negative problem orientation and cognitive avoidance the same measures were used in both studies and comparisons suggest that adolescents scored slightly lower than adults but still higher than the control groups reported in both studies. The fact that adolescents scored slightly lower on comparable anxiety related vulnerability factors compared to adults could be due to a number of factors. It is unclear if these small differences represent a real difference or are simply reflection of chance variation. If these differences are real one could hypothesize that certain developmental factors could account for these differences. Adolescents’ level of cognitive maturity could reflect their lower scores compared to adults. With older age these anxiety related vulnerability factors could become more established traits while in young people they are still developing. In other words, how young people approach problems, whether they adopt avoidance tendencies and hold positive beliefs about worry could be in the processes of forming and thus may not be as high as in adults who have been holding such beliefs for a longer time. Other factors include duration of the eating disorder and comorbid anxiety could also be playing a role in differences in levels on anxiety related vulnerability factors between adolescents and adults.

In order to understand better whether anxiety related vulnerability factors are elevated in the present sample because of high levels of comorbid anxiety or whether they share a more close relationship with
eating psychopathology independent of anxiety, differences on the examined anxiety related factors between adolescents with anorexia nervosa and healthy adolescents were examined taking into account levels of anxiety. Results showed that differences remained at a significant level for IU, negative problem orientation and worry while they disappeared for cognitive avoidance and positive beliefs about worry. The fact that differences remained for some anxiety related factors between the two groups even when levels of anxiety were accounted for suggests that these factors show a level of independence from anxiety and remain elevated in individuals with anorexia nervosa irrespective of presence of anxiety levels.

IU was one of the examined anxiety related factors which showed significantly elevated levels in adolescents with anorexia nervosa even when anxiety levels were accounted for. High levels of IU were also reflected in parental reports of their child’s level of tolerance of uncertainty, albeit to a lower extend than what the adolescents reported. Such findings are also in line with one of the themes that emerged from the qualitative study reported in Chapter 5, whereby parents expressed that they found their children to be rigid and fearful of uncertainty. Overall, both adolescent and parental reports for IU surpassed the proposed cut off point for IU (i.e., Mean score = 58) (Koerner & Dugas, 2008). This further confirms that adolescents with anorexia nervosa have difficulties tolerating uncertainty.

What factors are associated with each other at T1 and what factors predict eating disorder psychopathology?

Positive associations were found between all of the anxiety related factors and eating psychopathology, as well as, positive and negative beliefs about having an eating disorder. The relationship between IU and beliefs about having an eating disorder was examined in more detail. According to the proposed model in Chapter 2 IU is considered to play a part in maintaining positive beliefs about having an eating disorder. Present results indicate that IU shares a positive relationship with most of the pro subscales of the PCED including the subscale of safety and security. This is in line with the theoretical predictions made in Chapter 2. In other words, a dislike towards uncertainty is positively linked to experiencing one’s anorexia nervosa as something positive that is providing them with safety and security, which to some degree can be translated as providing them with a sense of certainty. Furthermore, positive associations between anxiety related factors, such as IU and eating psychopathology remained when considering confounding factors such as depression.

A number of examined associations that did not yield significant are worth mentioning. For instance, weight for height which did not correlate with any of the examined variables. In terms of eating disorder psychopathology this could suggest that patients’ cognitions and behaviours related to weight, shape and eating could be similarly disruptive irrespective of their weight. The relationship between depression and IU also did not yield significant. Previous research has been inconsistent at times regarding the link between IU and depression, a recent review concludes that IU is a relevant factor in
major depressive disorder (Gentes & Ruscio, 2011), however present findings seem to support research that has failed to find an association between IU and depression (Fergus & Wu, 2010).

In terms of what factors best predict eating disorder psychopathology at T1, the strongest predictor variables to explain the variance in eating psychopathology (T1) were IU, worry, positive and negative beliefs about having an eating disorder, out of which only IU and positive beliefs about having an eating disorder remained significant when the other variables were controlled for.

**What changes over the first three months of therapy and what factors moderate/mediate treatment response at T3?**

When looking at temporal changes both adolescent and parental factors remained largely stable throughout the three first months of treatment. Only weight for height in adolescents changed over time and showed a statistically significant increase from T1 to T3. This is in line with what we would expect to change in the first months of therapy where the main focus is restoring a healthy weight. One explanation for the lack of change in eating disorder related cognitions and behaviours, as measured by the EDEQ, is that such changes take place later on in treatment, post weigh restoration, which allows the clinician to work on challenging eating disorder related cognitions and behaviours. The lack of temporal changes on the remaining factors in adolescents and examined factors in parents could be interpreted in several ways. One explanation could be that the measures used have trait like and not state like properties. Another interpretation could be that these factors similar to eating disorder related cognitions and behaviours change later on in therapy past the three months that were examined in the present study. A final explanation could be that these factors are stable traits within an individual that remain constant with time and only if targeted and manipulated specifically they may change.

The lack of temporal changes in adolescents and in parents during the first three months did not permit to examine mediation effects. Furthermore, parents had essentially normal scores on the examined factors which remained normal throughout the three months of therapy. No parental factors were found to moderate eating psychopathology, this could be due to the overall healthy scores of parents. In terms of adolescent factors moderating response to therapy at three months, ambivalence and eating psychopathology prior commencement of therapy were found to significantly predict eating disorder psychopathology at three months into therapy, however only ambivalence remained a significant predictor when eating psychopathology at T1 was accounted for. Such findings provide some support that ambivalence and factors contributing to mixed feelings regarding one’s eating disorder may play a part in how one responds to treatment.

**6.12.2 Strengths of study**

The main strength of the present study was that it simultaneously examined anxiety, worry and anxiety related vulnerability factors of GAD in adolescents with anorexia nervosa, moving away from previous
research which has only focused on examining prevalence of comorbid anxiety disorders. A particular strong point of the present study is the investigations of the cognitive construct of IU, which has received limited empirical examination in the field of eating disorders, particularly in adolescents despite clinical and theoretical speculations of its importance. Up-to-date measures were also utilised and a longitudinal design was adopted to explore temporal changes in variables. Finally, the present study took into account possible confounding variables such as anxiety when examining differences on IU and related factors between adolescents with anorexia nervosa and healthy controls, as well as, age, weight for height, duration of symptoms and depression when examining possible associations between anxiety related factors and eating psychopathology. Research has previously stressed when looking at comorbid states of psychopathology in eating disorder to take into account confounding variables (Godart, et al., 2006).

6.12.3 Limitations and methodological shortcomings of study 4

The present results are important to be viewed in light of a number of limitations and methodological shortcomings. First, the study highly relied on self-report measures, which could be susceptible to both conscious and unconscious distortions. For instance, responses by adolescent on anxiety could be influenced by biases such as cognitive appraisal or social desirability (Dadds, Perrin, & Yule, 1998). Second, although most of the self report measures administered to the adolescents were formally adjusted and tailored for children and adolescents, three self report questionnaires measuring positive beliefs about worry, cognitive avoidance, and negative problem orientation were not. Previous research has however administered these measures to adolescents with anxiety disorders (Laugesen, et al., 2003). A further shortcoming was due to missing data the sample size was smaller than anticipated when carrying out regression analyses examining variables in adolescents and parents as moderators of eating psychopathology at three months. Furthermore, as many examined factors in adolescents and parents remained stable over the first three months of therapy little could be concluded regarding moderator and mediator effects. The design of the present study did not include a comparison treatment to family therapy thus conclusions regarding specific moderator effects for family therapy cannot be made. When looking at effects in one treatment it is difficult to know whether certain factors influence response to that specific treatment or could be to any kind of treatment. At the same time the examined factors could also be predictors of outcome irrespective of treatment type or treatment altogether. In terms of mediation effects the design of the study did not fully allow to test mediation hypothesis. For IU to be a mediator of response to family therapy a change in IU levels would have to follow an intervention and this should lead to a subsequent change in eating disorder symptoms. The study does allow though to initially rule out IU as a mediator of treatment response at it does not change in the first three months of family therapy, furthermore, a change of eating disorder symptoms was detected but this did not follow on from any change in the examined factors as they stayed the same throughout the initial phase of family therapy.
It is important to keep in mind that this does not necessarily mean that examined factors do not affect response to treatment. A lack of statistically significant findings in terms of moderator and mediator effects could be due to the small sample size. Finally, the control group of adolescents that was used in the present study could be criticized for not being a “pure control group” as it was only screened for current eating disorder psychopathology and anxiety psychopathology but not screened for depression or past psychopathology. Despite this significant differences were detected between the two adolescent groups.
Chapter 7

Discussion and Conclusions

7.1 Overview of Chapter

Two quantitative studies and two qualitative studies were reported in the present thesis all of which sought from different perspectives to empirically examine and increase our understanding of the role of IU and associated factors in relation to anorexia nervosa. This chapter brings together key findings across all four studies, common issues, specific and generic implications. Primarily it presents additional considerations with respect to the discussions and conclusions included in the previous chapters, in order to present an integrated view of IU, anxiety and anorexia nervosa based on the model and the studies conducted in the framework of this thesis. The findings are placed in the context of key previous literature and the proposed theoretical model for IU and anorexia nervosa, developed in Chapter2. What follows is a concise outline of the present thesis strengths, limitations and methodological considerations. The chapter ends with a discussion of theoretical and clinical implications and suggestions for future research.

7.2 Key findings of the thesis in light of existing literature

This thesis provides qualitative and quantitative answers to the following fundamental questions:

1. Is IU elevated in adults and adolescents with anorexia nervosa?
2. Are anxiety related factors elevated in adults and adolescents with anorexia nervosa and are they associated with eating disorder psychopathology?
3. Do parents of adolescents with anorexia nervosa show elevated levels of IU, depression, anxiety and stress?
4. What changes in terms of the examined factors in adolescents and parents over the first three months of therapy and do any of the examined factors moderate/mediate response to therapy?

In this section answers to the above four key questions are discussed in light of relevant existing theories and previous research.

7.2.1 Is IU elevated in adults and adolescents with anorexia nervosa?

Results across the four reported studies of the present thesis confirm that IU is significantly elevated in adults and adolescents with anorexia nervosa when compared to healthy individuals and remains elevated, even when levels of anxiety are accounted for.
Such findings are very much in line with the few recent studies that have also found elevated levels of IU in both clinical and non-clinical populations with eating psychopathology (Frank et al., 2012; Konstantellou & Reynolds, 2010; Stewart, 2009; Sternheim, Startup, & Schmidt, 2011). Furthermore in study 4 (Chapter 6), IU was found positively associated with eating disorder symptoms at the beginning of therapy even when depression was accounted for. This is in line with Stewart (2009) who also reported IU to be a strong predictor of eating psychopathology even after controlling for anxiety and depression in adults with an eating disorder.

Personal accounts of adolescents with anorexia nervosa further suggest that IU is a relevant and meaningful concept in anorexia nervosa. Qualitative findings in study 2 (Chapter 4) reveal that uncertainty indeed is experienced as something negative, that although it is acknowledged an essential part of life, with some positive sides to it, it is predominately a “bad” experience and the source of much distress, anxiety and worry. Anorexia related behaviours were experienced as functioning as a way of coping with uncertainty that is distressing by providing a sense of certainty and control. Anorexia nervosa related rules can function to decrease any uncertainties regarding one’s internal feelings about a situation and/or how other people may think of them. Uncertainties and difficult feelings that are inevitable in life are thus avoided within a world where anorexia nervosa dominates. A dislike towards uncertainty in adolescents was further confirmed by the parents taking part in study 3, who without being prompted, when discussing their own experiences of uncertainty highlighted how they found their children to be intolerant of uncertainty, and that they saw this fear of uncertainty as very much linked to the illness, the rigid attitudes and need to predict the future.

The findings on IU can be discussed with other theoretical models of eating disorders. For instance, Schmidt and Treasure’s (2006) cognitive interpersonal maintenance model of anorexia nervosa argues that anorexia nervosa psychopathology is maintained by four factors unrelated to eating, weight and shape, namely rigidity, experiential avoidance, pro anorectic beliefs and responses of close others. In particular, results in this thesis can be discussed in light of two of the components of Schmidt and Treasure’s maintenance model of anorexia nervosa: rigidity and pro anorectic beliefs. For instance, adolescents with anorexia nervosa were found to hold positive beliefs about having an eating disorder which at the beginning of therapy were found to be positively associated with IU and increased at three months into therapy. This supports Schmidt and Treasure’s (2006) maintenance model of anorexia nervosa and further suggests a possible relationship between IU, and positive beliefs of having an eating disorder.

Based on findings from study 2, elevated levels of IU found in individuals with anorexia nervosa could also be related to rigidity. A rigid attitude can result from a deficit in one’s set shifting abilities, which involves difficulties in shifting from one set of rules to a new set of rules and has been found impaired in individuals with anorexia nervosa (Roberts, Tchanturia, Stahl, Southgate, & Treasure, 2007; Siep, Jansen, Havermans, & Roefs, 2010). In fact, rigidity in childhood has been linked to a deficit in set shifting at
older age (Tchanturia et al., 2004). A rigid attitude can also be thought of in terms of psychological inflexibility (Merwin, 2011), which is suggested to be a fundamental aspect of psychological well-being (Kashdan & Rottenberg, 2010). In terms of the present findings, an aversion to uncertainty could be playing a part in increasing a rigid attitude, since a fear of uncertainty and change are also implicit when considering rigidity. In principle, it is difficult to know how neurocognitive deficits may interact with IU and whether IU underpins behavioural and cognitive expressions of rigidity. One of the themes identified when discussing uncertainty with the adolescents was an anticipatory fear of change and a need to stick to certain routines. Unexpected change of plans and holidays were mentioned as particularly difficult to manage by both the adolescents and their parents, possibly due to being faced with a new situation and the accompanied fear of the possibility of an unexpected negative outcome. IU then may be underlying these fears and enhancing rigidity.

What seems to underlie IU and a fear of change is the anticipation of a negative outcome. Expecting and fearing a worst case scenario was often mentioned by the adolescents and this was a key element of uncertainty that was characterised as “bad”. For instance, the adolescents often described how the unpredictability of their own feelings and how others thought of them was distressing and they wanted to know and predict the future. A change of plan to a schedule triggered feelings of fear and apprehension and anorexia related behaviours seemed to take over. This clearly underlies an information processing bias towards threat perception which is often mentioned in the anxiety literature (Dugas, et al., 1998; Dugas, Hedayati, et al., 2005). These underlying processes and fears can be understood as underpinning both anxiety related processes and anorexia nervosa related behaviours.

It was not always clear from study 2 how much particular behaviours were driven by the eating disorder and how much by the comorbid anxiety disorder. It may be more helpful instead of trying to allocate certain traits and behaviours to either one or other disorder to understand instead how they come together to maintain the present clinical profile of a patient and how they relate to current symptoms and treatment outcome.

Issues around control also need to be considered in light of the present findings on IU and in relation to rigidity and threat perception. The concept of control is often linked to eating psychopathology, in particular anorexia nervosa (see Chapter section 11.2.7, titled: Control and eating disorders). Individuals with anorexia nervosa are said to experience a high need for control (Bruch, 1978; Button, 1985; Fairburn, et al., 1999; Sassaroli, Gallucci, & Ruggiero, 2008; Reid, et al., 2008) but little is known of how this need for control may be linked to how one manages uncertainty. In the present thesis, the need for control was discussed when thinking of uncertainty by adolescents with anorexia and seems to be intertwined with IU. From results in study 2 & 3 a need for control seems to function as a way to decrease uncertainty and increase certainty which would eliminate any potential threatening scenarios from happening. This could involve both internal and external threatening scenarios. One element that differentiates the need for control and need for certainty is the interpersonal aspect of control. Being in control may meet the need for certainty but equally certainty in some contexts might be provided when
others are in control or when one is experiencing a relationship that is trusting and caring. Anorexia related behaviours then appear to be under one’s control, at least to begin with, and provide a sense of certainty and control. This then may lean individuals to rely on their illness to ensure certainty and safety. Anorexia nervosa has been previously conceptualised as a coping strategy through which one manages distressful emotions such as anxiety (Troop, Holbrey, Trowler, & Treasure, 1994; Troop, Holbrey & Treasure, 1998). Less is known whether anorexia nervosa takes up a functional role to start with or becomes a coping mechanism later on.

7.2.2 Are anxiety related factors elevated in adults and adolescents with anorexia nervosa and are they associated with eating disorder psychopathology?

The second set of key findings suggests that anxiety related vulnerability factors (i.e., negative problem orientation, cognitive avoidance, and beliefs about worry), other than IU, are also elevated in adults and adolescents with anorexia nervosa when compared to healthy controls. Some of which also remain elevated when anxiety is accounted for, such as negative problem orientation in both adolescents and adults and positive beliefs about worry in adults. Worry, the cardinal feature of GAD, was also found elevated in adolescents with anorexia nervosa, supporting previous research that has identified elevated levels of worry in adults with eating psychopathology (Wadden et al., 1991; Kekhof et al., 1991; Scattolon & Nicky, 1995; Sassaroli & Ruggiero, 2005). Worry has only recently received attention in a number of psychological disorders and has been considered to be a transdiagnostic factor of psychological distress not only restricted to GAD (Kertz 2011). Within the field of eating disorders Sassaroli & Ruggiero (2011) have developed a theoretical model and treatment protocol emphasising the importance of attending to elevated levels of worry in individuals with an eating disorder. Much of their proposed model is consistent with the present thesis and findings, although their principal emphasis is on addressing the need for control and worry rather than IU. In terms of temporal changes elevated levels of anxiety related vulnerability factors and worry according to findings reported in Chapter 6 remain elevated in the first three months of therapy. This to one extent may reflect the presence and temporal stability of anxiety as previously discussed in Chapter 1.

The present findings further show positive associations between most of the examined anxiety related factors and eating psychopathology in both adults, apart from positive beliefs about worry and cognitive avoidance and adolescents. Worry was also found positively correlated with eating psychopathology in adolescents. When looking at which factors best predicted variability in EDEQ scores, IU was an important predictor in both adults and adolescents while positive beliefs about having an eating disorder were also found significant in adolescents. Although anxiety related factors are associated with eating disorder psychopathology and some were found to predict eating disorder psychopathology at T1, such factors did not moderate response to therapy, only ambivalence was found to predict eating disorder psychopathology at three months into therapy.
Overall, anxiety related vulnerability factors seem to be relevant in individuals with anorexia nervosa and not necessarily present in relation to anxiety. There is a need to understand better their relationship with both eating disorder psychopathology and anxiety and whether they may be associated with other characteristics of individuals with anorexia nervosa. For instance, low self esteem often found in patients with anorexia nervosa could be associated with negative problem orientation. Negative problem orientation involves a tendency to find problems threatening, doubts about one’s problem-solving abilities and holding a pessimistic view about the outcome of a problem, which to some extent implies low levels of confidence and self esteem.

7.2.3 Do parents of adolescents with anorexia nervosa show elevated levels of IU, depression, anxiety and stress?

According to results from study 4 (Chapter 6), parents overall scored within the healthy range on factors relating to anxiety, worry, IU, and depression. In fact parents scored very similarly on cognitive avoidance, and slightly lower on scores relating to negative problem orientation and positive beliefs about worry when comparing their responses to those in the healthy adult group in study 1 (Table 3.3). Furthermore, parental scores on the IUS are substantially below the cut off point of 58 for determining high IU as reported by Koerner and Dugas (2008). Only scores relating to depression anxiety and stress, as measured by the DASS-21, were found above previously reported adult norms (Henry & Crawford, 2005). Parents own accounts when discussing uncertainty further revealed that overall uncertainty could be positive. Parents however, did show state IU in relation to their child’s illness. Uncertainty seemed to play a key role in their distress and was experienced as an integral part of their child’s illness which was intolerable and negative. Parents could discuss different levels of coping and managing stress and uncertainty in different life domains, with some parents finding uncertainty at times exciting. However, when they were referring to uncertainty in relation to their ill child, their coping strategies and confidence in their judgments as parents became severely impaired. According to present findings in study 4, parental levels on the examined factors remained healthy and stable over the first three months of therapy.

7.3 How do present findings fit with the proposed theoretical model of IU and anorexia nervosa

In Chapter 2 a conceptual model was proposed for the role of IU in anorexia nervosa. This model made a number of assumptions. These included that IU accounts to some extent for both the presence of comorbid states of anxiety/worry and factors often found in individuals with anorexia nervosa, such as, low novelty seeking, rigidity and need for control but also shares a close relationship with eating disorder psychopathology, such as restricting and holding positive beliefs about having an eating disorder. In other words, two pathways were proposed through which IU might play a role in maintaining eating disorder psychopathology and comorbid states of anxiety which can lead to a low motivation to change and make engagement in treatment difficult.

The findings presented in this thesis provide some support for the proposed model in the following ways. First, IU was found to be elevated in individuals with anorexia nervosa and was associated with
levels of eating psychopathology including dieting and with positive beliefs about having an eating disorder including the belief that the anorexia nervosa provides for a sense of safety and security. This supports initial suggestions in the proposed model. Secondly, the need for control and certainty were expressed by adolescents themselves as ways of dealing with a fear of uncertainty and preventing a worst case scenario from happening. The need to feel in control in different life situations and to feel certain about what will happen in the future was perceived as a way of ensuring that nothing negative would happen or provided a mean for dealing with negative events if they were to take place. Thirdly, in accordance with the presented model, parents also showed slightly elevated levels of IU but mostly uncertainty in relation to their child’s illness, which was described as having a paralysing effect on their confidence and trust in the decisions they had to make. The uncertain course of their child’s illness and the unpredictable behaviours of their children were also cause for much distress.

There were two unexpected findings in studies 1 & 4 that were not considered in the proposed model. Firstly, IU was also associated with negative beliefs about having an eating disorder. This was not predicted because a negative stance towards having an eating disorder might be thought to be associated with wanting to get better and a greater acceptance of change which would suggest the presence of low levels of IU. However, holding negative beliefs about having an eating disorder does not in itself indicate motivation to change. Secondly, no association was found between weight and IU in either the adolescent or adult group. Only self reported eating related cognitions and behaviours were associated with IU and not physical state. This is in contrast with the assumption that the more one dislikes uncertainty the more one will need certainty and control which will result in engaging in more restricting behaviours as they increase a sense of control and subsequently result in lower weight. One explanation could be that IU is present irrespective of one’s physical state. A further explanation could be that measuring state IU instead of trait IU would help understand better the relationship between fluctuations in weight and IU.

In terms of parental data, findings are in line with the proposed model in a number of ways. First, according to the proposed model high levels of IU are thought to play a part in how parents and the family as a whole adapt to the anorexia nervosa and manage it. One of the themes identified in study 3 was the impact of uncertainty on the family (see super-ordinate theme 7, Chapter 5), were parents described how as a family they responded to the illness by having strict routines that served to decrease any uncertain situations that were usually experienced as stressful. Second, some parents liked or disliked uncertainty in general while all parents disliked uncertainty in the face of their child’s illness. This provides some support to what was discussed in Chapter 2 in terms of IU showing both trait and state properties and that a dislike towards uncertainty can both be present in parents as a personality trait but also as a result of the illness and the threatening and unpredictable nature that comes along with it. Third, according to the proposed model parents are thought to find uncertainty distressing and prefer to approach their child’s illness in a way that does not leave any space for uncertainty and potential negative outcomes. This links to the theme of parental roles and abilities (see super-ordinate
theme 4, Chapter 5) especially how parents’ confidence and decision-making abilities become limited when faced with the uncertainty and their child’s illness.

Overall, the proposed model in Chapter 2 focuses mostly on cognitive processes, which were investigated in the thesis. It provides a starting point for a more elaborate model to be developed, which takes into account cognitive, emotional, developmental, neuropsychological and interpersonal factors.

7.4 Strengths of the thesis

The present thesis has contributed to the literature of eating disorders by examining the interrelated role of anxiety, IU and other factors such as worry in relation to eating disorder psychopathology in both adults and adolescents and has suggested a conceptual model which places IU as a key maintenance mechanism for anorexia nervosa. The proposed model of IU in anorexia nervosa provided a point of reference for the four research studies which combined both qualitative and quantitative designs, a methodological strength of the thesis. Adopting a mixed methods approach (quantitative and qualitative) is particularly important when exploring new concepts as it allows the patients’ own experience to accessed giving insight in to the possible role of IU in anorexia nervosa.

7.5 Limitations and methodological considerations of the thesis

Specific limitations and methodological shortcomings of each of the four studies in this thesis have been discusses in previous chapters (Chapters 3-6) and to avoid repetitions will not be mentioned in this chapter. A number of overarching limitations however of the thesis are important to be considered. The present thesis has provided some insights into the relationship between IU and anorexia nervosa, but these are far from making any firm conclusions. Many questions still remain unanswered regarding the role of IU in anorexia nervosa. It is not known, for instance, whether IU is a causal factor of positive beliefs about having an eating disorder and eating psychopathology. IU would have had to be experimentally manipulated and change in IU would have needed to be shown to predate change in eating psychopathology in order for IU to be considered as a causal factor. This was not examined in the present thesis. A further limitation was that the present thesis did not examine and control for OCD symptoms, which are known to share positive associations with IU. Other potential confounding variables were also not taken into account, such as, perfectionism, neuroticism, and self esteem which are part of the clinical presentation of anorexia nervosa and have been empirically found to maintain eating disorder psychopathology and could also be associated with IU. This would have required a much larger sample sized with broader aims of the thesis. Having a number of clinical control groups would have also allowed to directly compare anxiety related vulnerability factors across samples of individuals with an eating disorder, anxiety disorder and depression. This would have further advanced our understanding of whether such factors are common vulnerability factors across a number of disorders. Finally, lack of findings related to possible moderators and mediators of response to treatment do not necessarily mean that anxiety related factors or beliefs about having an eating disorder do not affect
response to treatment. A number of methodological shortcomings could be held accountable for non significant results, including, insufficient power of the sample, small completion rate of all three time points resulting in a small sample, measures selected not sufficiently sensitive to pick up on changes, or ceiling effects in measures.

7.6 Theoretical and clinical implications of the thesis

The findings presented in this thesis have the potential to contribute to current theoretical understanding of maintenance factors for anorexia nervosa and provide directions for new clinical advances for the treatment of anorexia nervosa.

7.6.1 Theoretical and clinical implications for patients with anorexia nervosa

Current models of anorexia nervosa for adults and adolescents need to incorporate better understandings of comorbid states in individuals with anorexia nervosa, how they are associated with eating psychopathology and how they affect treatment. Studies 1 & 4 have highlighted the importance of anxiety related vulnerability factors and worry in individuals with anorexia nervosa and in explaining high levels of comorbid anxiety, in particular GAD. Such findings further support the notion that anorexia nervosa and anxiety disorders have in common shared vulnerability factors (Pallister & Waller, 2008).

Clinically, patients with anorexia nervosa, who show elevated levels of IU and comorbid anxiety and who may not have responded well to otherwise effective treatments could benefit from interventions targeting IU and other related factors around anxiety and worry. Existing treatment interventions specifically aimed at patients with GAD (Dugas & Ladouceur, 2000; Dugas, Francis, & Bouchard, 2009; Ladouceur et al., 2000) and other types of anxiety (Hewitt, Egan, & Rees, 2009) could be adapted for eating disorder patients and incorporated into existing treatment formulations for patients with anorexia nervosa. The findings in this thesis highlight the need for IU to be considered in theoretical models of anorexia nervosa alongside other factors such as perfectionism and low self esteem. It also offers an alternative way of conceptualising the need for control, considered by some (e.g. Fairburn, et al 1998) as central factor to understanding anorexia nervosa that needs to be attended in treatment. Such models may benefit from including IU as a component of their model, as this will help understand better different pathways that may be maintaining a need for control, comorbidity and eating disorder symptoms.

Patients with anorexia nervosa who show elevated levels of IU without the presence of anxiety may also benefit from managing uncertainty better. This may help them detach from their anorexia nervosa behaviours that may be experienced as a source of control and certainty, as well, help them become less rigid, and come to terms with change. In study 2, uncertainty that was considered “bad” was also expressed by adolescents in different areas of their lives including when thinking about the future and what other people thought of them, the treatment process, what will happen and how they will feel if
they gained weight. Knowing then how to manage uncertainty better could be clinically important as it would help patients with anorexia nervosa tolerate uncertainty better in different aspects of their life.

Understanding also better the interaction between IU and the treatment process is also crucial. Although family therapy for adolescent anorexia nervosa does not specifically target elevated levels of IU and IU as a trait will be more difficult to change, therapy does touch upon issues of uncertainty. In relation to family therapy for eating disorders psycho-education and informing the family about the illness and treatment plan and prognosis can play an important role in decreasing state IU in relation to anorexia nervosa as does supporting parents to be firm and take the lead in managing their child’s illness. In other words, family therapy attempts to reduce uncertainty in the beginning of therapy by providing information to the patient and their parents while towards the end of therapy, attempts to increase tolerance of uncertainty e.g. by helping parents give back responsibility to the adolescent, questioning the absoluteness of expected healthy weight and discussing the need to accept some level of uncertainty as to what will happen in the future. Thus while it may be helpful to initially reduce uncertainty, over the course of treatment increasing the tolerance of uncertainty is likely to be a more important goal. Tolerating uncertainty then could prove as an important protective factor against psychopathology in general. Traditionally attention has been placed on identifying factors contributing to psychopathology however research has increasingly started examining factors that can have a protective impact against young people developing eating disorders.

Finally, according to results from study 4, ambivalence was associated with low mood and emerged as a moderator of eating psychopathology at three months into therapy. That is levels of ambivalence were found to predict levels of eating disorder psychopathology at three months into treatment. Such findings are in accordance with the notion that individuals with anorexia nervosa are ambivalent towards treatment. A growing body of research has looked at motivation interviewing (Price-Evans & Treasure, 2011; Wilson & Schlam, 2004) and the applicability of the transtheoretical stages of change model (Prochaska, DiClemente, & Norcross, 1992) in eating disorders (Blake, Turnbull, & Treasure, 1997; Hasler, Delsignore, Milos, Buddeberg, Schnyder, 2004; Ward, Troop, Todd, & Treasure, 1996). Indeed, increasing motivation at assessment of adolescents undergoing outpatient treatment increase engagement and behavioural changes (Gowers & Smyth, 2004). A recent systematic review of 13 studies suggests that treatments for eating disorder patients that included motivation interviewing showed favourable results especially in relation to one’s readiness to change (Macdonald, Hibbs, Corfield, & Treasure, 2012). A review looking of both the transtheoretical model of change and motivational interviewing in eating disorders suggests that there is some evidence that initial stage of change predicts outcome of eating disorder psychopathology, evidence regarding the efficacy of motivational interviewing is less convincing at present as there are few studies with varied methodology (Dray & Wade, 2012).
One area that has not been explicitly looked when considering the transtheoretical model of change for eating disorders and ways to increase patients’ motivation to change is IU. Directly targeting high levels of IU may help increase motivation to change and mobilise patients towards recovery. 7.6.2 Theoretical and clinical implications for parents

Overall, parents showed healthy levels of anxiety related vulnerability factors, with slightly elevated levels compared to reported norms on depression, anxiety and stress. This is understandable given the stressful situation of caring for a child with an eating disorder. In terms of IU, quantitative findings revealed that parents scored well below the cut off point. Parental levels on anxiety related vulnerability factors, depression, anxiety and stress were not associated with their child’s eating psychopathology nor did any parental factors moderate eating psychopathology at three months into treatment. However, qualitative findings reported in Chapter 5 highlight that parents of adolescents with anorexia nervosa did show a strong dislike towards uncertainty when thinking of uncertainty in relation to their child’s illness, which they described as very distressing. For instance, parents discussed how much uncertainty negatively affected their confidence as parents and their decision making skills making them crippled in the face of uncertainty associated with their child’s illness, which was a type of uncertainty that was extreme and they had never experienced before. In other words, parents showed state IU, that is, an IU that was related to a specific situation rather than a general trait IU.

Attending in therapy to the distressed state of parents and helping them manage uncertainty better, particularly in light of their child’s illness, could prove beneficial for the parents and subsequently for the child as well. At present, interventions targeting high levels of IU have only been developed for patients (Dugas & Ladouceur, 2000; Dugas, Francis, & Bouchard, 2009; Ladouceur et al., 2000) and not carers. Family therapy aims to reduce family burden, distress and guilt, empowering parents and helping them identify and use their own resources to manage their child’s illness. Present findings indicate that parents could benefit from an additional treatment component that targets IU, particularly in relation to their child’s illness. Learning to manage and tolerate uncertainty better could also prove useful for families to mobilise themselves, welcome change and move forward instead of feeling deskillled, incompetent and frightened. Providing parents with sufficient information and support to deal with anorexia nervosa, in addition to helping them manage uncertainty better could also contribute in parents feeling more able to take hopeful steps in the unknown future, challenging the illness and avoiding getting stuck in the present with unhelpful rigid patterns. End of therapy can be a very uncertain time and anxiety could become elevated due to worries whether their child will stay well or relapse. Parents who already have a predisposition to find uncertainty particularly upsetting may become quite fearful with the end of therapy in sight. Examining parental uncertainty can further shed light into factors that are associated with parental feelings of control and confidence. As previously discussed in Chapter 1 (section 1.4.1), parental management is a key component of family therapy for anorexia nervosa, which has also been found to predict treatment outcome (Ellison et al., 2012). If state IU in parents undermines their confidence and ability to be firm with their child this would be a promising area to attend to in treatment. Further research is needed to understand better the dynamic
relationship between parental experiences of uncertainty and management of eating symptoms and the therapeutic process. Suitable measures would need to be available to measure IU in parents and this could be done by either developing a new measure that captures both trait and state IU or adapt existing measures such as the Parental Perception of Uncertainty Scale (PPUS; Mischel, 1983) or the IUS-situation specific version (IUS-SS; Mahoney & McEvoy, 2012b) for parents of adolescents with anorexia nervosa.

7.7 Future research and developments

This thesis indicates that future research should continue to examine IU as a possible maintenance factor of anorexia nervosa. Future research would benefit from replicating the studies included in this thesis, which would add to the confidence of the thesis conclusions. Of particular value would be a study that addresses the need to understand better IU and its role in anorexia nervosa, as well as, its relationship with factors such as perfectionism, neuroticism, self esteem, rigidity and need for control. Research is further required that will look into examining the possible causal relationship between IU and eating psychopathology, possibly by manipulating IU and looking at levels of eating psychopathology, such as dieting. Future research would also be of value that explores changes in anxiety related underlying factors and beliefs about worry during a longer period of therapy and at the end of treatment, using a longitudinal design. This is important in order to ascertain better which factors moderate and mediate treatment outcome and may influence relapse as well.

Any future research would need to carefully consider what instrument is selected to measure IU. Using appropriate measurement for IU is important to understand the relationship between IU and anorexia nervosa. At present the IUS has been the most widely used measure for IU, used across different studies with different clinical and non clinical populations. The IUS however was initially developed within the GAD literature and is not a disorder neutral measure. Using the IUS within an eating disorder population will shed light into the extent to which these individuals find uncertainty intolerable but anxiety related references within the IUS may bias findings and capture individuals’ dislike towards uncertainty and anxiety as opposed to individuals dislike towards uncertainty per se. In other words, the IUS is biased in measuring IU in relation to worry and anxiety and may not be able to measure IU as a construct on its own irrespective of anxiety and worry. Different alternatives to the IUS have been developed in the form of the IUI, which has attempted to overcome the limitation of the IUS by introducing two parts to the measure, part A and part B. Part A aims to measure IU per se, while part B measures certain reactions to uncertainty. Future research could aim to develop a new measure for IU. Research is accumulating and showing that IU is relevant in a number of psychological disorders, which further supports the need for future research to develop a new ‘neutral free’ measure for IU. This would allow for comparisons to be made between studies with patients with different psychological diagnosis.

Further qualitative research in individuals with anorexia nervosa and carers is also needed, particularly in relation to uncertainty. Qualitative studies in the present thesis have provided some important insights in understanding in depth issues surrounding need for control, uncertainty, and anorexia
nervosa behaviour and how they may relate to one another. Future research may replicate studies 2 & 3 as this will increase confidence in present qualitative findings and may yield additional themes. Running similar focus groups with adolescents at different stages of their illness (i.e. at the start of therapy, during therapy, end of treatment, and post treatment), will also allow for better understanding of the temporal relationship between experiences of uncertainty and anorexia nervosa. Finally, further research is needed to understand better possible developmental differences in individuals with anorexia nervosa and how this may affect their symptoms and illness prognosis. Qualitative research with parents may attempt to examine parents’ experiences of uncertainty when caring for a child with anorexia nervosa at different stages recovery and at different treatment settings. This would increase our understanding of whether the experience of uncertainty had changed during the time their child was ill. Finally, it would be interesting to examine how parents of adolescents with bulimia nervosa experience uncertainty, and differences in themes, given the fewer physical complications seen in individuals with bulimia nervosa.

Last but not least results from the four studies presented in this thesis along with theoretical considerations point towards the possible value of helping adolescents and parents manage uncertainty better, particularly in the context of the anorexia nervosa. Future research developments, for instance, in the form of randomized control trials, could examine whether treatment as usual for anorexia nervosa compared to treatment with an add-on therapeutic component that directly targets IU, increases treatment effectiveness for patients and if it does for whom and under what conditions.

7.8 Conclusions
This thesis has extended our knowledge of anxiety related vulnerability factors in anorexia nervosa. Focus has mainly been placed on intolerance of uncertainty, a cognitive construct which has received little attention in the field of eating disorders, particularly in adolescents. Taken together the findings of the present thesis have answered some questions regarding the role of IU in anorexia nervosa and encourage future research that will inform and refine both theoretical conceptualisations considering the relationship between anxiety, anorexia nervosa and IU and possible new therapeutic avenues for both adolescents and adults.
CHAPTER 8

Outline of a future research study

8.1 Overview of chapter
The present thesis has examined IU and related factors in adults and adolescents with anorexia nervosa. Results presented in studies 1-4 (Chapters 3 to 6) have contributed to the limited literature that is available on IU in the field of eating disorders, in particular knowledge on IU in adolescents with anorexia nervosa was non-existent prior to this thesis. Overall findings and both clinical and theoretical implications are discussed in Chapter 7. The present Chapter highlights areas where future research is needed to advance our understanding of the role of IU in anorexia nervosa and a potential future research project is presented.

8.2 Promising areas for future research following on from studies 1-4
Replication of studies 1 to 4 is needed to increase credibility in findings. Further research is also paramount to add to our understanding of the role of IU in the field of eating disorders. So far only a handful of studies have examined IU in the eating disorders, all of which consistently show that IU is elevated in this clinical population. Many questions however remain unanswered. For instance, we do not know whether adolescents with anorexia nervosa show similar levels of IU compared to adolescents with an anxiety disorder. In other words, levels of IU in adolescents with anorexia nervosa have not been directly compared to a clinical control group. This will increase our understanding of whether these two disorders share common vulnerability factors. We know that IU, poor problem orientation, cognitive avoidance and worry are elevated in adults and adolescents with anorexia nervosa however we know less about the relevance of IU to adolescents with anorexia nervosa and whether similar pathways emerge as those seen in adolescents with an anxiety disorder (Fialko et al., 2012).

The limited available literature on IU and eating disorders has been dominated by cross-sectional studies, which restricts any causal inferences to be made. Study 4 is the only study at present to prospectively examine IU and associated factors in the first few months of treatment for adolescents with anorexia nervosa. Results from Study 4 did not detect any significant changes in anxiety related vulnerability factors suggesting that such factors remain stable throughout the first few months of family therapy for adolescent anorexia nervosa. As discussed in Chapter 6 this could also reflect the small sample size and insufficient power in the analysis and/or it could be down to the measures that were used to assess anxiety related vulnerability factors not being sensitive enough to pick up change. Longitudinal research is essential to our understanding of anxiety related vulnerability factors and temporal changes throughout the whole course of treatment, as well as, their relationship with eating psychopathology, beliefs about having an eating disorder and weight gain and whether such factors predict treatment outcome and relapse. For instance, IU may contribute in increasing relapse rates as
the more fearful of uncertainty you are the more likely you may resort to anorexia related behaviours in order to feel a sense of certainty and once treatment has ended this may prove a very sensitive period. We also have very little knowledge of factors that moderate and mediate response to effective treatments such as family therapy as only recently have moderators and mediators of family therapy started to be systematically examined (Le Grange, et al., 2012). Examining factors outside of those related to food, weight and shape, such as, IU and worry is also important as it can increase our understanding of a subgroup of patients who do not respond well to effective treatments.

A further key area for future research involves examining the potential beneficial role of interventions aimed specifically at helping patients with anorexia nervosa tolerate and manage uncertainty better and whether such interventions need to be targeted at specific subgroups. We would expect that such an intervention would benefit eating disorder patients who have comorbid anxiety disorders or anxiety symptoms since previous research suggests that targeting IU does decrease levels IU and shows some advantageous treatment outcome effects (Dugas, et al., 2003; Léger, et al., 2003). According to the proposed conceptual model in Chapter 2, targeting IU could benefit patients undergoing therapy for anorexia nervosa in a number of ways. First, helping patients accept and manage uncertainty better might reduce the general need for control when dealing with general life situations and life cycle changes. The initial urge for certainty and control can be understood as stemming from a cognitive bias where a fear of a worst case scenario prevails. A shift in perspective such as seeing uncertainty as providing opportunity for growth and change towards something positive can also help patients worry less and adopt a more flexible way of thinking and approaching life’s uncertainty. For instance, having the skills to manage uncertainty better can help adolescents when faced with different transitions in their lives and manage in a healthy way when confronted with uncertain situations, instead of engaging with maladaptive coping strategies. Second, decreasing levels of IU could also have positive effects in relation to patients’ anorexia nervosa. Patients often mention the positive attachment they hold towards their illness as it is experienced as providing them with a sense of control and certainty and tolerating uncertainty could decrease the value patients place on their illness. Greater tolerance of uncertainty and change could contribute to the development of a stronger therapeutic alliance, a key non-specific factor determining treatment outcome (Pereira, Lock, & Oggins, 2006).

Finally, another line of research is needed that examines more dynamically the role of IU on a family level. Findings from study 3 provide some support that parents who care for a young person with anorexia nervosa find uncertainty linked to their child’s illness to be extreme, distressing and deliberating. Further research is needed to confirm such findings and understand better how parental uncertainty is experienced throughout their child’s treatment, how it may influence parents’ confidence in managing their child’s eating disorder and whether there is a need to attend to parents’ uncertainty, which could subsequently lead to better treatment outcomes.
8.3 Proposed future study
The following sections present a proposal for a future study focusing on developing our understanding of IU in adolescent anorexia nervosa.

8.3.1 Study aims
The main aims of the proposed study are threefold:

1. To directly compare levels of anxiety related vulnerability factors, including IU, between adolescents with anorexia nervosa, healthy controls and a clinical control group of adolescents with an anxiety disorder (GAD). To further examine levels of anxiety related vulnerability factors across groups when controlling for levels of worry and depression and explore the relationship between IU, worry, GAD and eating psychopathology.

2. To examine the applicability of an IU path model (Dugas et al., 1998) to adolescents with an eating disorder, where IU is a higher order vulnerability factor for cognitive avoidance, poor problem orientation and cognitive avoidance and worry acts as a mediating factor between anxiety related vulnerability factors and anxiety. Fig 8.1 provides an illustration of the theoretical path model.

3. To conduct a longitudinal prospective study of treatment seeking adolescents with anorexia nervosa examining IU, and eating disorder symptoms including beliefs about having an eating disorder throughout treatment and after treatment has ended. This will enable two things. First, to understand whether IU at the start of therapy is a good predictor of treatment outcome and relapse out of worry, depression and eating psychopathology and identify which subgroup of patients may benefit from a treatment component that targets IU. Second, understand better the temporal relationship between IU, eating psychopathology and beliefs about having an eating disorder from start of treatment to end of treatment and at follow up. This will highlight whether IU changes at all throughout treatment and if it does whether change in IU predicts change in eating disorder symptomatology and/or beliefs about having an eating disorder.
8.3.2 Hypotheses

Hypothesis 1 (Study aim 1): Adolescents with anorexia nervosa and those with GAD will score significantly higher on the examined anxiety related vulnerability factors when compared to healthy adolescents, while adolescents with anorexia nervosa will score similar to adolescents with GAD even after controlling for levels of worry and depression.

Hypothesis 2 (Study aim 1): Adolescents with a primary disorder of anorexia nervosa and a comorbid anxiety disorder will score the highest on anxiety related vulnerability factors compared to adolescents with either a diagnosis of anorexia nervosa or GAD. This draws on from previous studies that have found that individuals with the most comorbid states of psychological distress have the highest levels of IU (Dupuy & Ladouceur, 2008; Holaway, et al., 2006; Yook, et al., 2010). [Please see Chapter 1 section 1.3.2 titled “IU as a generic factor of psychological distress” for further details].

Hypothesis 3 (Study aim 2): When testing the applicability of a pathway model of IU in adolescents with anorexia nervosa, IU will act as a higher order vulnerability factor for cognitive avoidance and problem orientation, whereby frequency of worry will mediate the relationship between these cognitive variables and anxiety.
Hypothesis 4 (Study aim 3): Patients with high levels of IU, at the beginning of therapy, will show a poorer treatment outcome and higher relapse rates compared to patients with low levels of IU.

Hypothesis 5 (Study aim 3): IU at the start of therapy will be a good predictor of treatment outcome and relapse out of worry, depression and eating psychopathology. Any change in IU throughout treatment will mediate change in eating psychopathology and beliefs about having an eating disorder.

8.3.3 Proposed Methodology
The proposed quantitative study is broken down into two parts, a cross sectional part and a longitudinal part.

8.3.3.1 Design
A cross sectional design was selected to examine hypotheses 1, 2 and 3, while a longitudinal design was selected to examine hypotheses 4 and 5.

8.3.3.2 Participants
Three groups of adolescent participants will be recruited for this study, a clinical eating disorder group, an anxiety disorder group and a healthy adolescent group. The clinical sample of adolescents with anorexia nervosa will be used to examine all five hypotheses. Adolescents will be eligible for the clinical groups if they are aged 13 to 18 years old, with a DSM-IV and ICD-10 diagnosis of anorexia nervosa/EDNOS-R or GAD currently seeking outpatient treatment. Adolescents forming the healthy control group will be eligible if they are aged 13-18 years of age, with no previous or current psychological disorder.

Adolescents will be excluded from all groups if they do not have an adequate understanding of the English language, if they have learning difficulties and if they have a severe comorbid psychological symptoms or disorder such as psychosis. In addition, adolescents will be excluded from the healthy control group if they surpass cut off points indicative of an anxiety disorder (SCARED), eating disorder (EDEQ) and depression (MFQ).

8.3.3.4 Assessment and measures
All participants will complete the same set of baseline measures to provide a comparison between the clinical groups and healthy adolescents. The anorexia nervosa group will further be assessed at 1 month, 3 months, 6 months, end of treatment and at 6 months follow-up to examine changes in IU, beliefs about having an eating disorder and their association with symptom recovery. Table 8.1 shows in detail which variables and measures will be completed by which groups and at what time points. To avoid repetitions, full descriptions of measures listed below can be found in Chapter 6, section 6.6.4. The sole new measure that has not been previously described is the IU Situation Specific (IUS-SS) questionnaire recently developed by Mahoney and McEvoy (2012b) to assess state IU related to disorder specific situations. The IUS-SS consists of 12 items adapted from the original IUS short version (IUS-12; Carelton,
Participants are asked to select an area of primary concern from a list that they are given of situations related to their illness. Responses are then made on the IUS-SS based on the situation they have selected. High internal consistency has been demonstrated for this measure (Carleton et al., 2007). This measure will be administered both at baseline along with the IUS-C to examine both state and trait IU and whether IU is higher in relation to a disorder specific situation to individuals with anorexia nervosa. The IUS-SS will also be administered throughout treatment as a more sensitive measure to change instead of the IUS-C, which measures IU as a trait variable.

Table 8.1 List of measures for all three groups

<table>
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<tr>
<th>Measure</th>
<th>AN Group</th>
<th>Anxiety Group</th>
<th>HC Group</th>
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</thead>
<tbody>
<tr>
<td>SCARED</td>
<td>-</td>
<td>-</td>
<td>SCARED</td>
</tr>
<tr>
<td>PSWQ-C</td>
<td>-</td>
<td>-</td>
<td>PSWQ-C</td>
</tr>
<tr>
<td>IUS-C</td>
<td>IUS-SS</td>
<td>IUS-C/IUS-SS</td>
<td>IUS-C</td>
</tr>
<tr>
<td>WW-II</td>
<td>-</td>
<td>--</td>
<td>WW-II</td>
</tr>
<tr>
<td>NPOQ</td>
<td>-</td>
<td>--</td>
<td>NPOQ</td>
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<tr>
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<td>CAQ</td>
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<tr>
<td>MFQ</td>
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<tr>
<td>EDEQ-V6</td>
<td>EDEQ-V6</td>
<td>EDEQ-V6</td>
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<tr>
<td>PCED</td>
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<tr>
<td>Weight for height %</td>
<td>Weight for height %</td>
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</tr>
</tbody>
</table>

Note: SCARED = The Screen for Child Anxiety related Emotional Disorders; PSWQ-C = Penn State Worry Questionnaire Child version; IUS-C = Intolerance of Uncertainty Child version; WW-II = Why Worry questionnaire version II; NPOQ = Negative Problem Orientation Questionnaire; CAQ = Cognitive Avoidance Questionnaire; MFQ = Mood and Feeling Questionnaire; EDEQ-V6 = Eating Disorder Examination Questionnaire version 6; PCED = Pros and Cons of Eating Disorders; EOT = End of Treatment; FU = 6 month follow-up after treatment has ended.

8.3.3.5 Sample size calculations

A power calculation was carried out taking into account the effect size from study 4 between the anorexia and control group on IU. A G*Power calculation showed that a sample size of 10 adolescents...
with anorexia nervosa and an equal number of healthy adolescents will have 90% power to detect an effect size of 1 using a two groups t-test with a .05 tailed sig. levels.

For the longitudinal part of the study after consultation with a statistician a sample size of 90 patients based on the number of examined variables will yield sufficient power to examine which baseline factors predict treatment outcome and relapse, whether IU changes during treatment and its temporal relationship with eating disorder psychopathology and beliefs about having an eating disorder. Taking into account deflation factor assuming 25% of patients do not complete all time points for various reasons, 120 patients will need to be recruited which will ensure a sample of 90 patients complete assessment measures at all time points.

8.3.3.6 Sources of recruitment
Adolescents with anorexia nervosa will be recruited from the Child and Adolescent Eating Disorder Service (CAEDS), South London and Maudsley NHS TRUST while adolescents with GAD will be recruited from Nationalist and specialist anxiety disorder clinics. Healthy adolescents will be recruited from various London based schools.

8.3.3.7 Recruitment and Procedure
Clinicians in both the adolescent eating disorder team and anxiety disorder team will assess whether new patients seeking treatment for either an eating disorder or an anxiety disorder meet the inclusion criteria for the study. If they do, information sheets and consent forms will be handed out and a time will be arranged to discuss the study further with the main researcher. If potential participants do decide to take part informed consent will be sought and a pack will be handed out containing baseline questionnaires for them to complete. A similar questionnaire pack will be administered at 1 month, 3 months, 6 months, end of treatment and at 6 months post treatment to all participants in the anorexia nervosa group. Participants in the anxiety group will only complete the battery of questionnaires at one time point that is at the beginning of treatment. Healthy adolescent controls will be recruited from various London based schools by the main researcher who will collaborate with different schools to circulate information sheets and consent forms to potential pupils.

8.3.3.8 Proposed statistical analysis
Part 1 – Cross sectional
Descriptive statistics will be used to illustrate the characteristics of the two clinical samples and healthy control group used in this study.

Hypotheses 1
Initial assumption testing will be conducted, including tests for normality. Assuming no major violations are detected, a set of ANOVAs will be conducted to examine differences between the three groups (i.e. ED group, GAD group, HC group). If tests yield significant pos hoc analysis will take place to detect
between which groups differences exist. ANCOVA analysis will be conducted to examine whether differences remain after entering depression and worry scores as covariates in the analysis.

Hypothesis 2
ANOVA will be conducted to examine differences between participants with both an eating disorder diagnosis and GAD and those with just a single diagnosis at time of assessment on examined anxiety related vulnerability factors.

Hypothesis 3
Path analysis will be carried out on the anorexia nervosa sample to examine whether the theoretical model under investigation was a good fit to the data.

Part 2 – Longitudinal

Hypothesis 4 & 5
A structural equation model (e.g. path analysis) will be used to examine whether baseline factors predict treatment outcome/relapse. A hierarchical linear modeling (HLM) analysis will be used to examine changes in trends over time. This analysis was chosen as HLM manages missing data in repeated measurements using empirical Bayesian estimates.

8.4 Conclusions
Results from the proposed study will indicate whether adolescents with anorexia nervosa are intolerant of uncertainty compared to healthy adolescents and whether they show similar levels of anxiety related vulnerability factors, including IU, to adolescents with an anxiety disorder, thus replicating and extending findings from study 4 using a much bigger sample size and increasing our understanding of shared vulnerability factors between anorexia nervosa and GAD. A better understanding will also be reached regarding the relationship between the examined anxiety related vulnerability factors and whether they show similar patterns as those seen in adolescents with an anxiety disorder (Fialko et al., 2012). Most importantly, the longitudinal part of the study will highlight the temporal relationship between IU, eating psychopathology and beliefs about having an eating disorder. It will demonstrate whether IU is a good predictor of treatment outcome and relapse. This will provide direction as to whether a specific treatment intervention that targets IU is worthwhile for adolescents with anorexia nervosa and for which subgroup of patients. At present a targeted intervention on IU is available based on Dugas and colleagues model of IU (Dugas & Ladouceur, 2000) and outlined in the treatment manual for GAD by Dugas and Robichaud (2007). More sophisticated behavioural treatment interventions targeting cognitive biases are also on the forefront of recent research that may also prove beneficial for individuals with anorexia nervosa. For instance, within the depression literature imagery is being used within a cognitive bias modification paradigm (Lang, Blackwell, Harmer, Davison, & Holmes, 2012). This involves helping patients with depression adopt a more ‘balanced’ interpretation when faced with
ambiguous/uncertain situations rather than negative interpretations. If IU is underpinned by a negative interpretation bias helping patients train their brain to have more positive future images ‘pop’ in their heads rather than negative images may be beneficial in reducing IU. In conclusion, the proposed study will extend findings from study 4 providing direction for future research in this field and contribute to the refinement of the conceptual model proposed in Chapter 2. Continuing to study the role of IU in anorexia nervosa is a promising area that will lead to further theoretical and clinical developments in the field of eating disorders and possibly better treatment outcomes for more patients.


Dare, C., Eisler, I., Colahan, M., Crowther, C., & et al. (1995). The listening heart and the chi square: Clinical and empirical perceptions in the family therapy of anorexia nervosa. *Journal of Family Therapy, 17*(1), 31-57.


interventions. [Clinical Trial Comparative Study Randomized Controlled Trial Research Support, Non-U.S. Gov't]. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 41(6), 727-736.


Tomkins, L., & Eatough, V. (2010). Reflecting on the use of IPA with focus groups: Pitfalls and potentials. Qualitative Research in Psychology, 7(3), 244-262.


APPENDICES

APPENDIX 1: DSM – IV-TR Diagnostic criteria for bulimia nervosa and EDNOS (APA)

Bulimia Nervosa

A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:

(1) eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances

(2) a sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating)

B. Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise.

C. The binge eating and inappropriate compensatory behaviors both occur, on average, at least twice a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Specify type:

Purging Type: during the current episode of Bulimia Nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas

Nonpurging Type: during the current episode of Bulimia Nervosa, the person has used other inappropriate compensatory behaviors, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas

Eating Disorder Not Otherwise Specified

The Eating Disorder Not Otherwise Specified category is for disorders of eating that do not meet the criteria for any specific Eating Disorder. Examples include

1. For females, all of the criteria for Anorexia Nervosa are met except that the individual has regular menses.

2. All of the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual’s current weight is in the normal range.
3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.

4. The regular use of inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two cookies).

5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.

APPENDIX 2: DSM-IV Diagnostic Criteria for Generalized Anxiety Disorder (APA)

Generalized Anxiety Disorder (Includes Overanxious Disorder of Childhood)

A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance).

B. The person finds it difficult to control the worry.

C. The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms present for more days than not for the past 6 months). Note: Only one item is required in children.

1. Restlessness or feeling keyed up or on edge

2. Being easily fatigued

3. Difficulty concentrating or mind going blank

4. Irritability

5. Muscle tension

6. Sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)

D. The focus of the anxiety and worry is not confined to features of an Axis I disorder, e.g., the anxiety or worry is not about having a Panic Attack (as in Panic Disorder), being embarrassed in public (as in Social Phobia), being contaminated (as in Obsessive-Compulsive Disorder), being away from home or close relatives (as in Separation Anxiety Disorder), gaining weight (as in Anorexia Nervosa), having multiple physical complaints (as in Somatization Disorder), or having a serious illness (as in Hypochondriasis), and the anxiety and worry do not occur exclusively during Posttraumatic Stress Disorder.

E. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

F. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism) and does not occur exclusively during a Mood Disorder, a Psychotic Disorder, or a Pervasive Developmental Disorder.
APPENDIX 3: Combined information and consent form (Study 1).

[Headed paper of research team]

Information sheet for participants

_A preliminary investigation of the four main components of a cognitive model of generalized anxiety disorder in eating disorders and their relationship with emotion regulation_

We would like to invite you to participate in this original research project aimed at investigating key components of generalized anxiety disorder in people with and without eating disorders. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, we will explain why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**What is the purpose of this study?**

Previous research has found that people with eating disorders share similar vulnerability factors with people with anxiety disorders. For instance, research has found people with eating disorders to worry more than people without.

The aim of the present study is to examine whether the four main components of a cognitive model of generalized anxiety disorder, which look at uncertainty, reactions to worry, problems, and cognitions are of relevance to people with eating disorders. We also want to examine the relationship of the above components with ways one deals with emotions.

By examining such new factors we can increase our understanding of the link between anxiety and eating disorders and improve existing treatments.

In order to investigate these factors, we need:

(i) Volunteers with no history of eating disorders aged 18 or older, and

(ii) Volunteers with a current or past eating disorder (anorexia nervosa or bulimia nervosa) aged 18 or older.

**Why have I been chosen to take part?**

In order to identify potential participants interested in taking part in this research we have sent a packet with information about our study to people registered in our volunteer data base from the Eating Disorders Research Unit at the Institute of Psychiatry. We have also invited people from the community via a flyer and email circulated within the University with no current or past history of an eating disorder to take part in our study. People that will have responded to the flyer and email with an interest in
taking part will be sent this packet. We hope to recruit at least 200 volunteers with current or past eating disorders. We also hope to recruit 200 healthy volunteers from the community to act as a comparison group for our study.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you should read this information sheet carefully, contact the researcher if you need some further information and complete the questionnaires. Returning or completing the questionnaires online implies that you consent to take part in the study. If you decide to take part you are still free to withdraw at any time and without giving any reason or affecting your present or future care for those from the volunteer eating disorder data base. All data provided by you would also be removed.

**What will I have to do if I take part?**

If you decide to participate, you will be asked to complete a set of 7 short questionnaires, which you will have received together with this information sheet. The questionnaires include questions or statements you are asked to show how much you agree on, on topics related to uncertainty, worry, anxiety, ways one reacts to problems and cognitions and strategies one uses to deal with emotions. This should take a maximum of 1 hour of your time. When you have completed the questionnaires, you should return them in the addressed envelope provided, for those that have received the packet via post. To receive your £5 payment, please also complete and return the attached payment form.

**What are the possible disadvantages and risks taking part?**

There are no known risks from taking part in this study. The questionnaires used for this study explore different anxiety related themes such as how one perceives uncertainty and worry as well as ways one approaches problems and emotions. By responding to questions on such areas particularly questions related to worry and dealing with problems and emotions may bring up sensitive information for some participants. If at any point completing the questionnaires becomes distressing for you, you can withdraw from the study. Otherwise there are no adverse effects expected from our study.

**What are the possible benefits of taking part?**

Participating in this study may help you understand better some of your *thinking styles* related to anxiety, worry, problems, cognitions, uncertainty, and emotions. This may benefit all participants, irrespective of whether you have an eating disorder or not, by understanding better yourself in these areas.

**Confidentiality**

All the information about you that is collected during the course of the research will be kept *strictly confidential* and analysed *anonymously* by the researcher only (any identifiable details such as name and
address removed). Information about you and your study answers will not be disclosed in a way that identifies or links them to you at any point of the analysis, presentation, or publication of the findings. All data relating to the study will be held at King’s College London and will be accessible by the researcher only.

Results of the study
The results of the study will be submitted for publishing to public journals. Updates on the study including findings and news of publication in journals will be published on our website (www.eatingresearch.com) and in the newsletter produced by the Eating Disorders Unit which is sent to all members of the volunteer database and is freely available from the unit.

Who is organising the research?
This study is a research project within the Eating Disorder Unit, Academic Psychiatry Department, Guy’s Hospital (Institute of Psychiatry). The researcher in charge of this study is Anna Konstantellou and the consultant in charge is Professor Janet Treasure.

Further Information
If you would like more information about this research or if this study has harmed you in any way you can contact King’s College London using the details below for further advice and information:

[Contact details of present author inserted here]/[Contact details of supervisor inserted here]

Thank you for reading this!
APPENDIX 4: The Intolerance of Uncertainty Inventory (IUI) (Study 1)

You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you. Please circle a number (1 to 5) that describes you best.

Part A

<table>
<thead>
<tr>
<th>1. I have difficulty accepting that the future is uncertain.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all characteristic of me</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

2. I find it unbearably to not have guarantees in life.

3. Others seem to better tolerate uncertainty than me.

4. I find it intolerable that certain aspects in life are not determined in advance.

5. I have difficulty tolerating the possibility that a negative event may happen to me.

6. When I am waiting for important news, I find it hard to remain in the dark.

7. I find it intolerable to have to deal with unpredictable situations.

8. I do not really tolerate situations in which
I do not know what
is going to happen. 1 2 3 4 5

9. Not knowing what will happen in advance
is often unacceptable to me 1 2 3 4 5

10. Waiting periods are unbearable for me when
I do not know what
is going to happen. 1 2 3 4 5

11. I have difficulty tolerating life’s
uncertainties. 1 2 3 4 5

12. When I think that something negative
might happen, I have difficulty
remaining in uncertainty. 1 2 3 4 5

13. I would rather know everything right
away rather than
remain uncertain. 1 2 3 4 5

14. I have difficulty dealing with the
possibility that something
unexpected may occur. 1 2 3 4 5

15. I need to be sure of
what I take on. 1 2 3 4 5

Part B

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Entirely</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>characteristic</td>
<td>characteristic</td>
<td>characteristic</td>
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<tr>
<td>of me</td>
<td>of me</td>
<td>of me</td>
<td></td>
</tr>
</tbody>
</table>

1. I prefer to avoid uncertain
situations. 1 2 3 4 5

2. When I find myself in an uncertain
situations I tend to have doubts about
what I am doing. ..................................1.............2..........................3.............4.............5

3. I often exaggerate the odds that
the worst will happen when something
unexpected occurs..................................1.............2..........................3.............4.............5

4. I tend to want to boss others around
so that nothing unexpected will
happen to them. ..................................1.............2..........................3.............4.............5

5. I often rely on others to reassure me
when I do not
know what will happen..................1.............2..........................3.............4.............5

6. I worry a lot about
life’s uncertainties. .........................1.............2..........................3.............4.............5

7. I often have doubts about myself when
a situation is uncertain. ................1.............2..........................3.............4.............5

8. The possibility that a negative event
may occur leads me to avoid
certain activities. .........................1.............2..........................3.............4.............5

9. When I am uncertain I need to be
reassured by others.........................1.............2..........................3.............4.............5

10. I must control everything in order
to prevent negative consequences
from happening..........................1.............2..........................3.............4.............5

11. I tend to ask for the opinion of others
when I am unsure
of what will happen. ..................1.............2..........................3.............4.............5

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12. I avoid situations that in which something unanticipated is likely to occur. .................................................................1........2.............................3........4........5..........................

13. When the outcome of an event is uncertain I often doubt having done all that was necessary. .................................................................1........2.............................3........4........5..........................

14. When a negative event might happen, I often overestimate the likelihood that it will take place. .................................................................1........2.............................3........4........5..........................

15. I tend to worry when I am uncertain about what will happen. .................................................................1........2.............................3........4........5..........................

16. I often ask for the same information from several people to reassure myself about what will happen. .................................................................1........2.............................3........4........5..........................

17. Uncertain situations worry me. .................................................................1........2.............................3........4........5..........................

18. When I am uncertain about what will happen, I try to control everything. .................................................................1........2.............................3........4........5..........................

19. I tend to overestimate the probability that something bad will occur when I do not know what will happen. .................................................................1........2.............................3........4........5..........................

20. Thinking that something unexpected may happen worries me. .................................................................1........2.............................3........4........5..........................

21. When I am uncertain, I tend to doubt my capabilities. .................................................................1........2.............................3........4........5..........................
22. I tend not to engage in activities involving some uncertainty

23. When I am uncertain, I tend to overestimate the odds that the events will turn out badly.

24. I tend to want to control my loved one’s activities in order to decrease the chances that something will happen to them.

25. Even if it is unlikely that a negative event may occur, I need to be told repeatedly that everything will go well.

26. I prefer to drop a project rather than have to live with uncertainty.

27. I prefer to control everything in order to decrease uncertainties.

28. Not knowing what the future holds for me worries me.

29. In an uncertain situation, I tend to exaggerate the chances that things may go badly.

30. I often tend to question my choices when I am uncertain about what will happen.
APPENDIX 5: Information sheet for young people (Study 2)

[Headed paper of research team]

Information sheet for young people

Examining the Meaning of Uncertainty in Adolescents with Anorexia Nervosa and their Parents

We would like to invite you to take part in a research study. Before you decide if you want to join in it is important to understand why the research is being done and what it will involve. So please consider this information sheet carefully. Talk about it with your family, friends, or doctor if you want to and feel free to ask us if there is anything that is not clear or if you would like more information.

You will have two weeks to decide whether you want to take part.

Why are we doing this research?
Everyone experiences uncertainty however people tolerate and cope with uncertainty in different ways. That is, people can find uncertainty distressing to different degrees. Our research aims to understand how young people with anorexia nervosa and their parents experience uncertainty. Understanding what the experience of uncertainty is like for young people with anorexia nervosa and their parents is important as such knowledge can help get a clearer picture of how uncertainty may affect the illness and therapy. Our aim is to explore what the experience is like for adolescents with anorexia nervosa and their parents when they are confronted with uncertainty.

Why have I been invited?
All young people and their parents referred to the eating disorder outpatient department at the Michael Rutter Centre, Maudsley Hospital London, between the ages of 11-18 with anorexia nervosa or eating disorders not otherwise specified are invited to participate in this study.

Do I have to take part?
No, it is up to you to decide whether or not to take part. We will describe the study and go through this information sheet, which we will then give to you. If you decide to take part you should read this information sheet and consent form carefully and if you agree to take part print your name and sign it. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive with the team in any way.

What will happen to me if I take part?
If you decide to take part we will ask you to join a focus group. This means that you and another 2-5 young people will form a group to talk about uncertainty. The main researcher and one other colleague will also be part of the group and will guide the discussion in a very relaxed environment. In other words, we would be asking you to give up 45 minutes to 1 hour of your time and along with a few other young people form a group to talk about your experience of uncertainty. Researchers running the group will have a set of questions in mind in order to encourage discussion. Similar groups will be run with parents of young people with anorexia nervosa.

What are the possible disadvantages and risks taking part?
There are no risks involved in taking part in this study. One possible disadvantage could be that you spend a little more time in the centre compared to families who are not taking part in our research. If for any reason during discussions you feel distressed and you don’t want to continue, you can leave the group and stop taking part in the study with no need to give any explanations. We would also encourage you if you do feel distressed after by being part of the group to talk to your doctor.

What are the possible benefits of taking part?
We believe that issues surrounding uncertainty may be important for young people with anorexia nervosa and their parents. By taking part in this study you will be helping us understand the possible role of uncertainty in anorexia nervosa. Furthermore, talking about uncertainty and hearing other people’s experiences may prove helpful. Other people may share same concerns as you or may have different experiences from you, which may be insightful. Finally, adults affected with anorexia nervosa who have taken part in past focus groups on uncertainty expressed that they found them very interesting and helpful.

What will happen if I do not want to carry on with the study?
You can stop taking part in the research at any time without giving an explanation and this will not affect you negatively in any way. Information collected will be destroyed if you or your parents wish.

What if there is a problem?
If you have any worries about any parts of the study you should ask to speak to the main researcher involved in the study who will do her best to answer your questions (Miss Anna Konstantellou: Tel: 07762286387; e-mail: anna.konstantellou@iop.kcl.ac.uk). If there is still a problem and you wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the Maudsley hospital.

What will happen if harm occurs to me from the study?
We do not think that any harm will happen from taking part in this study. You may want to know that the study is covered by the NHS indemnity scheme if harm does happen. If something does go wrong and it is because of someone’s carelessness then you may have grounds for a legal action for
compensation against the South London and Maudsley Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanism will still be available to you.

**Will taking part in the study be kept confidential?**
Researchers will ask politely participants at the start of the focus groups that anything discussed within the group should remain within the group and kept confidential. Discussions during focus groups will be audio recorded and later written up by researchers word for word to form a transcript of the discussion that took place in the focus group. All recordings will be stored in a locked cabinet in a locked office at the Institute of Psychiatry, KCL. Transcripts will be made anonymous, that is names will be replaced by ID numbers and any information that could be used to identify you will be erased.

The only time that confidentiality will be broken is if during the focus group a participant discloses something that gives the researcher reason to believe anyone (the participant or another person) is at risk to themselves or others then the researcher will discuss the situation with the clinician responsible for that individual, which is considered standard procedure.

**Does my General Practitioner (GP) get to know that I participate in the study?**
It is not necessary that we tell your GP if you decide to participate in this study. This is because the study does not affect the clinical care you receive.

**What will happen to the results of the study?**
The transcripts will be made anonymous, that is, your name will be replaced with an ID code and analysed by researchers as a summary without giving account of individual responses. If we want to use direct quotes from the focus group discussion you took part, we will ask for your permission first and only include them in our results if you are happy for us to do so. Any information that may identify you in any way will be removed from direct quotations that may be used when reporting findings from this study.

**Who is organising and funding the study?**
The Eating Disorder Service is funding this study. Your doctor will not be paid any fees for inviting you to take part in this study.

**Who has reviewed the study?**
All research in the NHS is looked at by a group of people, called a Research Committee to protect your safety, your rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by SLAM/IoP Research Ethics Committee.

**Further information and contact details**
For more information about the study and for advice as to whether you may want to participate or if you are unhappy with the study, please contact:

[Contact details of present author inserted here]

Thank you for reading this!

[Inserted as footer: REC Protocol Number: 09/H0807/65; Version 3 30/03/2010]
APPENDIX 6: Consent form for young people (Study 2).

[Headed paper of research team]

Consent form for young person

Examining the Meaning of Uncertainty in Adolescents with Anorexia Nervosa and their Parents

Name of Chief Researcher: Anna Konstantellou

1. I agree that I have read and understand the information sheet for the above study Version 3 dated 30/03/2010 and have had the opportunity to ask questions.

2. I agree for researchers only part of the present study to have access to my personal data to gather background information required for the study and contact details in order to be able to arrange dates for taking part.

3. I understand that taking part in this study is voluntary and that I am free to stop taking part at any time, without giving any reason, without my medical care or legal rights being affected in any way.

4. I understand that my responses in the focus group will be confidential and anonymous.

5. I understand that permission will first be sought before any direct quotations are used in the results of the study and that all identifiable information will be removed from direct quotations that may be used when reporting findings for this study.

6. I agree for the session to be recorded for research purposes only and I understand that all recordings will be used anonymously.

7. I agree to take part in the above study.

_________________   __________________   __________________
Name of participant     Date               Signature

_________________   __________________   __________________
Name of Researcher     Date               Signature

[Inserted as footer: REC Protocol Number: 09/H0807/65; Version 2 10/09/2009]
APPENDIX 7 Consent form for parents of young people under 16 (Study 2)

[Headed paper of research team]

Consent form for parents of young person under sixteen

Examining the Meaning of Uncertainty in Adolescents with Anorexia Nervosa and their Parents

Name of Chief Researcher: Anna Konstantellou

1. I confirm that I have read and understand the information sheet Version 3 dated 30.03.2010 for the above study and have had the opportunity to ask questions regarding my daughter taking part.

2. I agree for researchers only part of the present study to have access to my daughter’s personal data to gather background information required for the study and contact details in order to be able to arrange dates for taking part.

3. I understand that my daughter’s participation is voluntary and that she is free to withdraw at any time, without giving any reason, without her medical care or legal rights being affected.

4. I understand that my daughters’ responses in the focus group will be confidential and anonymous.

5. I understand that permission will first be sought before any direct quotations from my daughter are used in the results of the study and that all identifiable information will be removed from direct quotations that may be used when reporting findings from this study.

6. I agree for the focus group session my daughter is in to be recorded for research purposes only and I understand that all recordings will be used anonymously.

7.

8. I agree that my daughter takes part in this study.

____________   ___________   ___________
Name of participant   Date   Signature

____________   ___________
Name of Researcher   Date   Signature

[Inserted as footer: REC Protocol Number: 09/H0807/65; Version: 2 10/09/2009]
APPENDIX 8: Focus group schedule (Study 2)

Focus group schedule for focus group on uncertainty with adolescents (study 2)

We would like to understand more about your experience of what it feels like when things are uncertain in your life. In life we all come up against uncertainty some of the time and we can have all sorts of reactions to this. We want to learn more about what leads you to feel uncertain and what the experience of uncertainty is like for you in the various life domains in which it can crop up.

- Can you think of an uncertain situation?
- What makes this situation uncertain?
- What features of the situation were most troubling?
- Can you tell us a little more about what that experience of uncertainty (or ‘not knowing’) is like for you?
- Can you tell us more about the thoughts and feelings that come up when you are uncertain?
- What makes these thoughts and feelings worse?
- What helps at these times? How do you protect yourself?
- Are there other ways you try and cope?
- Are there good sides of feeling uncertain?
- Who experiences uncertainty? Everyone? Some people? Special groups?
- Can you tell us now whether the experience of uncertainty was different in any way before your illness?
APPENDIX 9: Information sheet for parents (Study 3)

Information sheet for parents

Examining the meaning of uncertainty in adolescents with Anorexia Nervosa and their parents

We would like to invite you and your child to take part in a research study. Before you decide whether you and/or your child can help we will explain why the research is being done and what it will involve. Please feel free to ask us if there is anything that is not clear or if you would like more information.

You will have two weeks to decide whether you want to take part

What is the purpose of the study?

Everyone experiences uncertainty however people tolerate and cope with uncertainty in different ways. That is, people can find uncertainty distressing to different degrees. Our research aims to understand how young people with anorexia nervosa and their parents experience uncertainty. Understanding what the experience of uncertainty is like for young people with anorexia nervosa and their parents is important as such knowledge may contribute to obtaining a clearer picture of the role of uncertainty in relation to therapy and symptom maintenance. Our aim is to explore what the experience is like for adolescents with anorexia nervosa and their parents when they are confronted with uncertainty.

Why have we been invited?

All adolescents with a diagnosis of anorexia nervosa or eating disorders not otherwise specified between the age of 11 and 18 years and parents with a child meeting the above criteria referred to the eating disorder outpatient department at the Michael Rutter Centre, Maudsley Hospital London will be invited to participate in this study.

Do we have to take part?

No, it is up to you and your child to decide whether or not to take part. You can still participate even if your child doesn’t and vice versa. We will describe the study and go through this information sheet, which we will then give to you. If you wish to take part, you should read this information sheet and consent form carefully, discuss it with your child and print your name and sign if you agree to participate. If both of you decide to take part you and your child are free to withdraw at any time, without giving a reason. This would not affect the standard of care you and your child receive.

What will happen to me and my child if we take part?

If you decide to take part this will involve being part of a focus group on uncertainty. In other words, we would be asking you to give up 45 minutes to 1 hour of your time and along with 3-5 other parents of young people with anorexia nervosa to form a group that will be discussing people’s experience of uncertainty. The chief investigator and one other researcher will also be part of the group and will have a set of questions in mind in order to encourage discussion. A non-formal environment will be
encouraged. If your child decides to take part she will be part of a similar focus group with other young people with anorexia nervosa that will be discussing uncertainty led by the same chief investigator.

**What are the possible disadvantages and risks taking part?**

There are thought to be no risks involved in taking part in this study. One possible disadvantage could be that you spend a little more time in the centre compared to families who are not taking part in our research. If for any reasons during the focus group discussions you become distressed, you can leave the group and stop taking part in the study with no need to give any explanations. We would also encourage you if discussions do become too sensitive and distressing to talk with your clinician about how you found taking part in the study.

**What are the possible benefits of taking part?**

We believe that issues surrounding uncertainty may be important for young people with anorexia nervosa and their parents. By taking part in this study you will be helping us understand the possible role of uncertainty in anorexia nervosa and issues of uncertainty at an individual and family level. Furthermore, talking about uncertainty and hearing other people’s experiences may prove helpful. Other people may share same concerns as you or may have different experiences from you, which may be insightful.

**What will happen if we do not want to carry on with the study?**

You and your child can withdraw from the research at any time. This will not affect you or your child negatively in any way. Information collected will be destroyed if you or your child wish.

**What if there is a problem?**

If you have any concerns about any aspects of the study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Anna Konstantellou, tel: 020 7848 0972 or email: anna.konstantellou@kcl.ac.uk. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the hospital.

**What will happen if harm occurs to you or your child due to the study?**

It is not expected from this study that any significant adverse effects arise for you or your child. The study is covered by the NHS indemnity scheme should such occur. In the event that something does go wrong and your child or you are harmed during the research and this is due to someone’s negligence, then you may have grounds for a legal action for compensation against the South London and Maudsley Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanism will still be available to you.

**Will taking part in the study be kept confidential?**
Researchers will ask politely participants at the start of the focus groups that anything discussed within the group should remain within the group and kept confidential. Discussions during focus groups will be audio recorded and later transcribed verbatim. All recordings will be stored in a locked cabinet in a locked office at the Institute of Psychiatry, KCL. Transcripts will be made anonymous, with names being replaced by ID numbers and any information that could be used to identify you will be erased. The only time that confidentiality will be broken is if during the focus group a participant discloses something that gives the researcher reason to believe anyone (the participant or another person) is at risk to themselves or others then the researcher will discuss the situation with the clinician responsible for that individual, which is considered standard procedure.

Does my General Practitioner (GP) get to know that we participate in the study?
It is not necessary that your GP is made aware that you and your child participate in this study. This is because the study does not affect the clinical care you or your child receives.

What will happen to the results of the study?
The transcripts will be made anonymous, that is, your name will be replaced with a code and analysed by researchers as a summary without giving account of individual responses. If we want to use direct quotes from the focus group discussion you took part, we will ask for your permission first and only include them in our results if you are happy for us to do so. Any information that may identify you in any way will be removed from direct quotations that may be used when reporting findings from this study.

Who is organising and funding the study?
The Adolescent Eating Disorder Service is funding this study. Your doctor will not be paid any fees for including you in this study.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the SLAM/IoP Research Ethics Committee.

Further information and contact details:
For more information about the study and for advice as to whether you may want to participate or if you are unhappy with the study, please contact:

[Contact details of present author inserted here]

Thank you for reading this!

[Inserted as footer: REC Protocol Number: 09/H0807/65; Version 3 30/03/2010]
APPENDIX 10: Consent form for parent (Study 3)

[Headed paper of research team]

Consent form for parents of young person

Examining the Meaning of Uncertainty in Adolescents with Anorexia Nervosa and their Parents

Name of Chief Researcher: Anna Konstantellou

1. I confirm that I have read and understand the information sheet Version 3 dated 30.03.2010 for the above study and have had the opportunity to ask questions.

2. I agree for researchers only part of the present study to have access to my personal data to gather background information required for the study and contact details in order to be able to arrange dates for taking part.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that my responses in the focus group will be confidential and anonymous.

5. I understand that permission will first be sought before any direct quotations are used in the results of the study and that all identifiable information will be removed from direct quotations that may be used when reporting findings from this study.

6. I agree for the session to be recorded for research purposes only and I understand that all recordings will be used anonymously.

7. I agree to take part in the above study.

_________________________ ________________ ________________
Name of participant Date Signature

_________________________ ________________ ________________
Name of Researcher Date Signature

[Inserted as footer: REC Protocol Number: 09/H0807/65; Version 2 10/09/2009]
APPENDIX 11: Focus group schedule (Study 3)

Focus group schedule for focus group on uncertainty with parents (study 3)

We would like to understand more about your experience of what it feels like when things are uncertain in your life. In life we all come up against uncertainty some of the time and we can have all sorts of reactions to this. We want to learn more about what leads you to feel uncertain and what the experience of uncertainty is like for you in the various life domains in which it can crop up.

- Can you think of an uncertain situation?
- What makes this situation uncertain?
- What features of the situation were most troubling?
- Can you tell us a little more about what that experience of uncertainty (or ‘not knowing’) is like for you?
- Can you tell us more about the thoughts and feelings that come up when you are uncertain?
- What makes these thoughts and feelings worse?
- What helps at these times? How do you protect yourself?
- Are there other ways you try and cope?
- Are there good sides of feeling uncertain?
- Who experiences uncertainty? Everyone? Some people? Special groups?
- Can you tell us now whether the experience of uncertainty was different in any way at a different time in your life?
APPENDIX 12: The Intolerance of Uncertainty Scale – Child version (IUS-C) (Study 4)

How well do these statements describe you?

1) Doubts stop me from having strong opinions.

1  2  3  4  5
Not at all  Somewhat  Very much

2) Being unsure means that a person is mixed-up.

1  2  3  4  5
Not at all  Somewhat  Very much

3) Not knowing what will happen in the future makes life hard.

1  2  3  4  5
Not at all  Somewhat  Very much

4) It’s not fair that we can’t predict the future.

1  2  3  4  5
Not at all  Somewhat  Very much

5) I can’t relax if I don’t know what will happen tomorrow.

1  2  3  4  5
Not at all  Somewhat  Very much

6) Not knowing what will happen in the future makes me uneasy, anxious, or stressed.

1  2  3  4  5
Not at all  Somewhat  Very much

7) Surprise events upset me greatly.

-225-
8) It frustrates me to not have all of the information I need.

9) Not knowing what could happen keeps me from enjoying life.

10) One should always think ahead to avoid surprises.

11) Plans can be ruined by things you didn’t think would happen.

12) When it is time to do things, not knowing what could happen keeps me from acting.

13) Being unsure of things means that I am not great.

14) When I am not sure of something I can’t go forward.
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<tbody>
<tr>
<td>15) When I am not sure of something I can’t work very well.</td>
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<td>3</td>
<td>4</td>
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<tr>
<td>Not at all</td>
<td>Somewhat</td>
<td>Very much</td>
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<tr>
<td>16) Other kids have less doubts than I do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>Not at all</td>
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<td>17) Not knowing what will happen makes me unhappy or sad.</td>
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<tr>
<td>Not at all</td>
<td>Somewhat</td>
<td>Very much</td>
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<td>18) I always want to know what will happen to me in the future.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>Not at all</td>
<td>Somewhat</td>
<td>Very much</td>
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<tr>
<td>19) I don’t like being taken by surprise.</td>
<td>1</td>
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<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>Not at all</td>
<td>Somewhat</td>
<td>Very much</td>
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<td>20) The smallest doubt can stop me from doing things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>Not at all</td>
<td>Somewhat</td>
<td>Very much</td>
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<td>21) I should be able to prepare for everything in advance.</td>
<td>1</td>
<td>2</td>
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<td>Not at all</td>
<td>Somewhat</td>
<td>Very much</td>
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22) Being unclear about things means that I am not confident.

Not at all | Somewhat | Very much

23) It’s not fair that other kids are more sure of things.

Not at all | Somewhat | Very much

24) Not knowing what can happen keeps me from sleeping well.

Not at all | Somewhat | Very much

25) I must get away from all situations where I don’t know what will happen.

Not at all | Somewhat | Very much

26) Things that are unclear stress me.

Not at all | Somewhat | Very much

27) I don’t like being undecided about the future.

Not at all | Somewhat | Very much

-228-
APPENDIX 13: The Intolerance of Uncertainty Scale (IUS) (Study 4)

You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you. Please circle a number (1 to 5) that describes you best.

<table>
<thead>
<tr>
<th>Not at all characteristic of me</th>
<th>Somewhat characteristic of me</th>
<th>Entirely characteristic of me</th>
</tr>
</thead>
</table>

1. Uncertainty stops me from having a firm opinion.

2. Being uncertain means that a person is disorganized.

3. Uncertainty makes life intolerable.

4. It's unfair not having any guarantees in life.

5. My mind can't be relaxed if I don't know what will happen tomorrow.

6. Uncertainty makes me uneasy, anxious, or stressed.

7. Unforeseen events upset me greatly.

8. It frustrates me not having all the information.
I need. ..................................1………..2…………..3………….4………….5…………

9. Uncertainty keeps me from
living a full life. ……….1………….2…………..3………….4………….5…………

10. One should always look ahead
so as to avoid surprises…….1………….2…………..3………….4………….5…………

11. A small unforeseen event can
spoil everything, even with the
best of planning. ………..1………….2…………..3………….4………….5…………

12. When it's time to act,
uncertainty
paralyses me. ……………1………….2…………..3………….4………….5…………

13. Being uncertain means that I am
not first rate. ………..1………….2…………..3………….4………….5…………

14. When I am uncertain, I can't go
forward. ……………1………….2…………..3………….4………….5…………

15. When I am uncertain I can't
function very well. ………..1………….2…………..3………….4………….5…………

16. Unlike me, others always seem
to know where they are going
with their lives. ………..1………….2…………..3………….4………….5…………

17. Uncertainty makes me
vulnerable,
unhappy, or sad…………1………….2…………..3………….4………….5…………

18. I always want to know
what the future has in
store for me. ……………1………….2…………..3………….4………….5…………

19. I can't stand being taken by
surprise. ……………1………….2…………..3………….4………….5…………

20. The smallest doubt can stop me
from acting. ............1............2............3............4............5............

21. I should be able to organize
everything in advance. ........1............2............3............4............5............

22. Being uncertain means that I
lack confidence. ........1............2............3............4............5............

23. I think it’s unfair that other
people seem sure about their
future. ....................1............2............3............4............5............

24. Uncertainty keeps me from
sleeping soundly. ........1............2............3............4............5............

25. I must get away from all
uncertain situations. ........1............2............3............4............5............

26. The ambiguities in
life stress me. ............1............2............3............4............5............

27. I can’t stand being undecided
about my future. ........1............2............3............4............5............
APPENDIX 14: Intolerance of Uncertainty Scale Child version – Parental report (IUSC-P) (Study 4)

You will find below a series of statements which describe how children may react to uncertainty. Please use the scale below to describe to what extent each item is characteristic of your child.

1) Uncertainty stops my child from having strong opinions

1 2 3 4 5
Not at all Somewhat Very much

2) My child believes that being uncertain means one is mixed-up

1 2 3 4 5
Not at all Somewhat Very much

3) Uncertainty makes my child’s life intolerable

1 2 3 4 5
Not at all Somewhat Very much

4) My child thinks it’s unfair that we can’t predict the future

1 2 3 4 5
Not at all Somewhat Very much

5) My child’s mind can’t be relaxed if he/she doesn’t know what will happen tomorrow

1 2 3 4 5

-232-
Not at all                             Somewhat                            Very much

6) Uncertainty makes my child uneasy, anxious, or stressed

   1                2                3                4                5
   Not at all                             Somewhat                            Very much

7) Unforeseen events upset my child greatly

   1                2                3                4                5
   Not at all                             Somewhat                            Very much

8) It frustrates my child to not have all the information he/she needs in a situation

   1                2                3                4                5
   Not at all                             Somewhat                            Very much

9) Uncertainty keeps my child from living a full life

   1                2                3                4                5
   Not at all                             Somewhat                            Very much

10) My child believes that one should always look ahead so as to avoid surprises
11) My child believes that a small unforeseen event can spoil everything, even with the best planning.

12) When it’s time to act, uncertainty paralyses my child

13) My child believes that being uncertain means that he/she is not first rate

14) When my child is uncertain he/she can’t go forward
15) When my child is uncertain he/she can’t function very well

1  2  3  4  5
Not at all  Somewhat  Very much

16) Other children seem to be more certain than my child

1  2  3  4  5
Not at all  Somewhat  Very much

17) Uncertainty makes my child unhappy or sad

1  2  3  4  5
Not at all  Somewhat  Very much

18) My child always wants to know what the future has in store for him/her

1  2  3  4  5
Not at all  Somewhat  Very much

19) My child can’t stand being taken by surprise

1  2  3  4  5
Not at all  Somewhat  Very much

-235-
20) The smallest doubt can stop my child from acting

1 2 3 4 5
Not at all Somewhat Very much

21) My child feels as though he/she should be able to organize everything in advance

1 2 3 4 5
Not at all Somewhat Very much

22) My child feels as though being uncertain means that he/she lacks confidence

1 2 3 4 5
Not at all Somewhat Very much

23) My child feels as though it’s unfair that other people seem to be sure about their future

1 2 3 4 5
Not at all Somewhat Very much

24) Uncertainty keeps my child from sleeping soundly

1 2 3 4 5

-236-
25) My child tries to get away from all uncertain situations

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<td>Not at all</td>
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26) The ambiguities of life stress my child

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27) My child can’t stand being undecided about the future.

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APPENDIX 15: Information sheet for adolescents in the clinical group (Study 4)

[Headed paper of research team]

Information sheet for young people

An Examination of Uncertainty and Related Factors in Anorexia Nervosa

We are asking if you would like to take part in a research project that examines uncertainty and related factors in anorexia nervosa. Before you decide if you want to join in it is important to understand why the research is being done and what it will involve for you. So please consider this information sheet carefully. Talk about it with your family, friends, or doctor if you want to and feel free to ask us if there is anything that is not clear or if you would like more information on.

You will have one week to decide whether you want to take part.

Why are we doing this research?
Our research aims to look at uncertainty and related factors such as anxiety and worry in individuals with anorexia nervosa. We want to see whether these factors are important in individuals with anorexia nervosa and in their parents and whether they may play a part in blocking the effect of therapy and maintaining symptoms. Overall, we are aiming to increase our understanding of the role of anxiety related factors in anorexia nervosa.

Why have I been invited?
All young people and their parents referred to the eating disorder outpatient department [name of centre inserted] between the ages of 13 and 18 with a diagnosis of anorexia nervosa or eating disorder not otherwise specified (EDNOS) are invited to participate in this study.

Do I have to take part?
No, it is up to you to decide whether or not to take part. We will describe the study and go through this information sheet, which we will then give to you. If you decide to take part you should read this information sheet and consent form carefully, discuss it with your parents and only if both you and your parents agree, print your name and sign it. You or your parents are free to stop taking part at any time during the research without giving a reason. If you or your parents decide to stop, this will not affect the care you receive with the team.

What will happen to me if I take part?
If you decide to take part this will involve completing a set of questionnaires either paper versions or you can complete them online, we will provide you with a link. The questionnaires look at uncertainty, worry, anxiety, willingness to change, attitudes towards anorexia nervosa and eating. We will also be asking you to take part in a computer game. We will be asking you to complete these measures prior
therapy begins, at four weeks into therapy and at ten weeks, as these time points are thought to be important in terms of change. We will also be asking your parents to complete a set of similar questionnaires at the same time points. Overall completing measures at each time point will take approximately one hour.

What are the possible disadvantages and risks taking part?
There are thought to be no risks or disadvantages involved in taking part in this study. Obviously taking part in the study will require time in the centre in addition to your therapy.

What are the possible benefits of taking part?
By taking part in our research you may find it valuable that you will be helping us understand better the role of anxiety related factors in anorexia nervosa and whether such factors affect the effectiveness of family therapy and maintain symptoms. This is important as it will help us improve present treatments and help young people affected by anorexia nervosa. A further possible benefit is that by completing questionnaires on areas such as anxiety and uncertainty you may get to understand better your own attitudes towards such factors that you may not have thought of before.

What will happen if I do not want to carry on with the study?
You can stop taking part in the research at any time without giving an explanation and this will not affect you negatively in any way. Information collected will be destroyed if you or your parents wish.

What if there is a problem?
If you have any worries about any parts of the study, you should ask to speak to the main researcher involved in the study who will do her best to answer your questions (Miss Anna Konstantellou: Tel: 07762286387; E-mail: anna.konstantellou@kcl.ac.uk). If there is still a problem and you wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the hospital.

What will happen if harm occurs to me from the study?
We do not think that any harm will happen from taking part in this study. You may want to know that the study is covered by the NHS indemnity scheme if harm does happen. If something does go wrong and it is because of someone’s carelessness then you may have grounds for a legal action for compensation against the South London and Maudsley Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanism will still be available to you.

Will taking part in the study be kept confidential?
All information that is collected from you during the research will be kept strictly confidential, and any information about you that leaves the [name of centre inserted] will have your name and address removed so that you cannot be recognised. The research data will be kept in a secure location during
and after the study. All questionnaires filled by you and your child will be stored in a locked cabinet in a locked office. Each participant will be given a specific ID. A separate electronic database will contain a list of each participants’ IDs and their responses. This list will be blocked from public use and kept at in an electronic drive created for the study and accessible from the Institute of Psychiatry computers only, for those working on the project and under security password access. The data will be analysed anonymously and only used in the context of this study. The data will be stored for seven years and will then be destroyed.

**Does my General Practitioner (GP) get to know that I participate in the study?**
It is not necessary that we tell your GP if you decide to participate in this study. This is because the study does not affect the clinical care you receive.

**What will happen to the results of the study?**
The results will be published as a summary of all the data collected without giving account of individual results.

**Who is organising and funding the study?**
The Eating Disorder Service is funding this study. Your doctor will not be paid any fees for inviting you to take part in this study.

**Who has reviewed the study?**
All research in the NHS is looked at by a group of people, called a Research Committee to protect your safety, your rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Camden and Islington Research Ethics Committee.

**Further information and contact details:**
For more information about the study and for advice as to whether you may want to participate or if you are unhappy with the study, please contact:

[Contact details of present author inserted here]

Thank you for reading this!

[Inserted as footer: REC Protocol Number: 08/H0722/65; Version 3 29/03/2010]
APPENDIX 16: Information sheet for parents of adolescents in the clinical group (Study 4)

[Headed paper of research team]

Information sheet for parents

An Examination of Uncertainty and Related Factors in Anorexia Nervosa

We would like you and your child to take part in our research project looking at the role of uncertainty and related factors in anorexia nervosa. Before you decide whether both of you can help we will explain why the research is being done and what it will involve. Please feel free to ask us if there is anything that is not clear or if you would like more information.

You will have one week to decide whether you want to take part

What is the purpose of the study?
Our research aims to look at uncertainty and related factors such as anxiety and worry in individuals with anorexia nervosa. We want to examine whether these factors are important in individuals with anorexia nervosa and in their parents and whether they may play a part in blocking the effectiveness of therapy and maintain symptoms. Overall, we are aiming to increase our understanding of the role of anxiety related factors in anorexia nervosa.

Why have we been invited?
All parents of adolescents with a diagnosis of anorexia nervosa or eating disorder not otherwise specified (EDNOS), between 13 and 18 years old and the young people themselves referred to the eating disorder outpatient department at the [name of centre inserted] will be invited to take part in this study.

Do we have to take part?
No, it is up to you and your child to decide whether or not to take part. We will describe the study and go through this information sheet, which we will then give to you. If you wish to take part, you should read this information sheet and consent form carefully, discuss it with your child and print your name and sign it only if both you and your child agree to participate. Due to the nature of this study we will only include families when parents and the young person are in agreement to take part. You and your child are free to withdraw at any time, without giving a reason. This would not affect the standard of care you and your child receive.

What will happen to us if we take part?
If you and your child decide to take part you will be asked to complete a set of questionnaires either paper versions or you can complete them online, we will provide you with a link. The questionnaires look at anxiety related factors such as uncertainty and worry. Your child will also be given a set of similar questionnaires looking at uncertainty, worry, anxiety, willingness to change, and attitudes towards eating. She will also be asked to take part in a computer game. We will be asking you and your child to
complete these measures prior therapy begins, at four weeks into therapy and at ten weeks, as these
time points are thought to be important in terms of change. Overall completing measures at each time
point will take approximately one hour.

What are the possible disadvantages and risks taking part?
There are thought to be no risks or disadvantages involved in taking part in this study. Obviously taking
part in the study will require time in the centre in addition to your therapy.

What are the possible benefits of taking part?
By taking part in our research you may find it valuable that you will be helping us understand better the
role of uncertainty and related factors in anorexia nervosa and whether such factors affect the
effectiveness of family therapy. This is important, as it will help us improve present treatments and help
young people affected by anorexia nervosa. A further possible benefit is that by completing
questionnaires on areas such as anxiety and uncertainty you may get to understand better your own
attitudes towards such factors that you may not have thought of before.

What will happen if we do not want to carry on with the study?
You and your child can withdraw from the research at any time. This will not affect you or your child
negatively in any way. Information collected will be destroyed if either you or your child wish.

What if there is a problem?
If you have any concerns about any aspects of the study, you should ask to speak to the researchers who
will do their best to answer your questions. Please contact: Anna Konstantellou Tel: 020 7848 0972 or
E-mail: anna.konstantellou@kcl.ac.uk. If you remain unhappy and wish to complain formally, you can do
this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the
hospital.

What will happen if harm occurs to you or your child due to the study?
It is not expected in this study that any significant adverse effects arise for you or your child. The study is
covered by the NHS indemnity scheme should such occur. In the event that something does go wrong
and your child or you are harmed during the research and this is due to someone’s negligence, then you
may have grounds for a legal action for compensation against the South London and Maudsley
Foundation Trust but you may have to pay your legal costs. The normal National Health Service
complaints mechanism will still be available to you.

Will taking part in the study be kept confidential?
All information that is collected about you during the course of the research will be kept strictly
confidential, and any information about you, which leaves the [name of centre inserted] will have your
name and address removed so that you cannot be recognised. The research data will be kept in a secure
location during and after the study. All questionnaires filled by you and your child will be stored in a locked cabinet in a locked office. Each participant will be given a specific ID. A separate electronic database will contain a list of each participants’ IDs and their responses. This list will be blocked from public use and kept at in an electronic drive created for the study and accessible from the Institute of Psychiatry computers only, for those working on the project and under security password access. The data will be analysed anonymously and only used in the context of this study. The data will be stored for seven years and will then be destroyed.

**Does my General Practitioner (GP) get to know that we participate in the study?**

It is not necessary that your GP is made aware that you and your child participate in this study. This is because the study does not affect the clinical care you or your child receives.

**What will happen to the results of the study?**

Participants will not be identified in any report or publication. The results will be published as a summary of all the data collected without giving account of individual results.

**Who is organising and funding the study?**

The Adolescent Eating Disorder Service is funding this study. Your doctor will not be paid any fees for including you in this study.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by Camden and Islington Research Ethics Committee.

**Further information and contact details:**

For more information about the study and for advice as to whether you may want to participate or if you are unhappy with the study, please contact:

[Contact details of present author inserted here]

Thank you for reading this!

[Inserted as footer: REC Protocol Number 08/H0722/65; Version 3 29/03/2010]
APPENDIX 17: Information sheet for healthy young people (Study 4)

[Headed paper of research team]

Information sheet for healthy young people

An Examination of Uncertainty and Related Factors in Adolescents with and without Anorexia Nervosa

We are asking if you would like to take part in a research project to help us understand the role of uncertainty and related factors in adolescents with and without anorexia nervosa. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. So please consider this information sheet carefully. Talk about it with your family and friends if you want to and feel free to ask us if there is anything that is not clear or if you would like more information.

You will have two weeks to decide whether you want to take part

Why are we doing this research?
This study aims to look at whether young people with anorexia nervosa compared to adolescents without respond similar or not to a set of questionnaires related to anxiety, such as uncertainty and worry. By examining such factors in adolescents with and without anorexia nervosa we can understand better whether these factors are important in individuals with anorexia nervosa possibly maintaining symptoms and blocking therapy. Such information will be of great value for improving existing therapies for adolescents with anorexia nervosa.

Why have I been invited?
You are invited to participate in our study because you are a young person without anorexia nervosa and without any mental health problems.

Do I have to take part?
No, it is up to you to decide whether or not to take part. We will describe the study and go through this information sheet, which we will then give to you. If you decide to take part you should read this information sheet and consent form carefully, discuss it with your parents and only if both you and your parents agree, print your name and sign it. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect you negatively in any way.

What will happen to me if I take part?
If you decide to take part this will involve completing a set of questionnaires either paper versions or you can complete them online, we will provide you with a link. The questionnaires are related to uncertainty, worry, anxiety and eating habits. You will be completing a measure on eating habits as we
are looking for young people with no eating disorders in order to compare responses with young people with anorexia nervosa. Overall we will be asking for approximately 30 minutes of your time to complete the above measures.

**What are the possible disadvantages and risks taking part?**
There are thought to be no risks or disadvantages involved in taking part in this study.

**What are the possible benefits of taking part?**
There are no direct benefits from taking part in this study. You may however find it valuable knowing that you are contributing in helping us understand better the role of anxiety related factors in adolescents with anorexia nervosa. This is important as it will help us improve present treatments and help young people affected by anorexia nervosa. A further possible benefit is that by completing questionnaires on areas such as anxiety and uncertainty you may get to understand better your own attitudes towards such factors that you may not have thought of before.

**What will happen if I do not want to carry on with the study?**
You can stop taking part in the research at any time and this will have not affect you negatively in any way. Information will be destroyed if you or your parents wish.

**What if there is a problem?**
If you have any worries about any parts of the study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Anna Konstantellou, Tel: 020 7848 0972 or email: anna.konstantellou@kcl.ac.uk.

**What will happen if harm occurs to me from the study?**
We do not think that any harm will happen from taking part in this study. You may want to know that the study is covered by the NHS indemnity scheme if harm does happen. If something does go wrong and it is because of someone’s carelessness then you may have grounds for a legal action for compensation against the South London and Maudsley Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanism will still be available to you.

**Will taking part in the study be kept confidential?**
All information that is collected from you during the research will be kept strictly confidential. The research data will be kept in a secure location during and after the study. All questionnaires filled by your child will be stored in a locked cabinet in a locked office. Each participant will be given a specific ID. A separate electronic database will contain a list of each participants’ IDs and their responses. This list will be blocked from public use and kept at in an electronic drive created for the study and accessible from the Institute of Psychiatry computers only, for those working on the project and under security
password access. The data will be analysed anonymously and only used in the context of this study. The data will be stored for seven years and will then be destroyed.

**What will happen to the results of the study?**
The results will be published as summary of all the data collected without giving account of individual results.

**Who is organising and funding the study?**
The Eating Disorder Service is funding this study.

**Who has reviewed the study?**
All research in the NHS is looked at by a group of people, called a Research Committee to protect your safety, your rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Camden and Islington Research Ethics Committee.

**Further information and contact details:**
For more information about the study and for advice as to whether you may want to participate or if you are unhappy with the study, please contact:

[Contact details of present author inserted here]

Thank you for reading this!
Consent form for adolescent in the clinical group (Study 4)

[Headed paper of research team]

Consent form for young people

An Examination of Uncertainty and Related Factors in Anorexia Nervosa

Name of Chief Researcher: Anna Konstantellou

1. I confirm that I have read and understand the information sheet Version 3 dated 29/03/2010 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree for researchers, only part of the present study to have access to my personal information and contact details only in relation to the present study.

4. I understand that my responses will be confidential and anonymous.

5. I agree to take part in the above study.

Please initial box

Name of participant                    Date                                   Signature

Name of Researcher               Date                                     Signature

[Inserted as footer: REC Protocol Number: 08/H0722/65; Version 1 19/08/09]
Consent form for parents of young person

An Examination of Uncertainty and Related Factors in Anorexia Nervosa

Name of Chief Researcher: Anna Konstantellou

1. I confirm that I have read and understand the information sheet Version 3 dated 29/03/2010 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree for researchers only part of the present study to have access to my personal data and my child’s and contact details only in relation to the present study.

4. I understand that my responses will be confidential and anonymous.

5. I agree to take part in the above study.

Name of participant                    Date                                   Signature

Name of Researcher               Date                                     Signature

[Inserted as footer: REC Protocol Number: 08/H0722/65; Version 1 19/08/09]
APPENDIX 20: Consent form for parents of adolescents in the clinical group (Study 4).

[Headed paper of research team]

Consent form for parents of young person under 16

An Examination of Uncertainty and Related Factors in Anorexia Nervosa

Name of Chief Researcher: Anna Konstantellou

1. I confirm that I have read and understand the information sheet Version 3 dated 29/03/2010 for the above study and have had the opportunity to ask questions regarding my daughter taking part.

2. I agree for researchers only part of the present study to have access to my daughter’s personal data and contact details only in relation to the present study.

3. I understand that my daughter’s participation is voluntary and that she is free to withdraw at any time, without giving any reason, without her medical care or legal rights being affected.

4. I understand that my daughters’ responses will be kept confidential and anonymous.

5. I agree that my daughter takes part in this study.

___________  ___________  ___________
Name of participant  Date  Signature

___________  ___________  ___________
Name of Researcher  Date  Signature

[Inserted as footer: REC Protocol Number: 08/H0722/65; Version 1 19/08/09]
APPENDIX 21: Consent form for healthy young people (study 4)

[Headed paper of research team]

Consent form for healthy young person
An Examination of Uncertainty and Related Factors in Adolescents with and without Anorexia Nervosa

Name of chief investigator: Anna Konstantellou

1. I confirm that I have read and understand the information sheet Version 2 dated 21/12/2009 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I understand that my responses will be kept confidential and anonymous.

4. I agree to take part in the above study.

Name of participant                    Date                                   Signature

Name of Researcher                                             Date                                     Signature

[Inserted as footer: REC Protocol Number: 08/H0722/65 Version 1 19/08/09 School: name inserted]
APPENDIX 22: Consent form for parents of healthy young people under 16 years of age (Study 4)
[Headed paper of research team]

Consent form for parents of healthy young people
An Examination of Uncertainty and Related Factors in Adolescents with and without Anorexia Nervosa

Name of Chief Investigator: Anna Konstantellou

Please initial box

1. I confirm that I have read and understand the information sheet Version 2 dated 21/12/2009 for the above study and have had the opportunity to ask questions.

2. I understand that my daughter’s participation is voluntary and that she is free to withdraw at any time, without giving any reason.

3. I understand that my daughter’s responses will be confidential and anonymous.

4. I agree that my daughter takes part in this study.

_________________  ___________  ___________
Name of Parent       Date            Signature

_________________  ___________  ___________
Name of Researcher   Date            Signature

[Inserted as footer: REC Protocol Number 08/H0722/65; Version 1 19/08/09; School: name inserted]