Anorexia nervosa –
treatment expectations, outcome and satisfaction
Örebro Studies in Medicine 76

Gunilla Paulson Karlsson

Anorexia nervosa –
treatment expectations, outcome and satisfaction
Abstract


Anorexia nervosa is a serious mental disorder with high mortality. It has the lowest prevalence compared with other eating-disorder diagnoses and the onset is related to adolescence, with a majority of female patients. The focus of this thesis is anorexia nervosa and the aim is to study adolescent and adult patients’ comprehension and the course of treatment in order to make a contribution to the clinical work relating to these patients. The areas that were studied are expectations of treatment, outcome, predictors of outcome and satisfaction with treatment. Four research papers are included; three originate from work at a specialist eating-disorder unit at Queen Silvia Children’s Hospital, Göteborg, Sweden and one from a multi-centre study comprising 15 specialised eating-disorder units in Sweden.

**Paper I** has a qualitative design, where participants, 18-25 years of age, were interviewed about their expectations while on the waiting list at a specialist eating-disorder unit. Three main categories of expectations emerged: “Treatment content,” “Treatment professionals” and “Treatment focus.” The participants expected to receive the appropriate therapy in a collaborative therapeutic relationship and to recover. **Paper II** evaluated the outcome of a family-based treatment for adolescent patients, 13-18 years old, and their parents. The results indicate that the treatment that is offered appears to be effective, as 78% of the patients were in full remission with less distance and a less chaotic family climate at the 36-month follow-up. **Paper III** examined the importance of motivation to change eating behaviour, treatment expectations and experiences, ED symptomatology, self-image and treatment alliance for predicting weight increase in adult patients, 18-46 years of age. Patients’ motivation to change eating habits, social relations, self-image, body image and duration of illness were found to predict weight increase both in both the short term (six months) and the long term (36 months). **Paper IV** studied adolescent patients’ and their parents’ satisfaction with a family-based treatment at an 18-month follow-up. The majority of patients (73%) and parents (83%) stated that their expectations had been fulfilled and individual sessions for patients and parents respectively were of great help. Family-based treatment with a combination of individual and family sessions corresponds well to patients’ and parents’ treatment expectations.

Young adult patients’ expectations before treatment are multifaceted and should be taken into account in the therapeutic relationship. From the start of treatment, issues relating to patients’ motivation, self-image, body image and social relationships should be continuously addressed in order to establish positive collaboration and a weight increase. Anorexia nervosa treatment for adolescents and their parents should be family-based and include family sessions as well as individual sessions for patients and parents. In addition, prevention programmes with the emphasis on early detection should be a prioritised area.

**Keywords:** Anorexia nervosa, treatment, adolescents, adults, expectations, outcome, predictors, weight increase, satisfaction.
List of Papers

This thesis is based on the following original papers, which will be referred to in the text by their Roman numerals:


Reprints have been made with the permission of the publishers.
### Abbreviations

- **AN** Anorexia Nervosa  
- **AFT** Adolescent-focused therapy  
- **APA** American Psychiatric Association  
- **ASD** Autism Spectrum Disorder  
- **BDI** Beck Depression Inventory  
- **BED** Binge Eating Disorder  
- **BN** Bulimia Nervosa  
- **BMI** Body Mass Index  
- **CAT** Cognitive Analytic Therapy  
- **CBT** Cognitive Behavioural Therapy  
- **CBT-E** Cognitive Behavioural Therapy – Enhanced  
- **CFT** Conjoint Family Therapy  
- **COEAT** Co-ordinated Research and Evaluation Project for specialist units in the treatment of eating disorders  
- **CO-RED** Co-ordinated Evaluation and Research at Specialist Units for Eating Disorders  
- **DBT** Dialectical Behaviour Therapy  
- **DSM-IV** Diagnostic and statistical manual of mental disorders, fourth edition  
- **DSM-5** Diagnostic and statistical manual of mental disorders, fifth edition  
- **ED** Eating Disorders  
- **EDE** Eating Disorder Examination  
- **EDI-2** Eating Disorder Inventory – 2  
- **EDI-C** Eating Disorder Inventory for Children  
- **EDNOS** Eating Disorder Not Otherwise Specified  
- **EDPEX** Eating Disorder Patients’ Expectations and Experiences of Treatment Questionnaire  
- **ES** Effect Size  
- **ET-A** Evaluation of Treatment – Adolescent  
- **ET-P** Evaluation of Treatment – Parent  
- **FBT** Family-based treatment  
- **FCS** Family Climate Self-rating scale  
- **FORAB-S** Follow-up Rating of Anorexia and Bulimia–Short  
- **FORAB-F** Follow-up Rating of Anorexia and Bulimia–Full  
- **ICD-10** International Classification of Diseases  
- **IPT** Interpersonal Psychotherapy
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>Mean</td>
</tr>
<tr>
<td>MANTRA</td>
<td>Maudsley model of anorexia nervosa treatment for adults</td>
</tr>
<tr>
<td>MET</td>
<td>Motivational Enhancement Therapy</td>
</tr>
<tr>
<td>MFT</td>
<td>Multi-family therapy</td>
</tr>
<tr>
<td>MI</td>
<td>Motivational Interviewing</td>
</tr>
<tr>
<td>MSCARED</td>
<td>Motivational Stages of Change for Adolescents Recovering from an Eating Disorder</td>
</tr>
<tr>
<td>N</td>
<td>Number</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
</tr>
<tr>
<td>OCD</td>
<td>Obsessive Compulsive Disorder</td>
</tr>
<tr>
<td>PSR</td>
<td>Psychiatric Rating Scale</td>
</tr>
<tr>
<td>R</td>
<td>Range</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>RAB</td>
<td>Rating of Anorexia and Bulimia nervosa</td>
</tr>
<tr>
<td>RAB-C</td>
<td>Rating of Anorexia and Bulimia nervosa-Children</td>
</tr>
<tr>
<td>RAB-P</td>
<td>Rating of Anorexia and Bulimia nervosa-Parents</td>
</tr>
<tr>
<td>RMI</td>
<td>Readiness and Motivation Interview</td>
</tr>
<tr>
<td>SAS</td>
<td>Statistical Analysis System</td>
</tr>
<tr>
<td>SASB</td>
<td>Structural Analysis of Social Behaviour</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>SFT</td>
<td>Separated Family Therapy</td>
</tr>
<tr>
<td>SSCM</td>
<td>Non-specific Supportive Clinical Management</td>
</tr>
<tr>
<td>SOP</td>
<td>Self-Oriented Perfectionism</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for Social Science</td>
</tr>
<tr>
<td>SWEAA</td>
<td>Swedish Eating Assessment for Autism spectrum disorders</td>
</tr>
<tr>
<td>TMC</td>
<td>Transtheoretical Model of Change</td>
</tr>
<tr>
<td>TSS</td>
<td>Treatment Satisfaction Scale</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>YSR</td>
<td>Youth Self-Report</td>
</tr>
</tbody>
</table>
# Table of contents

INTRODUCTION ................................................................................... 13  
Historical review ........................................................................... 14  
Diagnostic criteria ........................................................................... 15  
Onset and development of anorexia nervosa ........................................ 15  
Treatment expectations ..................................................................... 21  
Treatment of anorexia nervosa ......................................................... 24  
Treatment outcome .......................................................................... 33  
Outcome predictors ........................................................................... 39  
Treatment satisfaction ....................................................................... 41  
Epilogue .............................................................................................. 43  
Aims ................................................................................................. 45  

METHODS............................................................................................ 47  
Design ............................................................................................... 48  
Procedures .......................................................................................... 49  
Participants ........................................................................................ 51  
Measurements .................................................................................... 52  
Treatment model ............................................................................... 55  
Statistical methods ........................................................................... 57  
Qualitative methods ......................................................................... 59  

RESULTS.............................................................................................. 61  
Study I .................................................................................................. 61  
Study II ............................................................................................... 64  
Study III .............................................................................................. 67  
Study IV .............................................................................................. 68  

DISCUSSION.......................................................................................... 71  
Methodological considerations ............................................................ 71  
General discussions of main findings .................................................... 73  
Strengths ............................................................................................ 82  
Limitations ......................................................................................... 83  

CONCLUSIONS..................................................................................... 85  
Clinical implications ........................................................................... 86  
Research implications ....................................................................... 87  

SAMMANFATTNING PÅ SVENSKA ..................................................... 89  

ACKNOWLEDGEMENTS ...................................................................... 91  

REFERENCES ...................................................................................... 95  

APPENDICES ...................................................................................... 119
INTRODUCTION

This thesis is based on clinical experience, which has developed in a clinical environment during a period of many years with adolescent boys and girls, their families and foster families, at a specialist eating disorder unit. The unit is located at the Child and Adolescent Psychiatry Centre at Queen Silvia Children’s Hospital in Göteborg, Sweden, and includes out-patient, day-care and in-patient services for patients up to 25 years of age and their families. From the start of this unit in 1994, research and development has been integrated into the clinical work through national and local projects and two thesis and numerous articles and conference presentations have been produced. This breeding ground, spiced with a large amount of curiosity to know more about patients and families, was the starting point of this thesis.

At the unit, a family-based treatment model developed at the Maudsley Hospital in London, UK, was the prototype for the treatment of adolescent patients with anorexia nervosa. Many questions started to arise in the daily clinical work with these patients and their parents. Is this treatment helpful? Do patients recover and stay recovered? What are the living conditions for the families? What is their experience of the treatment? Over the years, research on adolescents and family-based treatment in anorexia nervosa, as described in the Maudsley model, has been in progress but not to any great extent and this explains why there is a need to study and develop the treatment still further. Examples of areas to explore and questions to answer are whether there exists an optimal format for family-based treatment, the different focus areas it is important to include in a family-based setting and what is the patients’ and parents’ own understanding of treatment. In addition, should family-based treatment differ in format and content based on the age of the patient – young adolescents, older adolescents and young adults, for example, and, if so, how? My personal interest in exploring patients’ own understanding of treatment and also investigating which features affect the core of anorexia nervosa treatment, weight increase, was a focal point at an early stage. Research on the treatment of adult patients with anorexia nervosa is sparse and knowledge on patients’ own perception of treatment and what is related to weight increase has not been explored in detail. It is necessary to continue searching for important areas to include in the treatment of adult patients, such as motivation to increase weight, self-image and body image. Finally, my personal treatment experience of eating disorders has also raised the question of the essential characteristics that are needed as a therapist.
The focus of this thesis is anorexia nervosa and the studies elucidate different perspectives of treatment for adolescent and adult patients and include an effort to integrate empirical research into clinical practice. The thesis comprises four empirical studies with clinical case material. The first study examines expectations prior to treatment, the second study explores the outcome of family-based treatment, the third investigates predictors of weight increase and the fourth focuses on satisfaction with family-based treatment. Methods and results from the four studies are presented after which the main findings are discussed. The thesis ends with a conclusion discussing clinical and research implications.

**Historical review**

The first recognised medical description of anorexia nervosa (AN) was documented by Richard Morton in 1689 (Vandereycken & van Deth, 1994). In an address to the British Medical Association in Oxford, Sir William Gull, a physician at Guy’s Hospital in London, described several female patients, between the ages of sixteen and twenty-three, with extreme emaciation (Gull, 1868). In 1873, he published his medical work describing three of his cases and, subsequently referring to the condition as Apepsia Hysterica and Anorexia Hysterica, he concluded that Anorexia Nervosa was more correct. In his paper, he also mentions the report of Dr. Lasègue in Paris, in which observations of the same condition had been made independently (Gull, 1873).

However, long before this, history tells us of ancient cultures in Egypt where voluntary fasting was a cure for different diseases, involved in punishment and a part of religious practice. Another example is the Pharaohs who fasted before important decisions were made. The most well-known self-starving example was Caterina de Siena, 1347-1380, an Italian Dominican patron saint, who ate, often in solitude, and prayed to see signs from God of allowance (Vandereycken & van Deth, 1994).

Anorexia nervosa has the lowest prevalence compared with other eating-disorder diagnoses (Clinton & Norring, 2002). Ever since the diagnosis of AN was introduced, the majority of patients have been female and the disorder is known to be nine to ten times more common in girls than in boys (Hoek, 2006). As there are minimal gender differences in symptom phenomenology (Strober et al., 2006), patients in the following text will be referred to as “she” or “female”. In the four studies presented in this thesis, all the participating patients were female.
Diagnostic criteria

There are two known classification systems for mental disorders, the Diagnostic Statistical Manual of Mental Disorders, 4th edition, DSM-IV (American Psychiatric Association, 1994), and the International Classification of Diseases, ICD-10 (World Health Organisation WHO, 1992). In practically all research on eating disorders, the DSM-IV is used, as is the case in this thesis.

The diagnostic criteria for (AN) include refusal to maintain normal body weight, intense fear of gaining weight or becoming fat, disturbance of body image and, in postmenarchal females, the absence of at least three consecutive menstrual cycles (see detailed criteria in Appendix I).

Since 1999, the process of revising the DSM-IV to the DSM-5 has been in progress. The Eating Disorder Work Group responsible for addressing these disorders has recommended that the category should be renamed Feeding and Eating Disorders. Changes proposed for the diagnoses of AN in the DSM-5 are that the word “refusal” should be changed to “restriction of energy intake” and low body weight should be defined in another way, the criterion amenorrhea should be deleted and, in sub-types 1 and 2, time should be specified for the last three months. The DSM-5 is expected to be published in May 2013.

Onset and development of anorexia nervosa

The onset of AN is generally related to adolescence, between 15 and 22 years of age (M=17) (Hsu, 1990) with the high risk-group of 15-19 year old girls (Smink, van Hoeken, & Hoek, 2012). Tasks to be dealt with in adolescence are changes related to biological and sexual maturation and the development of a personal identity. The physical changes mark the start of this period and interact together with psychological internal and external social changes. These changes loosen the childhood ties to parents in order to establish independence and autonomy and develop a stable personality structure that regulates mood, impulse and self-esteem within the socio-cultural environment (Attie & Brooks-Gunn, 1989; Christie & Viner, 2005). These different changes are dependent and rely on each other, occurring at the appropriate time in order to negotiate and achieve optimal development.
Developmental course in adolescence

The word adolescence comes from the Latin word *adolescere* and means “to grow into maturity” and it is the span of years between childhood and adulthood, starting with puberty and its physical changes in a child’s body (Papalia, Olds & Feldman, 2005). One distinguishing characteristic of female puberty is menarche and this sexual maturation is one of the most dramatic physical changes for the adolescent girl (Christie & Viner, 2005). During this developmental stage, there is an accumulation of large quantities of fat in subcutaneous tissue, a “fat spurt” that adds an average of 11 kg of weight in the form of body fat. The mean proportion of body fat in middle childhood is 8% compared with 22% after puberty (Schmidt, 2003). Contributory factors to the onset of puberty are adequate nutrition, achievement of sufficient body mass, adipose tissue and the absence of mental and psychical stress. However, within a population genetic factors are in the majority (74%) when it comes to the onset of puberty compared with environmental factors (27%). The mean age for the start of puberty for girls in Northern Europe is 10.7-11.2 years and for menarche 13.1-13.5 years, which can be compared with the Mediterranean countries with a younger age at the start of puberty, where the age of menarche is 12.0-12.6 years of age. Increased BMI increases the speed of bodily maturation (Hagenäs, 2008). Changes in physical appearance and bodily feelings result in a need for the adolescent to reorganise her body image and self-representation (Attie & Brooks-Gunn, 1989).

In addition, throughout adolescence, brain development undergoes important modifications, with structural and functional changes, and the brain is especially vulnerable during this period (Treasure & Russell, 2011). Other important psychological tasks during this stage are the development of abstract thinking, which enables us to think hypothetically about the future and evaluate different solutions, identify the difference between law and morality, develop verbal abilities, increase impulse control and further develop personal identity. The social changes in adolescence represent changes in the balance of dependence and independence in relation to other members of the system, i.e. parents, peers, adults and professionals. Adolescents start to define other people in relation to themselves and this is a position in which it may be difficult to understand the impact of one’s own behaviour on others or how others may be affected. Emotional separation from parents, strong peer identification, intimate relationships, vocational training and financial independence all contribute to social autonomy (Christie & Viner, 2005).
Early interacting factors

The causes of AN are unknown, but most clinicians and researchers agree that it is a multifactorial disorder in which no single factor or cause is enough to start or maintain the disorder. Instead, a complex interaction of biological, psychological and socio-cultural factors takes place over time, based on individual, familial and cultural predisposing factors (Garner, 1993). Crisp (1984), Attie and Brooks-Gunn (1989) and Gowers and Shore (2001) stated that puberty itself is a risk factor for eating problems in females and that AN is an attempt to adapt to and cope with maturational problems using the avoidance of biological maturity. Negative feelings about the body emerge as a response to pubertal change and these feelings of discontentment with body weight and shape, feeling “too fat”, can lead to the use of dieting as a tool to achieve thinness, feelings of self-control, autonomy and self-worth, which are the solution to happiness (Bruch, 1985; Cooper, 1995; Eisler, Dare, Hodes, Russell, Dodge & Le Grange, 2000; Garner, 1993; Nevonen & Broberg, 2000; Treasure & Schmidt, 2005; Wilson, Grilo & Vitousek, 2007). Additional risk factors associated with the development of AN are traits of perfectionism, negative self-evaluation and extreme compliance (Fairburn, Cooper, Doll & Welch, 1999).

Further, the concept of attachment in relation to eating disorders has been highlighted. Bowlby (1969) emphasised early experiences of relationships as being important to future relations and refers to the infant seeking safety and closeness to caregivers when feeling threatened. The nature of the attachment is determined by the interactions between the infant and the caregiver. Early relationship difficulties and their role in the development of eating disorders were pointed out at an early stage by Bruch (1982). During adolescence, one important assignment is to establish independence and autonomy primarily in relation to parents, which assumes a fruitful separation-individuation process. In overprotective, intrusive and controlling families with few opportunities for self-expression, self-starvation is “a defence against the feeling of not having a core personality of their own, of being powerless and ineffective” (Bruch, 1982, p. 1532). Further, Bruch discussed the fact that feelings of incompetence and “being not good enough” can generate difficulties identifying one’s own feelings and needs and contribute to a disturbed body image with feelings of being too fat. The anorexic girl's preoccupation with thinness represented the striving to take control of herself by controlling her body in order to gain feelings of self-respect and competence (Bruch, 1973; 1978).
The last decades of family studies have proposed that high-concern parenting in infancy is associated with the subsequent development of AN (Shoebridge & Gowers, 2000) and Broberg, Hjalmers and Nevonen (2001a) revealed that patients with AN have difficulty with autonomy/separation, attachment and identity. A recent literature review reveals that women with eating disorders show an insecure attachment style, with extreme separation anxiety and unresolved loss and trauma (O’Shaughnessy & Dallos, 2009). In addition, the relatives of individuals with AN run an increased risk of developing an eating disorder (Lilenfeld et al., 1998; Strober, Lampert, Morrell, Burroughs & Jacobs, 1990). In a review of 29 articles on attachment and eating disorders, Zachrisson and Skårderud (2010) found a greater prevalence of insecure attachment in patients with an eating disorder than in non-clinical samples. However, the authors stress that more research in this field is needed before conclusions can be drawn about patterns of attachment in relation to eating disorders.

To date, there are no findings indicating that specific family features are associated with eating disorders; on the contrary, eating disorders develop in a variety of family contexts (Eisler, 2005). In actual fact, the question is quite the reverse, what is the nature of the impact of the eating disorder on the family?

A young girl often starts dieting by excluding or reducing what she eats, such as sweets, snacks between meals, school lunches and family dinners. She avoids specific energy such as sugar, fat and carbohydrates in order to eat and become more “healthy”, feel capable and in control, often in combination with increased physical activity (Clinton & Norring, 2002). At first, she often receives appreciation of her appearance from friends and classmates, which fulfils her needs and encourages her to continue. However, people in her immediate circle, such as parents, relatives, friends, the school nurse or doctor, eventually react negatively to her looks and behaviour. For some girls, this is enough to stop dieting and return to a normal healthy life, but other girls experience the reactions of others as triggers to continue dieting. Clinton and Norring (2002) report that dieting teenage girls run an eight times higher risk of developing an eating disorder than non-dieting girls of the same age, but dieting alone is not enough for this multifactorial disorder to evolve. The role of maturation, together with psychological vulnerability, is relevant to the development of the symptoms. Girls who continue dieting to increase their feeling of self-control and self-worth, despite or due to the reactions of family and friends, reach a condition of starvation with serious psychological, emotional and physi-
cal consequences, which in turn become maintaining factors (Garner, 1993).

**Prevalence and incidence**

So what is the prevalence? How common is this disorder in a population? The results of an epidemiological study in Göteborg, Sweden, revealed that, at a certain point (the point prevalence), almost one per cent (0.94%) of all 16-year-old girls met the criteria for AN (Råstam, Gillberg & Gar- ton, 1989). The prevalence among young women during the last 25 years has been shown to be two to four cases per thousand persons (0.2-0.4%) (Lucas, Beard, O’Fallon & Kurland, 1991; Rosenvinge, Borgen & Boerresen, 1999; Engström, 2002; Hoek & van Hoeken, 2003).

What about the incidence? How many new cases does the health service encounter in one year? In a review of the literature, females aged 15-19 constituted approximately 40% of all identified cases and ran the greatest risk of developing AN and the incidence was eight cases per 100,000 population per year (Hoek & van Hoeken, 2003). A recent article shows that the overall incidence rate from the 1980s and onwards has been un-changed, while there has been an increase in the number of new cases in the high-risk group of 15- to 19-year-old girls. The authors say that it is unclear whether this is due to earlier age of onset together with earlier detection (Smink, van Hoeken & Hoek, 2012). In the UK, the annual incidence rate remained stable between 1988 and 2000, with 4.7 per 100,000 person-years in 2000 (Currin, Schmidt, Treasure & Jick, 2005). In the Netherlands, the incidence rate has remained stable as well, with 7.7 per 100,000 person-years in 1995-1999 (Smink, van Hoeken & Hoek, 2012).

**Physical signs of starvation**

Parents, siblings and others are generally alarmed when they observe physical changes and changes in mood and behaviour in a starving girl. Visible changes include amenorrhea, depression, fits of rage, sleeping problems, concentration problems, social withdrawal and a preoccupation with food, weight and body (Agras et al., 2004; Wilson et al., 2007).

The physical strain is severe when body weight is 15% or less below a healthy weight and the criteria for AN (Appendix I) are met with a number of medical problems. The body with its inner organs is dampened; pulse and blood pressure fall, reflexes and the power of muscles are reduced, the metabolic rate decreases, hair becomes brittle, the body temperature drops and the hands and feet become cold. Changes in hormone secretion with amenorrhea are a common early sign, as menstruation is closely associated
with weight and bodily fat tissue and osteoporosis affects approximately 38% of individuals with AN (Hägglöf, 2002, Agras et al., 2004, Wilson et al., 2007).

Co-morbidity
AN often starts in adolescence (Smink et al., 2012), a time when the personality is under development and unstable, and it interrupts and disturbs normal development and affects self-confidence (Attie & Brooks-Gunn, 1989; Christie & Viner, 2005). AN results in reduced cognitive abilities and emotional processing (Treasure, Claudino & Zucker, 2010) and research is growing in the field of neurobiology and the psychopathology of eating disorders. One aspect of executive functioning is set-shifting ability, the capability to display cognitive flexibility. This ability is commonly reduced in adult AN patients with current and past illness (Roberts, Tchanturia, Stahl, Southgate & Treasure, 2007; Roberts, Tchanturia, & Treasure, 2010; Tchanturia et al., 2004a; 2004b; Tchanturia et al., 2012). Roberts et al. (2010) suggest that poor cognitive flexibility is a factor of psychological illness rather than just a factor of medically low weight. In a recent study by Shott et al. (2012), impaired set-shifting was investigated in adolescent AN and adult patients compared with age-matched and gender-matched controls. The results revealed that adolescent patients had normal set-shifting compared with adolescent controls, but adult patients had impaired cognitive flexibility compared with adult controls.

Central coherence is the ability to understand context or to “see the big picture” commonly related to autism spectrum disorders (ASD). However, central coherence is also present in patients with AN, where starvation produces increased set-shifting problems and reduced social cognition (Treasure, 2012). The co-morbidity in AN and ASD is sparsely researched, but recent results from an 18-year follow-up of a longitudinal study in Sweden showed a co-morbidity of 32% of ASD in all cases with AN (Anckarsäter et al., 2011). An instrument, the Swedish Eating Assessment for Autism spectrum disorders (SWEAA), to explore the co-morbidity between ASD and AN has been developed and validated in Göteborg. This instrument may contribute to the early detection of AN patients with ASD in order to offer adequate treatment (Karlsson, Råstam, & Wentz, submitted 2012).

AN is frequently accompanied by serious co-morbid psychopathology, such as depression with feelings of helplessness and guilt, anxiety disorders, obsessive-compulsive disorder and substance use disorders. The depressive symptoms may not be associated in early adolescence, but, in the middle of
the period or later, when the eating problems are more clearly manifested, they are likely to occur as a result of underweight and malnutrition (Attie & Brooks-Gunn, 1989; Clinton & Norring, 2002). These symptoms often decrease when the weight increases, as shown in a follow-up study in which adult AN patients of normal weight reduced their paranoid and obsessive-compulsive personality indices to a larger extent than those who were still underweight (Agras et al., 2004; Cooper, 1995; Rø, Martinsen, Hoffart & Rosenvinge, 2005). However, in a 18-year follow-up of people with teenage-onset AN, 39% had a psychiatric disorder other than an eating disorder, where anxiety disorders were most common (Wentz, Gillberg, Anckarsäter, Gillberg & Råstam, 2009).

**Treatment expectations**

The Mental Health Action Plan for Europe (WHO, 2005) states that periodic population-based surveys on service users’ expectations of mental health should be carried out in order to improve the quality of those services and treatment planning. The patients’ view of treatment and service is also an important feature for the quality and practice of treatment. In a review, Noble, Douglas and Newman (2001) studied patients’ expectations of psychiatric services and reported that expectations of treatment may contain an element of inconsistency, in the sense that what patients expect to happen and what they desire to happen may be different. Expectations may relate to the likelihood of recovery or the effectiveness of the treatment process, while desires and wishes about treatment may be contradictory and ambivalent with regard to goals, interventions and therapists. Both expectations and desires are not necessarily communicated to service providers and may not always reflect what patients want.

Patients’ expectations of health care in general comprise doctors being respectful and knowledgeable, being involved in treatment decisions, experiencing a reduction in symptoms, being informed about their current condition and being given an opportunity to discuss problems (Bowling et al., 2012). Further, patients with major depression expect that ‘the doctor will give the patient fresh ideas’ referring to enhanced coping, ‘treat my depression’ and ‘provide advice on medication’ (Wilhelm et al., 2005). In addition, the absence of symptoms of depression, the presence of positive mental health and coping well and not getting overwhelmed in stressful situations were the most important expectations in terms of antidepressant treatment outcome (Pasquini et al., 2009). In a study of 550,000 adult patients from Swedish psychiatric hospital wards, the results show that
patients had significantly higher expectations regarding the quality of care on admission to hospital than they subsequently experienced. The dimensions explored were ‘dignity’ (patient being respected, confirmed and understood in a good relationship with the staff), ‘security’ (high level of access, continuity and trust towards staff), ‘participation’ (receiving relevant information, close collaboration with staff, opportunities for self-determination), ‘recovery’ (evidence-based medical treatment, supportive guidance, post-care follow-up) and ‘environment’ (personal space, aesthetics, calm atmosphere security) (Schröder, Wilde Larsson & Ahlström, 2007).

In health care, these studies show that patients have a range of expectations of the quality of treatment; how they are received and treated and also of the outcome.

However, there are few studies exploring the field of eating disorders and patients’ expectations of treatment; most results describe expectations in a retrospective view in relation to experiences after treatment. When eating-disorder treatment begins, the majority of patients and families have expectations, but patients with AN are a heterogeneous group and expectations of help and treatment can be multi-faceted when it comes to eating problems and starvation and vary in relation to age, symptoms, the need for control and personality (Vitousek, Watson, & Wilson, 1998). Expectations are also different depending on whether they relate to patients, parents, siblings, relatives or friends.

**Adolescents’ expectations**

According to Bruch (1985), adolescents and young girls generally want to be left alone with their dieting and their thoughts about finding a way to happiness and full control by starving and becoming extremely thin. Many girls report that they do not feel ill or think they have eating problems and therefore do not have any expectations of help and treatment with weight gain as a result. Due to poor insight into the danger of the illness, high levels of denial and low desire for help (Fisher, Schneider, Burns, Symons & Mandel, 2001), treatment is often searched for by parents and, as a result, the adolescents have few expectations other than to elude treatment. In addition, in adolescence, comparisons with peers are common and discussions of weight, appearance and dieting generate feelings of specific appearance to live up to in order to fit in (Aila Gustavsson, Edlund, Davén, Kjellin & Norring, 2009). In this perspective, treatment is feared and can be equated with being rejected by the peer group. For a starving girl, treatment can also mean surrendering the low body weight control mecha-
nism and being forced to return to the challenges of adolescence (Crisp, 1984).

**Parents’ expectations**
The school health service is one of the primary services that observe and report to parents and specialists when height and weight growth diverge from normal. The parents might be alarmed and they then turn to health centres or treatment units with expectations of help. They want their daughter to become well and everything to return to normal. The eating disorder has an impact on family life that is immense and it becomes “the organising principle in the whole family” which everyone tries to accommodate (Eisler, 2005). Parents often feel frightened, angry and guilty, as they are exposed to high levels of stress, distress and burden and they want to be included in the treatment of their daughters (Treasure et al., 2001a; Whitney & Eisler, 2005). When parents encounter professionals, they expect rapid progress with substantial changes; they expect to be a part of the treatment and to share information with the clinicians about their daughters’ state of health and treatment progress on a regular basis. Parents expect to be met with a positive attitude, to be listened to and respected and to be supported to enable them to cope with a serious illness (Honey et al., 2008).

**Adults’ expectations**
When young adults with AN enter treatment, relatives or friends have generally persuaded them and, if not, they often come because they are experiencing the negative effects of the illness, such as a preoccupation with food, depression, anxiety and binge eating. In the encounter with doctors and clinicians, they frequently expect to be helped with the negative consequences and become healthy without ending their dieting and abandoning the dream of happiness with a thin body (Vitousek et al., 1998). Patients with AN differ in terms of psychiatric symptomatology and personality structure and therefore vary in their expectations of treatment. There exist a denial of the illness and a refusal to acknowledge distress, thinness, hunger and fatigue, fear of weight gain, dietary rituals and laxative abuse. There is also an ambivalent motivation to engage in treatment and the patients expect defensive collaboration with interventions that do not threaten their delicate situation (Clinton, 1994).

When adult patients’ expectations of treatment were examined, the results showed that they wanted to achieve control of their eating habits by planning meals and being supported by a therapist with personal and practical involvement in the patient. They also expected to be listened to and to be
met with care and consideration during the treatment process (Clinton, 2001).

To sum up, patients’ expectations on treatment are generally comparable, regardless of illness or psychiatric disorder, but there is a difference in expectations of AN treatment, due to an ambivalence to engaging in treatment, since the core symptoms are perceived as both negative and positive. What patients expect to happen is not always the same as what they wish to happen and patients’ motivation to participate in treatment and change fluctuates in intensity and over time (Nordbø, et al., 2011; Vansteenkiste, Soenens, & Vandereycken, 2005) and this also affects treatment expectations.

Treatment of anorexia nervosa

The treatment of AN has developed through different phases since Sir William Gull observed that his patients were very persistent and urged themselves to exhaustion if allowed and he therefore recommended that “The patients should be fed at regular intervals and surrounded by persons who would have moral control over them; relations and friends being generally the worst attendants” (Gull, 1873, p 26). In 1914, Simmonds, who was a pathologist, treated starvation by transplanting the pituitary gland from animals to human beings, as he had found hormonal disturbances caused by injuries to the pituitary gland characterised by pronounced emaciation. This treatment proved to be fruitless and was abandoned (Simmonds, 1914).

From 1945, the treatment of AN was influenced by psychoanalytical theories about the causes of the disorder, such as intra-psychic conflicts about sexuality, which spread to psychiatry (Vandereycken & van Deth, 1994). In the 1960s, Hilde Bruch, a psychiatrist and psychotherapist, was a pioneer in developing a psychotherapeutic methodology that emphasised anorexic patients’ lack of self-esteem and their distorted body image, based on her own observations in clinical work. She pointed out that the main focus in therapy must be to help and support the anorexic patient to be aware of impulses, feelings and needs and thereby accomplish autonomy and self-respect (Skårderud, 2009).

Later, AH Crisp emphasised the fact that the central psychopathology in AN lies in the fear of growing up, a conflict relating to psychobiological maturity and a biological solution to an existential problem. This avoid-
ance of biological maturity involves the avoidance of mature body weight and the treatment should therefore focus on a gradual progress to regain a healthy weight through direct behavioural measures and by psychotherapy, with the emphasis on developmental issues and maturity fears (Crisp, 1980; 1984).

The structural and systemic treatment approaches broke into the field of AN treatment and the origin of the family-based treatment approach of today started with Minuchin and colleagues (1975, 1978) at the Philadelphia Child Guidance Clinic, USA, and the development of structural family therapy. The focal areas were the organisation of the family, with communication and dysfunctional patterns of overprotection, rigidity and unresolved conflicts as the predisposing, precipitating and perpetuating factors of psychosomatic symptoms. Later on in the early 1980s, Selvini Palazzoli (1978) developed systemic family therapy in Italy, inspired by Minuchin, and used positive interpretations such as family interventions without approaching the actual starvation. She generated a hypothesis about the function of the symptom in the family, with the emphasis on patterns of communication, alliances, coalitions and self-sacrifice.

White and Epston (1990) developed narrative therapy, which contributed significantly to the treatment of AN by the narrative of the illness being separated from patient and parents. This externalisation process allows the family members to consider the impact of the illness in the family system and on its relations and provides an opportunity for parents to co-operate and help their daughter take control of the disorder (White & Epston, 1990).

**Clinical guidelines**

Patients and parents seeking treatment for an eating disorder expect to be treated by experts with a knowledge of reliable treatment and experience in the field. So what treatment and management of AN is currently recommended?

In clinical guidelines (American Psychiatric Association, APA, 2000; NICE, 2004) on interventions in the treatment of AN, physical monitoring, nutritional rehabilitation and psychological treatment that emphasise the seriousness of the illness and assess the physical risks should be offered at the earliest opportunity. In the National Institute for Clinical Excellence (NICE, 2004), this treatment should be provided by specialised health-care professionals, preferably on an out-patient basis and always starting with weight gain and healthy eating. In these evidence-based guidelines, recom-
recommendations for treatment are graded at A, B or C levels. The A level includes evidence obtained from a single randomised controlled trial or a meta-analysis of randomised controlled trials, the B level has evidence obtained from a controlled study without randomisation and the C level contains evidence obtained from expert committee reports or clinical experience. Swedish clinical guidelines and regional guidelines for Göteborg are in line with NICE (2004) regarding AN, recommending that a medical examination is performed and that treatment should be offered as soon as possible on an out-patient basis with interventions focusing on eating behaviour and weight gain. Initially, the main objective was to interrupt starvation and to normalise eating behaviour in a family setting for younger patients and in individual psychotherapy with a cognitive or an interpersonal approach for adults (Swedish Psychiatric Association, Svenska Psykiatriska Föreningen, 2005).

**Family-based interventions**

In the 21st century, the general assumption is that there are no “anorexogenic” families and that eating disorders develop in all variants of family contexts. Living with a life-threatening illness is like being invaded by a foreign power and each family member tries to cope in his or her own way, forced by high levels of anxiety to focus on the “here and now” when the disorder assumes a central role in daily life. The way the family currently acts can help to maintain the problem and obstruct efforts to overcome the disorder and it is therefore very important to investigate and understand how the family has re-organised its life around the disorder. This should be the context and starting point for all eating-disorder treatment, regardless of the age of the patient, and interest must focus on helping families to stop adjusting to or acting in favour of the disorder (Eisler, 2005; Whitney & Eisler, 2005; Treasure et al., 2008).

NICE (2004) recommendations for the treatment of children and adolescents with AN consist of family interventions that directly address the eating disorder and they have been graduated at B level. Clinicians and researchers currently explain eating disorders using a multifactorial model (described in Early interacting factors) and the most frequently studied and best-known specific form of family-based treatment for adolescent AN patients is the Maudsley model.

**The Maudsley model**

This family-based treatment was developed at the Maudsley Hospital in London and was first used in the early 1980s. It has since been developed by clinicians and researchers in the UK (Dare, 1983; Eisler, Dare, Russell,
Family-based research
Few psychotherapy studies of AN have been conducted over the past 20 years. Most interest has focused on out-patient treatment trials and the most extensively researched treatment is family therapy with adolescents and their families (Agras et al., 2004; Wilson et al., 2007). The Maudsley treatment approach was manualised by Lock et al. (2001) and was evaluated in an outcome study where the results show that 56% had a good outcome, 33% an intermediate outcome and 11% a poor outcome using

Multi-family therapy
Multi-family therapy (MFT) comprises several families attending treatment together and was first used in the 1960s for patients with schizophrenia and their families and subsequently in a day setting in London (Dare & Eisler, 2000) and in Dresden (Scholz & Asen, 2001) with adolescents with eating disorders. In MFT, families exchange experiences that can provide new perspectives that can facilitate recovery and meeting other families also helps to interrupt isolation and stigma. In London, four to six families attend a 24-week programme and, in Dresden (Scholz, Rix, Scholz, Ganchev & Thömke, 2005), six to eight families attend treatment consisting of twenty days over twelve months. There are on-going systematic studies of MTF in adolescent eating disorders in the UK and Sweden, but no results have as yet been published.
the Morgan-Russell (Morgan & Hayward, 1988) outcome categories (Le Grange, Binford & Loeb, 2005). Moreover, patients’ and parents’ satisfaction with the manualised family-based treatment was investigated and almost 60% of the patients and 80% of the parents reported high degrees of satisfaction with therapists, with interventions and with outcome. However, a minority of patients requested more individual sessions (Krautter & Lock, 2004).

Wallin & Kronvall (2002) examined the change in the family dynamic at a two-year follow-up after family-based treatment and the results revealed that 65.4% of the patients were in recovery and 26.9% were much improved or improved. The families were less enmeshed and the family climate in families with a recovered patient had changed positively in contrast to those families where the patient had not recovered.

Randomised clinical trials (RCTs) for adolescents with AN are difficult to conduct with adolescent patients due to low incident rates and high dropout rates, often because of the need for hospitalisation. Further, RCTs are time and money consuming. To date, few RCTs investigating family-based therapy in adolescent patients have been conducted and existing studies illustrate different variations of the Maudsley model. The most important family-based studies are presented in time order as follows.

**Family therapy vs. individual therapy**

The earliest study was conducted by Russell et al. (1987) and compared family therapy with individual therapy and 57 adolescent and young adult patients with AN were recruited following in-patient weight restoration. The results showed that 38% obtained a good or intermediate outcome and family therapy was more effective than individual therapy if the onset of illness took place before 19 years of age and the duration was less than three years. However in a five-year follow-up (Eisler et al., 1997), 90% had a good outcome.

**Family sessions vs. individual sessions**

In order to examine the outcome of different treatment forms, conjoint family sessions were compared with family counselling, with separate support sessions for patient and parents. Eighteen patients participated in this study and, after 32 weeks, no differences were found in terms of symptom reduction between the two groups (Le Grange et al., 1992). In 2000, Eisler et al. conducted a similar study in which 40 adolescents and their families participated and two treatment approaches were compared; Conjoint Family Therapy (CFT) vs. Separated Family Therapy (SFT). The two treatment
approaches were equivalent in outcome results, although patients did better in SFT in families with a high level of maternal criticism, while, in less critical families, the patients did equally well in both SFT and CFT. A five-year follow-up revealed no differences in outcome results; 76.3% had no eating disorder symptoms and 73% had a good outcome (Eisler et al., 2007).

**Behavioural family therapy vs. cognitive behavioural therapy**

Two studies compared behavioural system family therapy with ego-oriented individual therapy (Robin, Siegel, Koepke, Moye & Tice, 1994; Robin et al., 1999). Each of the studies comprised 24–37 adolescent female participants and, in both studies, behavioural system family therapy produced a greater weight gain with more patients reaching menstruation than in the ego-oriented individual therapy.

**Length of treatment: short term vs. long term**

To examine the optimal length of family therapy for adolescents, a study was conducted to compare results at the end of one year for patients (n=44) treated for six months (short term, 10 sessions) with patients (n=42) treated for the entire period of one year (long term, 20 sessions). No significant differences were found between the treatment groups, but patients with more eating-related obsessive-compulsive thinking and no intact families responded better to long-term treatment (Lock, Agras, Bryson & Kraemer, 2005). The patients participated in a four-year follow-up and there were still no significant differences between short- or long-term treatment (Lock, Couturier, & Agras, 2006).

**In-patient – specialist out-patient – general mental health service**

This study comprised adolescents and aimed to compare in-patient psychiatric treatment (n=54), specialist out-patient treatment (including a variety of interventions including individual cognitive behavioural therapy and parental counselling; n=53) and the usual first-line treatment approach in the community offered in the UK (n=54). At the one-year follow-up, all the participants irrespective of treatment had made substantial mean improvements in weight, global measures and self-reported psychopathology. No significant differences were found between the three groups. The two-year follow-up showed additional improvements, 33% with a good outcome, and still no significant differences between the groups, no advantage for specialist treatment over general treatment and no advantage for in-patient over out-patient treatment (Gowers et al., 2007).
Family-based treatment vs. adolescent-focused individual therapy

In this study, family-based treatment (FBT) (n= 61) was compared with adolescent-focused therapy (AFT) (n=60), i.e. individual psychotherapy with a psychodynamic approach with the emphasis on increasing autonomy, self-efficacy and individuation. There was contact with parents outside the individual sessions. AFT is similar to the ego-oriented individual therapy described by Robin et al. (1999). There were no significant differences in full remission at the end of treatment, although FBT was statistically superior to AFT at the six-month and 12-month follow-ups. In addition, partial remission at the end of treatment was greater in FBT than in AFT, but there were no differences at the follow-ups (Lock et al., 2010).

It appears that family-based treatment for adolescents with AN is the best choice of treatment and has good outcome in follow-ups, but there is still not sufficient evidence to achieve an A in clinical guidelines. However, more research has to be done, more RCTs with large sample sizes, and the next step would be to compare a family-based approach with a transdiagnostic approach. As family therapy has not been found to be suitable for adult patients (Bulik, Berkman, Brownley, Sedway & Lohr, 2007), this is another important area for further investigation. In a review comprising patients of any age, the results indicated that there is some evidence that family therapy may be more effective than other psychological treatments (Fisher, Hetrick & Rushford, 2010). Today, few clinicians would disagree about including parents in the treatment of children and adolescents with an eating disorder and, despite the lack of evidence, family therapy also has a role to play in the treatment of adults with AN (Dare, Eisler, Russell, Treasure & Dodge, 2001; Eisler, 2005; Eisler et al., 2007).

Psychological and pharmacological interventions

There are no treatment interventions for AN at the A level; in general, all psychological treatment, such as cognitive behavioural therapy (CBT), interpersonal psychotherapy (IPT), cognitive analytic therapy (CAT), focal psychodynamic therapy and family interventions, which focus explicitly on eating disorders, together with pharmacological interventions, are assigned level C (NICE, 2004).

There are a small number of randomised controlled trials (RCT) and other studies for adult AN patients and drawing conclusions relating to effective psychotherapy treatments is therefore difficult.
Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is a psychological approach that addresses dysfunctional emotions, behaviours and cognitions through a goal-oriented, systematic process and it has long been the treatment of choice for bulimia nervosa. In AN, CBT has been shown to be no more helpful than other therapies in the acute underweight state of adult patients (Bulik et al., 2007). However, an enhanced form of CBT (CBT-E), based on transdiagnostic theory, was presented by Fairburn, Cooper and Shafran (2003), including four additional mechanisms (‘clinical perfectionism,’ ‘core low self-esteem,’ ‘mood intolerance’ and ‘interpersonal difficulties’) interacting with the core of eating disorders. Recent findings have revealed that CBT-E can also be applied as treatment to about 60% of adult out-patients with AN and with a BMI of between 15 and 17.5. Of these patients, 60% will have a good outcome (Murphy, Straebler, Cooper & Fairburn, 2010). There are two forms of CBT-E, the focused form (CBT-Ef) that addresses eating-disorder psychopathology and the broader form (CBT-Eb) that also addresses obstacles to change, such as mood intolerance, clinical perfectionism, low self-esteem and interpersonal difficulties. The two forms were compared in a study of patients with all kinds of eating-disorder diagnosis and a BMI of over 17.5 and the results revealed that the two forms did not differ in terms of recovery, but CBT-Eb was preferred in patients with substantial additional psychopathology (Fairburn et al., 2009). Recently, CBT-E for low-weight adult AN patients showed that a full or partial remission was achieved by 50% of the patients who completed treatment, but there was a 50% drop-out rate (Byrne, Fursland, Allen & Watson, 2011).

In Göteborg CBT-Eb is one of two manualised treatments that are being compared in an on-going RCT of young adults with AN and with a BMI of < 17.5. The therapy form is based on the Fairburn et al. (2003) model and runs over a period of 18 months. The results will be compared with a family-based treatment model, which is the other treatment in the RCT.

Comparison of four treatments

Dare and colleagues (2001) compared focal psychoanalytic psychotherapy, family therapy, cognitive-analytic therapy (CAT) and ‘routine’ treatment in a sample of adults with AN (n=84) with a BMI of < 17.5. The focal therapy is time-limited with the emphasis on the meaning, effects and manifestation of the symptom in the patient’s relationships with others. The family therapy that was used, described in Dare and Eisler (1997), focuses on symptoms of the disorder, its effect on family life for all family members and its controlling role in the relationship between the patient and family.
members. CAT combines cognitive therapy and psychodynamic psychotherapy and helps the patient to explore the illness and to acquire an understanding of his/her need for the function of the illness. The ‘routine’ treatment was a low-contact standard practice of an eating-disorder service, where no specific psychotherapies were used. At the one-year follow-up, two-thirds were underweight and patients in focal therapy and family therapy had the largest increased in weight compared with the others. Specialist psychotherapies were more effective than routine treatment.

**Interpersonal psychotherapy**

Interpersonal psychotherapy (IPT) is a time-limited supportive psychotherapy that encourages the patient to regain control of mood and function and is used as treatment where binge eating is involved. Very few studies of IPT in the treatment of AN patients have been conducted. In a randomised controlled study comparing CBT, IPT and non-specific supportive clinical management (SSCM), IPT was found to be the least effective treatment, where 30% had a good outcome or were considerably improved (McIntosh et al., 2005). However, in a long-term follow-up, on average 6.7 years following the treatment of patients in the McIntosh et al. (2005) study, patients randomised to IPT now had the best results and no significant differences were found between the three treatments, CBT, IPT and SSCM (Carter et al., 2011). Since research on AN is relatively rare, there is a need for further research on both CBT and IPT and other treatments especially when it comes to patients with anorexia nervosa (Murphy, Straebler, Basden, Cooper & Fairburn, 2012).

**Maudsley model of anorexia nervosa treatment for adults (MANTRA) vs. specialist supportive clinical management (SSCM).**

A recently published RCT study compared two out-patient therapies for adult AN patients. In the MANTRA model, patient and the therapist collaborate around parts relevant to work, using a patient workbook, and the therapist helps the patient to examine ambivalence to treatment using motivational interviewing, MI, described by Treasure and Ward (1997). The treatment starts with a dialogue about change after which a treatment plan is developed, followed by active work for change and, finally, relapse prevention and conclusion. The SSCM model combines clinical management and supportive psychotherapy and emphasises the restoration of weight and normal eating. The patient decides about other content in the therapy. The therapists use a manual with psychoeducational hand-outs for patients.
34 patients were randomised to MANTRA and 37 to SSCM and in both treatments, patients received 20 once-weekly individual sessions and four monthly follow-up sessions. The mean number of sessions in MANTRA was 14.4 and in SSCM 14.2. The mean age in MANTRA was 25.6 years and in SSCM 27.5 years.

There was a significant improvement in terms of BMI, weight, eating disorder symptoms, affective symptoms or psychosocial impairment and no differences were found between the two treatments. The authors conclude that SSCM is a useful treatment for out-patients with AN and that MANTRA needs to be further developed (Schmidt et al., 2012).

Pharmacological interventions
Pharmacological interventions should not be used as the sole or primary treatment for AN (NICE, 2004). Few controlled treatment studies have been conducted and none has confirmed any efficacy of medication (Agras et al., 2004). Walsh et al. (2006) conducted a randomised controlled trial with the aim of determining whether fluoxetine compared with placebo reduced the relapse rate after weight normalisation. No evidence was found to indicate that fluoxetine provided any significant benefit compared with placebo. In addition, in a review of RCT in AN treatment, no pharmacological intervention with a significant impact on weight gain or the psychological features of AN has been found (Bulik et al., 2007).

While treatment for children and adolescents is well defined, treatment for adults is more ambiguous and the results are more discouraging. Research must therefore continue and focus on different parts of the treatment spectrum, including treatment forms, length of treatment, treatment interventions and treatment alliance.

Treatment outcome

Outcome measures
The majority of patients and, without question, every parent want to know whether it is possible fully to recover from AN and, if so, how long it will take. Among researchers, there is no consensus on the definitions of outcome and remission and existing measures can include physical, behavioural and psychological symptoms related to the eating disorder. A description of the most frequently used outcome measures now follows.
In a review of 119 studies of AN, outcome was defined on the basis of good (recovery from all essential clinical symptoms), fair (improvement with some residual symptoms), poor (chronicity of the illness), a normalisation of core symptoms (weight, menstruation, eating behaviour) and psychiatric diagnoses other than eating disorders (Steinhausen, 2002). One of the most well-known and commonly used clinical assessments of AN outcome is the Morgan Russell Scales (Morgan & Hayward, 1988), a guided interview comprising five scales: food intake, menstrual state, mental state, psychosexual state and socioeconomic state, with outcome classified in three scores: good, intermediate and poor.

Another scale is the Psychiatric Rating Scale (PSR) adjusted to AN and bulimia nervosa (BN) by Herzog and colleagues (1993) and based on DSM-IV diagnostic criteria. State of health is classified with a rating ranging from 0 (no evidence of disorder) to 6 (definite criteria severe), where good outcome is defined as a PSR level of 1; intermediate outcome as a PSR level of 2, 3 or 4 and poor outcome as a PSR level of 5 or 6.

In a randomised controlled trial involving adult AN patients (Dare et al., 2001), outcome was classified in four categories (recovered, significantly improved, improved and poor), based on weight, menstrual status and frequency of bulimic symptoms.

Kordy and colleagues (2002) tested the validity of a classification system for both symptom level and time, applying the terms partial and full remission, relapse, recovery and recurrence to eating disorders. This classification was suggested by a group of experts from 19 European countries and was originally used by Frank et al. (1991) to describe depression. AN in full remission was defined as three months with a BMI of > 19 without AN symptoms and recovery was defined as 12 months with a BMI of > 19 without AN symptoms.

Further ways of looking at outcome include improvement based on both statistical and clinical significance. Kraemer et al. (2003) present three basic questions that are important to consider when examining the relationship between variables. 1) Is the observed result real or attributed to chance (statistical significance)? 2) How large is the difference in statistical significance (effect size)? 3) Is the result large enough to be meaningful and useful (clinical significance)? When it comes to the outcome of psychotherapy, the clinical significance of a treatment should be considered, as it refers to its ability to meet the expectations of consumers, clinicians and researchers. A clinically significant change illustrates the patients’ process.
of returning to normal function. The patients process from the start of therapy, as part of a dysfunctional population, to the end of therapy and not being part of that population could be evaluated in different ways. By moving two standard deviations (SDs) away from the mean in the dysfunctional population in the direction of functionality, moving within the range of the normal population or, by the level of functioning, the patient could be placed in the mean of the functional population rather than the mean of the dysfunctional population (Jacobson & Traux, 1991).

In a recent study, the impact of different outcome measures on estimates of remission rates in eating disorders have been examined and the authors report a substantial difference in remission estimates depending on different outcome definitions (Björk, Clinton & Norring, 2011). This highlights the importance of the development of standardised definitions of outcome measures in order to validate, compare and contrast research results. There is a need carefully to define remission measures regularly in treatment studies (Couturier & Lock, 2006a) and to establish definitions of recovery (Couturier & Lock, 2006c). Further, a differentiation between statistically significant and clinically meaningful results in AN should also be of high priority among researchers (Bulik et al., 2007).

Research methods
The most common way to collect feedback information is by conducting outcome studies, preferably following the six criteria outlined by Hsu (1996): (1) explicitly stated diagnostic criteria, atypical excluded, (2) more than 25 subjects in the study, (3) minimum follow-up of four years from the onset of illness, (4) failure-to-trace rate of less than 10%, (5) the use of direct interviews in more than 50% of subjects and (6) the use of multiple well-defined outcome measurements. In a guide for designing an optimal treatment outcome study, Najavits (2003) important issues regarding comorbidity, treatment, standard design features, assessment, patients, therapists and replication are presented. The use of outcome studies increased during the 20th century and, even if they are demanding with respect to time and money, they are the most rewarding way of demonstrating whether a treatment works by providing data on the interventions that are helpful within a given treatment. In longitudinal outcome studies, subjects are followed over time with continuous and repeated monitoring through follow-ups and valuable information about recovery is presented. In addition, the aetiology of the disorder and ways of making rational selections of effective treatments are illuminated (Coggon, Rose, & Barker, 1997; Najavits, 2003).
A randomised controlled trial (RCT) is another way to study the effectiveness of different treatment interventions. This type of study also consumes time and money and it requires large sample sizes in order to obtain sufficient statistical power to draw reliable conclusions. Conducting a pilot study, a mini-version of a full-scale study, is a good way of testing the design, thereby providing researchers with valuable information and hopefully identifying the main difficulties that need to be adjusted before carrying out an expensive full-scale study.

Few controlled treatment trials of AN have been published and the number is extremely low compared with trials relating to other psychiatric disorders including BN and binge eating disorders, BED. Moreover, the assessment protocols are insufficient, the outcome measurements are inadequately defined and the results of treatment outcome are underpowered with many limitations (Agras et al., 2004).

From both an expert and patient perspective, there is a need for more large-scale treatment intervention studies for AN with adequate sample sizes, standardised assessments and treatment in order to create credible comparison conditions. Patients’ and carers’ satisfaction should also be examined as a matter of routine, since expectations and experiences of treatment influence treatment approaches and compliance (Agras et al., 2004; NICE 2004).

One successful example in which clinicians and researchers have developed a treatment method by systematically conducting several studies comparing different forms of treatment intervention is the development of the family-based model in London (Dare, 1983; Russell et al., 1987; Le Grange et al., 1992; Eisler et al., 1997; Eisler et al., 2000). This family-based treatment for adolescent AN patients has been manualised and patient satisfaction has been studied (Lock et al., 2001; Krautter & Lock, 2004).

Another example of a large-scale project providing a great deal of feedback is a population-based study of all 15 year olds in a Swedish urban region relating to the prevalence of anorexia nervosa (Råstam et al., 1989; Råstam, Gillberg, & Wentz, 2003). This is the only controlled, prospective community-based study of adolescent-onset AN conducted with four follow-up studies, the latest 18 years after AN onset (Wentz et al., 2009).

Other examples are two national research projects in Sweden; the “Coordinated research and evaluation project for specialist units in treatment of eating disorders” (COEAT), which was a naturalistic multi-centre study
in which six units for adolescent patients participated, and the “Co-ordinated Evaluation and Research at Specialist Units for Eating Disorders” (CO-RED) that was a longitudinal study investigating the treatment of eating disorders for adults at 15 specialist centres. In these studies, several specialist eating-disorder units participated and a large amount of patient data was collected.

Research findings
AN is a life-threatening illness with the highest mortality rate of psychiatric disorders (Treasure et al., 2010, Keel et al., 2003). In a review of outcome studies from 1953 to 1999, Steinhausen (2002) studied the outcome of 119 AN studies with a total of 5,590 adult patients. The results showed full recovery, defined as recovery from all essential clinical symptoms, in 46.9% of the patients, while 33.5% had improved with some residual symptoms and 20.8% developed a chronic course. The mortality rate was 5-10%. These results show a fairly poor prognosis for adult patients, but early age at the onset of illness and short duration of symptoms favoured a good outcome. Steinhausen (2002) also found that outcome improved with increased duration of follow-up and treatment units are therefore recommended to extend the follow-up periods with their patients.

A better prognosis was presented in an international collaborative study in Europe with 338 adolescent eating-disorder patients, diagnosed with AN and initially treated between 1979-1992 (Steinhausen, Boyadjieva, Griogoriu-Serbanescu & Neumärker, 2003); 70% had recovered and did not meet the criteria for an eating disorder, while the mortality rate was 2.9%. All patients had an early age at onset and the results are in accordance with those of other studies comprising patients of the same age (Strober, Freeman, & Morrell, 1997). In a 21-year follow-up study of AN patients that received in-patient treatment between 1971-1980, 51% had fully recovered, 21% had partially recovered and 10% still met the diagnostic criteria for AN, while 16% had died (Löwe et al., 2001).

Recently, a one-year follow-up of a multi-centre study of adults with AN reported that recovery from eating-disorder psychopathology was stable from the end of treatment to follow-up; 40% had a global score within the normal range on the Eating Disorder Examination (EDE), while 21% of the follow-up completer sample had recovered (Yu et al., 2011). In addition, in terms of the long-term outcome study of residential treatment for adults, 89% had a good or intermediate outcome, with significant improvements in BMI, Eating Disorders Inventory-2 (EDI-2) and Beck Depression Inventory (BDI) (Brewerton & Costin, 2011).
A five-year follow-up RCT study, with 38 adolescent patients with anorexia nervosa, revealed that more than 75% had recovered from eating-disorder symptoms and 73% had a good outcome (Eisler et al., 2007), results that are all in line with other studies of adolescent patients (Halvorsen, Andersen & Heyerdahl, 2004; Nilsson & Hägglöf, 2005). The importance of starting treatment as early as possible in adolescence to increase the possibility of full recovery was also pointed out. Based on the above results, conclusions can be drawn that adolescents appear to have a better outcome prognosis than adults, which is confirmed in a review of course and outcome of eating disorders by Fisher (2003). He also concluded that adolescents have a better outcome, the longer the duration of follow-ups.

Reflections on outcome

Lack of consensus on outcome measures for EDs in general and AN in particular is a major methodological problem when comparing the outcome results of studies. It is also difficult actually to determine what the outcome results represent. A range of treatment models with different interventions used together with occupational differences between the staff treating eating disorder patients makes comparisons of the outcome results difficult. One way to deal with this is to use treatment manuals when conducting an outcome study in which treatment model and therapists’ skills and experience are defined. The complexity of the disorder creates different theoretical assumptions about defining outcome and it is now time for clinicians and researchers to reach a consensus on reliable and valid outcome measures.

There is still no answer to the question of how long it will take to recover from AN. It is a question with no clear-cut answer; every patient is unique when it comes to life history, history of illness and current situation and responds individually to each treatment model on the basis of individual needs. In addition, there are a variety of treatment models for both outpatients and in-patients with different duration of therapy. However, there is a link between expectations and satisfaction with outcome where satisfied customers, in this case patients and parents, are more likely to come back for booster sessions than those with negative experiences of treatment and therapists and they are also more likely to recommend the treatment unit to others. This informal feedback, from the results of a treatment intervention in direct contact with the patients, is naturally valuable and important in the clinical work, primarily for the therapist. However, systematically collected information is a necessary prerequisite when organising an eating-disorder unit, in treatment planning, in the development of
methods to implement in treatment and as basic data for political decision-making. Last but not least, it adds valuable knowledge about the aetiology of the disorder.

**Outcome predictors**

Predictors of outcome provide us with important information on the aetiology of the disorder and in the development of effective treatment methods.

Early age at onset and short duration of symptoms before treatment have been shown to be double edged; associated with a positive outcome in some studies and found to be of no significance in others. However, increased duration of follow-up improved the course of illness (Ben-Tovim et al., 2001; Steinhausen, 2002; Clausen, 2008). In addition, results from a 21-year follow-up showed that duration of illness and a low BMI before treatment were associated with a poor outcome (Zipfel, Löwe, Reas, Deter, & Herzog, 2000). Psychiatric comorbidity, onset before puberty and late onset of menarche are factors indicating a poor outcome (Fichter, Quadflieg & Rehm, 2003; Thurfjell, Eliasson, Swenne, von Knorring & Engström, 2006). Brewerton and Costin (2011) found that discharge BMI was the best predictor of a full recovery from AN at follow-up, which indicates that weight restoration during treatment is essential for continued recovery. Other outcome studies have also reported the same results (Clausen, 2008; Steinhausen, Grigoriou-Serbanescu, Boyadjieva, Neumarker & Metzke, 2009).

In the field of neuropsychology, cognitive capacity prior to the onset of AN and the AN subtype predicted neuropsychological improvement during inpatient treatment, while the AN binge eating/purging type showed a significantly greater improvement than patients with the AN restricting type (Keifer et al., 2010).

AN patients’ self-image has also an impact on outcome (Björck, Clinton, Sohlberg & Norring, 2007) where high levels of initial self-control, self-neglect and self-protection predicted a poorer outcome three years after the start of treatment (Birgegård, Björck, Norring, Sohlberg & Clinton, 2009). Despite many different clinical features tested in different studies, few factors with a significant predictive outcome value have been found.
One area highlighted in relation to treatment outcome is patients’ motivation to change behaviour in eating disorders, mentioned in both clinical work and research, and this has increased in recent decades. Vitousek, Watson and Wilson (1998) described AN patients as having low motivation to attend treatment due to their perception of positive effects of the illness and an ambivalence to recover. Starvation and its physical consequences aggravate the patients’ ability to consider their condition rationally and think in a different way. Not admitting the seriousness of the illness and underestimating the effects of starvation are obstacles when it comes to patients’ commitment to treatment, especially at a first assessment when the severity of the illness is determined (Beaumont, Russell, & Touyz, 1993; Couturier & Lock, 2006b).

The Transtheoretical Model of Change (TMC) has been the most frequently used model for understanding patients’ motivation and endorsing behaviour change in AN (Prochaska, DiClemente & Norcross, 1992; Hasler, Delsignore, Milos, Buddeberg & Schnyder, 2004). This model outlines five stages of change: 1) precontemplation, in which patients do not think about change, 2) contemplation, where there are thoughts about change, 3) preparation, planning to change, 4) action, making behavioural changes, and 5) maintenance, having made behavioural changes for a longer period of time. However, it is not certain how these baseline stages of change can be linked to increased motivation or outcome in AN (Wilson & Schlam, 2004). AN patients’ motivation challenges clinicians and researchers and different questionnaires, scales and instruments have been developed to map this area and to find suitable treatment interventions. Treasure and Ward (1997) developed motivational enhancement therapy, MET, inspired by TMC, with a specific therapeutic approach to the assessment and treatment of AN. In a pilot study, MET was evaluated in ED patients and the results showed an increase in the patients’ motivation to change. However, there was a high drop-out rate and the study did not include a control group, so it is difficult to determine whether the results could be associated with the MET (Feld, Woodside, Kaplan, Olmsted, & Carter, 2001).

Within the framework of TMC, the Readiness and Motivation Interview, RMI, a semi-structured interview over the course of treatment, was developed in order to determine to what extent and how patients were making changes (Geller, 2002a; 2002b). Using the RMI in ED patients, Geller, Zaitsoff and Srikameswaran (2005) found that readiness to change behavioural domains occurred earlier in treatment than readiness to change cognitive domains and that ambivalence in AN patients remained constant throughout treatment. Wade, Frayne, Edwards, Robertson & Gilchrist,
(2009) randomly assigned inpatients to four sessions of motivational interviewing (MI), where patients were helped to explore and resolve their ambivalence, before treatment as usual or to treatment as usual alone. Results at a six-week follow-up showed that more patients that had received MI than patients with no MI sessions moved from low readiness to change to high readiness to change.

The majority of studies of motivation to change comprise adult participants and few studies have examined adolescent patients’ motivation to change. Geller et al. (2008) assessed adolescent ED patients with the RMI and compared the results with those of adult patients. The results showed that lower readiness to change was associated with more severe ED symptoms and internalising problems. Little difference was found between adults’ and adolescents’ motivation for change. A questionnaire for adolescents measuring the stages of change (MSCARED) was developed by Gusella, Butler, Nichols and Bird (2003) and, when applied to adolescent ED patients’ results, revealed that motivation to change was related to the severity of symptoms. Greater motivation was related to less severe symptoms, fewer problems in their relationship to parents and fewer depressive symptoms (Zaitsoff, & Taylor, 2009).

Recently Waller (2012) discussed patients’ motivation to change in a different perspective. He examined the evidence supporting our theories of motivation and stated that little evidence has been found to indicate that motivational interventions have an impact on patients’ motivation or on outcome. In clinical work, patients’ verbally expressed motivation should be questioned when there is no progress in treatment and interest should instead focus on a behaviour-based analysis of motivation.

**Treatment satisfaction**

Treatment satisfaction is defined by Rentrop, Böhm and Kissling (1999) as the relationship between patients’ expectations at the start of treatment and experiences of treatment received. Investigating patients’ views of their experienced treatment is important in quality assurance in psychiatric services but also because a better knowledge of patients’ satisfaction with treatment could help to develop existing treatment models and individual treatment planning (Clinton, Björck, Sohlberg, & Norring, 2004). NICE (2004) has presented research recommendations that patient satisfaction should be investigated as a matter of routine because of its influence on treatment approach and subsequently on outcome.
When psychiatric adult patients’ expectations and experiences do not coincide or when there is disagreement between patients’ and professionals’ expectations of treatment, dissatisfaction affects both treatment outcome and drop-out. Patients who receive information about their treatment are more prepared and this reflects experiences of positive effects in the treatment process and results in a high level of treatment satisfaction. Investigating expectations and clarifying disagreements, both at the start of treatment and during the treatment process, creates a positive patient-therapist alliance and reveals the patients’ readiness to change in relation to both symptom reduction and outcome (Clinton, 1996; Clinton et al., 2004; Treasure, Katzman, Schmidt, Troop & de Silva, 1999). Treatment given by supportive expert professionals at a specialist centre for eating disorders, where interest focuses on both eating-disorder symptoms, such as control of eating habits, as well as underlying issues, are other factors that contribute to a high level of treatment satisfaction for adult patients (de la Rie, Noordenbos, Donker, & van Furth 2006; Noble et al., 2001; Rosenvinge, Khulefelt Klusmeier, 2000; Swain-Campbell, Surgenor, Snell, 2001).

Parents with an adolescent daughter with anorexia nervosa expect to be included in the treatment, to be informed about the treatment process and to be listened to, while participating in treatment decisions and receiving help and support from therapists (Honey et al., 2008). This statement is supported by a group of adolescent patients and parents that were offered a manualised family-based treatment and were satisfied in overall terms although a need for individual sessions was expressed (Krautter & Lock, 2004).

To date, patients’ treatment satisfaction has not been a preferred aim for clinicians and researchers, despite its impact on and importance to the therapeutic alliance, treatment process, drop-out and outcome. This is surprising, as information relating to treatment satisfaction can be used on many different levels; in clinical work, in the development of effective treatment methods and, moreover, units with satisfied customers are more likely to be treated favourably when it comes to political and economic decisions.
Epilogue

In ancient history, voluntary fasting was documented as existing, but the first medical description of anorexia nervosa was given in 1689 and the name was established in 1873. AN is a serious mental disorder with comorbidity with other psychiatric disorders and girls in adolescence are a high-risk group. Patients perceive the core symptoms as both negative and positive and there is therefore ambivalence to treatment and recovery. Family-based treatment is the treatment of choice for adolescent patients and their parents, while individual psychotherapy is used for adult patients. Adolescents have a better outcome prognosis than adults, but little is known about what contributes to recovery, especially in the treatment of adult patients. Little is also known about patients’ own expectations and perceptions of illness, treatment and therapists.
Aims

The overall aim of this thesis was to study adolescent and adult patients’ comprehension and the course of AN treatment in order to make a contribution to the clinical work relating to these patients. The areas that were studied were expectations of treatment, outcome, predictors of outcome and satisfaction with treatment.

This thesis consists of four papers, each with separate aims as follows.

Study I
• To examine potential adult patients’ expectations while on the waiting list at a specialist eating-disorder unit

Study II
• To examine the outcome of family-based treatment for adolescents with anorexia nervosa between 13-18 years of age at an eating-disorder out-patient unit. In particular, the study focused on changes from pre-treatment to the 18- and 36-month follow-ups

Study III
• To examine the relative importance of motivation to change eating behaviour, treatment expectations and experiences, ED symptomatology, self-image and treatment alliance for predicting weight gain in AN at six- and 36-month follow-ups

Study IV
• To examine adolescent anorexia nervosa patients’ and their parents’ expectations of and satisfaction with a family-based treatment approach. The aim of the study was to shed light on the following five questions. What expectations were there at the beginning of treatment? Were the expectations fulfilled? How useful were the different states of treatment? What were the experiences of the therapists? How important was the degree of recovery for treatment satisfaction at the 18-month follow-up?
METHODS

As an introduction, an overview of the four papers presented in this thesis is shown in Table 1.

Table 1. Papers I-IV

<table>
<thead>
<tr>
<th>Study</th>
<th>Aims</th>
<th>Participants</th>
<th>Data collection</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To examine potential adult AN patients’ expectations while on the waiting list at a specialist eating-disorder unit</td>
<td>n = 15, 18- to 25-year-old women from the eating-disorder outpatient unit (ED-unit), Queen Silvia Children’s Hospital, Göteborg</td>
<td>Qualitative interview before first assessment</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>II</td>
<td>To examine the outcome of family-based treatment for adolescents with AN</td>
<td>n = 32, 13- to 18-year-old female patients and n = 48 parents (COEAT) from the eating-disorder outpatient unit (ED-unit), Queen Silvia Children’s Hospital, Göteborg</td>
<td>Semi-structured interview (RAB-C, RAB-P), self-report questionnaires (EDI-C, YSR, FCS) and medical examination pre-treatment and at 18- and 36-month follow-ups</td>
<td>Wilcoxon’s matched-pairs signed-ranks test. Effect size (ES) Clinically significant change.</td>
</tr>
<tr>
<td>III</td>
<td>To examine the relative importance of motivation to change eating behaviour, treatment expectations and experiences, ED symptomatology, self-image and treatment alliance for predicting weight gain in AN at six- and 36-month follow-ups</td>
<td>n = 89, 18- to 46-year-old female patients from 15 treatment units in Sweden included (CORE-RED)</td>
<td>Semi-structured Interview (RAB), self-report questionnaires: (EDPEX, TSS, EDI-2, SASB) and medical examination Pre-treatment and at six- and 36-month follow-ups</td>
<td>Wilcoxon’s matched-pairs signed-ranks test Univariable analyses Multivariable analysis</td>
</tr>
<tr>
<td>IV</td>
<td>To examine adolescent anorexia nervosa patients’ and their parents’ expectations of and satisfaction with a family-based treatment approach</td>
<td>n = 32, 13- to 18-year-old female patients and 41 parents (COEAT) from the eating disorder outpatient unit, Queen Silvia Children’s Hospital, Göteborg</td>
<td>Self-report questionnaires: Evaluation of Treatment (ET-A, ET-P) for adolescents and parents at the 18-month follow-up</td>
<td>Content analysis Chi-square Fisher’s exact probability test.</td>
</tr>
</tbody>
</table>
Design

These four studies represent both qualitative (Study I) and quantitative methods (Studies II, III, and IV). In Study I, a qualitative content analysis was applied; this is a well-known method for examining a body of text and, according to the definition formulated by Krippendorff (2004, p. 18), as “a research technique for making replicable and valid inferences from texts to the contexts of their use”. The purpose of this study was to try and understand women’s subjective expectations and data were therefore collected based on qualitative interviews in order to identify the participants’ thoughts and feelings. The interviews were performed at the specialist eating-disorder out-patient unit (ED unit), Queen Silvia Children’s Hospital in Göteborg, and comprised adult patients on the waiting list for assessment for treatment. The Regional Ethics Committee in Göteborg, Sweden, approved the study.

Studies II and IV were conducted within the framework of the ‘Coordinated Research and Evaluation Project for specialist units in treatment of eating disorders’ (COEAT) (Engström, I, 1995). The COEAT project was a naturalistic multi-centre study in which six Swedish units specialising in eating disorders at university hospitals (Göteborg, Linköping, Lund, Umeå, Uppsala and Örebro) participated and it was run as a network programme. A local project leader at each unit and a general project leader at the Psychiatric Research Centre in Örebro met on a regular basis to coordinate data collection procedures. The project was run in clinical settings according to the treatment programmes at the individual units and the inclusion criteria were 13 to 18 years of age, suffering from an eating disorder according to DSM-IV (1994) criteria and on the basis of the initial professional clinical assessment intention to treat. All the included patients were asked to participate in follow-up assessments after nine, 18 and 36 months. Data were collected between 1996 and 2001, using a semi-structured interview and self-report questionnaires. For the purpose of Studies II and IV, data from patients in Göteborg from the first assessment and the 18- and 36-month follow-ups were used.

Study III was conducted as part of the CO-RED (Co-ordinated Evaluation and Research at Specialist Units for Eating Disorders) project, a longitudinal naturalistic study investigating eating-disorder patients at 15 publicly and privately financed specialist centres for ED across Sweden (Norring, Clinton, Eriksson, Enzell & Hällström, 1996a). The aim of the project was to study central aspects of treatment for eating disorders and the patients included in the project were adults aged 18 or older at units with intention
to treat in an in-patient, day-patient and/or out-patient setting. The project used a repeated-measures design and included data from the initial assessment and subsequently after six, 12, 18 and 36 months. Data were collected between August 1996 and December 2001 using a battery of self-report questionnaires and a semi-structured interview. For the purpose of Study III, data from the first assessment and the six-month and 36-month follow-ups were used.

**Procedures**

In **Study I**, women, 18-25 years of age, with anorexic problems, seeking treatment or having been referred by health services and on the waiting list at a specialist eating-disorder out-patient unit (ED unit) in Göteborg were asked to participate in a qualitative interview. The first contact was via telephone, where they were informed about the study and were asked to participate. An appointment for the interview was agreed upon at acceptance. At the time of the interviews, conducted on the unit’s premises, the participants received written and verbal information about the study, as well as secrecy rules, and they then gave their informed consent. The participants were interviewed individually on one occasion; each interview was given a code number, was audio-taped and lasted from 30 to 40 minutes. One open-ended question was used: ‘What are your expectations of this unit while waiting on the waiting list?’ Follow-up questions and clarifying questions were used to stimulate the participants to express and expand their thoughts and feelings. The interviews were transcribed verbatim into textual data by an independent secretary. After a maximum of 30 days, all the participants were offered treatment at the ED unit.

For the purpose of **Study II**, all the participants aged 13-18, on the waiting list at the ED unit in Göteborg, were asked to participate in the COEAT project.

Sixty-five participants were informed about the project and fifty-five were included. At pre-treatment both participants and parents were interviewed and asked to answer a battery of self-report questionnaires relating to eating disorder symptoms, social relations and family climate. The participants were examined by a general practitioner and diagnosed by a child and adolescent psychiatrist according to DSM-IV (1994) as AN = 35, BN = 6 and Eating disorders not otherwise specified (EDNOS) = 14. Two participants with AN did not complete the first assessment and were excluded, together with one boy. In Study II, 32 female AN patients and 48 of their parents participated. They were all assessed pre-treatment and at the 18-
and 36-month follow-ups performed at the ED unit, regarding eating disorder symptoms, general psychopathology, social skills, the emotional atmosphere in the family, expectations and experiences of treatment and therapists. Patients answered the questionnaires separately from their parents. In families with both parents present, they were able to sit together and had an opportunity to collaborate on the parental questionnaires. Accordingly, the parents’ results are accounted for as one group.

In **Study III**, data from 15 eating-disorder units in Sweden were collected by psychiatrists, clinical psychologists, clinical social workers and psychiatric nurses with experience of eating disorders. In this study 89 adult AN patients participated and the administration of initial measures took place at the diagnostic assessment prior to treatment or within two (in-patient) to four (out-patient) weeks of commencing treatment at the latest. Follow-up measures were completed in conjunction with personal interviews with treatment staff, or, if patients were unable to attend, in conjunction with telephone interviews, in which case patients completed and returned their questionnaires by post. Roughly 10-20% of all participants with different ED diagnoses were interviewed by telephone at the 36-month follow-up. In all cases, treatment units had declared their “intention to treat” the participating patients.

In **Study IV**, participants aged 13-18, on the waiting list at the ED unit in Göteborg and taking part in the COEAT project, a total of sixty-four participants, were informed about the study (one boy was excluded). At pretreatment, fifty-four participants and their parents were assessed with an interview and a battery of self-report questionnaires relating to eating disorder symptoms, social relations and family climate. A general practitioner examined the participants and they were diagnosed by a child and adolescent psychiatrist according to DSM-IV (1994) as AN = 34, BN = 6 and EDNOS = 14. Two of the participants with AN did not complete the first assessment and were excluded. In Study IV, 32 female AN patients and 41 of their parents participated. The assessments pre-treatment and at the 18- and 36-month follow-ups were performed at the ED unit and the procedure included the same interviews and questionnaires presented in Study II.

Ten participants, AN = 6 and EDNOS = 4, and their parents were early drop-outs in both Study II and Study IV. The mean age of the six participants diagnosed with AN was 13.8 years and the mean BMI was 15.7, two were referred for emergency treatment due to severe somatic status and being suicidal and one was referred for OCD treatment. The remaining three AN patients and their parents declined to participate in the study.
Compared with the 32 remaining participants in both studies, these six were younger and had a lower BMI.

**Participants**

**Study I** consisted of 15 consecutive women, 18-25 years of age, on the waiting list at the specialist ED unit in Göteborg, Sweden. Their mean age was 21.7 years (range 19-24), their mean BMI was 17.2 (range 15-19.6) and the mean duration was 4.8 years (range 1-10). Four participants had previous experience of eating-disorder treatment, eight called the unit themselves and seven were referred by general practitioners or psychiatric clinics. Seven were employed and eight were studying.

**Study II** comprised 32 female patients with anorexia nervosa, between 13 and 18 years of age, and 48 of their parents participated. At first admission, the mean age was 15.4 years (SD = 1.4, R = 13-17.5), the mean duration was 14 months (SD = 0.76, R = 0-39) and the mean BMI was 16.3 (SD = 1.0, R = 13-18). All the patients had amenorrhea, five pre-menarche, and one patient also had an obsessive-compulsive disorder (OCD). Further, they were involved in a median of three sports and three hobbies and they reported a median of three friends; 74% lived with both their biological parents, 6% with one biological parent with a partner and 20% came from single-parent families. Twelve per cent of the parents reported their own experience of eating disorders, 6% reported an eating disorder among siblings and seven patients (21%) had a parent with present or previous problems with alcohol and/or substance abuse.

**Study III** comprised 89 adult women diagnosed with AN and treated at 15 special eating-disorder units and followed up over a three-year period. Their ages ranged from 18 to 46 years (M = 23.9 years, SD = 6.0), their mean duration of eating disorder at presentation was 6.7 years (SD = 5.9) and their mean BMI at treatment start was 15.7 (SD = 1.6). No exclusion criteria were applied.

**Study IV** involved 32 female adolescent patients, 13-18 years old, and 41 of their parents. At the assessment pre-treatment, their mean age was 15 years and the mean duration was 13 months. The majority, 71%, lived with both their biological parents, 20% with one parent and 9% with one biological parent with a partner.
In Studies II and IV, all the participants were taking part in the COEAT project and the majority but not all are identical in the two studies. This explains why there are differences in the description. This is mainly due to differences in responses to the measurements used in Study IV.

**Measurements**

*The Rating of Anorexia and Bulimia nervosa-children* (RAB-C) and *parent version* (RAB-P) includes a semi-structured interview used to diagnose eating-disorder symptoms according to the DSM-IV and has been developed and validated in Sweden (Clinton & Norring, 1999; Nevonen, Broberg, Clinton, & Norring, 2003). Both interviews assess eating problems, eating habits, weight and body shape, binge eating, weight control, other psychiatric symptoms, alcohol and drug use, previous treatment, motivation and relations to family and friends. At the 18- and 36-month follow-ups, a modified shorter version for both patients and parents was used (Norring, Thurfjell, Engström, Clinton, & Eriksson, 1996b). The RAB-C/P was used in Study II.

*The Eating Disorders Inventory-2* (EDI-2; Garner, 1991a) was used to assess eating-disorder symptoms. The EDI-2 is a self-report questionnaire consisting of 91 items subdivided into 11 subscales: three symptom subscales (Drive for Thinness; Bulimia; Body Dissatisfaction) and eight psychological subscales (Ineffectiveness; Perfectionism; Interpersonal Distrust; Interoceptive Awareness; Maturity Fears; Asceticism; Impulse Regulation; Social Insecurity). The psychometric properties of the Swedish version of the EDI-2 have been established by Nevonen and Broberg (2001) and Nevonen, Clinton and Norring (2006). The EDI-2 symptom subscales were used in Study III.

*The Eating Disorder Inventory for Children* (EDI-C) is a self-report questionnaire and it is a children’s version of the Eating Disorder Inventory-2 (EDI-2) developed by Garner (1991b) and translated into a Swedish version by Edlund (1997). The instrument assesses eating disorder symptoms and general psychopathology and consists of 91 items subdivided into 11 subscales: Drive for Thinness (DT), Bulimia (B), Body Dissatisfaction (BD), Ineffectiveness (I), Perfectionism (P), Interpersonal Distrust (ID), Interoceptive Awareness (IA), Maturity Fears (MF), Asceticism (A), Impulse Regulation (IR) and Social Insecurity (SI). The Swedish version of the EDI-C has been evaluated and provided with normative data for pre-adolescents and
adolescents and proved to be equivalent to the EDI-2 (Thurfjell, Edlund, Arinell, Hägglöf, & Engström, 2003). The EDI-C was used in Study II.

The Youth Self-Report (YSR) is a self-report questionnaire for youngsters developed by Achenbach (1991) and evaluated for Swedish conditions by Broberg et al. (2001b). It is divided into two parts; the first part is a competence section, consisting of an activity scale, a social competence scale, school performance and a total competence scale. The second part is a problem section with two broad groupings of syndromes designated as Internalising and Externalising. The internalising section includes the syndrome scales designated as ‘Withdrawn’, ‘Somatic Complaints’ and ‘Anxious/Depressed’, while ‘Delinquent Behaviour’ and ‘Aggressive Behaviour’ are included in the externalising section. In addition, the second part also comprises three scales that are neither internalising nor externalising, ‘Social Problems’, ‘Thought Problems’ and ‘Attention Problems’. The instrument was used in Study II to present the statements of internalising and externalising problems, as they are associated with ED patients and internalising psychopathology specially related to adolescent AN patients (Ekeroth, Engström, Hägglöf, & Broberg, 2003; Muratory, Viglione, Maestro & Picchi, 2004). There are normative data for YSR representing Swedish girls aged 13-18 and the mean scores for the syndrome dimensions used in Study II (Ekeroth et al., 2003). The YSR was used in Study II.

The Family Climate Self-rating scale (FCS) was developed by Hansson (1989). It is a family diagnostic self-report instrument in which patients and parents separately evaluate the emotional atmosphere in the family. From a list of 85 adjectives representing four independent subscales, ‘Closeness’, ‘Distance’, ‘Spontaneity’ and ‘Chaos’, a minimum of 15 should be chosen. In Study II, three scales were used, ‘Closeness’, ‘Distance’ and ‘Chaos’, as the validity of the ‘Spontaneity’ scale has been questioned (Söderlind & Johnsson, 2004). ‘Closeness’ represents a positive climate with warmth, security and harmony, ‘Distance’ symbolises a negative climate with coolness and rejection and ‘Chaos’ expresses a chaotic climate with confusion, instability and disturbances. Data from a non-clinical group of Swedish girls of the same age as those in Study II are available from Söderlind and Johnsson (2004). The FCS has been used in several Swedish studies and results have emerged to strengthen both reliability and validity in different populations (Hansson et al., 1992; Hansson, Rydén & Johnsson, 1994; Wallin & Hansson, 1999; Wallin, 2000). The FCS was used in Study II.
The Eating Disorder Patient’s Expectations and Experiences of Treatment Questionnaire (EDPEX; Clinton, 2001) was used to study both expectations and experiences of specific treatment interventions for ED. The EDPEX is a 28-item self-report measure in two versions, one used at the initial assessment to assess expectations and the other used at subsequent follow-ups to assess experiences. It comprises three subscales: Control, Insight and Support. Control reflects questions dealing with practical strategies for planning and mastering eating problems, Insight focuses on self-reflection and understanding the patient’s problems, while Support relates to the therapist’s activity and emotional engagement in the patient’s problems. Responses are given on a 6-point scale, scored from 1 (disagree completely) to 6 (agree completely). The EDPEX was used in Study III.

The Treatment Satisfaction Scale (TSS, Clinton & Norring, 2000) is a short questionnaire developed for the CO-RED project and it was used to measure general satisfaction with treatment. Patients were asked to rate five questions on a three-point scale: 1) How well were you treated when you first came to the unit?, 2) How suitable has the treatment programme been for you?, 3) Have staff been able to listen and understand the issues you have raised during treatment?, 4) Do you feel trust and confidence in the staff? And 5) Were you and the staff in agreement about the goals of treatment?. For the purposes of the present study, questions 1, 3 and 4 were also used to measure the patients’ perception of the treatment alliance. The TSS was used in Study III.

The Rating of Anorexia and Bulimia Nervosa (RAB, Clinton & Norring, 1999; Nevonen et al., 2003). This is a 56-item semi-structured interview developed and validated in Sweden, which is used to assess ED and general psychopathology. The RAB covers a wide range of ED symptoms, such as eating problems, eating habits, weight and body shape, binge eating and weight control, as well as other psychiatric symptoms, background variables, alcohol and drug use, previous treatment, motivation and relationships with family and friends. One particular question relating to the patients’ own motivation for treatment was used in the present study. The question used was “If recovering from your problems requires that you change your eating habits, how prepared are you to change them?”. Interviewers could categorise patients’ responses as “prepared to change eating habits radically”, “prepared to change eating habits quite a lot”, “prepared to change eating habits somewhat” or “not prepared to change eating habits”. At the follow-ups a version of RAB (Nevonen et al., 2006) suitable for this specific purpose was used, FORAB-S (Follow-up Rating of Anorexia and Bulimia–Short) at the six-month follow-up and FORAB-F (Follow-up
Rating of Anorexia and Bulimia–Full) at the 36-month follow-up. The difference between the RAB and the follow-up versions is that questions relating to the patients’ medical history and previous treatment experience were removed. The RAB was used in Study III.

*The Structural Analysis of Social Behavior* (SASB; Intrex version, 3rd surface, self-image) was used to assess self-image (Benjamin, 1974). The questionnaire comprises 36 self-referential statements and responses are given on a scale from 0 to 100 with 10-point increments. Responses can be used to delineate individual interpersonal profiles with eight clusters of self-image: (1) self-emancipation; (2) self-affirmation; (3) active self-love; (4) self-protection; (5) self-control; (6) self-blame; (7) self-hate and (8) self-neglect. This instrument was used in Study III.

*Evaluation of Treatment – Adolescent* (ET-A) and *Evaluation of Treatment – Parent* (ET-P) is a self-report questionnaire for both patients and parents specially designed for the COEAT project in 1997 by Wallin, Hägglöf, Engström and Lago, containing eleven open-ended questions and thirty-eight questions with multiple-choice answers. In this study, patients and parents were asked to answer one of eleven open-ended questions: ‘When you started treatment, what did you expect to be helped with?’ and to rate a follow-up question: ‘Have you got any help according to what you expected?’ on a three-point scale. They were also asked to rate twelve of thirty-eight questions with multiple-choice answers on a three-point or six-point scale in which three and six respectively were the most positive values. These selected questions describe experiences of treatment and therapists, aims of treatment and how they were accomplished. The ET-A and ET-P are forerunners of the subsequent development of the Treatment Satisfaction Scale (TSS), described previously. The ET-A/P was used in Study IV.

*The Body Mass Index* (BMI) is the weight in kilograms divided by the square of height in metres and it was used in Studies I-III.

**Treatment model**

The treatment offered in Studies II and IV was a family-based treatment model inspired by the Maudsley model (Dare & Eisler, 1997; Eisler et al., 2000) and patients and parents took part in family sessions combined with separate sessions for patients and parents. The family-based treatment was adapted to local conditions and clinical experiences at the ED unit in Gö-
Anorexia nervosa ... borg and comprised three main parts. The first stage focuses on information about the physical and psychological effects of self-starvation and defining the influence of the disorders on the everyday life of the family. The therapists support the parents to co-operate in helping their daughter to eat and gain weight and the patient to release control over food and eating. The content and organisation of meals are planned and reactions to eating, thoughts and feelings related to the eating disorder are dealt with. The second stage starts when the patient steadily increases in weight and the mealtime structure is regular. The patient should now start to take responsibility for her own eating, with help and support from parents and therapists. Alongside weight and eating patterns, issues relating to adolescent needs in relation to autonomy, parental roles and other important issues introduced by family members can be discussed. When weight and eating habits are maintained focus is now on the family relations in the third stage of the treatment. Less attention is paid to the eating disorder and more attention focuses on the patients’ identity, relationships and future plans and their re-organisation towards a family with an adolescent. Patients’ and parents’ experiences of illness and treatment are examined. Parallel individual sessions for patients and parents enable each family member to discuss important issues which also can be elucidated in family sessions. The treatment lasts for approximately 18 months, once a week at the beginning, every second week thereafter and once a month at the end. The intensity of sessions was decided by the therapists based on the patients’ and parents’ needs. Each family was treated by two therapists authorised by the Swedish National Board of Health and Welfare with long experience of eating disorders.

The “Maudsley model” is the most researched treatment in this area and it was manualised by Lock and colleagues in 2001. Even if the outcome of this treatment is well documented, chiefly in Great Britain, the outcome results in this study represent an important contribution to research in this area for two reasons. First, the family-based treatment in Göteborg was based on the three phases in the Maudsley model but with considerable differences. In Göteborg, two therapists treated each family compared with one. There were family sessions combined with individual sessions for patient and parents, instead of just family sessions. The average treatment period was 13.5 months with a total mean of 27 sessions for each family compared with 12 months and 20 sessions. Second, this was a pilot study evaluating the treatment model and assessment measures before the start of a controlled randomised study. The family-based treatment in Göteborg followed the clinical guidelines recommendation (NICE, 2004) for treatment for adolescents and, if weight decreases or if there are relapses, the
therapists stay or return to stage one and investigate obstacles in the treatment process.

In Study III, patients at the participating units were offered a wide variety of treatment forms, such as in-patient, day patient, out-patient, individual, group and family therapy. In addition, a selection of different treatment methods was offered; they included individual, family and group psychotherapy, art and dance therapy and psychopharmacological treatment. All the treatments focus on weight gain and this was often addressed in structured programmes together with other relevant issues. In out-patient settings, individual therapy and family sessions were most common in the work on weight gain.

**Statistical methods**

In Study II, patients were defined as recovered when they were in full remission according to the DSM-IV (1994). Outcome changes were examined between the first assessment and the 18-month follow-up and the first assessment and the 36-month follow-up using Wilcoxon’s matched-pairs signed-rank test in order to compare the magnitude and direction of differences within pairs.

The magnitude of the treatment effect, the effect size (ES), was calculated; this is one variable in a power analysis in behavioural science. The ES was calculated as the mean differences between pre-treatment and the 18-month follow-up and pre-treatment and the 36-month follow-up divided by the pooled within-group standard deviation (SD). Formula: $(\mu_{\text{pre}}-\mu_{\text{post}})/\sqrt{((n_{\text{pre}}-1)s_{\text{pre2}}^2+(n_{\text{post}}-1)s_{\text{post2}}^2)/ (n_{\text{pre}}+n_{\text{post}}-2)}^{1/2}$, where $\mu$ is mean value, $s$ is SD and $n$ is number of patients. Cohen’s (1988) definition of ES values has been used, where values of $< 0.2$ indicate no effect, $0.2-0.49$ indicate a small effect, $0.5-0.8$ indicate a medium effect and values of $> 0.8$ indicate a large effect.

Clinical significance was used to examine a treatment effect, a change to normal functioning due to therapy, and to identify patients who made statistically reliable changes. There are three ways in which this process can be operationalised and in this study the least arbitrary definition was used. Clinically significant change was defined as being half way between the mean from the baseline level of the patients and the mean of the normal group, the cut-off point (Jacobson & Truax, 1991), together with the number of participants who moved $> 30\%$ from their pre-treatment values.
towards normality at the two follow-up assessments (Webster-Stratton, Hollingsworth & Kolpacoff, 1989).

The statistical analysis was performed with the Statistical Package for Social Science (SPSS) for Windows (version 13.0).

In Study III, patients were defined as recovered when they were in full remission according to the DSM-IV (1994). Outcome changes in BMI, EDI-2 and EDPEX between the first assessment and the six-month follow-up and the first assessment and the 36-month follow-up were examined using Wilcoxon’s matched-pairs signed-rank test in order to compare the magnitude and direction of differences within pairs. Two satisfaction variables were calculated based on the TSS; one classified patients as ‘highly satisfied’/‘satisfied’/‘dissatisfied’ and the other, a dichotomous variable, generated a ‘satisfied’-‘unsatisfied’ distinction by merging the ‘highly satisfied’ and ‘satisfied’ patients.

Linear regression was performed in the analyses in order to select the best predictors of weight increase. Baseline variables and variables at the six-month follow-up were investigated as possible predictors of weight increase from baseline to six and 36 months. The dependent variable, increase in weight, at six and 36 months has been transformed by using Blom’s transformation (1958), as it was not normally distributed. The p-value and R2 are presented from these models. Estimates with a 95% CI from the model with the original values have been presented for the descriptive purpose. The set of statistically significant predictors with the largest R2 has been regarded as the best one. Initially, two univariable analyses were performed; the first with explanatory variables pre-treatment and weight increase from 0 to six months as the dependent variable and the second with explanatory variables pre-treatment and weight increase from 0 to 36 months as the dependent variable. From the univariable analyses for each of the two dependent variables, the seven best predictive variables were selected as possible predictors in the multivariable analysis. The statistical analysis was performed with SPSS for Windows (version 16.0) and SAS 9.2.

In Study IV, patients’ and parents’ treatment expectations and experiences of treatment and therapists were examined and the statistical significance of differences in responses was evaluated with the chi-square and Fisher’s exact probability test. A content analysis approach was used to analyse the written answers to the one open-ended question, When you started treatment, what did you expect to be helped with. Patients’ and parents’ an-
answers were analysed separately (Krippendorff, 2004). As a first step in the analysis, the text was read through several times, question by question, and statements and words related to the same central meaning were subsequently brought together into content units. Each unit was then condensed and coded according to its content, after which the codes were compared and those with similar content were grouped together into eight categories. The statistical analysis was performed with the Statistical Package for Social Science (SPSS) for Windows (version 12.0).

Qualitative methods

In Study I, a qualitative content analysis was performed step by step according to Graneheim & Lundman’s approach (2003) in order to describe patterns and themes. First of all, the interviews were read through several times to obtain a general overview. Text from each interview was then assembled as the unit of analysis. Thereafter, meaning units were created in which sentences, statements or paragraphs related to each other through content and context were gathered. The text in each meaning unit is condensed, shortened but still with its core and abstracted by being labelled with codes. The next step involves creating categories which are the essence of qualitative content analysis, where codes are sorted on the basis of differences and similarities. A category answers to the question “What?” and reflects the manifest content of the text. It is important that data should not be excluded because they do not belong to a category or fit into more than one category (Krippendorff, 2004). Categories were then brought together in main categories. In order to express the latent content, the underlying meaning, a theme was created, answering the question “How?”. Both authors of Paper I performed the steps in the analysis separately, the second author from codes to categories and main categories, after which differences were discussed and consensus was reached. The two authors formulated the theme together. The coding process and analysis was performed using the NVivo9 program.
RESULTS

Study I

The 15 participants’ responses to the question “What do you expect now that you are on the waiting list for a specialist eating-disorder unit?” contained 196 statements and they were categorised in ten categories and three main categories. The categories and main categories were constructed so that no data should be excluded due to a lack of category or fitting into more than one category and answers to the question ‘What?’

In the first main category, Treatment content, all the participants were represented. The participants’ expectations were to be informed about adequate treatment offered, including specific methods like CBT, family therapy and group therapy, and to receive a medical opinion about health status and physical training. Further, participants expected to come and talk to someone about their problems and the causes, to receive support and help when working with problems in their daily life, to recover from the illness, feel happy and lead a normal life.

The second main category, Treatment professionals, represented by ten participants, revealed expectations of meeting someone neutral with no connection to their life, a professional experienced in eating disorders, preferably a psychologist, doctor or dietician, and being treated with respect, listened to, understood and taken seriously. Further, they expected to meet someone strong-minded and fearless who understood the patient’s situation and got to know the patient and not only the disorder. It was important to see someone not involved in their daily life. The participants also expressed confidence in the care unit’s knowing how to treat eating disorders.

In the third main category, Treatment focus, all the participants were represented. The participants expected substantial concrete help, advice and information about food and eating, how to eat, what to eat, how much and to learn to eat regularly. They also wanted to release their negative control of eating and to obtain healthy control, keeping the eating disorder in check and not being dominated by the illness. Further expectations were changes related to bodily symptoms, such as feeling weak, tired, cold and infirm, changing distorted thoughts about food, eating, weight and compensation and depressive and expecting anxious feelings to change into more positive feelings about themselves. Expectations also included the
hope of reaching an acceptance of body and of feelings, to obtain a better self-image. The results are presented in Table 2.

The most frequent expectations overall were “changing distorted thoughts,” “changing eating behaviours” and “living a normal life”. The least frequent were “specific psychotherapy approaches,” “talking about problems,” “being informed about treatment” and “changing control behaviours”.

These results suggest that treatment for AN should be a specific therapy method including someone to talk to with knowledge and experience of eating disorders, with the ability to be empathetic and direct and to listen and understand the patients’ situation. Further, treatment should include interventions relating to symptoms of the illness, psychological issues and physical issues. A theme of an underlying meaning of the way the participants understood these expectations was created as an expression of the latent content answering the question ‘How?’. The theme is: “Receiving adequate therapy in a collaborative therapeutic relationship and recovering”.

Table 2. Sub-categories, categories, main categories and the overall theme from content analysis of narratives about expectations before treatment

<table>
<thead>
<tr>
<th>Theme</th>
<th>Receiving adequate therapy in a collaborative therapeutic relationship and recovering</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main category</strong></td>
<td>Treatment content</td>
</tr>
<tr>
<td><strong>Category</strong></td>
<td>Therapy</td>
</tr>
<tr>
<td><strong>Sub-category</strong></td>
<td>A specific psychotherapy approach</td>
</tr>
<tr>
<td> </td>
<td>Different treatment methods</td>
</tr>
</tbody>
</table>
Study II

Of the 32 patients examined, 23 (72%) at the 18-month follow-up and 25 (78%) at the 36-month follow-up had recovered. The mean BMI increased to 19.4 at the 18-month follow-up and to 20.1 at the 36-month follow-up. At first admission, one patient had an additional diagnosis other than AN and this increased to five patients at the 18-month and three at the 36-month follow-up.

There was a significant positive change over time on all the subscales relating to eating-disorder symptoms and general psychopathology (EDI-C, RAB-C), except for Perfectionism and Maturity fears. Effect sizes were medium to high on the EDI-C and high on the RAB-C. There was a significant positive change at follow-up on the subscales of Withdrawn, Somatic complaints and Anxious/depressed (YSR), with low effect sizes. In addition, there was a significant decrease in ‘Distance’ and ‘Chaos’ (FCS) in the family climate, with low to medium effect sizes.

The results relating to clinically significant changes at both follow-ups revealed that, on the EDI-C, 72%-75% of the patients had moved more than 30% towards normality, while, on the YSR, 52%-53% of the patients had moved more than 30% towards normality (the internalising dimensions). The clinically significant change was greatest at the 36-month follow-up for ‘Distance’ and ‘Chaos’, where 37% and 40% of the patients respectively had moved more than 30% towards normality. The results are presented in Tables 3 and 4.
Table 3. Two-related sample test, Wilcoxon’s matched-pairs signed ranks test of patients pre-treatment to the 18-month follow-up and pre-treatment to the 36-month follow-up with effect sizes

<table>
<thead>
<tr>
<th>Table 3. Two-related sample test, Wilcoxon’s matched-pairs signed ranks test of patients pre-treatment to the 18-month follow-up and pre-treatment to the 36-month follow-up with effect sizes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>EDI-C</strong></td>
</tr>
<tr>
<td>Drive for Thinness</td>
</tr>
<tr>
<td>11.63</td>
</tr>
<tr>
<td>Bulimia</td>
</tr>
<tr>
<td>2.06</td>
</tr>
<tr>
<td>Body Dissatisfaction</td>
</tr>
<tr>
<td>14.28</td>
</tr>
<tr>
<td>Ineffectiveness</td>
</tr>
<tr>
<td>8.38</td>
</tr>
<tr>
<td>Perfectionism</td>
</tr>
<tr>
<td>4.50</td>
</tr>
<tr>
<td>Self-oriented (SOP)</td>
</tr>
<tr>
<td>3.28</td>
</tr>
<tr>
<td>Socially prescribed (SPP)</td>
</tr>
<tr>
<td>1.06</td>
</tr>
<tr>
<td>Interpersonal Distrust</td>
</tr>
<tr>
<td>5.59</td>
</tr>
<tr>
<td>Interoceptive Awareness</td>
</tr>
<tr>
<td>8.28</td>
</tr>
<tr>
<td>Maturity Fears</td>
</tr>
<tr>
<td>5.41</td>
</tr>
<tr>
<td>Asceticism</td>
</tr>
<tr>
<td>10.72</td>
</tr>
<tr>
<td>Impulse Regulation</td>
</tr>
<tr>
<td>7.75</td>
</tr>
<tr>
<td>Social Insecurity</td>
</tr>
<tr>
<td>5.25</td>
</tr>
<tr>
<td><strong>RAB-C</strong></td>
</tr>
<tr>
<td>Anxiety at meals</td>
</tr>
<tr>
<td>2.43</td>
</tr>
<tr>
<td>Fear of gaining weight</td>
</tr>
<tr>
<td>2.14</td>
</tr>
<tr>
<td>Body image</td>
</tr>
<tr>
<td>1.18</td>
</tr>
<tr>
<td>Importance of weight and shape for image</td>
</tr>
<tr>
<td>1.71</td>
</tr>
<tr>
<td><strong>YSR</strong></td>
</tr>
<tr>
<td>Internalising dimensions:</td>
</tr>
<tr>
<td>Withdrawn</td>
</tr>
<tr>
<td>5.79</td>
</tr>
<tr>
<td>Somatic complaints</td>
</tr>
<tr>
<td>5.17</td>
</tr>
<tr>
<td>Anxious/depressed</td>
</tr>
<tr>
<td>13.03</td>
</tr>
<tr>
<td>Externalising dimensions:</td>
</tr>
<tr>
<td>Delinquent behaviour</td>
</tr>
<tr>
<td>3.17</td>
</tr>
<tr>
<td>Aggressive behaviour</td>
</tr>
<tr>
<td>9.93</td>
</tr>
<tr>
<td><strong>FCS</strong></td>
</tr>
<tr>
<td>Closeness</td>
</tr>
<tr>
<td>1.51</td>
</tr>
<tr>
<td>Distance</td>
</tr>
<tr>
<td>0.60</td>
</tr>
<tr>
<td>Chaos</td>
</tr>
<tr>
<td>0.92</td>
</tr>
</tbody>
</table>

* p < .05; ** p < .01; *** p < .000;  Es = Effect size, ≤ 0.20 = low effect; 0.50 = medium effect; ≥ 0.80 = high effect (Cohen 1988).
Table 4. Cut-off points, medians and individual clinically significant change

<table>
<thead>
<tr>
<th></th>
<th>Pre-treatment</th>
<th>18-month follow-up</th>
<th>36-month follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cut-off point†</td>
<td>n &lt; Cut off Median</td>
<td>n &lt; Cut off Median</td>
</tr>
<tr>
<td>EDI-C, 1-3</td>
<td>15</td>
<td>8</td>
<td>25%</td>
</tr>
<tr>
<td>EDI-C, 4-11</td>
<td>42</td>
<td>12</td>
<td>38%</td>
</tr>
<tr>
<td>EDI-C, total</td>
<td>59</td>
<td>10</td>
<td>31%</td>
</tr>
<tr>
<td>YSR, internal</td>
<td>19</td>
<td>9</td>
<td>28%</td>
</tr>
<tr>
<td>YSR, external</td>
<td>13</td>
<td>16</td>
<td>50%</td>
</tr>
<tr>
<td>FCS, closeness</td>
<td>2</td>
<td>15</td>
<td>50%</td>
</tr>
<tr>
<td>FCS, distance</td>
<td>0.43</td>
<td>16</td>
<td>53%</td>
</tr>
<tr>
<td>FCS, chaos</td>
<td>0.68</td>
<td>14</td>
<td>47%</td>
</tr>
</tbody>
</table>

† Defined as half way between the pre-treatment mean for the patient group and the mean for the non-clinical group.
‡ Number of participants that changed > 30% towards normality from pre-treatment to the 18- and 36-month follow-ups.
Study III

A total of 89 patients were assessed pre-treatment, while the frequency of non-participation varied for both questionnaires and follow-ups at the participating units; on average 62%-75% were re-assessed at the six-month and the 36-month follow-up respectively.

At the initial assessment, 67 (77.9%) patients said that they were motivated to change their eating habits radically/very much, 18 (20.9%) to some extent and one (1.2%) not at all.

At the 36-month follow-up of 89 patients, 34 (38.2%) had recovered, 14 (15.7%) still had AN, while 41 (46.1%) had BN, BED or EDNOS. The mean BMI increased to 17.3 at the six-month follow-up and to 19.2 at the 36-month follow-up. There was a significant positive change over time on all the subscales relating to eating-disorder symptoms and general psychopathology (EDI-2), except for Perfectionism and Interpersonal Distrust. Patients’ expectations of Support (EDPEX) were significantly higher than those experienced at both follow-ups and expectations of Insight and Control were higher than experienced at the 36-month follow-up. Satisfaction with treatment was high, irrespective of recovery, and the majority said that the treatment alliance was positive at both follow-ups.

In order to find predictors of weight increase, seven best predictive variables were selected for weight increase from 0-6 months (‘Motivation to change eating habits,’ ‘Bulimia,’ ‘Perfectionism,’ ‘Social insecurity,’ ‘Expectations of insight,’ ‘Self-emancipation,’ and ‘Self-neglect’) and seven best predictive variables were selected for weight increase from 0-36 months (BMI, Duration, ‘Body dissatisfaction,’ ‘Interoceptive awareness,’ ‘Maturity fears,’ ‘Ascetism’ and ‘Self-emancipation’).

The best predictors of weight increase from 0-6 months were: ‘Motivation to change eating habits,’ ‘Social insecurity’ and ‘Self-neglect’ and they explained 23% of the variance (adjusted R2). The best predictors of weight increase from 0-36 months were: Duration, ‘Body dissatisfaction’ and ‘Interoceptive awareness’ and they explained 18% of the variance (adjusted R2).
Study IV

At the 18-month follow-up of a family-based treatment, patients and parents were asked about their expectations of help at the start of treatment. The answers were divided into eight categories: Increase in weight, Depression, Self-esteem, Cognitive distortions, Eating behaviour Normal healthy life, Help and support and Do not want help.

The category with the most patients (40%) represented was ‘Do not want help’ and the categories with the fewest patients represented (3%-13%) were Increase in weight, Depression, Self-esteem and Cognitive distortions. Parents were most frequently represented (56%) in the categories of Help and support and Eating behaviour and least represented in the categories of Self-esteem, Depression and Cognitive distortions. There were statistically significant differences between patients and parents in terms of ‘eating behaviour,’ ‘do not want any help’ and ‘help and support.’ The results are presented in Table 5.

Table 5. “When you started treatment, what did you expect to be helped with?”

<table>
<thead>
<tr>
<th>Categories</th>
<th>Patients (n=30)</th>
<th>Parents (n=41)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>(%)</td>
</tr>
<tr>
<td>Increase in weight</td>
<td>1</td>
<td>(3)</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>(3)</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>3</td>
<td>(10)</td>
</tr>
<tr>
<td>Cognitive distortions</td>
<td>5</td>
<td>(17)</td>
</tr>
<tr>
<td>Eating behaviour</td>
<td>6</td>
<td>(20)</td>
</tr>
<tr>
<td>Normal healthy life</td>
<td>8</td>
<td>(27)</td>
</tr>
<tr>
<td>Help and support</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td>Do not want help</td>
<td>12</td>
<td>(40)</td>
</tr>
</tbody>
</table>
Patients and parents were also asked if they received any help according to what they expected and the majority, 73%-83% of patients and parents respectively, said that their pre-treatment expectations had been met.

The majority of patients and parents agreed that individual patient sessions were of great help, but there was disagreement regarding individual sessions for parents and family therapy sessions, both rated as more helpful by the parents than by the patients.

Parents were significantly more satisfied with the therapist than their adolescent daughters. Experiences of the therapist differed to a statistically significant degree between patients and parents when it came to agreeing on treatment goals, therapist’s knowledge of eating disorders, being listened to, understanding your problems and being met in a kind way.

At the 18-month follow-up, the majority (82%) of the recovered patients and their parents (93%) were satisfied with the treatment and half (50%) the patients who still had an eating disorder and their parents (58%) also reported satisfaction with treatment.
DISCUSSION

The focus of this thesis was to study different perspectives of treatment and the concept was to follow the process from expectations of treatment, to treatment outcome and predictors of weight increase and, finally, to satisfaction with treatment in order to increase our understanding of adolescents and young women with anorexia nervosa. An effort was also made to contribute to clinical work with the results from patients and families.

Methodological considerations

The studies in the present thesis illuminate aspects of treatment in different areas which contribute to a widespread perspective of one eating disorder diagnosis, anorexia nervosa. In Study I, patients’ expectations are investigated before being assessed for treatment, which is unique. Existing research in this field focuses on patients’ expectations retrospectively and in relation to their experiences of treatment regarding eating disorders in general. Studies II and IV contribute valuable information relating to both outcome and treatment satisfaction in relation to a specific treatment method including different interventions. Further, both patients and parents participated and this then created an opportunity to compare their results in terms of expectations and experiences of treatment over time. As extremely few studies of the expectations of treatment and experiences of treatment received have been performed, this is an important contribution in this arena. In Study III, several predictors of weight increase were found, a result of importance as research on weight increase is sparse and it is most commonly examined in relation to weight maintenance after treatment. Most research on predictors in eating-disorder treatment has related to recovery.

Representativeness of the study group

This thesis comprises adolescent patients, parents and adult patients, either potential patients (Study I), or patients diagnosed according to the DSM-IV (1994) and treated at different specialist eating-disorder units in Sweden (Studies II-IV) participating in the COEAT and the CO-RED project. This should vouch for the representativeness of the study group, at least with respect to anorexia nervosa. Moreover, a qualitative prospective interview design was used (Study I), making it easier for the participants to express their thoughts and perspectives. Study II met most of the six criteria that Hsu (1996) outlined for a good outcome study; explicitly stated diagnostic criteria, more than 25 subjects in the study, a minimum follow-up duration
of at least four years from onset of illness, a failure-to-trace rate of less than 10%, the use of direct interviews in more than 50% of subjects and the use of multiple well-defined outcome measurements.

**Appropriateness of methods used**

The studies encompass both a qualitative and a quantitative design, including interviews and self-report questionnaires. In the qualitative Study I, the participants were assessed with a qualitative interview performed by the same interviewer and with one open-ended question enabling the participants to express expectations of all kinds.

Studies II and IV were part of a multi-centre study (CORED) with six participating units and with common measurements. Study III was part of a longitudinal naturalistic study with 15 participating units with common measurements. All the instruments used in these two projects are well established and reliable and are commonly used in psychiatric and eating-disorder research.

There is, however, one exception; the Evaluation of Treatment for Adolescents and Parents (ET-A; ET-P) was a self-questionnaire designed for the CORED project and was not validated, but the questions used in Study IV have since been developed into the Treatment Satisfaction Scale (TSS) that is frequently used to measure satisfaction.

**Validity and reliability aspects**

In qualitative content analysis, credibility, dependability and transferability describe the trustworthiness of research findings. In Study I, credibility was established through the selection of participants and context that corresponded well to the intended focus; categories and theme were illustrated in a table and in representative quotations and all the text was read through and analysed by the first author, after which the second author performed the analysis separately and the results were discussed and revised. Dependability was accomplished by the fact that all the interviews were performed during a short period of time and no changes were made to the data collection or interview process. Transferability was achieved by the description of participants, data collection, process of analysis and presentation of results.

With respect to psychiatric diagnosis, DSM-IV (1994) criteria were used in Studies II-IV.

Adolescent patients and their parents in the COEAT-project in Studies II and IV were assessed by one and the same child and adolescent psychiatrist...
assisted by a psychiatric nurse, pre-treatment and at the following assessments. Data in the CO-RED project (Study III) were collected by psychiatrists, clinical psychologists, clinical social workers and psychiatric nurses with experience of eating disorders. Both the COEAT-project and the CO-RED-project had a well-documented design with assessments pre-treatment and at follow-ups that allow repeated trials. The instruments used in all four studies (except the ET-A/ET-P) have been tested for reliability and validity and are all extensively used.

**General discussions of main findings**

**Expectations before treatment**

When the participants were contacted and asked to take part in the interviews, they all agreed. The majority were pleased to be able to come to the unit before the actual assessment to make themselves familiar with the route and premises. During the interviews, all the participants were positive about treatment even though they were worried about how it would be and also about not being accepted for treatment. They were well informed about treatment options; some had searched on websites for appropriate treatment and some had read about the treatment options at the unit, and expected a change.

All the participants expressed motivation and a positive attitude towards attending treatment and an intention to recover and lead a normal life. There were a variety of expectations in terms of treatment content, treatment professionals and treatment focus. This is in contrast to the description of AN patients having poor motivation at the beginning of treatment (Prochaska et al., 1992) and low expectations of recovery (Holliday, Wall, Treasure & Weinman, 2005; Treasure & Schmidt, 2001b). However, the wish to recover from AN fluctuates in intensity and over time (Nordbø et al., 2011) and so the patients’ expressed motivation before assessment does not tell us about their motivation once in treatment.

The participants expressed expectations of information about treatment, of professionals being supportive, empathetic and understanding with expertise in eating disorders, which is in agreement with several studies reporting patients’ experiences of treatment and quality of care (Bowling et al., 2012; Clinton, 2001; Clinton et al., 2004; de la Rie et al., 2006; 2008; Escobar-Koch et al., 2010; Gulliksen et al., 2012; Pettersen & Rosenvinge, 2002; Rosenvinge & Khulefelt Klusmeier, 2000; Schröder et al., 2007). However, a third of participants did not declare any expectations of treatment professionals, as they instead prioritised treatment content and focus. This
may elucidate their own focus on being in need of treatment and the fact that who they met was of secondary interest.

Expectations linked to eating-disorder symptoms, such as eating behaviour, the body, thoughts and feelings, were characterised by concrete action; to work with, deal with, change and take control. Some participants requested specific therapy approaches.

Taken as a whole, at the interview, the participants presented positive expectations of varying character, some previously known from other studies, others not as well known, such as expectations of a specific treatment and of concrete tasks. No negative expectations were expressed with regard to the interview question but worries were expressed about not managing treatment and not recovering. All the participants were represented in terms of expectations of treatment content and focus, but five participants did not have any specific expectations of treatment professionals and their qualities, as they focused on their problems and getting help.

The participants were young adults who still had hopes of a future, recovering and leading a normal life, which could partly explain their positive attitude. In addition, eight participants contacted the unit themselves and three of them had had previous treatment experience elsewhere, which could also have affected their expectations in a positive way. It is also possible that the participants wanted to make a good impression, be accommodating, but they were informed at the beginning of the interview that the interviewer was detached from the upcoming assessment and that all material was kept secret.

**Outcome of treatment**

The majority of adolescent patients had recovered and primary eating-disorder symptoms, such as BMI, menstruation, weight phobia, body dissatisfaction, attitudes towards shape and body and anxiety at meals, had all improved. These results are in line with other clinical studies of adolescent AN patients (Eisler et al., 2007; Halvorsen et al., 2004; Nilsson & Hägglöf, 2005) and of adolescent ED patients (Steinhausen et al., 2003) and young adult AN patients (Fichter, Quadflieg, & Hedlund, 2006). There were also significantly reduced changes in symptoms in terms of general psychopathology, except for ‘perfectionism’, ‘maturity fears’ and externalising dimensions. Compared with a non-clinical group of adolescents of the same age and gender, the results from eating-disorder symptoms and psychopathology were equal to or lower at the 36-month follow-up, except for ‘perfectionism’, ‘ascetism’ and ‘impulse regulation’ (Thurfjell et al., 2003). Nilsson, Sundbom, Hägglöf (2008) reported equal results and
also found that patients with higher levels of perfectionism at the start of treatment require more time to recover than those with lower levels.

**Duration – co-morbidity**

Young age at onset and short duration may have had an impact on our results (Steinhausen et al., 2003) and the high effect sizes, together with the clinically significant changes, could be attributed to the family-based treatment having a decreasing effect on eating-disorder symptoms. There was low co-morbidity in the study sample, one patient (3%) with obsessive-compulsive disorder (OCD) at the first assessment, five patients (16%) with depression, OCD, panic syndrome and social phobia at the 18-month follow-up and three patients (9%) with depression at the 36-month follow-up. In a 10-year follow-up in adolescent AN, 51% had a current psychiatric disorder (Herpertz-Dahlmann, Muller, Herpertz, & Heussen, 2001) and the outcome of co-morbidity of adolescent eating disorders at a mean follow-up of 6.4 years was 49% (Steinhausen et al., 2003). In an 18-year outcome of adolescent-onset AN, the co-morbidity rate was 39% (Wentz et al., 2009). One possible cause is that patients in the current study were referred to and treated at a specialist eating-disorder out-patient unit with an eating-disorder diagnosis as the primary diagnosis and a basic condition for treatment, while participants in Wentz’s study, for example were recruited by community screening. The sample in the study by Herpertz-Dahlman et al. (2001) consisted of 39 adolescents who were admitted to in-patient treatment, while in the study by Steinhausen et al. (2003), the sample comprised 338 adolescents in in-patient and out-patient treatment.

**General psychopathology – internalising dimensions**

Perfectionism is associated with high expectations of oneself and one’s life and also with depressive feelings (Bizeul, Sadowsky, & Rigaud, 2003). A perfectionist with AN strives for control of eating, shape and weight, despite the consequences, and the need to control every situation could lead to the progression of obsessive traits. Lack of control is a failure and a proof of being worthless, which creates more rigorous control and feelings of anxiety and depression (Fairburn et al., 2003; Shafran, Cooper, & Fairburn, 2002). Perfectionism and its impact on eating disorders has been highlighted as being involved in the onset of the disorder and it has been identified as a key maintenance mechanism in its continuity (Fairburn et al., 2003). In this study, ‘perfectionism’ did not change despite recovery, results that are in concordance with several studies including both adolescent and adult AN patients (Bastiani, Rao, Weltzin, & Kaye, 1995; Cassin, & von Ranson, 2005; Castro-Fornieles et. al, 2007; Halmi et al., 2000; Halvorsen et al., 2004; Nilsson & Hägglöf, 2005). Self-oriented perfectionism, SOP and high standards are elevated in patients with AN compared
Adolescence is a time of developing a personal identity and, in daily life, adolescent girls compare themselves with each other in terms of appearance, behaviour and performance. Adolescent girls with an eating disorder continuously struggle to strike the right balance between different expectations that are in conflict with each other or equally incompatible (Aila Gustavsson, et al., 2011) and this can contribute to the consistently high scores for perfectionism. Previous AN patients’ own ideas of the most common causes of their anorexia nervosa were their own high demands and their self-oriented perfectionism (Nilsson, Abrahamsson, Torbiornsson & Hägglöf, 2007).

‘Asceticism’ and ‘impulse regulation’ had scores that were twice as high as those in the control group pre-treatment, but they changed significantly over time, while ‘maturity fears’ obtained the same scores as the control group but did not change. AN patients with an onset before 16 years of age had higher scores for asceticism and maturity fears pre-treatment than patients with an onset after 16 years of age (Abbate Daga et al., 2007). Asceticism has been shown to be related to perfectionism and is associated with self-discipline, self-denial and hyper-control over bodily needs and self-sacrifice. Asceticism is also related to maturity fears and is seen as a way of accomplishing self-control in the process of maturity and adulthood, an angry protest against expectations and pressure (Fassino, et al., 2006).

Asceticism and impulse regulation significantly decreased in this study and it can be assumed that the structure of the family-based treatment with individual sessions offers an opportunity for patients to deal with ascetic issues. Perfectionism and maturity fears, however, endure and this could perhaps be a result of the time factor; perfectionism is not altogether negative, but, in the context of AN, it is destructive and maintaining and it may take a longer period of time in treatment to achieve a balance and learn how to deal with fears of growing up.

At treatment start, the patients in this study had higher scores for internalising dimensions and almost the same for externalising dimensions compared with a non-clinical group. At the 36-month follow-up, the scores for both dimensions were on the same levels as or lower than those of the non-clinical group (Broberg et al., 2001b). The scores are also comparable to the total CORED, AN sample (Ekeroth et al., 2003). Patients with AN are...
often described as introvert, anxious and depressed and the family-based treatment appears to have had an impact on internalising dimensions, since there was a decrease over time. Adolescent AN patients do not normally display delinquent, aggressive behaviour directed towards other people, but more to themselves, while externalising dimensions were unchanged.

**Family climate**
The family climate at treatment start revealed lower scores for closeness and higher scores for distance and chaos for both patients and parents compared with non-clinical adolescents and non-clinical families (Söderlind & Johnsson, 2004). This is most definitely influenced by the illness and its impact on family life, where all the family members are exposed to high levels of stress, distress and burden (Eisler, 2005; Treasure et al., 2001a; Whitney & Eisler, 2005). In the family-based treatment, described earlier in the section entitled “Treatment model” in Study II, interventions provide an opportunity for the family members to address these negative aspects. At the 36-month follow-up, closeness increased and distance decreased for both patients and parents. Chaos decreased significantly for both patients and parents. Compared with non-clinical groups, the scores for ‘closeness’ and ‘distance’ and ‘chaos’ were lower for the patients, while they were lower for ‘closeness’ and higher for ‘distance’ and ‘chaos’ for parents at the 36-month follow-up. The quality of closeness may have changed during the recovery process from a feeling of close parental control, because of the life-threatening condition, to a more age-relevant relationship. The differences between patients and parents at this point may correspond to the degree of anxiety. Parents’ reactions to positive changes may be warily optimistic, reflecting, for example, fear of setbacks. It is also possible that a feeling of chaos might correspond to feelings of anxiety due to the state of illness and the recovery of the family climate therefore takes longer than the recovery of the patient (Wallin & Hansson, 1999).

No significant differences were found between mothers’ and fathers’ estimations, but, as the parents had an opportunity to collaborate on the questionnaires, it is difficult to draw any conclusions about differences or similarities between their answers. One conclusion that can be drawn from these results is that, as the treatment proceeds, hopefully with improvements in symptoms, the family climate improves as well. A recent study has revealed that changes in eating disorder symptoms preceded changes in family climate (Nilsson, Engström, & Hägglöf, 2012).

Current results of treatment outcome indicate that the structured multidimensional treatment approach with a combination of family and individual interventions has been fairly effective in relation to eating disorder symp-
toms, general psychopathology and family climate. This family-based treatment used in Göteborg corresponds well with clinical guideline recommendations for interventions that directly address the eating-disorder symptoms from the start of treatment provided on an out-patient basis by professionals specialising in eating disorders (NICE, 2004; Swedish Psychiatric Association, 2005). The set-up of the treatment comprises three stages (described in Treatment model) and the emphasis in the first stage is placed on weight increase, healthy eating and the patient’s and family’s everyday life. If weight is decreasing or stationary, the support of professionals increases with more frequent sessions every week, medical monitoring and, if necessary, a short period of admission to in-patient treatment with the purpose of increasing weight. Work on cognitive symptoms, such as fear of weight gain, feeling fat and body dissatisfaction, begins in parallel with the weight increases and, in the latter half of the treatment, adolescent developmental issues are also illuminated. At relapses with weight loss, the support of professionals increases.

**Predictors of weight increase**

Weight increase is an essential aim in the treatment of AN and, when different areas were examined, three predictors of short-term weight increase and three predictors of long-term weight increase were found. Pre-treatment, patients expressed the motivation to change eating habits and ‘social insecurity’ and ‘self-neglect’ were the best predictors of weight increase at the six-month follow-up.

This indicates that, if patients have a positive attitude towards changing their eating habits as treatment starts, this will influence the progress of weight increase. AN patients’ motivation fluctuates (Nordbo et al., 2011; Vansteenkiste et al., 2005) and, in order to support this development, it is essential to explore and address patients’ expressed motivation from the beginning and on-going to help them to maintain a positive attitude to change.

AN patients’ obtain significantly higher scorers for social insecurity compared with other eating disorder patients (Nevonen et al., 2006) and the current results underline its importance in relation to weight increase. For this reason patients’ experiences of their social relationships should also be a focal area early in treatment (Zipfel et al., 2000). In addition, AN patients tend to have a more negative self-image than patients with other eating disorders (Björck et al., 2007). Self-neglect was found to be a predictor of weight increase in the current results, which is in line with other studies where high levels of initial self-neglect, self-control and self-
protection in AN predicted a poorer outcome three years after treatment start (Birgegård et al., 2009).

Duration, ‘body dissatisfaction’ and ‘interoceptive awareness’ pre-treatment were the best predictors of weight increase at the 36-month follow-up. Duration is in agreement with several other results that identify short duration as a predictor of a good outcome (Agras et al., 2004; Fichter et al., 2006; Steinhausen, 2002; Treasure & Russell, 2011; Zipfel, et al., 2000), while others find that duration is of no importance to outcome (Ben-Tovim et al., 2001). Both body dissatisfaction and interoceptive awareness are related to AN symptoms and part of the anorectic identity and an acceptance of the body and awareness of bodily needs facilitates weight increase in the long term. However, changes in cognitive symptoms such as the fear of gaining weight, feelings of fatness and the over-evaluation of shape and weight, will occur when the patient has decided to change and is actively engaged in change (Geller et al., 2005).

We found different predictors of weight increase at the six-month follow-up (motivation to change, social relations, self-neglect) and at the 36-month follow-up (duration, body dissatisfaction, misperception of bodily needs). The entrance to weight increase appears to be patients’ readiness to change and permit themselves to eat and confront interpersonal problems. To obtain a lasting weight increase, patients’ thoughts and feelings about their body need to be addressed and this is possible when patients have decided actively to change (Geller et al., 2005). The predictors serve as building blocks to achieve weight increase, first patients need to be receptive to treatment and changes and then tackle the anorexic identity.

**Treatment satisfaction**

Patients’, and parents’, experiences of family-based treatment were very positive in overall terms. The individual sessions for patients and parents respectively were of great help and were appreciated, as they offered an opportunity to discuss their own feelings and thoughts openly and unconditionally and these results are in line with previous studies (Eisler et al., 2000; Krautter & Lock, 2004). There was general satisfaction with the therapists, although the parents were far more satisfied than the patients. This could be due to the treatment model, especially the first half, where patients may feel that the therapists are more supportive towards and listen more to their parents, with the overall aim of stopping the starvation. However, the majority of the patients thought that they participated in treatment planning and that they were listened to and encouraged by the therapist to talk about important issues which could be discussed in individual sessions. Patients may feel that the therapists do not understand their situation and, together with their parents, they are going to stop the
patients’ only solution to their unhappiness, starving and reaching the desired weight. As the treatment proceeds and the patients gain weight, experiences of the therapists will be more positive, as will the patients’ readiness to change (Treasure et al., 1999). Almost all the parents trusted the therapists’ capability to help and their knowledge of eating disorders, compared with half the patients, which is related to satisfaction with treatment. The more therapists are regarded as experts, the greater the satisfaction (Rosenvinge & Khulefelt Klusmeier, 2000). The majority of satisfied patients recovered and the majority of parents who were satisfied had a daughter that had recovered, which is understandable, as life with AN is not desirable for anyone.

There are, however, two results worth pointing out. First, 40% of the patients had not wanted any help when treatment started but, despite this, 73% of them had experienced help and said that their expectations had been met at the follow-up. The severe physical and mental state, caused by starvation, affects patients’ judgement at the start of treatment (Dare & Eisler, 1997), together with being forced into treatment by parents. In addition, poor understanding of the danger of the illness and denial of symptoms contribute to a low desire for help (Fisher et al., 2001). Adolescents generally say that they want to be left alone with their dieting and control over eating (Bruch, 1985) and, once in treatment, they expect to be forced to surrender, start eating and gain weight, which tends to result in treatment resistance. In contrast to adults, adolescent patients describe their readiness to change as: not at all interested in change or actively engaged in change (Geller et al., 2008), which may illustrate the current results. At treatment start no need for help was expressed but as the treatment proceeds, the improvement in basic conditions with weight gain creates opportunities for the patients to feel and reflect on their situation, explain the kind of help they want and work on important issues in the individual sessions. Most patients want to be well, but it is impossible at the start of treatment to express those wishes or even think they could come true.

Second, the family sessions were very much appreciated by the parents but not by the patients. In these sessions, the therapists pass on information about the illness, the physical effects on body and soul and about difficulties involved in recovery. Parents are supported to overcome fears and to co-operate in feeding the patient and the patients are encouraged to do what they do not want, at least during the first half of the treatment. It also becomes evident how the illness affects and controls the family and all the decisions about change are discussed and approved and followed up in the next session. However, a combination of family sessions and individual sessions is important and necessary to help adolescent patients to cope with
the difficult situation in terms of recovery and for adolescent parents to hold out and tackle the challenges of the illness. The family-based treatment offered in this study corresponded well to both patients’ and parents’ treatment expectations.

**The therapist**

At the beginning of the introduction to this thesis, a question was raised: What essential characteristics are needed as a therapist in the treatment of patients with AN? On the basis of the current results, there are some answers to this question. In all psychotherapeutic work, there is a therapist-patient relationship and, in order to build a collaborative therapeutic alliance, this relationship needs to be healthy and trusting and include three features: an agreement on goals, an assignment of tasks and the development of bonds (Bordin, 1979). A strong alliance affects outcome in a positive way and, to accomplish strength, the therapist requires characteristics such as being flexible, experienced, honest, respectful, trustworthy, confident, interested, alert, friendly, warm and open. In addition, techniques of being reflective, supportive, active, noticing therapy success, providing accurate interpretations and facilitating emotional expression strengthen the alliance (Ackerman, & Hilsenroth, 2003; Baldwin, Wampold, & Imel, 2007).

In psychotherapeutic work with ED patients, research on therapists’ characteristics is scarce and existing studies focus on the alliance in relation to specific treatments. In this thesis, adolescent and young adult patients’ appreciation of therapists was explored and revealed the following preferred characteristics: being an expert with knowledge and experience of eating disorders, showing an interest in the patient and not only in the disorder, listening to, respecting and understanding the patient’s situation, being kind, encouraging, supportive and being strong-minded and fearless. The current results are in line with a recent qualitative study by Gulliksen et al. (2012), where four factors were found when it came to therapists’ characteristics that were preferred by AN patients: ‘Acceptance’ (generosity, respect and patience), ‘Vitality’ (active interest and a sense of humour), ‘Challenge’ (focus on patient’s resources and support through difficult situations) and ‘Expertise’ (experienced knowledge and authoritativeness).

Being an expert means having knowledge and being experienced in the field of eating disorders, which was expected and highly valued in the current results. However, apart from expert skills, the therapist’s personal qualities were highlighted and conclusions can be drawn that knowledge and experience of eating disorders is not enough to build a strong alliance. Knowledge of eating disorders can be obtained from education and
through training and years of experience also have an impact on the therapeu-
tic style, but qualities associated with personality are something else. Is there a way to obtain the characteristics required to build a collaborative therapeutic alliance in the treatment of AN patients?

AN symptoms and their implications for treatment and outcome have pre-
viously been discussed in this thesis, but they also have implications for the therapist-patient relationship evoking therapists’ own needs and negative feelings (Birgegård et al., 2009; Kaplan & Garfinkel, 1999).

Research on therapists’ characteristics and their importance in ED treat-
ment and outcome is very sparse. Clinton (2010) points out that the ther-
pist effects in treatment are underestimated or not estimated at all, in out-
come research and that outcome results are strongly influenced by the way treatment interventions are delivered by the therapist. Patients assessed in current studies appear to agree on this point and therapists’ characteristics are a future area which it is important to explore in order to find the “the lost variable” in treatment research, as Clinton (2010) advocates.

**Strengths**

A qualitative, prospective interview study makes it easier for the partici-
pants to express their thoughts and perspectives. The interviews were per-
formed with one open-ended question starting with “What do you ex-
pect?”, which made it possible for the participants to express expectations of all kinds. The data were analysed according to a content analysis which provides an in-depth understanding of the participants’ expectations.

Two studies comprised both patients and parents and there were no drop-
outs at the follow-ups, except for some reduction in the self-report ques-
tionnaires. The follow-up sessions were performed at the unit after making an appointment with each family. The family-based treatment that was offered was well defined and based on an established family-based treat-
ment for eating disorders, performed by authorised psychotherapists with long experience of eating disorders. The results show several clear points of significance which increase the reliability of the conclusions.

One study included data collected within the framework of the CO-RED project, a longitudinal naturalistic study with patients at 15 specialist units in Sweden, which has produced results expected to be representative of the study-group. Further, the repeated-measure design included both inter-
views and self-report questionnaires. The combination of quantitative and qualitative approaches gives extra strength to this thesis.

**Limitations**

Study I comprised a sample with a narrow age range and all the participants were recruited from one specialist eating-disorder out-patient unit, which affected the generalisability of the results.

Studies II and IV included a homogeneous study group and the duration of follow-up was short, which could be a restriction regarding the generalisability of the expectations. In addition, there is no information about other possible interventions after discharge from treatment that could have influenced the results at follow-ups. Expectations before the start of treatment were investigated at the first follow-up, which created a risk of missing significant information and retrospective bias.

In Study III, the number of participants fluctuated at follow-ups, which could have influenced the results. There was no inclusive assessment of motivation before treatment, only one question was asked about motivation to change eating habits, and the results therefore report the motivation expressed at the time. Further, the telephone-interviews at follow-ups might have concealed relevant information.
CONCLUSIONS

• Young adult women with anorexic symptoms had a positive attitude to attending treatment and an intention to recover. Their expectations before treatment related to receiving appropriate therapy, a reduction in negative physical and psychological symptoms and being supported by experts on eating disorders. Examining expressed motivation and expectations systematically at the initial assessment and continually during treatment might help to enhance the therapeutic relationship and affect the treatment process in a positive way.

• A multifactorial family-based treatment for adolescents and their parents, including a combination of family and individual sessions, was favourable in many cases; a significant reduction in eating-disorder symptoms, a significant decrease in general psychopathology, although perfectionism and maturity fears appeared to be more difficult to attain, and a significantly less chaotic and distant family climate. This family-based treatment, extended to include interventions assessing perfectionism and fears of growing up, should be manualised and offered to adolescent patients and their parents.

• Weight increase in AN treatment is essential to recovery and predictors of weight increase were found to be related to: expressed motivation to change eating habits, social relations, self-image, body image and bodily needs. Therapists need to address these areas in the therapeutic work in order to facilitate weight increase. In addition, duration of illness was also a predictor of weight increase and early detection should therefore be a focal point in preventive programmes for eating disorders.

• Adolescent patients’ and their parents’ were satisfied in overall terms with a family-based treatment that included a combination of family and individual sessions. However, due to resistance at the beginning of treatment, patients’ expectations should be explored as early as possible and addressed at a later stage during treatment. For this reason, parents’ expectations are equally important to investigate before treatment to establish collaboration. In family sessions, therapists should pay attention to patients’ experiences and maintain a balance between the situation of parents and patients.
Clinical implications

Patients’ express a variety of expectations before treatment and they are important to capture and identify in order to enhance the therapeutic relationship. The obligation to examine patients’ expectations lies with the therapist. In order better to understand the nature of these expectations, patients should be given the task of writing a list at the start of treatment to use as a basis for discussion at this point and continually in monthly treatment planning, for example. Expectations were expressed as receiving appropriate therapy and meeting experts with knowledge in the field of eating disorders and units working with eating disorders must therefore be well informed about research on current treatment methods and continuously educate therapists.

A family-based treatment for adolescents and their parents is preferable on the basis of both results relating to recovery and treatment satisfaction. However, as perfectionism and fears of growing up persist even after recovery, these areas should be specially included and addressed, preferably in individual sessions. The family-based treatment used in Göteborg should be manualised with the proposed additions and include guidelines describing the stages in the treatment in order to help experienced therapists in their clinical work and in the introduction of skilled therapists inexperienced in eating disorders. Therapists should also address expectations continuously in order to build a solid therapeutic alliance with both patients and parents. Revealing and discussing discrepancies is especially important when it comes to core features, approaches and goals, as hidden disagreements can undermine and affect the therapeutic alliance in a negative way and create dissatisfaction.

Weight increase is essential in AN treatment and is a measure of success. The current results point to different areas outside food and eating that contribute to weight increase in young adult patients and are consequently important for therapists to address in clinical work. These areas are patients’ motivation to change, social relations, bodily needs, body acceptance and self-image and treatment should therefore include a variety of interventions based on current areas. Treatment is generally performed on a patient-therapist basis, but current areas could also be included on a group-therapy basis with a number of patients and two therapists.

Further, duration of illness was also a predictor of weight increase. Parents and professionals that meet adolescents at school, in health care and in sports organisations for example, should be informed about the early signs
of eating disorders, what to do when and who to contact in order to promote early detection.

Family-based treatment is the treatment of choice for adolescent AN patients and their parents, but treatment with a family perspective should also be offered to young adult patients and their parents. Within the framework of a family perspective, treatment of this kind could comprise individual sessions integrated with family sessions and interventions with the patient’s needs in focus.

In clinical work, therapists should continuously have an opportunity to meet, discuss and exchange experience with other clinicians and researchers and experienced therapists should serve as models for more inexperienced therapists in patient work. Finally, discussion should focus on how to build a strong treatment alliance and not only on the methods we are using.

**Research implications**

In order to further investigate AN patients’ expectations before treatment, a short questionnaire could be developed on the basis of the findings in the qualitative study and tested in a pilot study, after which the results of both studies could form the basis of an assessment of expectations in clinical work. The questionnaire could also be used for all eating-disorder patients to investigate similarities and differences linked to eating-disorder symptoms. Future qualitative research should focus on patients’ perceptions of their illness in relation to treatment expectations. This knowledge could be taken into account in clinical work in the reception of patients, in information and standards at a treatment unit. A follow-up study of participants from the qualitative study could be performed to explore whether their positive attitudes before treatment have had any impact on motivation, treatment outcome and staying engaged in treatment. Is there a relationship between pre-treatment expectations and outcome?

Future research should focus on controlled and RCT studies in order to follow up the results in the current study relating to family-based treatment for adolescent patients and parents. In addition, a RCT study should investigate manualised family-based treatment with young adult patients and their parents in relation to alternative treatments. Treatment manuals allow comparison of psychotherapies and facilitate therapists to deliver what is intended in a particular psychotherapy.
The family climate is an area it is important to explore in more detail in relation to eating disorders. Available valid and reliable measurements should be examined and studies of family climate, including parents and patients with different eating-disorder diagnoses should be conducted. Information about different aspects of the family climate could prove useful in treatment planning and clinical work. Adolescent patients with high levels of perfectionism need a long time to recover and further research in this area should concentrate on finding appropriate interventions for treatment. Future research should address treatment satisfaction in the family-based treatment used in Göteborg, the benefit of the present experience and investigate expectations before treatment. The results of this thesis did not find a relationship between expectations and experiences of treatment and these are therefore important areas to examine in more detail.

Treatment outcome for adult AN patients is generally poor and so future research ought to examine current predictors in a large sample of patients to compare results. Further studies could also evaluate a structured treatment method based on the predictor areas in relation to weight increase and outcome.

In several studies, patients’ perspectives of their therapists are presented, but therapists’ characteristics are a field that has been only sparsely explored. The time has now come to explore the therapist effect in relation to treatment alliance and treatment outcome and to identify the essential characteristics that are required as a therapist.
SAMMANFATTNING PÅ SVENSKA  
(SUMMARY IN SWEDISH)

Anorexia nervosa är en allvarlig psykiatrisk sjukdom med hög mortalitet. Den har lägsta prevalens, minst förekommande, jämfört med övriga ätstörning diagnosser och börjar ofta utvecklas i tonåren. Fokus i denna avhandling är anorexia nervosa och det övergripande syftet är att studera ungdomar och vuxna patienters uppfattning om och förlopp av sjukdomen för att på så sätt bidra till kliniskt arbete relaterat till dessa patienter. Ömråden som studerats är förväntningar på behandling, utfall, prediktorer för utfall och tillfredsställelse med behandling. Fyra studier ingår i avhandlingen; tre studier har sitt ursprung ur arbetet vid en specialiserad ätstörningsenhet på Drottning Silvia’s barn-ungdomssjukhus i Göteborg och en studie härrör från en multicenterstudie som inkluderade 15 specialiserade ätstörningsenheter i Sverige.


Sökord: anorexia nervosa, behandling, tonåringar, vuxna, förväntningar, utfall, prediktorer, viktökning, behandlingstillfredsställelse.
ACKNOWLEDGEMENTS

Writing this doctoral thesis is nothing I could have done on my own! It consists of different contributions from many people at different times. The first spark of my interest in research was lit when I met Professor Sigvard Rubenowitz many years ago and he introduced me to the world of research methods and practice. When I started working at the Anorexia-Bulimia Unit in Göteborg, I met inspiring colleagues with a strong interest in development and research and the spark burst into flames. This thesis is one proof of my passion for research.

I wish to express my deepest gratitude to the following persons who have supported me and contributed to making this thesis possible.

This is a clinical thesis and, first and foremost, I would like to thank all the patients and families who participated in the studies. They all shared their expectations and experiences in several interviews and self-report questionnaires during a vulnerable period of their lives.

I especially want to thank Associate Professor Lauri Nevonen, my main scientific supervisor, co-author, colleague and friend. You are responsible for introducing me to the world of research in eating disorders and I am proud to have been your first doctoral student. Your purposefulness, continuous enthusiasm, together with important advice and constructive comments, have been most helpful and encouraging. Without our discussions and your support, this thesis could not have been completed.

I also want to express my gratitude to Professor Ingemar Engström, co-author and co-supervisor, who welcomed me to the Psychiatric Research Centre in Örebro. Your knowledge and experience has been valuable and your constructive comments are much appreciated.

I would like to express my sincere thanks to Associate Professor David Clinton, co-author and researcher at the Resource Centre for Eating Disorders, Stockholm. Our Friday meetings have been most fruitful and I have appreciated our discussions, statistical work and your supporting me in becoming a “syntaxare.” Thank you, also, for introducing me to Dickens, Eliot and Hardy.
I had the privilege to have Associate Professor Per Johnsson, Head of the Department of Psychology, Lund, as the opponent at my “kappa” (dissertation) seminar. I am grateful for your valuable comments and suggestions for changes and additions to the text. I also appreciated your encouragement about my work.

Many thanks go to Tomas Hermander, Head of the Anorexia-Bulimia Unit and my boss. Your interest, support and encouragement have been invaluable.

In clinical work and in research, I have had fruitful discussions with Birgitta Levin, colleague and friend. I am very grateful for all the knowledge and enthusiasm you have shared with me and for all your support.

I owe thanks to former colleagues at the Anorexia-Bulimia Unit for inspiring discussions and for collecting data. Further, I want to thank all my present colleagues, for their support and patience with me in clinical work, and all the secretaries who have put up with me forgetting administrative tasks.

I wish to express thanks to Associate Professor Elisabeth Wentz, deputy manager of the Gillberg Neuropsychiatric Centre, colleague and friend, for your interest and useful comments. You have really been encouraging all the way and I especially appreciated afternoon tea.

Thanks to Sanna Aila Gustavsson, Psychiatric Research Centre in Örebro, for your support and valuable comments on my “kappa”. Thanks also to Andreas Birgegård, Resource Centre for Eating Disorders in Stockholm, for much-appreciated support.

Gunnar Ekeroth and Aldina Pivodic have supported me with excellent statistical help in different areas, for which I am most grateful.

The British English in this thesis has been thoroughly reviewed by Jeanette Kliger. I really appreciate all your work.
Finally, I want to thank my family for the patience, engagement and support you have all shown in different ways!

Göran, my husband, you never stop believing in me. Your understanding, support and continuous optimism have encouraged me to stay focused on my work on this thesis. You have also done most of the practical work at home and the next year or so is on me.

Louise, you played an active part in writing down all the essential comments at seminars and you also share my interest in research. Kristoffer, you have helped me a lot with technical support and you have been available at all times. Beatrice, you have been considerate and shown an interest in the different stages of the process and you made sure that I regularly came out of the basement.

Thank you all for being my family!
REFERENCES


APPENDICES

Appendix I:

Diagnostic Criteria for Anorexia Nervosa according to the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Revised (DSM-IV)

Patients must meet all of the following criteria.

A. Refusal to maintain body weight 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 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 postmenarchal 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. oestrogen, administration).

Specify type:

Restricting Type (type 1): 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 misuse of laxatives, diuretics or enemas).

Binge-Eating/Purging Type (type 2): 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).
<table>
<thead>
<tr>
<th></th>
<th>Authors</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bergemalm, Per-Olof</td>
<td>Audiologic and cognitive long-term sequelae from closed head injury.</td>
</tr>
<tr>
<td>2</td>
<td>Jansson, Kjell</td>
<td>Intraperitoneal Microdialysis. Technique and Results.</td>
</tr>
<tr>
<td>5</td>
<td>Wågsäter, Dick</td>
<td>CXCL16 and CD137 in Atherosclerosis.</td>
</tr>
<tr>
<td>6</td>
<td>Jatta, Ken</td>
<td>Inflammation in Atherosclerosis.</td>
</tr>
<tr>
<td>7</td>
<td>Dreifaldt, Ann Charlotte</td>
<td>Epidemiological Aspects on Malignant Diseases in Childhood.</td>
</tr>
<tr>
<td>8</td>
<td>Jurstrand, Margaretha</td>
<td>Detection of Chlamydia trachomatis and Mycoplasma genitalium by genetic and serological methods.</td>
</tr>
<tr>
<td>9</td>
<td>Norén, Torbjörn</td>
<td>Clostridium difficile, epidemiology and antibiotic resistance.</td>
</tr>
<tr>
<td>10</td>
<td>Anderzén Carlsson, Agneta</td>
<td>Children with Cancer – Focusing on their Fear and on how their Fear is Handled.</td>
</tr>
<tr>
<td>11</td>
<td>Ocaya, Pauline</td>
<td>Retinoid metabolism and signalling in vascular smooth muscle cells.</td>
</tr>
<tr>
<td>12</td>
<td>Nilsson, Andreas</td>
<td>Physical activity assessed by accelerometry in children.</td>
</tr>
<tr>
<td>13</td>
<td>Eliasson, Henrik</td>
<td>Tularemia – epidemiological, clinical and diagnostic aspects.</td>
</tr>
<tr>
<td>14</td>
<td>Walldén, Jakob</td>
<td>The influence of opioids on gastric function: experimental and clinical studies.</td>
</tr>
<tr>
<td>15</td>
<td>Andrén, Ove</td>
<td>Natural history and prognostic factors in localized prostate cancer.</td>
</tr>
<tr>
<td>16</td>
<td>Svantesson, Mia</td>
<td>Postpone death? Nurse-physician perspectives and ethics rounds.</td>
</tr>
</tbody>
</table>


35. Söderqvist, Fredrik (2009). Health symptoms and potential effects on the blood-brain and blood-cerebrospinal fluid barriers associated with use of wireless telephones.


41. Gustafsson, Sanna Aila (2010). The importance of being thin – Perceived expectations from self and others and the effect on self-evaluation in girls with disordered eating.

42. Johansson, Bengt (2010). Long-term outcome research on PDR brachytherapy with focus on breast, base of tongue and lip cancer.

43. Tina, Elisabet (2010). Biological markers in breast cancer and acute leukaemia with focus on drug resistance.


46. de Leon, Alex (2010). Effects of Anesthesia on Esophageal Sphincters in Obese Patients.


52. Loiske, Karin (2011). Echocardiographic measurements of the heart. With focus on the right ventricle.


64. Nordin Olsson, Inger (2012). Rational drug treatment in the elderly: ”To treat or not to treat”.


67. Thuresson, Marie (2012). The Initial Phase of an Acute Coronary Syndrome. Symptoms, patients’ response to symptoms and opportunity to reduce time to seek care and to increase ambulance use.


75. Gustavsson, Anders (2012): Therapy in Inflammatory Bowel Disease.
