A life put on hold – Inside and outside perspectives on illness, treatment, and recovery in adolescents with restrictive eating disorders
All is well.
A life put on hold – Inside and outside perspectives on illness, treatment, and recovery in adolescents with restrictive eating disorders
Abstract

The overall aim of this thesis was to study adolescents with restrictive eating disorders in relation to illness, treatment, and recovery from an inside and outside perspective. Studies I and II are based on data from a national quality register for eating-disorder treatment. Studies III and IV are based on interviews with adolescents previously treated in outpatient care for a restrictive eating disorder.

The results showed that 55% of the adolescents were in remission at the end of treatment, and 85% were within a healthy weight range. The average treatment duration was 15 months. Over the years 1999–2014, remission rates and weight recovery increased, whereas treatment duration decreased. Young patients who received mainly family-based treatment had the highest probability of achieving remission at one-year follow-up, but the patients themselves were most satisfied with individual therapy.

The interviews with the adolescents revealed that they often felt a strong ambivalence during the first treatment sessions, both regarding being defined as sick and the involvement of their parents. In retrospect they believed that family involvement was important, but that individual treatment sessions were crucial. The informants highlighted that trust in the therapist was the key to successful treatment. The adolescents’ narratives drew a picture of a life that was “put on hold” during the time of illness, as their involvement in social contexts outside the family was strongly influenced. It was in these contexts that their problems first became visible, and the quality of their interpersonal relationships played a great role in the recovery process.

The results suggest that treatment for adolescents with restrictive eating disorders should be better adapted to changed social structures and patients’ individual contexts – a relevant area for future research.

Keywords: Adolescents, Anorexia Nervosa, restrictive eating disorders, family involvement, treatment outcome, patient perspectives, qualitative research, social contexts, interpersonal relationships.

Katarina Lindstedt, School of Medicine Örebro University, SE-701 82 Örebro, Sweden, katarina.lindstedt@regionorebrolan.se
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II. Lindstedt K, Forss, E, Elwin, M, Kjellin L, Gustafsson SA. Adolescents with full or subthreshold anorexia nervosa in a naturalistic sample – treatment interventions and patient satisfaction. In manuscript.


## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AN</td>
<td>Anorexia Nervosa</td>
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<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
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<tr>
<td>ARFID</td>
<td>Avoidant Restrictive Food Intake Disorder</td>
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<tr>
<td>BED</td>
<td>Binge Eating Disorder</td>
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<tr>
<td>BMI</td>
<td>Body Mass Index</td>
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<tr>
<td>BN</td>
<td>Bulimia Nervosa</td>
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<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual – Fourth edition</td>
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<tr>
<td>DSM-5</td>
<td>Diagnostic and Statistical Manual – Fifth edition</td>
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<tr>
<td>ED</td>
<td>Eating disorder</td>
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<td>EDNOS</td>
<td>Eating Disorder Not Otherwise Specified</td>
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<tr>
<td>EMT</td>
<td>Extensive mixed treatment (cluster)</td>
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<tr>
<td>FT</td>
<td>Family treatment</td>
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<td>FIT</td>
<td>Family based treatment and individual therapy (cluster)</td>
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<td>IT</td>
<td>Individual therapy</td>
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<tr>
<td>M</td>
<td>Mean</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<tr>
<td>OSFED</td>
<td>Other Specified Feeding or Eating Disorders</td>
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<tr>
<td>RAB</td>
<td>Rating of Anorexia and Bulimia interview</td>
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<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
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<tr>
<td>SD</td>
<td>Standard Deviation</td>
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<tr>
<td>SEDI</td>
<td>Structured Eating Disorder Interview</td>
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<tr>
<td>SwEat</td>
<td>Swedish national quality register for eating disorder treatment</td>
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<tr>
<td>TA</td>
<td>Thematic analysis</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Preface

In my teens I came into close contact with eating disorders as a relative. Within a few years, two young women close to me were affected by a restrictive eating disorder, one of them so severely that inpatient care was necessary. The different symptomatology of these women, involving behavioral as well as cognitive symptoms that affected them in their everyday life, although in quite different ways, left me puzzled.

Fortunately, both of the young women recovered, although at different stages in life. The questions raised in my mind during their illness followed me through high school and my early twenties, and it was not until I started my psychology studies in 2001 that I began to seek answers to them. The moment I did, I was instantly absorbed by this complex and multidimensional field of eating disorders.

For adolescents with eating disorders, there are no forms of treatment with satisfactory evidence, despite extensive research. For several years, family-based treatment has been the single form of treatment with established, albeit somewhat contentious, evidence. One point of entry to this research project was my curiosity concerning the clinical implications of this situation. I had an impression that family-based treatment was introduced to young people more or less automatically, without any alternative interventions being presented, and I strongly questioned the rationality of such an approach. I was (and still am) convinced that no single psychological treatment works for everyone – not even within a homogeneous patient group in terms of age, gender, and diagnosis. I wanted to learn more about characteristics of the patient group, treatment outcome, in what sort of cases family-based treatment was more, or less, effective, appropriate alternatives to treatment, the impact of interpersonal relationships, and the patients’ own perceptions about their illness and their time in treatment. Some of these ideas were later formulated into more concrete research questions.

During my time as a doctoral student, my interest in the field of eating disorders has further increased. Since I started working clinically with psychiatric disorders, and in later years primarily with eating disorders, this interest constitutes an important part of my life. The final result of my research project, which started as an embryo in my teenage mind, is now in your hand.
Background

An eating disorder (ED) is a psychiatric illness which is sometimes regarded as a social phenomenon, due to its association with body shape and appearance. The illness can manifest itself in many different ways, but there are common basic symptoms such as fear of weight gain and the central importance of body weight and shape for self-esteem. Today, many people in clinics and among the general public recognize signs of the illness, but sometimes these signs are confused with symptoms of more general problematic eating. For the symptoms to be considered pathological, they should be persistent and strongly affect physical health or psychological functioning. However, the problem is also the reverse, since only about one third of individuals with an ED are detected by healthcare and participate in treatment.

The overall incidence of EDs in the general population has remained stable over the past few decades, or has slightly increased, according to some studies. EDs affect mainly women, but increasingly boys and young men as well. It has been suggested that the prevalence for men in some ED diagnoses is up to one fourth of the prevalence for women. In Sweden, according to a report from 2017, an estimated 190,000 individuals (men and women, 15–60 years old) suffer from an ED. However, incidence rates are difficult to measure in an accurate way, and differences in rates over time could be due to e.g. changed diagnostic definitions or increased public awareness.

Regarding treatment, early intervention is important for a satisfactory prognosis. However, EDs are underdiagnosed and treatment is often prolonged. A comorbidity between EDs and other psychiatric disorders, which often complicates treatment, is quite common. Such comorbid diagnoses include for example anxiety, substance use disorders, and depression.

It has been suggested that approximately 13% of a population will develop an ED by the age of 20, and EDs are some of the most prevalent psychiatric disorders among adolescents. Despite that, our knowledge about the course, treatment outcome, and prognosis is still inadequate. The illness and the subsequent treatment, which is often very demanding, are likely to hinder life from continuing as usual. Therefore, a relevant clinical question is: how can we help these young people recover from their ED, while simultaneously trying to reduce the damage that may arise from such an interruption in life?
A biopsychosocial framework
In this thesis, and with the question above in mind, the phenomenon is highlighted from a biopsychosocial perspective. From such a perspective, illness is a reflection of a dynamic and mutual interaction between biological, psychological, and social factors. In clinical care, the biopsychosocial model functions both as a philosophy and as a practical guide. It offers an understanding of how suffering and illness are affected by multiple levels of organization and points to the importance of taking the patient’s subjective experience into account in treatment. In a biopsychosocial perspective, various aspects of health and illness are interdependent and tend to interact, which is why health issues should be addressed and reflected upon from different angles.

Eating disorders and Anorexia Nervosa
During the years examined in this thesis, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) constituted the basis for ED diagnoses. In DSM-IV, diagnoses of EDs are divided into the three main categories: Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorders Not Otherwise Specified (EDNOS). AN is characterized by e.g. restrictive eating patterns, intense fear of gaining weight, and body image disturbance, and have two subtypes: restricting type or binge-eating/purging type. BN includes recurrent episodes of binge eating and inappropriate compensatory behavior. EDNOS are divided into different subtypes and represent EDs of a clinical severity that do not meet the full diagnostic criteria for AN (subthreshold AN) or BN.

In this thesis, individuals with AN and subthreshold AN (defined as EDNOS with all criteria for AN fulfilled except the weight criterion and/or the criterion of amenorrhea) are included, and the criteria for both diagnoses according to DSM-IV are presented in Appendix A. The decision to include patients with subthreshold AN is based on results from previous studies, suggesting that patients with subthreshold AN most often suffer from symptoms to the same extent as patients with AN, despite a higher Body Mass Index (BMI, kg/m2) in general. In this thesis, I will most often use the abbreviation AN for describing both diagnoses, although I will occasionally use the concept restrictive ED, as restrictive eating is the common main symptom for both diagnoses.

Including subthreshold AN when studying patients with AN is also in line with the updated criteria in the Diagnostic and Statistical Manual of...
Mental Disorders, Fifth Edition (DSM-5), from 2013, in which the definition of AN has been broadened, for example by lifting out the amenorrhea criterion. It has been suggested that one of the most important changes from DSM-IV to DSM-5 is the reduction of residual diagnosis by lowering the thresholds for AN. In DSM-5, diagnoses are divided into the main categories AN, BN, and Binge Eating Disorder (BED). Just like BN, BED includes recurrent episodes of binge eating, but these are not followed by any compensatory behavior. Additional ED diagnoses in DSM-5 are Other Specified Feeding or Eating Disorders (OSFED), which represent EDs of clinical severity that do not meet the full diagnostic criteria for AN, BN, or BED. This accounts for e.g. atypical AN (when the weight criterion is not fulfilled) or atypical BN (when the time frame criteria for binge eating and/or compensatory behavior are not fulfilled). Avoidant Restrictive Food Intake Disorder (ARFID) is yet another new diagnosis in the DSM-5, which was previously referred to as “Selective Eating Disorder”. Although DSM-5 was released in 2013, the implementation of DSM-5 at ED units in Sweden began only around two years ago, and it is not yet fully implemented.

Discussions about whether the number of diagnoses is optimal, and whether the criteria are optimally defined, are ongoing. Diagnostic crossover from one ED diagnosis to another is quite common, especially in the early stages of the disorder. In 2003, a suggestion was presented that all ED diagnoses should be treated as a single diagnostic entity, with the focus on common elements. Although health care is still largely organized around the diagnostic system, this is still discussed occasionally, and EDs are increasingly being conceptualized and treated trans-diagnostically in clinical practice. As will be shown in this thesis, a large number of results from previous research is applicable to all ED diagnoses.

Psychiatric comorbidity is quite common among individuals with an ED, although adolescents seem to present fewer comorbid diagnoses than do adults. Comorbid diagnoses include various mood disorders, substance-use disorders, and anxiety. In addition, there are often high rates of medical comorbidity. Severe and prolonged starvation can for example have serious consequences on brain and bone development, especially in young individuals, and adolescents with AN might also experience severe effects on their pubertal development.

Patients with AN have a main focus on restriction of energy intake and a persistent behavior that interferes with weight gain, for example excessive physical activity. The illness is characterized by dissatisfaction with one's
own body, or parts of it, which might lead to weight phobia and eating difficulties. Eating difficulties include differentiating between “good” and “bad” food items, practicing rituals while eating, avoiding any fat, and eating slowly and finically. It is common for persons with AN to weigh themselves and observe themselves in the mirror several times a day. Some individuals suffer from a disturbed body image, including an unrealistic view of the body and/or an overestimation of certain body parts, while others are fully aware of their often very lean body and perceive it as attractive. Symptom presentation can vary between young women and men with EDs, including males sometimes reporting a greater desire to be more muscular and endorsing less weight concern and body dissatisfaction.

Incidence rates are difficult to measure accurately, and differences over time could be due to changed diagnostic definitions or increased public awareness. The effect of lowering the thresholds for AN in DSM-5 has for example been shown in epidemiological studies. The rates also differ remarkably across community studies and health-care studies, since many cases of AN are undetected by health care. However, both community studies and health-care studies have shown that the highest incidence rates of AN are found among girls between 15 and 19 years of age, and according to Smink and colleagues (2012) the incidence rates in this age group have even increased. In general, incidence rates of AN have remained rather stable over the last two decades, in both women and men. Considering lifetime prevalence, suggested rates of AN in adolescent samples are 0.3–0.6% for women and 0.3% for men. The overall rates for women in general are suggested to be 2.0%. These numbers are mainly based on diagnostic criteria in DSM-IV.

In patients with AN, rates of death are almost six times higher than would be expected in an age- and sex-matched population, and death causes are for example suicide or disruption of major organ systems. Psychiatric comorbidity (e.g. substance abuse) is also a risk factor for mortality in people with AN.

**Anorexia Nervosa in adolescence**

Although most individuals go through adolescence without major difficulties, the path from youth to adulthood is quite a bumpy ride for some people. It implies changes in the brain function, as well as changes in physical, social, cognitive, and emotional behaviors. Adolescence is characterized by identity creation, which is a changing process influenced by intimate relationships, education, and friendship relationships, as well as...
striving towards greater independence from parents\textsuperscript{35-38}. The structural changes in the brain of adolescents, which mainly target the prefrontal cortex and might be affected by endocrine levels in puberty, are aimed at optimizing emotional and cognitive control, in order for the youth to be able to act as an independent individual in adulthood\textsuperscript{34}.

In addition, adolescence is a problematic and hazardous phase since young people often engage in risky behaviors\textsuperscript{39,40}. Such behaviors can be caused by diminished self-control and peer pressure\textsuperscript{40}. These problems are not to be seen as an inescapable norm, however, but an indication that adolescents need help and support\textsuperscript{41}. Changes during adolescence often lead to parental conflicts, but how parents respond to the adolescent’s behavior and need for autonomy affects the young person’s mood to a great extent\textsuperscript{38}. Supporting young people, working for healthy relationships and giving young people the opportunity to grow and develop has been shown to prevent ill health and unfavorable behavior during the teenage years\textsuperscript{38}.

As early as 2006, classroom surveys showed that an increasing number of young people in Sweden received child and adolescent psychiatric care\textsuperscript{42}. It has been suggested that psychiatric disorders in adolescents arise from aberrations of maturational changes that occur in the adolescent brain, which are more likely to occur in combination with stress\textsuperscript{36}. Alternatively, changes in the brain represent a vulnerability over a certain period of time, which increases the risk of young people developing a mental disorder when exposed to stress\textsuperscript{34}. Many adolescents experience stress, connected to parental conflicts, bullying, physical and sexual abuse, and school work, for example\textsuperscript{41,42}. Adolescents spend an increasing amount of time with peers, which is why stress often involves peer behavior. Stressed individuals are more likely to feel worse about themselves\textsuperscript{41}, and it has been shown that symptoms are especially prevalent among adolescent females\textsuperscript{41,42}. Overall, there is a difference between girls and boys in prevalence regarding internalizing symptoms, and the burden has been shown to increase for girls\textsuperscript{43}. During certain periods, many adolescents have an unhealthy relation to food and body shape, which might turn pathological if not observed in time. There are many reasons why young people begin to eat in a problematic manner, and many of these ways only deal indirectly with food and body image\textsuperscript{44}.

AN particularly affects young people during this developmentally important stage of adolescence, which is characterized by changes that have effects on various areas of life. This is true for both boys and girls, although the sorts of developmental changes might differ\textsuperscript{39}. Puberty involves an
increase in sex steroids and growth hormone in both genders but is associated with a greater increase in fat mass in girls than in boys, for example 45. The World Health Organization (WHO) defines an adolescent as a person between the ages of 10 and 19 years 46. However, in this thesis, adolescents are defined as persons between the ages of 13 and 19 years, as most young people have not entered puberty until the age of 13, and the onset of AN is most common in mid-adolescence 4. Regarding both genders, suffering from AN has severe effects on puberty 1.

Young peoples’ perceptions of their identity are challenged in adolescence, because they begin to think differently about themselves and/or because they are perceived differently by their peers 47. A sense of confusion regarding identity sometimes occurs in adolescence, which might reduce self-esteem 48. Body image is viewed as one important part of self-esteem which is an especially salient domain in female adolescents but is a highly ranked concern in both adolescent boys and girls 48. According to Frisén, Lunde & Berg (2015) it has been shown that body esteem, the so-called self-esteem domain of physical appearance, is correlated to body dissatisfaction and undergoes a negative change from childhood to early adolescence. In their study on developmental patterns in body esteem, appearance and weight esteem decreased among both boys and girls, but particularly among girls 47.

An experienced discrepancy between self and ideal is what leads to body dissatisfaction 49, and it has been suggested that pubertal development brings girls further away from slim female ideal 47. In an American survey from 2015, approximately 60% of girls and 30% of boys engaged in dieting behaviors with the aim of losing weight or avoiding weight gain, probably connected to body dissatisfaction 50. Results from a previous study on adolescent girls show that they often feel stressed in school and among friends regarding how they should look and act, and feel required to be slim and fit 51. Many young women seem to have difficulties managing such expectations adequately 51, which increases the risk for dieting behaviors and disordered eating 52.

AN among adolescents involves certain challenges regarding identification and diagnosis. Younger patients are likely to have atypical presentations of eating disorders and are therefore at risk for delayed diagnosis 13. Diagnostic criteria used for adults do not take into account physiological, psychological, and developmental differences, which entails that many children in early stages of their ED are overlooked 11.
Aetiology

Today, it is clearly stated that EDs are multi-determined with a wide range of genetic, biological, personality, psychological, and social factors interacting \(^{13,45,53}\), which is well in line with the biopsychosocial perspective. EDs develop over time, with causative factors emerging at different stages, so it is important to distinguish between predisposing factors, precipitating factors, and perpetuating factors. A predisposing factor is defined as a vulnerability that seems to be required for the development of the disorder, and that can be biological or psychosocial, associated with e.g. endocrine problems or different personality traits. A precipitating factor is a “triggering” factor, like a tragic event, sexual harassment, or bullying. A perpetuating factor is a factor that serves to maintain the illness, for example a stressful job which leads to irregular eating habits \(^{45}\). In this background to etiology, the focus is on predisposing factors and precipitating factors involved in the development of an ED, which may overlap in certain individuals \(^{45}\).

Predisposing and precipitating factors involve so-called risk factors, which are factors that have shown to be correlated to the illness and clearly precede onset \(^{45}\). Identification of risk factors is important for targeting interventions and designing prevention programs, among other things \(^{49}\). One of the prominent psychological factors implicated in the onset of ED pathology is considered to be low self-esteem \(^{54}\), and it is suggested that EDs in young people often begin with dieting \(^{1,45}\). Examples of causes presented by patients themselves, or by previous patients are dieting, sexual abuse, stress, family dysfunction, and adolescence \(^{55-57}\). Specific risk factors for AN are suggested to be, for example, feeding and sleeping problems in childhood and high levels of physical exercise \(^{45,58}\).

Socio-cultural theories of the development of EDs are probably the best-known ones among the general public, suggesting that pressure to be thin is a source of body dissatisfaction and problematic eating behaviors \(^{45,49,59}\). EDs have previously been regarded as something that exists predominantly in Western cultures, that is, cultures with high socioeconomic status in general and social norms about female thinness, but during the last few decades, EDs have increased worldwide \(^{12,49}\). The media might play an important role in the internalization of beauty ideals \(^{45,59}\), and a possible reason for the increasing rates of EDs in developing countries might be the spreading of Western influences through media \(^{12}\). Peer influence, as a sociocultural factor, has also been identified as an important risk factor among adolescents \(^{60}\).
The single best predictor of risk for developing an ED, and AN in particular, is being a female. This might be due to a combination of gender prescriptions that makes girls more susceptible than boys for certain precipitating factors, e.g. comments on looks and appearance. However, not all women are affected, and given the high prevalence of some of the risk factors mentioned, remarkably few adolescents in general develop an AN. This indicates that the risk factors may be necessary in the development of an ED, but not sufficient, and that an interaction between predisposing and precipitating factors is a prerequisite. The evidence is fairly strong that biological factors contribute to risk factors for AN, and the role of genetics in biological mechanisms of EDs is being increasingly examined and discussed.

Most current treatments are aimed at relevant perpetuating factors, since these factors are often easier to influence than predisposing and precipitating factors. Nevertheless, treatment is best accomplished when at least something is known about possible causes of the disorder.

Treatment for eating disorders

The main goals for the treatment of EDs are suggested to be reduction of body image distortion and dysfunctional eating habits, a return to social engagement, and a resumption of full physical activities. Regarding AN, treatment is particularly complicated due to the egosyntonic aspect of the illness, which implies that individuals place value on their symptoms. Many patients with AN identify with their illness, and despite their perceived weakness and incapability of doing “ordinary things” they find it difficult to let go. For these patients, it has been suggested that the perceived advantages with the illness, such as thinness and/or an inner sense of strength, are outweighing its disadvantages.

It has also been proposed that puberty and the physical and mental development that adolescents go through, along with major life changes, such as moving away from home, change of school, or meeting a partner, pose major challenges for ED treatment. When making treatment decisions for young patients, therapists also need to pay attention to unexpected symptoms and behaviors, such as diffuse behavioral symptoms, and to differences in symptoms between young women and men.

At specialized ED units providing outpatient care, patients are often offered a “main treatment”. This treatment is conducted either on an individual basis, or together with family, or in a group with other patients or mixed. The main treatment is often complemented by additional
interventions, targeting certain ED symptoms. Sometimes brief inpatient care is necessary, e.g. in medically severe cases, although outpatient treatment is recommended and suitable for most patients. Medical treatment (e.g. with antidepressants) does occur, but the evidence for pharmacotherapy in patients with AN is weak. Many therapists at specialized ED units work in an eclectic or integrative way, and different professions often apply an interdisciplinary approach, working in teams. It has been stated that treatment is most effective when it includes a multidisciplinary, team-based approach. In Sweden, county councils are responsible for funding and providing specialized ED units and child- and adolescent-psychiatry services, although some services are privately owned. All services for child- and adolescent psychiatry are tax-funded and free of charge.

Individual therapy means individual meetings with a therapist and normally includes psychoeducation and counselling based on cognitive behavioral therapy or interpersonal therapy. Family-based treatment has been defined as any intervention where the family constitutes a core intervention component, and implies meetings with a therapist where the patient’s parent/s and sometimes siblings are involved. The treatment is often based on systematic, cognitive behavioral or psychodynamic principles. Group therapy for patients with an ED is often based on a shared symptomatology and includes one or two therapists who meet with a group of patients together. An example is a group treatment based on Acceptance and Commitment Therapy (ACT), which is a behavioral therapy with mindfulness influences. Group therapy is offered to patients who might benefit from exchanging experiences with others in group sessions, but existing interventions are primarily targeting other diagnostic groups than patients with AN. However, multi-family therapy is a systemic group therapy of increasing interest for adolescents with AN based on conjoint sessions with three or four patients and their families, including siblings. Complementary interventions include for example diet counselling, meal trainings, physiotherapy, medical treatment, and somatic treatment with a focus on health issues caused by the ED. Somatic efforts regarding patients with AN are primarily about monitoring bodily effects of starvation and compensatory behavior which can be very serious and require extensive actions. In recent years, psychotherapeutic interventions in ED treatment are also offered on the Internet.

There are many forms of treatment available to adolescents with an ED, but only a few uniform recommendations on which treatment to use in
different situations and for different patients. Limiting factors when trying to apply the best available treatment for a certain individual are for example inadequate studies, with samples too small to base the decision on. Comparing results from different treatment studies is also difficult, due to e.g. different criteria for diagnoses and measurements of recovery. In addition, there are cultural differences concerning what treatments are considered appropriate for different ED diagnoses and also concerning tendencies to use more or less evidence-based therapies.

The American Psychological Association (APA) defines evidence-based practice in psychology as “the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences”. The field of EDs has generated a considerable amount of research during the last decades, including treatment studies. However, despite such efforts to acquire new knowledge, the evidence position has not changed significantly over the last decade. Among adolescents, family-based treatment has the strongest evidence for patients with AN. Nevertheless, the empirical support for family-based treatment is disputed, and there are researchers who argue that it does not have the strong empirical support proposed from various quarters. Certain forms of individual therapies are on the rise.

**Treatment for adolescents with Anorexia Nervosa**

In family-based treatment, the family system is viewed as central to the cure of illness. The main focus in treatment is on how the parents can support their child’s recovery and on how the illness affects family relationships. The family plays a central role in helping the therapist(s) understand the development of the problems and how they have occurred. It is important to find out if there are any problems in the family which contribute to maintain the ED and to get a picture of the role the adolescent has received in the family since the onset of illness. As recovery progresses, the parents are supposed to gradually return responsibility to the adolescent and help the adolescent re-integrate into developmentally appropriate activities. Siblings are encouraged to attend the treatment sessions, but the degree of involvement varies significantly. The effect of sibling attendance on treatment outcome has recently been debated, but participation might have benefits for siblings themselves. It has previously been suggested that sibling support is often lacking in treatment of adolescents with AN.
It has been described that family-based treatment first attracted attention in
the 1980s when a family-based treatment for adolescents with AN and BN
was compared with supportive psychotherapy, and where family-based
treatment was preferred for patients with AN \(^83,93\). The form of family-based
treatment used has been known since than as the Maudsley model, which
has been further developed in recent years \(^88\). In a second study, a similar
form of family-based treatment for adolescents with AN was compared to
individual psycho-dynamically oriented treatment with occasional
supportive sessions for the parents \(^94\). The results indicated that both
treatments were effective, but that family-based treatment had faster results
\(^94\). However, according to Fairburn (2005), the findings were
uninterpretable due to methodological limitations \(^83\). In 2004, Ball et al.
conducted a small Randomized Controlled Trial (RCT) on adolescents and
young adults with AN in which they compared cognitive behavioral therapy
with family therapy, which was a family-based intervention slightly
different from the Maudsley model. The results showed that there were no
significant differences between the two approaches \(^95\).

In a review from 2007, Bulik stated that “evidence for AN treatment is
weak,” that “evidence for treatment-related harms and factors associated
with efficacy of treatment are weak,” and that “evidence for differential
outcome by sociodemographic factors is non-existent” \(^96\). Just like Fairburn,
she signaled a need for attention to be paid to sample size and statistical
power in the studies conducted \(^83,96\). In 2010, it was stated in a Cochrane
report that there was evidence to suggest that family-based treatment may
be effective compared to treatment as usual in the short term, but it was still
based on few trials including only a small number of participants \(^97\). Later
the same year, Lock et al. conducted an RCT on adolescents, in which they
compared family-based treatment to adolescent-focused individual therapy.
The results showed that there were no differences in full remission between
the therapies at end of treatment, but that family-based treatment was more
effective in facilitating full remission at both follow-up points \(^82\). In 2013,
an update on treatment for AN was published, in which it was stated that
the evidence base for AN treatment was advancing and that existing
evidence pointed to the benefit of family-based treatment for adolescents \(^98\).
Two years later, Lock drew the same conclusion in yet another update \(^99\).
Today, family-based treatment is recommended by the National Institute
for Health and Care Excellence (NICE) as the first-line treatment for AN in
young people \(^65\), although still with moderate evidence.
The Maudsley model, which is the most commonly used family-based treatment, is a manualized treatment including different phases. In clinical reality, for various reasons, it might be difficult to follow a strict treatment manual, e.g. including daily meals together with the whole family. At many specialized ED units, therapists include family-based interventions in the course of treatment, even if not exactly replicating the Maudsley model. Some have for example used approaches where they work with the family and the adolescent separately, combining joint sessions with separate sessions and focusing mainly on parents in treatment. It has also been suggested that family-based treatment in clinical practice is often adjusted and adapted to the adolescents’ different ages.

There is some concern with family-based treatment. It has been suggested for example that pushing too hard for weight gain in treatment, before a patient has made any cognitive shifts, may contribute to purging behaviors and/or severely distorted thoughts. In family-based therapy, parents’ own patterns of eating as well as a high level of parental expressed emotion may also be a potential barrier for a successful outcome. In addition, family-based treatment involves demanding challenges for the therapist/s, such as building a therapeutic alliance with several participants. A possible disadvantage with family-based treatment is that physical symptoms are given too much emphasis and that patients might improve in order to please family and therapists. In addition, family organization can work in an interfering way, restricting the adolescents’ autonomy and independence. In such cases, cognitive and affective symptoms might persist after end of treatment.

Other recommended treatment forms apart from family-based treatment, although with lower empirical support, are individual treatment forms such as interpersonal psychotherapy, adolescent-focused treatment, and enhanced cognitive therapy. Enhanced cognitive therapy is recommended, in particular, if family involvement is unacceptable or ineffective. In individual therapy, the focus in treatment should be on improving the adolescent’s coping skills, in order to achieve a long-term recovery and decrease the risk of relapse. It is recommended that all adolescents be offered an opportunity to speak with a therapist on their own since there may be things they do not feel comfortable talking about when the parents are in the room.
Treatment for adolescents with AN is often prolonged, due to a slow treatment progress \(^1\). Factors that might affect this are comorbidity with other psychiatric diagnoses \(^{15, 68, 110}\), patients’ difficulty to receive treatment when in starvation \(^{111}\), patients’ denial of the seriousness of the problems \(^4, 68, 110\), and patients’ unwillingness to gain weight – in line with the egosyntonic aspect of the illness \(^{66}\). In addition, AN with an onset in early age often has a particularly unfavorable course in many patients \(^{112, 113}\) and lower-weight patients often require extended treatments with a main focus on weight gain \(^{24}\). It has also been suggested that the physical and cognitive development that occurs during adolescence, in addition to major life changes connected to adolescents’ transition into adulthood, makes treatment planning complex \(^{13, 68}\). It has been shown that approximately 20–40\% relapse within the first year after end of treatment, a rate that is somewhat lower among adolescents than among adults \(^{114}\).

In this thesis, the concept *treatment outcome* is used instead of treatment effect, in order to open up for the possibility that outcome is partly affected by factors outside treatment. In a previous study, results showed that outcome may be positively affected by, for example, patients’ internal motivation to change, religion and spirituality, supportive relationships, good therapeutic relationships, and relevant turning points \(^{115}\). Only some of these factors have direct relevance to treatment, although all of them might be relevant in a more indirect way. Other factors suggested to affect treatment outcome are, for instance, participation and control in treatment \(^{116, 117}\), social support from friends and family \(^{35, 92, 118}\), specialized treatment conducted by therapists with extensive expertise \(^{35, 92, 118, 119}\), and interventions focusing on cognitive symptoms \(^{35, 120}\).

Predictors, moderators, and mediators of outcome are important to examine in order to improve outcomes in ED treatment \(^{121}\). Predictors of outcome are, for instance, lower levels of ED pathology and higher BMI at baseline \(^{122}\), lower depression, higher self-esteem, lower weight/shape concern, lower comorbid psychopathology, older age of onset, better interpersonal functioning, and fewer problems in the family environment \(^{121}\). Moderators are, for instance, the severity of ED psychopathology and family structure, and, regarding mediators, the mechanism of greater symptom changes early during treatment seems to be the most robust predictor of a positive outcome both at end of treatment and at follow-up \(^{121}\). Several studies have shown evidence for the importance of early treatment interventions \(^{68, 110, 123, 124}\), and there is a risk for complicated
progression and increased long-term symptoms if treatment is delayed. Examining treatment outcome is quite a broad and complex task, and researchers are required to adopt shared and consistent definitions of outcome, in order to facilitate comparisons across studies. In this thesis, the concept *in remission* is used as a main outcome variable, defined as not meeting criteria for any ED diagnosis.

Historically, weight status has been a preferred index of recovery, and previous studies measuring weight recovery have shown quite promising results. In a study by Rosling et al. (2016) all patients with AN had gained weight at one-year follow-up and in a study by Herpertz Dahlman (2014) the corresponding number was 80%. However, since the symptom profile in AN comprises both physiological and cognitive features, weight status does not necessarily indicate recovery. In patients’ opinions, terms of weight and BMI do not necessarily reflect an improvement in ED symptomatology, which is true even for patients who have achieved remission.

In some studies, the main outcome variable is *recovery*, which might be rather difficult to define. Full recovery is suggested to include attainment of normal attitudes toward food and the body, increased self-esteem, and interpersonal and occupational functioning. Full recovery is expected in about 50% of AN cases, and it has been suggested that rates of full recovery are higher among adolescents than adults. A Swedish longitudinal study showed that long-term recovery is better for adolescents than adults as only one out of four previous adolescent patients still had an ED diagnosis at a 10-year follow-up. The definition of recovery is particularly important to consider when discussing residual symptoms in patients.

Treatment for AN is often characterized by high dropout rates, which might have serious implications for recovery. However, results from a previous study showed that patients who dropped out of ED treatment had less psychiatric comorbidity and more positive self-evaluation at treatment onset than other patients, indicating that drop-out from ED treatment is less pathological than previously assumed.

**Patient perspectives in treatment**

According to the biopsychosocial perspective, the adolescents’ own preferences and values are an important component in treatment, and patient perspectives constitute one of three legs in the three-legged stool of evidence-based practice in ED treatment, together with research evidence.
and clinical expertise. The importance of taking patients’ preferences and values into consideration is also mentioned in clinical guidelines.

Something that has been shown to affect treatment outcome in the field of EDs, at least in the long term, is patient satisfaction. Dissatisfaction with treatment has been linked to treatment delay, to premature termination of treatment, and to the fact that treatment interventions have not had the desired outcome. In addition, negative affective symptoms might remain in patients after end of treatment, which increases the risk for weight loss and relapse. Studies on treatment satisfaction among patients with AN are quite rare, and they have shown diverse results. Some studies suggest that patients or previous patients have somewhat mixed opinions about their treatment, but are mostly dissatisfied, whereas other studies indicate that the majority are quite satisfied.

Naturally, the egosyntonic aspect of the illness and the ambivalence many patients experience affects their views on treatment. Nonetheless, even people who experienced a positive treatment outcome, as defined by clinically established criteria, state that they have not been understood or that the therapist/s could not help them. According to previous research, patients often feel they have only little input in their treatment, and that the therapeutic alliance is inadequate, which might have an effect on patient satisfaction. Factors related to the therapist/s that have shown to contribute to high patient satisfaction are therapists’ positive support and engagement in treatment, perceived warmth and empathy of the therapists, and good generic psychotherapeutic skills. The way the patients’ expectations on treatment are received and handled by the therapist/s has also proven to make a difference. One definition of patient satisfaction is actually “the appraisal of the extent to which the care provided has met the individual’s expectations and preferences.”

Patients’ points of view, together with research evidence and clinical expertise have been suggested to be useful when trying to improve existing interventions and developing new forms of treatment.

**Rationale**

- Although research in this field is constantly progressing, our knowledge about treatment effects and prognosis for adolescents with AN is still insufficient. In addition, recovery rates are still unsatisfactorily low. The main focus of research has been on comparing different forms of treatment, often in controlled
settings, which are of limited interest in clinical practice where treatment is conducted in multidisciplinary teams and where different methods often are integrated. This thesis will contribute to our knowledge about treatment outcome in adolescents with AN and potential factors associated with remission as an outcome variable, with results from two naturalistic studies.

- Patients' own preferences, values and experiences have been highlighted in recent years as an important component in treatment. This thesis will contribute to our knowledge about patient perspectives in two different ways: patient satisfaction with treatment is examined in a large naturalistic sample and previous patients' experiences of treatment are investigated through interviews.

- According to previous research, there seems to be a discrepancy between the general focus in treatment for adolescents with AN and our existing knowledge of the importance of different contexts in treatment and how these interact, which is why areas including different forms of interpersonal processes should be further acknowledged and explored. This thesis will contribute to our knowledge of the importance of different contexts in treatment for adolescents with AN, by investigating, through qualitative interviews, how adolescents describe their illness and their time in treatment in relation to social contexts outside the family.

- To sum up, research questions in this thesis are addressed from either a professional perspective (outside) or a patient perspective (inside), or from both directions in order to provide an idea of whether young people with AN receive the treatment they are most helped by.
Aims

The overall aim of this thesis was to study adolescents with restrictive eating disorders in relation to illness, treatment, and recovery from an inside and outside perspective.

The studies’ specific aims were as follows:

I. To examine characteristics and treatment outcome in a naturalistic sample of adolescents with AN or subthreshold AN, treated in outpatient care. Additional aims were to examine potential factors associated with remission as an outcome variable, and possible differences in sample characteristics and treatment outcome between three time periods for treatment onset.

II. To examine treatment interventions and patient satisfaction in a naturalistic sample of adolescents with AN or subthreshold AN, and possible correlations to outcome defined as being in remission or not at treatment follow-up.

III. To investigate how young people with experience from adolescent outpatient treatment for eating disorders, involving family based and individual based interventions, perceive their time in treatment.

IV. To investigate how adolescents with experience of a restrictive eating disorder describe their illness and their time in treatment in relation to social contexts outside the family.
Methods

This thesis includes four papers. Studies I and II are quantitative and based on data from the Swedish national quality register for eating disorder treatment (SwEat), whereas Studies III and IV are derived from qualitative interviews. As to methodology, Studies I and II are linked to each other, and this is also the case for Studies III and IV. Thus, the presentation below is organized into two sections.

Studies I & II

Naturalistic studies

In a naturalistic study, the daily routines in treatment can be followed, thus allowing a generalizability of the results to a clinical environment. As a complement to RCTs, naturalistic studies can provide valuable knowledge about results of different treatments in real-life settings.

In Sweden, approximately 100 national quality registries in the healthcare system constitute an important source for research in the form of naturalistic studies. It has been stated that register-based studies are of great value for psychiatric research. Nevertheless, in Sweden, there is still an under-utilization of data from quality registries for research purposes.

SwEat

In Studies I and II, participants are identified through SwEat, which is a longitudinal internet-based quality assurance register, developed in 1999. Patients are included in SwEat regardless of age and gender, and the objective of SwEat is to gather information about a treatment episode, from the moment a patient enters treatment until completion of treatment. Information is registered in SwEat when the unit has decided to initiate treatment and the patient (or guardians, when the patient is underage) has given her/his consent to registration. After initial registration, the patient is followed up once a year until end of treatment. The initial registration and the follow-ups are conducted by a therapist at the treatment unit, in collaboration with the patient. Previously, by the time for follow-up, the patients were also sent a patient-satisfaction questionnaire from the register administration, to fill in and send back. If a patient terminates treatment and later on enters a new treatment episode, information in SwEat is registered again, which means that an individual might be initially registered in SwEat more than once.
All specialized ED units in Sweden, and several general psychiatric units in which patients with EDs are treated, are included in the register. Between 1999 and 2014, a total of 108 units participated in SwEat and a total of 17,611 initial registrations were made. The information collected in SwEat comprises clinically important key variables, such as waiting time, treatment duration, different types of treatment interventions (e.g. outpatient, day patient or inpatient treatment), and treatment outcome. The patient-satisfaction questionnaire includes questions about the value of different treatment forms, patients’ perceptions of their therapist/s, perceived improvements in symptoms over the last year, and importance and fulfillment of treatment goals. Diagnoses in SwEat are recorded according to DSM-IV.

**Participants**

**Samples in Studies I and II**

Participants in Studies I and II were identified through SwEat, and all patients who met the following criteria were included: medical referral or self-referral to one of the participating treatment units between 1999 and 2014, 13–19 years of age at initial entry into SwEat, and diagnosed with AN or subthreshold AN according to DSM-IV, which constituted the basis for diagnoses at Swedish ED units during the years examined.

The patients were diagnosed by experienced staff, usually in multidisciplinary teams, and on the basis of a structured interview guide. The Structured Eating Disorder Interview (SEDI) has for example been used at Swedish ED units since 2008 and before that the most commonly used interview guide was the Rating of Anorexia and Bulimia interview (RAB). In Studies I and II, as described in the Background section, patients with AN and subthreshold AN were included. In clinical practice, patients with subthreshold AN are most often subject to the same treatment interventions as patients with AN.

In Studies I and II, focus was on registered individuals instead of registered treatment episodes. Thus, for patients who had more than one treatment episode registered, only information about the first episode was included. As a result, most information gathered was from patients who entered treatment for the first time.

The total number of individuals meeting the main criteria was n=4345 (see Fig. 1 for an overview of the inclusion). In the first analysis, when examining sample characteristics at treatment onset, patients were excluded...
who i) were followed-up, but had an incomplete follow-up registration, due for instance to inaccurate data, or ii) were still in treatment when the data collection in SwEat was discontinued in 2014. All included patients formed a first study sample (n=3997). Patients who were registered at end of treatment as being in remission or as completed for other reasons, and available for analysis of treatment outcome, formed a second study sample (n=2195). Patients who were registered at one-year follow-up, and available for analysis of treatment interventions, were included in a third study sample (n=1899), and patients who had completed a one-year patient satisfaction registration, and thus available for analysis of patient satisfaction, were included in a fourth study sample (n=474).

In study I, the included individuals were registered at one of 83 treatment units, 42 of which were specialist ED units. In study II the corresponding numbers were 72 and 40. At these units, patients received outpatient treatment in the form of individual therapy, family-based treatment, or group interventions, and, less often, inpatient treatment and day care.

Of the patients in the first study sample (n=3997), 35% were lost to follow-up. In comparisons between followed-up and non-followed-up patients regarding baseline characteristics, the results showed only a few significant differences: 1) the patients lost to follow-up had been ill for rather longer when entering treatment (2.2 years vs 1.9 years), 2) the patients lost to follow-up were younger at first symptoms (14.4 years vs 14.7 years), and 3) the followed-up patients had more social complications at treatment onset (15.6% vs 9.9%), which was the most obvious difference.

Measures
In Studies I and II, data were explored regarding sample characteristics, treatment duration, premature termination of treatment, treatment outcome, outpatient treatment, inpatient care, health-care consumption, and patient satisfaction. Participants in both studies were examined on the basis of initial registrations and follow-up registrations in SwEat, and participants in Study II were also examined on the basis of patient satisfaction registrations. SwEat requires information about the following variables, used in the two studies (see Tables 1, 2 and 3).
The internet-based system, into which SwEat is incorporated, requires that all questions be answered before a registration form can be submitted. Even so, due to technical issues and human factors, most of the variables in the registration forms have 1–3 % missing or invalid answers. In the patient-satisfaction questionnaires, which were answered manually, most of the variables have 1–9 % missing or invalid answers, and a few of them up to 30%.

In Study II, in some analyses of the one-year follow-up registrations (n=1899) the patients were categorized into three different age groups. These were: 1) 13–14 years (n= 434); 2) 15–17 years (n= 970) and 3) 18–19 years (n= 495).
Table 1. Data collected at SwEat initial registration.

<table>
<thead>
<tr>
<th>Initial registration</th>
<th>Study I</th>
<th>Study II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Civic registration number (YYYY-MM-DD-XXXX, the last four digits comprise the Swedish social security number and specify gender)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Does the patient have symptoms consistent with a specific or unspecific ED, according to DSM-IV? (Yes/No)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Does the clinic intend to treat the patient? (Yes/No)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Has the patient been informed about SwEat and given his/her oral consent for registration? (Yes/No)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Civic registration number (YYYY-MM-DD-XXXX, the last four digits comprise the Swedish social security number and specify gender)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Date of treatment onset (YYYY-MM-DD)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient’s current ED diagnosis (DSM-IV Axis I/No current ED)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient’s age at onset of ED symptoms (years)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The patient’s current weight (kg, to one decimal)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient’s current height (cm, to one decimal)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Are there one or several factors that clearly complicate treatment? (Yes, of psychiatric nature/Yes, of somatic nature/Yes, of social nature/No)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Who referred the patient to the unit? (Patient/Relative/Other treatment unit or school)</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
What previous contact with the health care services did the patient have for the eating disorder? (This is the first contact/Previous contact of an occasional nature/Previous treatment) | X
---|---
The patient's living conditions (Single/With kids/With parents/With partner/Other) | X
The patient's employment (Studying/Working/On sick leave) | X

**Note:** This table only includes data presented in the study. The SwEat registration contains additional data.

**Table 2. Data collected at SwEat follow-up registration.**

<table>
<thead>
<tr>
<th>Follow-up registration</th>
<th>Study I</th>
<th>Study II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Civic registration number (YYYY-MM-DD-XXXX, the last four digits comprise the Swedish social security number and specify gender)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient's current ED diagnosis (DSM-IV Axis I/No current ED)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient's current weight (kg, to one decimal)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient's current height (cm, to one decimal)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The patient's living conditions (Single/With kids/With parents/With partner/Other)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The patient's employment (Studying/Working/On sick leave)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Is the treatment finished? (Yes/No)</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>If the treatment is finished: What date? (YY-MM-DD)</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
If the treatment is finished: How did it end? (In agreement between patient and therapist/Patient terminated treatment prematurely/Patient was referred to another treatment unit/Other reason) | X | X |
---|---|---|
Treatment interventions during the last year – outpatient treatment (Individual treatment/Family treatment/Group therapy/Complementary interventions)/No outpatient treatment – Number of sessions |  | X |
Treatment interventions during the last year – inpatient care (Specialized ED/General psychiatric/General somatic)/No inpatient care – Number of days |  | X |
Treatment interventions during the last year – medical treatment (Sedatives-Hypnotics/Antidepressants/Neuroleptic/Other)/No psychopharmaceutic treatment) – Number of days |  | X |

**Note:** This table only includes data presented in the study. The SwEat registration contains additional data.

**Table 3. Data collected at SwEat patient satisfaction registration.**

**Patient satisfaction registration**

State below which form of treatment intervention you have received during the last year and estimate, where applicable, how valuable the treatment has been: (Answer alternatives: Yes/No/Very helpful, Somewhat helpful, Not helpful and The problem got worse)
- Regular talks between you and a therapist
- Talks with your family together with a therapist
- Group discussions together with other persons with ED
- Diet consultation
- Eating/Meal training
- Physiotherapy
- Doctor consultation about your bodily health
- Day care
- Inpatient care at a specialized ED department
- Inpatient care at a general psychiatric department
- Inpatient treatment at a general somatic department
- Medication (e.g. sedatives and antidepressants)
- Other treatment

Questions about the contact between you and your therapist/s during the last year:
(Answer alternatives: Always, Very often, Often, Sometimes, Rarely and Never)
(In the analysis, the answers were trichotomized into: Always/Very often, Often/Sometimes and Rarely/Never)

- Did you feel like your therapist/s understood your problems?
- Were you initially received in a good way?
- Have you felt respected as a person during your treatment?
- Have you been encouraged to talk about what’s important to you?
- Have your therapist/s been listening to you?
- Have you been participating in the planning of your treatment?
- Did you feel like your therapist/s could help you?
- Did you and your therapist/s agree about the goals for the treatment?
- Did you and your therapist/s agree about how the treatment should be conducted?
- Did the therapist/s have enough knowledge about ED, and about what they were doing?
- Could the therapist/s correctly estimate your own struggle against the ED?
Below follows a number of goals for treatment of eating disorders that could have been more or less important to you. State if a goal has been relevant to you and, where applicable, estimate how important the goal has been to you and to what degree it has been fulfilled:
(Answer alternatives: Relevance: Yes/No Importance; Very important/Important/Not so Important and Not Important Fulfillment of goal: Yes, completely/Yes, almost/To some extent and Not at all)
(In the analysis, the answers were dichotomized into: Very important/Important and Completely fulfilled/almost fulfilled)

<table>
<thead>
<tr>
<th>Goal</th>
<th>Relevance</th>
<th>Importance</th>
<th>Fulfillment</th>
</tr>
</thead>
<tbody>
<tr>
<td>To learn more about the nature of eating disorders</td>
<td>Yes</td>
<td>Very important</td>
<td>Completely fulfilled</td>
</tr>
<tr>
<td>To get help to talk about painful experiences</td>
<td>Yes</td>
<td>Very important</td>
<td>Completely fulfilled</td>
</tr>
<tr>
<td>To learn to eat normally</td>
<td>Yes</td>
<td>Important</td>
<td>Almost fulfilled</td>
</tr>
<tr>
<td>To learn how to handle unreasonable views on food and body size</td>
<td>Yes</td>
<td>Important</td>
<td>To some extent</td>
</tr>
<tr>
<td>To be more satisfied with myself and my body</td>
<td>Yes</td>
<td>Not so important</td>
<td>Not at all</td>
</tr>
<tr>
<td>To get help to stand up for what I feel</td>
<td>Yes</td>
<td>Not so important</td>
<td>Not at all</td>
</tr>
<tr>
<td>To reduce my feelings of guilt and self-accusations</td>
<td>Yes</td>
<td>Not so important</td>
<td>Not at all</td>
</tr>
<tr>
<td>To get support in crisis situations</td>
<td>Yes</td>
<td>Not so important</td>
<td>Not at all</td>
</tr>
<tr>
<td>To get help to handle strong emotions, like sadness and anxiety</td>
<td>Yes</td>
<td>Not so important</td>
<td>Not at all</td>
</tr>
<tr>
<td>To reduce conflicts within the family regarding ED symptoms</td>
<td>Yes</td>
<td>Not so important</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

Compared with how it was one year ago and how is it now considering:
(Answer alternatives: Much worse, Worse, Somewhat worse, Unchanged, Somewhat better, Better, Much better, Not relevant)
(In the analysis, the answer alternatives were trichotomized into: Not improved/Unchanged/Improved, and the statements were divided into the categories eating habits, excessive physical activity and thought processes.)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety before meals</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Impulses to avoid eating</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Consistent thoughts about food and weight</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Irregular and insufficient meals</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Fear of gaining weight</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Feeling fat and chubby</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Impulses to be constantly active and in motion</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Excessive physical activity</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Overall issues with food, eating and weight</td>
<td>Not relevant</td>
</tr>
</tbody>
</table>

**Note:** This table only includes data presented in the study. The SwEat registration contains additional data.
Clarifications of recurrent terms:

_Treatment duration_
Treatment duration was possible to calculate for the patients who had a registered date for their first and last treatment session and was measured in months (Study I).

_Premature termination of treatment_
The term has previously been used for patients who do not complete treatment, regardless of reason \(^{152}\). In Study I, in which all patients who did not complete their initial treatment were examined, it was used for patients who terminated treatment either on their own or the parents’ initiative, or due to referral to another treatment unit. In Study II, in which only patients who chose to withdraw were examined, the term was used for those patients who terminated treatment either on their own or their parents’ initiative.

_Treatment completion_
Used in Study II. The term is defined as completion of treatment in agreement between patient and therapist.

_Weight status_
In SwEat, the patients’ BMI is calculated at initial registration and follow-up, based on height and weight, either measured by a therapist or self-reported by the patient. In Studies I and II, patients were assessed as being within a normal or low weight range, based on the BMI percentile method for calculating expected body weight \(^{153}\) and by using Swedish reference values for BMI, adjusted for age and gender \(^{154}\).

_Sick leave_
At initial registration and follow-up in SwEat, clinicians are asked to provide information about the patient’s occupation and register if the patient is on full- or part-time sick leave from work or school. When using the term in Studies I and II, no difference was made between patients on full- or part-time sick leave.

_In remission_
In both studies, the term was used for patients not fulfilling criteria for any ED diagnosis at follow-up.
Statistical analyses

Statistical analyses were carried out using IBM SPSS Statistics 22\textsuperscript{155} and 23\textsuperscript{156}.

In order to compare variable values between different patient groups (e.g. followed-up and non-followed-up patients), Pearson’s chi-square test, independent samples t-test, and analysis of variance (ANOVA) were used (Study I and II). These methods were also used for exploring possible differences across three time periods, which were further analyzed post hoc by examining possible differences between two groups at one time and by using Scheffe’s post hoc test (Study I).

Treatment interventions were examined by using frequencies to determine the ratio of patients who received different interventions and cluster analysis was used for identifying subgroups of patients who received certain combinations, and various amounts, of treatment forms (Study II). As the data in Study II included both binary and continuous variables, a two-step cluster analysis method was used. The cluster solutions were compared using Schwarz’s Bayesian criterion (BIC), and the log-likelihood was used as distance measure. Cluster data were compared through Pearson’s chi-square test, independent-samples t-test and analysis of variance (ANOVA) tests, if appropriate.

In order to examine factors associated with remission as an outcome variable, logistic and multiple logistic regressions were conducted (Study I and II). In Study I, the regressions were performed using only independent variables found to differ significantly between the groups in remission and not in remission. In Study II, the clusters from the two-step cluster analysis were used as predictors in the logistic and multiple logistic regression together with the following variables: age, diagnosis (AN or subthreshold AN), and weight status (low- or normal weight) at treatment onset, and premature termination of treatment (on patients’ or parents’ initiative).

Descriptive measures were used in Study II to gather percentage and mean numbers concerning statements in the patient-satisfaction questionnaire. When examining differences between clusters regarding patient satisfaction of treatment interventions, paired-samples t-test was used. Related-Samples McNemar test, which is a nonparametric test, was used when examining differences between the proportion of patients who felt a certain goal was important and the proportion who considered it fulfilled.

In Study I, in order to correct for multiple analyses, Bonferroni correction was used. In both studies, thresholds were set at $p = .001$. 
Studies III & IV

Participants
Data for Studies III and IV were obtained from interviews with 15 adolescents, 14 young women and one young man. The participants had previously been treated for AN or EDNOS with a predominantly restrictive symptomatology, according to DSM-IV \(^1\), and were aged 13 to 18 at the outset of treatment. Within a treatment period of approximately 1–2 years, most of them were given 11–30 treatment sessions, based on individual therapy and/or family-based treatment (defined as treatment when at least one parent participated; see Table 4).

Data collection
The data collection was conducted within the framework of Study III and formed the basis for study IV only at a later stage.

The recruitment process lasted between October 2011 and December 2013, in collaboration with four specialized eating disorder units in central Sweden. The treatment units were selected based on age group accepted for treatment (13–19 years) and the treatment program offered (family-based and individual treatment). Inclusion criteria were that participants had been 13–19 years old during treatment at one of the units, had completed treatment without meeting criteria for any eating-disorder diagnosis and did not have any ongoing eating-disorder treatment at the time of the interview. No diagnoses were excluded, but all the persons who agreed to participate had been treated for a restrictive eating disorder.

Clinicians at the four units asked a total of 20 women and four men who met the inclusion criteria if they wanted to be contacted by me for further information about the study. Initially, 16 women and three males accepted, but at a later stage, two women and two men declined to participate. The individuals who accepted to be contacted first got a letter describing the project and the conditions for participating. The letter was followed by a phone call, during which those who were interested had the opportunity to ask me questions about the study, and I could go through practical details.
Table 4. Details of participants in study III and IV.

<table>
<thead>
<tr>
<th></th>
<th>Age (start of treatm), years</th>
<th>Treatm duration, years</th>
<th>Nr of treatm sessions</th>
<th>Age (time of interview), years</th>
<th>ED diagnosis</th>
<th>Main treatm.</th>
<th>Inpat. care, months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agnes</td>
<td>14</td>
<td>1</td>
<td>11-30</td>
<td>15</td>
<td>EDNOS</td>
<td>FT</td>
<td>-</td>
</tr>
<tr>
<td>Bim</td>
<td>17</td>
<td>&lt;1</td>
<td>31-50</td>
<td>20</td>
<td>AN</td>
<td>IT + some FT</td>
<td>1</td>
</tr>
<tr>
<td>Camilla</td>
<td>17</td>
<td>1</td>
<td>&gt;50</td>
<td>20</td>
<td>AN</td>
<td>IT + some FT</td>
<td>6</td>
</tr>
<tr>
<td>Diana</td>
<td>13</td>
<td>2</td>
<td>31-50</td>
<td>18</td>
<td>AN</td>
<td>IT + some FT</td>
<td>3</td>
</tr>
<tr>
<td>Emma</td>
<td>18</td>
<td>1.5</td>
<td>11-30</td>
<td>21</td>
<td>EDNOS</td>
<td>FT</td>
<td>-</td>
</tr>
<tr>
<td>Frida</td>
<td>13</td>
<td>1.5</td>
<td>31-50</td>
<td>17</td>
<td>EDNOS</td>
<td>IT + some FT</td>
<td>-</td>
</tr>
<tr>
<td>Gerda</td>
<td>18</td>
<td>&lt;1</td>
<td>11-30</td>
<td>21</td>
<td>EDNOS</td>
<td>IT + FT</td>
<td>-</td>
</tr>
<tr>
<td>Helene</td>
<td>14</td>
<td>&gt;2</td>
<td>31-50</td>
<td>19</td>
<td>AN</td>
<td>IT + some FT</td>
<td>-</td>
</tr>
<tr>
<td>Iris</td>
<td>16</td>
<td>1</td>
<td>11-30</td>
<td>19</td>
<td>AN</td>
<td>FT + some IT</td>
<td>-</td>
</tr>
<tr>
<td>Johanna</td>
<td>14</td>
<td>&gt;2</td>
<td>&gt;50</td>
<td>18</td>
<td>EDNOS</td>
<td>IT + FT</td>
<td>-</td>
</tr>
<tr>
<td>Kalle</td>
<td>16</td>
<td>&lt;1</td>
<td>5</td>
<td>18</td>
<td>EDNOS</td>
<td>FT</td>
<td>-</td>
</tr>
<tr>
<td>Linda</td>
<td>17</td>
<td>&lt;1</td>
<td>11-30</td>
<td>20</td>
<td>EDNOS</td>
<td>IT + some FT</td>
<td>-</td>
</tr>
<tr>
<td>Matilda</td>
<td>13</td>
<td>&gt;2</td>
<td>11-30</td>
<td>17</td>
<td>AN</td>
<td>IT + some FT</td>
<td>1</td>
</tr>
<tr>
<td>Nelly</td>
<td>18</td>
<td>1</td>
<td>31-50</td>
<td>21</td>
<td>EDNOS</td>
<td>IT + some FT</td>
<td>-</td>
</tr>
<tr>
<td>Ofelia</td>
<td>17</td>
<td>1.5</td>
<td>31-50</td>
<td>20</td>
<td>EDNOS</td>
<td>IT + some FT</td>
<td>-</td>
</tr>
</tbody>
</table>
Before I conducted the interviews, each participant had to sign a written consent statement. If an individual had been under the age of 15, the individual’s parents would have been informed about the study and would have been asked to give their written consent for their child to take part. However, all participants were 15 years old or older.

In the instructions to the units regarding the recruitment of former patients, it was requested that a minimum of six months and a maximum of three years should have passed since end of treatment. The interviews were conducted approximately 1–3 years after completion of treatment, apart from a trial interview undertaken with a young woman shortly after completion of her treatment.

The interviews were conducted by me, at meeting places chosen by the participants. In most cases, we met in the participant’s home, but in some cases we met, for example, at a library or a quiet café. The participants were asked to talk openly around the question “Can you tell me about your time in treatment?” and an interview guide, which was developed for this purpose, was used when needed to move the story forward. The interviews were audio-recorded and lasted between 45 and 90 minutes, and all of them were transcribed verbatim by me, with some administrative assistance. For the purpose of enhancing credibility and confirmability, the participants who wanted to read their interview in written form had it sent to them and were given an opportunity to add or change things.

Data analyses

Narrative research

Gathering narratives, by letting the informants speak freely around quite broad themes or questions, is proposed to be a good way to truly capture people’s experiences and thoughts about a phenomenon. However, it involves certain challenges for me as a researcher, for example, to stay objective and not spontaneously deselect “irrelevant” stories from those that are clearly relevant. Furthermore, although little keywords can trigger rewarding stories, it is important not to put words in the informant’s mouth, by asking leading follow-up questions. For a researcher, it is essential to establish a personal, although not private, relation to the informants in order to respond to them and to their narratives in an appropriate way. If I am vague in my responses, I may plant uncertainty in the informants, and thus affect their narratives. Gathering narratives entails leaving the strictly scientific approach and adopting a somewhat poetical
one, since one aim with telling about a phenomenon is to contextualize it and not only describe it. As defined by Skott (2004): “The purpose of telling is not first and foremost to accurately reproduce an event, but to convey an attempt to understand the world.”

In Study III, the question “Can you tell me about your time in treatment?” resulted in narratives about how the adolescents experienced their treatment in relation to parents, siblings, and therapists. These narratives were the focus of Study III. To a considerable extent, and quite unexpectedly, the interviews also came to deal with the young people’s illness in relation to social contexts outside the family. These narratives emerged both spontaneously and in response to background questions, such as: “How did you manage in school during your time in treatment?” These narratives were the focus of Study IV. Data in studies III and IV were analyzed on the basis of two different methods.

Hermeneutic phenomenology
Data in Study III were analyzed on the basis of a hermeneutic phenomenological approach according to Max van Manen, a method that allowed us to gather narratives, sometimes referred to as “phenomenology of praxis.” The phenomenological aspect involves an attempt to understand how people give meaning to their experiences of significant events. The interpretive hermeneutic aspect implies putting these narratives into their context, trying to make them understandable from a social and psychological perspective. Van Manen (1997) suggests that phenomenology becomes hermeneutical when its method is taken to be interpretative, rather than purely descriptive.

The aim of this approach is to gain a deeper understanding of the nature and meaning of our everyday experiences by transforming personal reflections from interview texts into a more general understanding. Morse (1994) describes the method as “a research process of textual reflection that contributes to understanding practical action.” Basic themes of hermeneutic phenomenology are: 1) interpretation – finding out what lies behind the words, 2) textual meaning – finding the meaning in the text through writing and rewriting in an ongoing process, 3) dialogue – engaging participants as co-researchers, in order to find the meaning of a certain phenomenon, 4) pre-understanding – as something that has to be made transparent, and 5) tradition – as something that constantly reinvents itself.
The analysis according to van Manen’s approach is conducted in different stages in order to find themes that created meaning. From this point of view, themes are not “items” or conceptual formulations that we come across in the text, but rather means of describing the content of a concept. In addition, van Manen differentiates between incidental and essential themes. The first stage of the analysis is called the holistic or sententious approach and involves several naive readings of the transcriptions. In Study III, these readings were carried out independently by two of my co-researchers and myself, before the meaning in each interview and tentative themes in the text as a whole were sought and discussed. The ideas that were prompted were noted, as were thoughts about the meaning of each interview, such as “This woman found the treatment helpful, but seems to be disappointed that no one tried to find out about her family situation.” During the second stage, the selective or highlighting approach, systematic interpretation took place, using QSR International’s NVivo 10 qualitative data analysis software. In close collaboration, my co-researchers and I looked for short narratives that stood out, and each one was given a heading, such as “The therapist’s words made me choose another way” or “How come they didn’t see what I did?” The content in these narratives was analyzed, which generated the formulation of subthemes. In the next step, the relationships between the subthemes were analyzed and major themes together with an overarching theme were identified. In accordance with the hermeneutic circle, the formulations of the themes at different levels were tested against the totality and were rejected, retained, and reformulated in a process of writing and rewriting. Not until the subthemes, the major themes, and the overarching theme together constituted a totality, which according my co-researchers and myself captured the meaning of the text, did the process cease. In the final detailed or line-by-line approach, the themes were again tested against each sentence or paragraph.

When I describe this method, it might seem like a linear process following a number of steps or phases, but in reality, it is more of an iterative and dynamic process, moving forth and back.

Thematic analysis
In Study IV, thematic analysis (TA) according to Braun and Clark (2006) was used for implementing the data. TA is a method for identifying, analyzing, and reporting patterns within data, independent of theory and/or epistemology, which made it suitable for application to previously
conducted interviews. Despite its theoretically flexible approach, the method can result in a rich and detailed data analysis, if accurately used.

TA according to Braun and Clark (2006) implies considering a number of choices before initiating the process. In Study IV, we chose an inductive approach of the method, which can be considered data-driven, as opposed to a more theoretical or deductive approach. We also decided to identify themes at an interpretative level, and thereby step beyond the semantic content of the data. At a following stage, we decided that the objective of the analysis was a detailed account of a few themes, as opposed to a broader description of the entire data set.

In practice, the method means working towards a result through six phases of analysis. The first phase – familiarization with data – includes immersion in the data through repeated readings of the interviews, performed in an active way, searching for meanings and patterns. Two of my co-researchers and I read the transcriptions several times and wrote down our initial impressions independently. The second phase – generating initial codes – includes organization of the data into broad groups, which was done using QSR International’s NVivo 10 qualitative data analysis software. The third phase – searching for themes – begins when all data have been initially coded and involves sorting the different codes into potential themes. The fourth phase – reviewing themes – involves the refinement of those themes. During these last two phases, two of my co-researchers and I met and discussed what could be designated as a theme in the particular study, how the findings could be sorted from broad groups into candidate themes and what overall story the themes tell about the data. In the fifth phase – defining and naming themes – all three of my co-researchers and I worked together. We agreed on themes and subthemes that we believed captured the meaning of the text and agreed on how to name them. The sixth phase – producing the report – involved providing a concise and interesting account of the story told by the data, which I did in collaboration with my co-researchers.
Results

Study I
In Study I, participants were examined based on initial registrations and follow-up registrations in SwEat, and data were explored regarding sample characteristics, treatment duration, and treatment outcome. In some analyses, the patients were divided into three groups based on different time periods for treatment onset: 1) 1999–2004, 2) 2005–2009 and 3) 2010–2014.

Sample characteristics
Most patients in the first study sample (n=3997) were girls who were studying and living at home with their parents or other relatives at the time for treatment onset (see Table 5). More than half of the patients were considered to have low body weight when entering treatment and almost as many had an AN diagnosis. Only a few patients were registered as being on sick leave. Approximately one third of the patients had previous experience of treatment for an ED and even more had complicating social, psychiatric, or somatic factors, most of which were psychiatric. More than half of the patients were referred to treatment by, for instance, another treatment unit or a school-health service. On average, the patients had been ill for two years when entering treatment. If including only those entering treatment for the first time (n=2737), illness duration was approximately four months shorter.

The number of patients who were considered to have low body weight at treatment onset was lower in time period 3 (significantly lower than in period 1), and for each period significantly fewer patients had entered treatment with an AN diagnosis: 1) 67.8%, 2) 56.0%, and 3) 47.6%. The proportion of patients entering treatment with experience of previous ED treatment and social or psychiatric complications was lower in period 2 and 3, compared to period 1.

Treatment duration
It was possible to calculate treatment duration for the patients who had a registered date for their first and last treatment session (n=1904), and the average treatment duration was approximately 15 months (SD = 11.8). Treatment duration shortened significantly for each time period: 1) 19.2 (SD = 15.8), 2) 14.4 (SD = 10.8), and 3) 11.4 (SD = 7.7).
### Table 5. Total sample characteristics at treatment onset.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample (n = 3997)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women (%)</td>
<td>3823 (95.6)</td>
</tr>
<tr>
<td>Studying (%)</td>
<td>3574 (89.4)</td>
</tr>
<tr>
<td>Living with parents/other relatives (%)</td>
<td>3785 (94.7)</td>
</tr>
<tr>
<td>Low weight (%)</td>
<td>2385 (59.7)</td>
</tr>
<tr>
<td>AN (%)</td>
<td>2284 (57.1)</td>
</tr>
<tr>
<td>Previous ED treatment (%)</td>
<td>1221 (30.5)</td>
</tr>
<tr>
<td>Social complications (%)</td>
<td>543 (13.6)</td>
</tr>
<tr>
<td>Psychiatric complications (%)</td>
<td>685 (17.1)</td>
</tr>
<tr>
<td>Somatic complications (%)</td>
<td>149 (3.7)</td>
</tr>
<tr>
<td>Sick leave (%)</td>
<td>265 (6.6)</td>
</tr>
<tr>
<td>Referred by other treatment unit/school (%)</td>
<td>2424 (60.6)</td>
</tr>
<tr>
<td>Age at first symptoms of ED M (SD)</td>
<td>14.6 (1.9)</td>
</tr>
<tr>
<td>Age when entering treatment M (SD)</td>
<td>16.6 (1.8)</td>
</tr>
<tr>
<td>Illness duration at treatment onset (in years) M (SD)</td>
<td>2.0 (1.8)</td>
</tr>
</tbody>
</table>

Separate analyses of patients who were registered at end of treatment, as being in remission or as completed for other reasons, showed that just over two thirds ended treatment according to an initial treatment plan or because they were in remission. Other patients ended treatment prematurely, either on their own or on their parents’ initiative (n=283, 12.9%) or due to referral to another treatment unit (n=350, 15.9%).
Treatment outcome

Regarding patients who were registered at end of treatment as being in remission or as completed for other reasons \( (n=2195) \), just above 55\% were in remission at end of treatment and just below 85\% were within a normal weight range. Separate analyses of patients who ended treatment according to plan \( (n=1564) \), revealed that just below 70\% were in remission at end of treatment and 90\% were within a normal weight range.

Analysis of treatment outcome also showed that there were a reduced number of patients who were considered to have a low weight at end of treatment in period 3 (significantly lower than in period 1), and a larger number of patients in remission (significantly larger than in period 1). Furthermore, remission was more likely for patients who entered treatment in time period 3 compared to period 1.

Patients who terminated treatment prematurely had a decreased chance of achieving remission whereas there was a clear albeit not significant tendency in the adjusted analyses that longer treatment duration was positively correlated to remission.

Study II

In study II, participants were examined based on initial registrations, follow-up registrations and patient satisfaction registrations in SwEat. Data were explored regarding treatment interventions, health-care consumption and patient satisfaction. A two-step cluster analysis was used for identifying subgroups of patients who received certain combinations and various amounts of treatment forms.

Treatment interventions

A total of 94.3\% of the patients received some sort of outpatient treatment and 20.7\% received inpatient care. The most common form of outpatient treatment was individual therapy, which was received by 73.9\% of the patients. The least common treatment intervention was group therapy (8.1\%). Treatment interventions were also examined in three age groups: 1) 13–14 years, 2) 15–17 years, and 3) 18–19 years. The percentage treated with individual therapy increased with every age group (57.8\%, 75.6\%, 84.6\%), whereas the percentage treated with family-based treatment decreased (80.4\%, 72.0\%, 36.4\%). The percentage treated with somatic treatment also decreased, although not significantly across all age groups.

The two-step cluster solution resulted in four clusters: 1) “family-based treatment” (FT), which consisted of the youngest individuals who received
family-based treatment as a main treatment and had quite a low rate of health-care consumption, 2) “extensive mixed treatment” (EMT), which had the highest rates of health-care consumption and was the only group who received a mix of all treatment forms, including group therapy and inpatient care, 3) “individual treatment” (IT), which consisted of the oldest individuals who received individual treatment as a main treatment, more than half of whom had subthreshold AN, and 4) “family-based and individual treatment” (FIT), which was the largest cluster and included individuals who received a mix of those treatment forms, although not significantly distinguishable in any other aspect. See Table 6 for demographic and clinical data distributed by treatment clusters.

The number of patients who ended treatment prematurely was highest in IT (17.4%, significantly higher than in EMT and FIT). At one-year follow-up, FT had the largest number of patients in remission (49.0%, significantly larger than in EMT and IT), and the number of patients on sick leave was highest in EMT (6.3%, significantly higher than in FIT). IT had the largest number of individuals who had completed treatment at one-year follow-up (45.9%, significantly higher than in EMT and FIT). There were no significant differences across clusters regarding weight status at one-year follow-up.

The regression analysis showed that patients in FT had the best chance of achieving remission at one-year follow-up, compared to patients in EMT and FIT. Furthermore, the patients who terminated treatment prematurely had a decreased chance of achieving remission.

Patient satisfaction
Out of those who answered the patient-satisfaction questionnaire, a total of 92.6% of the patients who received individual therapy rated the intervention as “very helpful” or “somewhat helpful,” which makes it the highest-rated treatment form. The corresponding number for the remaining treatment forms were: group therapy (85.1%), family-based treatment (83.2%), inpatient care (81.4%), and complementary interventions (70.0%). The patients in the clusters EMT and FIT, who received both individual therapy and family-based treatment, gave higher rankings to individual therapy than family-based treatment. Patients in EMT, IT and FIT, who received both individual therapy and complementary interventions, assigned higher rankings to individual therapy than complementary interventions.
Table 6. Demographic and clinical data distributed on treatment clusters.

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Family-based treatment (FT)</th>
<th>Extensive mixed treatment (EMT)</th>
<th>Individual treatment (IT)</th>
<th>Family-based and individual treatment (FIT)</th>
<th>Sign.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=1899</td>
<td>n=471/25.1%</td>
<td>n=383/20.4%</td>
<td>n=357/19.1%</td>
<td>n=663/35.4%</td>
<td></td>
</tr>
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</table>

### Treatment onset

<table>
<thead>
<tr>
<th></th>
<th>Women n (%)</th>
<th>Age M (SD)</th>
<th>AN n (%)</th>
<th>Normal weight n (%)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1707 (94.1)</td>
<td>16.1 (1.8)</td>
<td>1050 (55.3)</td>
<td>840 (44.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>446 (94.7)</td>
<td>15.4 (1.8)</td>
<td>295 (62.6)</td>
<td>194 (41.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>366 (95.6)</td>
<td>16.1 (1.8)</td>
<td>257 (67.1)</td>
<td>128 (33.4)</td>
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<td></td>
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<tr>
<td></td>
<td>337 (94.4)</td>
<td>17.1 (1.6)</td>
<td>160 (44.8)</td>
<td>174 (48.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>638 (96.2)</td>
<td>16.0 (1.6)</td>
<td>324 (48.9)</td>
<td>327 (49.3)</td>
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<tr>
<td></td>
<td>.496</td>
<td>&lt;.001</td>
<td>FT&lt;EMT</td>
<td>FT&lt;IT</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>FT&lt;FIT</td>
<td>EMT&lt;IT</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>FT&lt;FIT</td>
<td>EMT&lt;IT</td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>FT&lt;FIT</td>
<td>EMT&lt;IT</td>
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### Treatment

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
<th>% of total</th>
<th>n (%)</th>
<th>% of total</th>
<th>n (%)</th>
<th>% of total</th>
<th>n (%)</th>
<th>% of total</th>
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<tbody>
<tr>
<td>Individual therapy</td>
<td>1403</td>
<td>(73.9)</td>
<td>0 (0)</td>
<td>369 (96.3)</td>
<td>19.4</td>
<td>357 (100)</td>
<td>18.8</td>
<td>663 (100)</td>
</tr>
<tr>
<td>Family based therapy</td>
<td>1227</td>
<td>(64.6)</td>
<td>283 (60.1)</td>
<td>14.9</td>
<td>265 (69.2)</td>
<td>14.0</td>
<td>0 (0)</td>
<td>663 (100)</td>
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<td>Group therapy</td>
<td>154</td>
<td>(8.1)</td>
<td>0 (0)</td>
<td>152 (39.7)</td>
<td>8.0</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Complementary interventions</td>
<td>1299</td>
<td>(68.4)</td>
<td>258 (54.8)</td>
<td>13.6</td>
<td>287 (74.9)</td>
<td>15.1</td>
<td>197 (55.2)</td>
<td>10.4</td>
</tr>
<tr>
<td>Inpatient treatment</td>
<td>393</td>
<td>(20.7)</td>
<td>156 (33.1)</td>
<td>8.2</td>
<td>237 (61.9)</td>
<td>12.5</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&lt;.001</td>
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<td></td>
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### Number of sessions M (SD)

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
<th>n (%)</th>
<th>% of total</th>
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<th>% of total</th>
<th>n (%)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care consumption (basic)</td>
<td>45</td>
<td>(63)</td>
<td>29 (33)</td>
<td>86 (111)</td>
<td>29 (31)</td>
<td>40 (34)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Health care consumption (complementary)</td>
<td>12</td>
<td>(29)</td>
<td>6 (10)</td>
<td>29 (56)</td>
<td>5 (9)</td>
<td>10 (13)</td>
<td>&lt;.001</td>
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The majority of the responding patients (77.4%) reported an overall improvement in issues with food, weight, and eating at one-year follow-up. Primarily, the patients reported improvements in eating habits, based on the variables “impulses to avoid eating” (84.6%), “anxiety before meals” (77.6%), and “irregular and insufficient meals” (79.5%). The proportion of patients who reported improvements regarding compulsive physical activity was slightly smaller, based on the variables “impulses to be constantly active and in motion” (66.9%), and “excessive physical activity” (58.6%). An even smaller proportion of patients reported improvements regarding thought processes, based on the variables “consistent thoughts of food and weight” (68.6%), “fear of gaining weight” (61.6%), and “feeling fat and chubby” (51.1%).

Many patients experienced that their therapist/s listened to them in treatment and had sufficient knowledge about EDs. However, fewer patients felt that their therapist/s could help them, that they as patients had a part in the planning of their treatment and agreed with the therapist/s about how the treatment should be conducted. See Figure 2 for the highest and lowest evaluations.

The treatment goal that the patients evaluated as most important was “to learn to eat normally”; a total of 84% rated it as “very important” and a total of 96% rated it as “very important” or “important.”. This was also a highly rated goal concerning fulfillment, as 69% rated it as “completed” or “almost completed.” Other treatment goals that were rated as “very important” or “important” by more than 90% of the patients were: “to be more satisfied with myself and my body” (96%), “to learn how to handle unreasonable views on food and body size” (93%), “to get help to handle strong emotions like sadness and anxiety” (93%), and “to reduce my feelings of guilt and self-accusations” (90%). In general, the proportions of patients who felt a certain goal was important differed significantly from the proportions who considered the goal as fulfilled, except regarding the goal “to learn more about the nature of eating disorders” (68% vs. 59%).

Significantly fewer patients among those who terminated treatment prematurely, on their own or on their parents’ initiative, considered treatment interventions as helpful (69.0% vs. 92.4%), and were less satisfied with fulfillment of treatment goals (26.9% vs. 63.9%).
Figure 2. Patients’ highest and lowest evaluations of their therapist/s. Estimations in percent (%), total number of patients between 457 and 464 for every question.

Study III
The analysis of the adolescents’ narratives regarding their time in treatment resulted in two major themes and three subthemes within each major theme (see Table 7).

Having to involve family in treatment – in one way or another
Since the adolescents were minors when entering treatment, they were obliged to involve their family to at least some extent. In most cases the parents took the initiative of treatment, but the level of family commitment and support during treatment varied. Some of the young people had a
complicated family situation, which affected the role the parents were given or took on.

The adolescents describe that they were struggling with a balance between independence and dependence in treatment. Although the family most often provided an important context, the adolescents were striving for greater autonomy. They were also expected to do most of the work as individuals and recover “for their own sake” despite their common ambivalent feelings about whether and how to participate in treatment. In retrospect, most adolescents think that the parents’ participation had a positive effect on treatment outcome. However, they underline the importance of individual sessions in treatment, for having an opportunity to talk more freely when alone with the therapist/s.

**Table 7. Major themes and subthemes in Study III.**

<table>
<thead>
<tr>
<th>Subthemes</th>
<th>Major themes</th>
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<tbody>
<tr>
<td>Crossing the border to treatment</td>
<td>Having to involve family in treatment</td>
</tr>
<tr>
<td>- pushed forward by parents</td>
<td>- in one way or another</td>
</tr>
<tr>
<td>The degree of family involvement - up to whom?</td>
<td></td>
</tr>
<tr>
<td>Being the focus of attention - at someone else’s expense?</td>
<td></td>
</tr>
<tr>
<td>Letting someone else take over the reins - temporarily</td>
<td>Making progress in treatment - a matter of trust</td>
</tr>
<tr>
<td>Finding someone right for you</td>
<td></td>
</tr>
<tr>
<td>Coming to an end - it’s all about timing</td>
<td></td>
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</tbody>
</table>

The narratives reveal that many of the adolescents have a guilty conscience about their siblings and how they were treated during the adolescents’ time in treatment. The illness led to many conflicts in the family, during which the siblings were put aside, or chose to withdraw. The adolescents can now
see how their siblings were left alone with their concerns and worries and wish that they had been offered some kind of support.

Making progress in treatment – a matter of trust
The adolescents emphasize the importance of certain therapist characteristics for a good treatment outcome and reflect on the need for a therapist who involves the patient in the treatment planning but also has the strength to “take over” and make tough decisions when needed. Such capability is suggested to be particularly important when the patient’s parents are involved, in order not to let their needs overshadow those of the adolescents. Many of the adolescents were quite passive in their treatment, particularly in the beginning, something that was more or less self-selected. For some of them it felt good to hand control over to the therapist/s, while some of them wanted to demand a more participatory role but did not have the courage. Some of the adolescents, however, never reflected on what possibilities they had to influence the treatment process. In retrospect, the adolescents wish that the therapist/s had invited them to try, and had been more open to alternative solutions, which would probably have strengthened the patients’ sense of responsibility.

According to the young people, honesty is a crucial concept in meeting with the therapist, which requires a sustainable relationship based on mutual trust. They also emphasize the importance of the therapist seeing the human being behind the disease and validating the patient’s feelings. In the narratives, the therapist is often described as an important person, who served as a complement to other significant relationships in the young peoples’ lives during their time in treatment.

Thoughts around coming to an end in treatment are mainly centered around timing, the importance of ending treatment at the right moment, but they are also about goals. Some of the adolescents mention how therapists set up goals related to weight as a benchmark for ending treatment, which they retrospectively think is a rather incomplete measure of recovery. Instead, the adolescents highlight the importance of feeling strong and having improved their relationship to food. Many of the young people describe that they lacked confidence after ending treatment. Some of them were helped by follow-up contacts with their therapists, while others never received such an offer.


**Study IV**

The young people’s descriptions of their illness in relation to their social context outside the family follow a clear timeline, which is illustrated in Figure 3. Reflections are assembled under three major themes and two subthemes.

*The problems emerging in everyday life (outside the family)*

In the narratives, the young people describe the onset of their illness as a successive and somewhat unclear process, but for most of them, the first symptoms became apparent in a context that the family did not have insight into or control over. The adolescents mention triggering factors such as a comment on their body or a friendship conflict. However, the narratives reveal that the triggering parts in these factors essentially had to do with changes in identity, self-esteem, and a yearning to live up to demands and expectations from others. With a few exceptions, those who first acted on the symptoms were e.g. teachers or close friends.

*A life put on hold*

The young people describe that when the illness was a fact and the initiative for treatment had been taken, their life became different. Most of them had lived an active life up to this point, but now they lost energy and their life became limited in various ways. According to the young people, this was due both to external and internal influences.

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<table>
<thead>
<tr>
<th>Themes</th>
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<tbody>
<tr>
<td>The problems emerging in everyday life (outside the family)</td>
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</table>

<table>
<thead>
<tr>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living in a confined world</td>
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*Figure 3. Themes and subthemes in Study IV.*
Because of their physical and mental health, many of the adolescents did not have the strength or ability to participate in social activities. For some of them, reduced physical training also meant losing important contacts with teammates and coaches.

School, which was something all of the adolescents had to relate to, was quite hard to manage during their illness and their time in treatment. Although many of them had previously spent a lot of time on schoolwork and on relationships with schoolmates and teachers, all of the young people had to give these areas less priority for some time, in favor of treatment. It was not possible to keep up the same pace at school while simultaneously concentrating on recovery, although only a few of the young people had to stay at home. Retrospectively, the adolescents think that their school should have been more involved in the treatment and in the recovery process. Back then, it was not very clear from the adolescents’ perspectives what the school actually knew about their situation, and for some of them school was a place where they felt that they could hide with their ED.

Some adolescents speak about loneliness and friends who disappeared, and they reflect upon how some of their friends felt insecure and most likely wanted to help, but did not know how to, or did not dare. However, the adolescents also describe friends who did what they could to help out, and who gave the adolescents something to hold on to. They can now see that their confined world was strongly affected by friends, coaches, and school staff who were supportive and had the ability to reach in and attract them back into life. By continuing to remain who they were, these individuals comprised an important complement to the adolescents’ treatment relationships.

Creating a new life context

With recovery, the adolescents slowly “woke up” again and gradually returned to a life more similar to the one they had lived before the illness, although a great deal had changed for most of them. Many of the young people wanted to start over, and therefore chose to create new contexts, like going to a new school or meeting new friends. Some of the young people reflected upon the purpose of their previous sports activities, which for certain individuals had been strongly connected to the ED, whereas for others they had been a source of positive energy. Creating a new life context was often quite a complicated process, involving questioning previous values and re-evaluating earlier decisions, leaving the disease behind while letting new things develop. The process also meant reflecting on what had
been missed and lost, and sometimes the adolescents had to live with a persistent fear of relapse. Despite some descriptions of difficulty in finding a new identity, the feeling of coming out on the other side was described as generally positive, and the illness was often viewed as an important experience.

Summary of main findings

- At end of treatment, a total of 55% of adolescents (13-19 years) were rated by clinicians as being in remission, and approximately 85% were within a healthy body-weight range. (I)

- Treatment duration was approximately 15 months and completing treatment seemed to increase the chance of achieving remission. (I)

- Remission rates and weight recovery increased over time (1999-2014), whereas treatment duration decreased, which indicates that treatment has become more efficient in later years. (I)

- Young adolescents who received mainly family-based treatment seemed to respond more rapidly to treatment compared to older adolescents who more often received individual therapy or mixed-treatment interventions. (II)

- Individual therapy was the most common treatment form, followed by family-based treatment and somatic treatment, and among adolescents who answered a patient-satisfaction questionnaire at the time of one-year follow-up, individual therapy was the most highly appreciated treatment form. (II)

- Many of these adolescents reported improvements in behavioral ED symptoms at the time of one-year follow-up, but far fewer reported improvements regarding cognitive symptoms. They were quite satisfied with their therapist relationships but gave low ratings to aspects associated with their own participation in treatment. (II)
• Significantly fewer patients among those who terminated treatment prematurely, on their own or on their parents’ initiative, considered treatment interventions as helpful, and were satisfied with fulfillment of treatment goals. (II)

• Retrospectively, adolescents described that they sometimes felt more or less forced into treatment and struggled with a balance between independence and dependence. Although the family most often provided an important context, the adolescents were expected to do most of the work in treatment as individuals and recover “for their own sake.” (III)

• These adolescents highlight the importance of certain therapist characteristics for a good treatment outcome and reflect on the need for a therapist who involves the patient in the treatment planning but has the strength to “take over” and make tough decisions when needed. (III)

• According to the same adolescents, it is sometimes necessary to prioritize individual treatment interventions, so that the therapist, instead of sorting out difficult family situations, can focus on enhancing the young persons’ resilience. (III)

• Social contexts and relational interactions outside the family were described as important in the onset process and during treatment and recovery. (IV)

• These adolescents’ reflections indicate that thoughts about looks and appearance, which usually occur in adolescence, often are strongly associated with identity, self-esteem, and a yearning to live up to demands and expectations from others. (IV)

• How the informants experienced their life contexts after recovery seemed to depend largely on the scope and quality of peer support and on how school and sports activities affected and were affected by the ED. (IV)
Discussion

Reflections on main findings

The main findings in this thesis give us an idea of whether young people with AN receive the treatment they are most helped by, from an inside as well as outside perspective. Over the past two decades, a multitude of treatment studies have shown that family-based treatment is preferable for young people with AN, and it is also presented as such in national guidelines. The results from the studies included in this thesis suggest that younger adolescents who receive family-based treatment have the greatest chance of a successful outcome within one year in treatment, but the results also show that the area is a complex one. For example, just over half of the participants in the total sample achieved remission at end of treatment, and less than half had achieved remission at one-year follow-up. The young people themselves valued individual therapy higher than family-based treatment and emphasized the importance of social contexts and relational interactions outside the family, in the onset process as well as during recovery.

From a biopsychosocial perspective – as described in the Background section – the area is expected to be complex, as all patients are unique, and various aspects of health and illness are interdependent and tend to interact. I will discuss the results from such an overarching theoretical viewpoint, within the three areas of illness, treatment, and recovery. In the discussion, I will relate the biopsychosocial perspective to different theoretical models and concepts linked to the importance of social contexts and interpersonal relationships for the mental health of young people. These are mainly Urie Bronfenbrenner’s ecological theory (originally developed in the 1970s which evolved into the bioecological theory in the 1990s, with a focus on development through complex interactions within nested contexts, and Ann Mastens’ work in the field of resilience.

Illness

Today, EDs are generally viewed as complex and multifactorial illnesses, with many different critical factors needed to interact for the illness to develop. Examining possible underlying causes was beyond the scope of this thesis, but in Study IV, the adolescents describe how the illness emerged in social contexts outside the family, and what it meant for them in everyday life. According to the young peoples’ narratives in Study IV, processes
related to adolescence in itself seem to have affected the development of the illness. In adolescence, young people are expected to take more responsibility for their schooling, for their activities, and their interpersonal relationships. They are also expected to manage what they have learned during their childhood and be able to use the knowledge they have received. At the same time, adolescents in general are increasingly aware of social codes and the potential to communicate through appearance, as well as of the demands placed on them from different directions. To shift the emphasis in life from family to new contexts is a complex process that will greatly increase the vulnerability of the individual in question. The adolescents suddenly need to take a role, in school and at working places, and interactions with peers require the adolescent to handle new habits and norms. The social network gets wider, but also more impersonal in some ways. The family affiliation that previously defined the individual needs to be replaced by another belonging, and with that often follows a fear of not fitting in. Additionally, most young people enter puberty during this period, which causes major and complex biological changes that might increase their vulnerability for a less balanced mental state.

However, most young people go through adolescence without developing an ED, or any other psychiatric disorder, and a theoretical perspective to understand why people have different tendencies to become ill is summarized by the concept of resilience. In this thesis I will use this concept in accordance to the definition presented by Ann S. Masten (2014): The capacity of a dynamic system to adapt successfully to disturbances that threaten system function, viability, or development. Research in resilience began in the 1960s but has been further developed over the years, by Masten, for example. It goes under the umbrella of developmental psychopathology, in which research on mental illness – traditionally focused on undesirable behavior – has been integrated with research on competence and developmental tasks, with a primary focus on desirable behavior and protective factors. The construct of the concept resilience is grounded in an ecological model that emphasizes the importance of external factors along with intra-individual assets in promoting healthy youth development. It has been suggested that resilience can be more or less present in different contexts and during certain time periods and is often strongly affected by culture and the pattern of interpersonal relationships.

Factors related to resilience, which in risk situations have shown to decrease the likelihood of negative outcomes and increase the likelihood of
positive outcomes, can be intrinsic (e.g. high self-esteem and a certain temperament within the individual) or extrinsic (e.g. high-quality relationships, effective parenting and well-functioning schools)\textsuperscript{167, 171}. These factors can occur at all levels of influence: at the individual level, within a family or at school, or within the community. Sometimes these factors can be viewed as quite powerful protective forces, for example, a person in the individual’s environment who is supportive and “just right” or something crucial that suddenly happens in life\textsuperscript{167}. It is important to clarify that resilience is about ordinary human resources and not, in the vast majority of cases, an extraordinary talent. It is about different systems interacting, the individual believing in herself and being lifted within different contexts\textsuperscript{167}, and can be viewed as processes rather than factors\textsuperscript{169}. In this thesis, the focus is on contextual factors, or processes, promoting resilience in young people at risk for mental health problems, that lie beyond personal attributes like intelligence, ingenuity, and problem-solving capabilities.

In the field of EDs, different resilience models can be of interest in discussions about the development of the illness. Examples of such models are: 1) \textit{the compensatory or main effect model}, which means that there might be a risk for the development of an ED in an individual, e.g. weight issues, and at the same time, the individual has a certain resource that is positive when present to some degree. A third factor, e.g. a prevention program or parental support, might compensate for the present of risk and thus predict the final outcome, 2) \textit{the mediator model}, suggesting that the risk factor for developing an ED are affecting an individual indirectly, e.g. through parents’ alcohol abuse. In such a model, the focus should be on firstly providing support to parents, and 3) \textit{the moderator model}, with a focus on moderators of risk factors, some of which are risk-activated. For example, a risk factor for developing an ED is present, which leads to a risk-activated moderator being actualized. This could be, for example, a healthcare contact. Other moderators, which are not risk-activated, might be a close friend or a spare-time activity, which do not affect the risk factor, either positively or negatively. If predisposing factors for an ED are present in an individual, but a triggering risk factor still does not lead to the development of an ED, resilience might be an explanation\textsuperscript{167}.

Furthermore, results that are related to illness as a phenomenon are those from Study I, presenting demographical characteristics of a large sample of adolescents with AN, by the time for treatment onset. In Study I, 94.1\% of the adolescents were girls, which is in line with previous results from both community studies and health-care studies, showing that the highest
incidence rates of AN are found among girls and young women. Yet, there is evidence that EDs burden boys in a similar way, on an individual basis, in spite of the low ED prevalence in males. Almost 60% of the adolescents had an AN diagnosis at treatment onset, which is a fairly large proportion according to earlier studies, in which it was suggested that most young patients have variants of subthreshold diagnoses. However, since the updated criteria for AN in DSM-5, a larger proportion of young people are diagnosed with AN. The adolescents’ mean age when entering treatment (16.6) is in line with results from studies suggesting that the peak age of presentation for treatment is mid-adolescence. The mean age at the development of first ED symptoms was 14.6, which means that the adolescents’ illness duration when entering treatment was approximately two years. If we exclude those who had previously been in treatment for an ED (30.5%), the illness duration was somewhat shorter. There was no difference in illness duration at treatment onset between the different time periods: 1) 1999–2004, 2) 2005–2009, and 3) 2010–2014. It has previously been suggested that duration between onset of illness and initiation of treatment is often quite long, particularly in individuals with an early onset of illness. Long duration of untreated illness is associated with severe complications and has proven to be one of the strongest predictors of poor outcomes among individuals with AN. In addition, an ED often affects the whole family and can wear down family relationships to a large extent, as the informants in Study IV described in their narratives, and such a situation is likely to worsen as long as the youth remains untreated.

As a way to reduce the length of time between onset of illness and initiation of treatment, a systemic public health intervention has been suggested, including e.g. the publication of a treatment guide for patients, relatives, and therapists and the distribution of information concerning EDs. Such an intervention might be particularly important for adolescents, as many young people are likely to have atypical presentations of EDs, which increases the risk for delayed diagnoses. Adolescents might for example have difficulties expressing themselves in a way that reveals potential body-weight phobia, and behavioral symptoms might be quite diffuse. Newly commenced vegetarianism might be a sign, just like the development of certain food rituals. In addition, categorization in low and normal weight based on BMI is difficult among adolescents. A BMI within a normal range does not necessarily mean that the patient is healthy, as the patient may have a low weight in relation to his or her own body-
weight curve. It is also important to bear in mind that suffering from AN can be critical regardless of weight \(^{13}\). In Study I, approximately 40% of the adolescents were normal weight at treatment onset. However, the results in Study I indicate that, over the years 1999–2014, patients who entered treatment for AN became less low-weight and fewer had complicating medical, social, or psychiatric factors, which may reflect that health care today is more available to the general public, and that there is an increased knowledge of EDs among parents, school and other caregivers.

A systemic public health intervention, like the one described above \(^{175}\), is tangential to the field of preventive work, which has been rather controversial in the field of EDs. Although discussions about risks and benefits with prevention programs have been less polarized in later years, preventive work is a kind of balancing act. AN is a frightening illness in many ways, due to its common severe somatic complications. At the same time, some people perceive AN as quite fascinating and appealing, based on societal ideals relating to appearance and body shape. Regarding EDs in general, despite available diagnostic criteria, the distinction in society between being ill and being healthy is sometimes rather unclear. Since people of different ages talk a lot about food, dieting, and exercising, and many exclude certain sorts of food for various reasons, there is a risk that ED symptoms are confused with symptoms of more general problematic eating.

The fact that adolescence seems to be a vulnerable period in an individual’s life can make it appropriate for prevention, assuming that the information is conducted thoughtfully and has a main focus on protective factors, rather than on potential risk factors for psychopathology \(^{169}\). Evidence for available preventions programs has been ambiguous and with significant limitations \(^{17,176}\), but some interventions have been suggested to have an impact on knowledge about EDs in the community \(^{17}\). For example, Weigel and colleagues (2015) have invented a gender-adapted intervention program for EDs for use in schools, which contains interactive and educational elements. It focuses on risk factors as well as resources and encourages participants to reflect on self-esteem, body perception, and influences of the media \(^{59}\). Raising awareness of EDs in society is important not least for helping young men to recognize their illness and seek help in time \(^{7}\), which makes it essential that the intervention be gender-adapted. It often takes extra time for men to realize that they have an ED, and to seek help for it, as they do not expect to be affected and are ashamed and fearful of being faced with doubt and mistrust \(^{7,177}\).
According to the informants in Study IV, their first ED symptoms were discovered in social contexts outside the family, e.g. the school environment or sports activities. This can also be linked to the results of Study I, in that 60% of the patients were referred to the unit by e.g. another unit or a school nurse, compared to seeking specialized care on their own or on the initiative of their parents. This is despite the fact that almost 95% of the informants were living with their parents or other relatives. However, as many adolescents often spend an increasing amount of time in different social contexts outside the family, in their attempts to achieve more independent living, this is not very surprising. In the transition phase between childhood and adulthood, microsystems other than family of origin naturally have an increased impact on the young people’s lives 167.

A notion of how processes within different microsystems affect young people and are mutually affected by the adolescents in these contexts, is described in Bronfenbrenner’s bioecological theory 166. According to Bronfenbrenner, a context can be explained as a multidimensional construction containing different layers of unique developmental processes, within which the development of a social identity, social network dynamics, peer influences, and school- based friendship patterns might be studied 178. Bronfenbrenner states that processes within any microsystem in which young people spend time on a regular basis might affect them to largely the same extent as family processes 166. As many parents today spend a lot of time apart from their children, microsystems other than family of origin have a greater part in their children’s lives, for example, the school environment, the neighborhood, or a circle of friends. Attachment, that is initially directed toward one’s parents, might be applied to other adults and close friends 167. In the bioecological theory, as individual characteristics play a significant role in what a person attracts in her environment, equal emphasis is placed on the individual and on the environment 166, 179. Bronfenbrenner states that the environment is important but that the individual’s experiences of the environment, and the perceived importance of it, are what truly matters 166. The bioecological theory mainly focuses on an individual’s development in relation to different contexts placed within four interrelated systems, which are illustrated in Figure 4.
Figure 4. Bronfenbrenner’s bioecological theory model.

The microsystem includes an individual’s immediate contexts and close relationships over time, e.g. the family or school environment. The *mesosystem* consists of an individual’s different microsystems integrating with each other, during certain time periods in life. As the adolescent grows up, he or she will be included in several different microsystems simultaneously, and these will affect each other in different ways. The *exosystem*, which is called an extension of the mesosystem, embraces formal and informal social structures. The *macrosystem* includes the overarching institutions of the culture or subculture and can be described as a map of
the prevailing conditions within a given culture. All these systems influence each other in different ways and influence the individual more or less in certain time periods. In the 1990s, an additional system was included in the theory, which is the *chronosystem*. It includes any transitions and socio-historical events that occur throughout a child’s life and can be applied to the complex and multidimensional changes that occur during adolescence.

Bronfenbrenner states that an individual’s psychosocial development is a result of different socialization processes that occur in interaction between the individual and his or her immediate context and highlights the importance of reciprocal processes within and across different contexts. Thus, an adolescent can choose to participate in a spare-time activity with other young people, and then be influenced by these individuals over the course of time and interactions. Such interactions are referred to as proximal processes. According to Bronfenbrenner, a process of development within one context is most often transferred into other contexts.

The bioecological model can be used as an explanatory model for the development of an ED, given, among other things, the predisposing, precipitating, and perpetuating factors found within individuals’ different contexts. For instance, interpersonal problems might be a precipitating factor that can lead to the development of an ED in an individual where predisposing factors are present. To avoid food, eat restrictively, or starve in order to get thin, is to some people equal to renouncing the interpersonal function of food as a mediating link between people. Not eating might become an escape from interaction with others, from a socialization that may be hard to handle emotionally. Interpersonal problems might also function as a perpetuating factor, related to adolescents’ social support and family system, for example. In addition, proximal processes in an adolescent’s life, which goes from being mostly about family to be more about social contexts outside the family, open up for extensive influences regarding appearance and social identity, which can increase youth vulnerability.

After the family, school is the most organized system in which children all around the world spend most of their time as they grow up. It is described by Bronfenbrenner as one of the major microsystems in an adolescent’s life. In Study I, almost 90% were students when entering treatment. This makes the school context extremely important when it comes to recognizing symptoms, and it is desirable that all people working with children and adolescents be educated in matters relating to
food, eating, and body sensation. Unfortunately, the knowledge and understanding of the illness is often insufficient among school staff. It has previously been shown that many teachers feel uncomfortable discussing EDs with their students, which might lead to increased stigmatization. It has also been shown that many young people lack knowledge and understanding of EDs, but that they often have preconceived ideas and prejudices. For example, a study revealed that the general public perceived possible causes of EDs differently than individuals with an ED. In Study IV, some of the adolescents described how their friends tried to help them but failed to give the kind of help that they needed, and peers of adolescents with EDs have themselves pointed to a need for education, including information about common symptoms of EDs and proper ways to help. This suggests a need for information and psychoeducation regarding EDs among students as well as teachers.

Thus, different social contexts outside the family, and the interpersonal relationships within them, can be both health promotive and stressful. Teachers and sports coaches, for example, can have an impact on resilience by being nurturing and supportive and by helping the adolescents to find their own way in life, and peers can influence and inspire the adolescents in their search for a social identity. This is particularly helpful when the family situation is complicated. However, those environments, just like the family environment, can be destructive and hazardous, involving, for example, bullying and alienation.

According to the informants’ narratives in Study IV, the role of peers was quite important in the development of the ED, and the adolescents described different sorts of interactions with peers, teammates and friends that they believed had a part in the process. It has previously been suggested that individuals with AN tend to feel disconnected from their peers, and that they have difficulties with establishing and maintaining positive social relationships. In Study IV, the informants reflected upon how hard it was to keep people close when they were ill. Some of the adolescents chose to withdraw in social situations, while others tried to interact but were too weak to manage. Regardless of whether this was an active choice or not, such isolation from social interactions contributed to a confined world. The young people often found it hard to talk about their issues regarding food and eating and felt that their friends also avoided the subject in conversations. It has previously been suggested that suffering from an ED often lead to a mistrust in people, which is why many adolescents create a façade as a strategy to keep people away from their inner thoughts and
feelings. It has also been shown that people with AN have impairments in several domains related to interpersonal relationships, and that reduced social processing skills are a risk factor for developing an ED, perhaps due to an increased sensitivity to negative judgements from others (e.g. teasing about weight). The communication deficits are often accentuated as a result of starvation, which leads to even more problematic social situations, and the individual is often left alone with the illness, which thereby perpetuates itself. Such a circulative effect, in this case biologically influenced, can be applied to several different AN symptoms, psychological as well as social, and is important to break as early as possible.

Symptoms connected to psychiatric comorbidity might also affect the adolescents’ interactions with other people and have shown to increase vulnerability for AN. Psychiatric comorbidity is quite common among adolescents with AN, and comprises mainly mood- and anxiety disorders, obsessive-compulsive disorder, substance abuse, and personality disorders. In Study I, approximately one third of the patients had complicating social, psychiatric, or somatic factors when entering treatment, most of which were psychiatric.

To sum up, the development of an ED can be described as a dynamic occurrence in which biological, psychological, and social processes intersect. Although AN is triggered by primarily psychological or social factors, according to the results in this thesis, the biological processes associated with starvation will play a significant role in maintaining the illness. Knowledge of the individuals’ paths into the disease, of relevant factors and processes for preventing or inhibiting negative development, and of the role that treatment can play is crucial in helping young people who struggle with problems related to body, weight, and eating.

**Treatment**

Being the complex, multifactorial, and biopsychosocial illnesses, they are, EDs require complex, multifactorial, and biopsychosocial treatments. If a treatment is successful or not is most likely determined by an interplay of the treatment method, the specific patient, the specific therapist, the relationship between them, and other interactions within the patient’s different social contexts, which is consistent with the results from the four studies in this thesis.

In Study II, we examined which treatment forms were most common in a naturalistic sample of adolescents and found that 94.3% of the patients received some sort of outpatient treatment and 20.1% received inpatient...
care at some point during their treatment. It has previously been stated that outpatient treatment is suitable for most young patients with AN, and that inpatient care should be used only for patients who are medically unstable. The most common form of outpatient treatment was individual therapy, followed by family-based treatment and somatic treatment. It has been suggested that family-based treatment is the most common intervention among adolescents with AN, but some of the patients in Study II may have received individual treatment sessions as a complement to family-based treatment. If we divide the sample into the three age groups: 1) 13–14 years, 2) 15–17 years, and 3) 18–19 years, the results show that the proportion of patients treated with individual therapy increased with every age group, whereas the opposite was true for family-based treatment. This is in line with previous results, indicating that family-based treatment in clinical practice is often adjusted and adapted to different age groups, which might entail offering more individual sessions to older adolescents.

As also shown in Study II, among patients who answered a patient-satisfaction questionnaire at one-year follow-up, individual therapy was the most appreciated treatment form. In Study III, the informants stated that they preferred individual therapy sessions in combination with family-based treatment, as they wanted to talk about certain things without parental involvement, in their striving for independence. This is in line with previous research, which suggests that individual sessions are important, at least as a complement to family-based treatment. Furthermore, the narratives revealed that individual therapy was perceived as the only conceivable treatment form when the family-situation was complicated, and the parents or the patients themselves refrained from bringing up certain issues with the therapist in conjoint treatment sessions. In general, parents are often worried about their child’s ED, and this can lead to a strained relationship between the parents. In addition, the parents may have other conflicts to deal with, for example handling their own psychiatric problems. In family-based treatment, the importance of parents keeping their own problems outside the sessions has been emphasized, but there is a potential for conflict between such an approach and the ambition to understand the problems of the adolescents in their context. The prevailing family situation is sometimes a central part of the problem that needs to be brought to light, which also is revealed in the adolescents’ narratives, and in such cases individual therapy might be a suitable option.

Individual therapy might also be preferable among adolescents because it offers a greater opportunity than family-based treatment to focus on other
aspects of the illness than behavioral symptoms. Previously, patients have been critical to treatment with too much focus on physical symptoms and have described a need for treatment with a stronger emphasis on thought processes \textsuperscript{120, 141, 197}. In Study II, among the patients who answered the patient-satisfaction questionnaire, the goal that was rated as most important was “to learn to eat normally,” which is in line with the actual groundwork in ED treatment, including meal planning and striving to achieve regular and sufficient eating \textsuperscript{65}. That was also a highly rated goal concerning fulfilment. However, other highly rated goals were “to learn how to handle unreasonable views on food and body size,” “to be more satisfied with myself and my body,” and “get help to handle strong emotions like sadness and anxiety,” and fewer than 60\% of the patients considered these goals completed or almost completed. In addition, although the majority of the patients reported overall improvement in issues with food, weight, and eating at one-year follow-up, only quite a small proportion reported improvements in thought processes associated to eating and weight, such as “consistent thoughts of food and weight,” “fear of gaining weight,” and “feeling fat and chubby.” This indicates a need for a greater focus in treatment on, for example, body image issues, self-perception, and emotion regulation, which is something that patients themselves have previously argued for \textsuperscript{198}. Some adolescents also need to work on a broader level in treatment with the underlying confusion that often preceded their illness, which is a conclusion derived from the informants’ narratives in Study IV.

In family-based treatment, the main focus is on how the parents can support their child’s recovery and on how the illness affects family relationships \textsuperscript{65, 69, 75}. For an adolescent, regardless of age, living in a well-functioning family, family-support is most likely beneficial, although not sufficient for a satisfying treatment outcome. Therefore, a mix of both treatment forms might be preferable and will most likely give the treatment added value, which also was described in the adolescents’ narratives. However, in Study II, treatment outcome at one-year follow-up, defined as being in remission or not, was quite unsatisfying among patients who received a mix of family-based treatment and individual therapy. Instead, young adolescents who received family-based treatment and complementary interventions seemed to respond more rapidly to treatment. This result points to the importance of starting treatment as early as possible in the process, and to the value of family support, particularly in younger adolescents. Since many patients in clinical practice receive more than one
type of treatment, our intention in Study II was also to look at possible differences across patients with different treatment combinations and various amounts of treatment forms. Using cluster analysis, the patients were organized into four clusters: 1) “family-based treatment” (FT), 2) “extensive mixed treatment” (EMT), 3) “individual therapy” (IT), and 4) “family-based and individual treatment” (FIT). Whereas FT had the largest proportion of patients in remission at one-year follow-up, older adolescents who received individual therapy and complementary interventions were less likely to achieve remission, possibly illustrating practical difficulties for older adolescents in combining treatment with other areas in life. However, it might also indicate a need for stronger social support also among older adolescents.

As mentioned previously, the need for family-based treatment sessions often decreases in later adolescence, as the young people become more independent 199, and in such cases it might be beneficial to put more focus on social contexts outside the family. Treatment for an ED is not something that can be “put off to the side,” separated from everyday life, as it affects life in several areas, just like the illness itself. This was revealed in Study IV, in narratives regarding feelings of being limited and restricted and how the young peoples’ time in treatment affected school environment and sports activities, assembled under the theme “a life put on hold.” In his bioecological theory, Bronfenbrenner states that family processes during adolescence are successively replaced by proximal processes within other microsystem, and that new relationships are often created with significant people (e.g. teachers, relatives, peers, and sports coaches) who will partly fill the function of the parents 166. For example, organized sports activities, largely based on voluntary participation, provide great opportunities for proximal processes. During training and competitions, the adolescents participate in activities that often generate strong emotional experiences that can strengthen relationships with other people in the close environment 200. In this way, attachment, which is initially linked to one’s parents, might be applied to other adults and close friends 167. The fact that these changes occur during adolescence points to a need for bringing patients’ different social contexts into treatment to a greater extent 201, and perhaps adjusting treatment to different family constellations 202.

In Study IV, sports activities were mentioned in the narratives as important social contexts, although this meant different things for different individuals. For some of the young people, sports had been in the picture long before the onset of the ED, while, for others, it was anxiety-alleviating
and used as an escape from difficult thoughts associated with the illness. Compulsive training is a common part of the ED symptomatology \(^{58, 65}\), particularly in patients with AN \(^{203}\), and is therefore an important area to deal with in treatment. In Study IV, some of the adolescents stated that they were not allowed to attend sports activities or sports classes in school for a certain period, due to their physical state, based on a decision made in treatment. When reflecting upon it retrospectively, they believed that restrictions in physical activity were a good thing, although it was difficult for many of them at the time. Some of the young people had all their friends on a team or in a sports organization, and the sudden distance from them affected their interpersonal relationships as well as their sense of belonging. According to Bronfenbrenner, being restricted in such way in adolescence means a disruption in one’s ongoing personal development \(^{166}\). In an environment with the same conditions, individuals who are highly involved in different proximal processes will develop general skills to a greater extent than individuals with similar characteristics, but who participate to a lower extent in proximal processes \(^{200}\). It is important to consider how patients’ feelings of loss caused by restrictions in physical activity, and other potential negative effects, are discussed in treatment. According to Kolnes (2016), sports activities, which often are good arenas for socialization, can be helpful in the recovery process, if practiced moderately \(^{58, 204, 205}\). It is of great value that a patient who has trained compulsively in the past is helped to dare to start being physically active again, in order not to miss out on the benefits of exercise and movement. In such a situation, it might be useful to turn to a physical therapist \(^{204}\).

However, compulsive training has proven to be difficult to address in treatment in a successful manner \(^{203}\). In Study II, among the adolescents who answered the patient-satisfaction questionnaire, approximately 67% reported improvements regarding “impulses to be constantly active and in motion” and approximately 59% regarding “excessive physical activity” at one-year follow-up, both of which figures are less than the proportion who reported improvements in eating habits, but slightly more than the proportion who reported improvements in thought processes. As a therapist, it is important not to be blind to the risks of excessive physical activity and of investing in a specific sport, which may be triggering factors for developing an ED as well as a maintaining factor. Previous studies have shown that young athletes and people who exercise a lot often face pressure to lose weight and often get injuries or symptoms of overtraining that prevent them from exercising periodically, which makes them vulnerable
for developing ED symptoms. Participation in competitive sports is a factor that may be especially relevant for ED treatment among young males, as it has been shown that male athletes who seek treatment and continue participation in competitive sports are at risk for a poor treatment outcome.

Regarding therapist decisions in general – about moderate exercising as well as altered eating habits – the relation between the patient and the therapist affects to a large extent whether the patient will follow these decisions or not. It has been suggested that adolescents in general attach great importance to the therapist relationship and that a poor relationship between patient and therapist usually leads to a weak therapeutic alliance, which in turn is linked to an unsatisfactory treatment outcome. In Study II, the adolescents who answered the patient-satisfaction questionnaire were quite satisfied with the therapist relationship at one-year follow-up of treatment. Many patients experienced that their therapist/s listened to them, showed them respect, received them in a good way, and had sufficient knowledge about EDs. However, fewer patients felt that their therapist/s could help them, that they as patients played a role in the planning of their treatment and agreed with the therapist/s about goals in treatment and how the treatment should be conducted. The narratives in Study III revealed that the adolescents preferred a therapist who actively involved them in treatment but who was also able to make tough decisions when needed. The young people valued highly that they met resistance at times, that the therapist/s dared to put them against the wall and did not accept excuses and delusions, which is in line with results from a previous review study. Treatment of AN requires therapists who have a broad repertoire of behaviors to use in contact with their patients. Therapist characteristics that have previously been suggested to be preferred by patients and might facilitate the development of a strong therapeutic alliance, include generosity, warmth, vitality, ability to focus, experience, and competence. In Study III, the adolescents also emphasized the importance of certain therapist characteristics, and the qualities they highlighted in their narratives were quite contradictory. They preferred, for example, the therapist/s to be “kind” but at the same time “firm,” and “professional” but at the same time “human.” In addition, they highlighted the importance of extensive experience, at the same time as the they wanted the therapist to put aside prior understanding and consider each patient’s unique conditions. Several of the young people mentioned therapists with whom they had better relationships than with others, which suggest that personal chemistry is an important factor in the therapist relationship.
therapeutic alliance might be a question of understanding each other and recognizing each other’s thoughts, since the therapist was often described in the narratives as an important person in the young peoples’ lives who served as a complement to other significant relationships during their time in treatment. From a biopsychosocial perspective, the content and emotions that constitute the relationship between the patient and the therapist/s are the fundamental principles of biopsychosocially oriented clinical practice 19.

Children and adolescents, like all individuals, are experts on their own conditions 210, although the egosyntonic nature of AN makes some adolescents resist the treatment offered 127. Young people with AN are sometimes described as obstinate, but perhaps they need to be listened to more carefully, and to be taken more seriously. In Study III, the adolescents described how the therapists’ behavior at the beginning of the treatment had a positive impact on their motivation, even if they did not respond until later, partly due to starvation. During their illness, individuals with AN often create a life based on routines, characterized by control. Entering treatment means a whole new experience, and the narratives about the beginning of treatment revealed feelings of shame, ambivalence, insanity, apathy and anger. The fact that only a few of the adolescents mentioned the therapist/s at all when describing their first treatment session implied that they were not able to take in the situation, and instead let their parents speak for them. In clinical practice, one might therefore need to add a few additional sessions at the beginning, as some patients are not emotional available, even if they are physically present. The young people found it helpful when the therapist invited them to cooperate, over and over again, until they felt ready. This can be associated with the idea of “emerging mutual trust,” meaning that trust might not come about immediately in a therapeutic relationship 211. In treatment for adolescents with AN, it is important not to use the patients’ starvation as an alibi for avoiding working with participation. In their narratives, the adolescents expressed that it was important to meet a therapist who wanted to see treatment as a joint project that they could work on together, who did not pretend to always have the final solution.

In family-based treatment, a solid therapeutic relationship should also be built up with the parents 67, 212. It has been suggested that it is more difficult to create a strong alliance in family-based treatment, as there needs to be balance in the different relationships at the same time as the therapist has to focus on the whole family’s needs. The result is often that the parents' alliance with the therapist becomes stronger than the patient's 67, which
might contribute to an uneven distribution of power in the treatment setting\textsuperscript{213}. In order to reduce the negative consequences of such a disruption in youth development, the main responsibility in treatment should be handed over from the parents to the patient as soon as the adolescent is strong enough. In Study III, the adolescents described retrospectively how they sometimes felt more or less forced into treatment, and that they were struggling with balance between independence and dependence. The family most often provided an important context and were given a role as co-therapists in between the treatment sessions. At the same time, the adolescents were expected to do most of the work in treatment as individuals and recover “for their own sake.”

During treatment for adolescents with AN, many parents devote most of their time to supervising their child, which can wear down family relationships to a great extent. The family also needs to handle temporary changes, as well as more permanent ones, which might lead to frustration. Such changes include a decreased ability in the adolescent to engage in school work and spare-time activities\textsuperscript{214}. The adolescents’ narratives revealed that certain conflicts in the family were hard to solve, but also that the hard times could strengthen family ties. Parental support, and an opportunity for parents to share experiences with others in the same situation, has been shown to increase the understanding of the illness and give parents the strength to support the adolescent\textsuperscript{168, 214, 215}. According to previous research, as treatment progresses, the family climate often improves\textsuperscript{195}.

In Study III, the adolescents reflected upon their siblings, and their situation during the time in treatment, and, in retrospect, they felt guilty towards them. They felt that they took up too much space in the family when they were ill, and that their siblings were put aside, or sometimes chose to withdraw. The young people were also worried that they had affected their siblings in a negative way. It has been suggested that parents often try to protect the siblings by withholding information about the affected adolescent’s illness\textsuperscript{216}, which may, however, make the siblings feel even more sidelined and left alone with their concerns and worries\textsuperscript{217}. The adolescents themselves expressed a wish for the possibility in treatment to involve the siblings to a greater extent.

An important foundation in family-based treatment is the aim to release both the adolescent and family from feelings of guilt, due to, for instance, thoughts about possible causes. This is done by putting the current situation in a broader context, helping the patient to see how she is influenced by her
different contexts. From a biopsychosocial point of view, this can be compared to bringing the situation back to where it once started – in its contexts. Just like sports activities, the school environment might play a role in the development of an ED, as well as in the maintenance of the illness. There should be clear routines in each school for how patients with an ED should be supported before, during, and after treatment. A close collaboration between the health–care system and the school environment is important for promoting equal educational opportunities for all children in society, also for those with medical disabilities, and such collaboration is most often beneficial for all individuals who are involved in treatment. Due to their illness, patients often suffer setbacks in school that severely impair their physical and mental health. Some patients with an ED need special arrangements in school, such as snack breaks in class or allowance for missed physical activities in school. In addition, some ED units recommend the patient to be absent from school at the beginning of the treatment, when, often in collaboration with the parents, they try to get the patient to gain weight. The results in Study I showed that approximately 7% of the patients were on sick leave from school or work when entering treatment. Several of the narratives in Study III were about mentors in school who supported the young people and were highly involved in treatment, but also about school staffs’ insufficient insights into the problem and their lack of understanding. It appeared that there were factors in the school environment, as well as in the home environment and other social contexts, that perpetuated the illness and kept the symptoms alive.

None of the adolescents mentioned anything about what method their treatment was based on, which is in line with previous results. This might be because different treatment forms were integrated with each other and with other treatment interventions, which is a common approach in clinical practice, and in accordance with results from Study II. It has also been suggested previously that the value of treatment method is linked to the relational context in which it is applied, and that adherence to a treatment manual is irrelevant for treatment outcome when a strong treatment alliance is present. One aspect of the therapeutic alliance is the extent to which patients experience their involvement in the treatment planning, in terms of goals and how the treatment should be conducted. For a young patient with AN, being involved is often about being invited to take part in a dialogue. If a dialogue occurs, the result will most likely be that the outside perspective of the therapist and the inside perspective of the adolescent meet, which in turn might increase the chances for a good
treatment outcome. The distinction between the two perspectives will be prominent in the next section, in the light of different views on treatment outcome and recovery.

**Recovery**

The results in Study I showed that the average treatment duration was approximately 15 months, and according to the results in Study II, approximately 36% had completed treatment within one year. Just over 55% of the patients had achieved remission at end of treatment, and approximately 85% were of normal weight. These results are quite in line with other naturalistic studies examining treatment outcome among adolescents with AN in outpatient care (e.g. 73, 145, 220), although some of these studies are quite old and/or differ from Study I in elementary methodological aspects. It is not possible to fully match the results from Study I to results from RCTs (e.g. 82, 125, 221), due for instance to divergent study structures and different ways of measuring outcome, but in comparison, the remission rates in Study I are within the higher range.

According to the results in Study I, remission rates and weight recovery increased over time (1999–2014), whereas treatment duration decreased. Although this needs to be further investigated, the results indicate that treatment has become more efficient in later years. Even if the patients were healthier when entering treatment in the later time periods, it cannot fully explain the better outcome, since neither low weight nor complicating factors at treatment onset were associated with a poor outcome. In Study I, separate analyses of patients who ended treatment according to plan revealed that just under 70% were in remission at end of treatment, and approximately 90% were of normal weight, indicating that completion of treatment was associated with a better outcome. This was supported by the results from Study II, which showed that patients who terminated treatment prematurely had a decreased chance of achieving remission. Results from previous studies have shown that unsuccessful treatment periods can complicate future attempts at treatment, due to disappointment and decreased motivation 68. However, according to the results in Study I, the chance of achieving remission was not affected by previous experiences of treatment for EDs.

It has previously been suggested that patients with a severe EDs, often with psychiatric comorbidity, generally requires comprehensive treatment efforts and extended treatments 3, 222, and that they are at risk for poor treatment outcome 121. Although not significant in the statistical analysis,
the results in Study I indicated that psychiatric complications at treatment onset were associated with a poor outcome. In addition, in Study II, only a small proportion of the patients who received “extensive mixed treatment,” including e.g. inpatient care in more than half of the cases, had achieved remission at one-year follow-up, indicating that these patients needed more time in treatment than less severely afflicted patients.

Recovery is most likely a process that is created stepwise\(^\text{137, 177, 223}\), and treatment completion is one of several steps. Possibly, the process begins with the patient and the therapist creating a shared view of treatment goals. It has previously been shown that high drop-out rates and lack of compliance among patients with an ED can be viewed as a consequence of the discrepancy in goals between the therapist and the patients\(^\text{127}\), and according to the results in Study II, significantly fewer patients among those who terminated treatment prematurely, on their own or on their parents’ initiative, considered treatment interventions as helpful and were satisfied with fulfillment of treatment goals. In Study III, the adolescents reflected upon treatment goals and factors that affected how the treatment was terminated, and the importance of ending treatment at the right moment. The results indicate that it is useful to formulate what has been achieved in treatment after a while, when, for some reason, the condition has changed, and in relation to that begin to discuss termination. A therapist, for example, might experience a change in treatment, for instance, that the patient looks healthier, a view that the patient in question might not agree with. In order to decrease the risk of ending a patient prematurely, it is therefore important to create a shared view of the situation.

Setting up a certain body weight as a treatment goal can be problematic and lead to a situation where the therapist gets just as preoccupied with weight as the patient\(^\text{224}\). This is also mentioned in a previous study, where it is suggested that focus in treatment should be on challenging the patient’s rigidness instead of strengthening the control domain in the disorder\(^\text{225}\). In Study III, the adolescents described how treatment goals that were related to weight made them feel uncomfortable, and retrospectively they questioned the value of such goal. Instead, they emphasized the importance of improving their relationship to food and, above all, getting mentally stronger. However, professionals and patients have been shown to differ in their perspectives on treatment goals, and results indicate that professionals have a tendency to focus more on physical symptoms than psychological functioning\(^\text{120}\).
The adolescents’ narratives about completion of treatment dealt mainly with timing, and the importance of not ending treatment prematurely. Too much responsibility too soon was described as devastating, and the adolescents expressed a need for a safety line or "crutch," as one of them called it, which they could lean on for a while after end of treatment. Some of the young people were offered boosting treatment sessions, which were highly appreciated and made them feel less insecure. A fear of not being able to handle the situation without treatment support might remain in individuals for quite a long time, according to the narratives in Study IV, assembled under the theme “creating a new life context.” There is a risk of falling ill again after end of treatment 114, which many adolescents are aware of 109, and the narratives revealed that it was something the informants had to live with. They described how they were sometimes afraid to eat too much, or to train more than usual, because they were worried it would trigger a relapse.

As mentioned in the Background section, full recovery is suggested to include attainment of normal eating patterns 13, normal attitudes toward food and the body 128, increased self-esteem, and interpersonal and occupational functioning 13. According to the results in Study II, adolescents seem to improve faster in behavioral symptoms than in cognitive symptoms, and, according to the narratives in Study IV, cognitive symptoms often remain after weight recovery. Perhaps such symptoms illustrate a further step in the recovery process, which the adolescents need to work on after end of treatment. It might be important to be cautious for some time after treatment completion, as results have shown that individuals who relapsed often had an illusion that the most difficult part in the process was behind them 137.

Nilsson & Hägglöf (2006) studied turning points, and found that, outside treatment, factors as family, friends, boyfriends, personal decisions, and activities were beneficial in the recovery process 226. In Study IV, the adolescents mentioned similar factors that they believed moved recovery forward. However, it can be difficult for relatives or close friends to observe remaining symptoms and to be aware of the adolescents’ need for support, as recovered individuals often function similarly to those with no eating pathology in terms of psychosocial adjustment 128. This can be rather confusing and can lead to incomprehension among e.g. friends, teachers, and sports coaches.

According to the bioecological theory 166, the macrosystem might affect the recovery process to a great extent, in terms of social norms and
structures that constitute our close environment. In society, as mentioned previously, people of different ages are often preoccupied with food, weight, and eating, although not in a pathological way, which might make it quite hard for individuals trying to recover from AN. It has been suggested that one of the key factors when distinguishing between partially and fully recovered individuals is body-image disturbances\textsuperscript{128}, which is not surprising given the importance of appearance in most Western cultures. Many adolescents believe that looks and body shape are important for being popular among friends, and even for future success\textsuperscript{52,190}. In order to recover from AN one needs to choose another path, and, in Study IV, the narratives revealed that the adolescents, after end of treatment, preferred to hang out with people who had another focus. From the adolescents’ perspective, recovery was a question of letting new relationships develop. Moreover, according to the adolescents, recovery enabled some habits and types of behaviors to change, and new activities to be added, which is in accordance with previous results\textsuperscript{137}. Helping partly recovered adolescents to see how they are influenced by their different contexts, that their problems are partly about society, can free them from guilt and help them to move on in the recovery process\textsuperscript{218}.

During recovery, many people usually begin to reflect upon the past to a greater extent\textsuperscript{227}. After some years, individuals might look back and view their illness quite differently and reflect in a different way on, for instance, possible causes and first symptoms. In a follow-up study with previous adolescent patients with AN, 8 and 16 years after end of treatment, respectively, the most common answers about causes in the first follow-up were things that had to do with self, such as a perfectionist personality or very high ambitions. In the second follow-up, there were more answers about family causes. However, in the same study, problems with peers/bullying, socio-cultural ideals, and sports, which were also mentioned at treatment onset, were stable across first and second follow-up\textsuperscript{57}.

When looking back, adolescents might realize that the AN had a negative impact on their lives in several aspects\textsuperscript{109}. An illustrative quote from Study IV reads: “I lost two years of my life; that’s how I feel about it, for such an unnecessary thing.” For some of the adolescents the illness experience led to a negative image of self, according to the narratives.

It has previously been suggested that approximately one-half of adolescents with AN fully recover, 30\% achieve partial recovery and 20\% remain chronically ill\textsuperscript{123,228}. The chances of achieving full recovery are better among adolescents than adults\textsuperscript{123}, but results have shown that a large
proportion of previous patients with adolescent onset of AN are at risk for poor psycho-social functioning in adulthood \(^{112}\).

Although resilience is more obviously relevant for whether or not an individual develops an ED, it might be helpful also when struggling to recover. As young people with healthy interpersonal relationships are more likely to recover from chronic adversity \(^{229}\), improving resilience may be an important target for treatment as well as for prevention \(^{230,231}\). According to a perspective that takes into account biological, psychological, and social aspects, young people are responsible for their own recovery, although sharing the responsibility with various actors \(^{218}\). Regarding adolescents with AN, the importance of healthy social surroundings and a supportive environment are prominent in the process, from illness and all the way to recovery.

**Methodological and ethical considerations**

For a researcher, when discussing the research process – the design of the studies, the methods used, the choice of research variables, and the interpretation of the data – it is important to reflect upon the influence of one’s pre-understanding, which has certainly influenced the process in every step. Reflexivity, which is to critically review the influence of one’s pre-understanding, is relevant through the whole process, since one’s pre-understanding is under constant development. When I started working on this thesis, which is almost 8 years ago, I was in a totally different place from now. I had experiences from working with adolescents in school and at spare-time activities, which prompted my interest in this topic, but I had no professional experience from working with individuals with an ED. Today, I have greater professional experience regarding young people, EDs, and other psychiatric diagnoses and therapeutic processes, as well as greater personal experience in general. I will discuss this further in this section, as well as the research process, methodological strengths and limitations, and ethical issues in the different studies. Data were collected using both quantitative methods (Studies I and II) and qualitative interviews (Studies III and IV).

**Studies I & II**

Naturalistic studies in the quantitative research field – sometimes called observational studies or naturalistic observations – imply examining a phenomenon in a real-life setting \(^{146,147}\). Naturalistic studies can be used as an alternative to RCTs, and they offer stronger generalizability to a clinical
environment. In a study comparing results from an RCT with those from a specialized clinical-care survey, relatively few contextual differences were found. Yet, these differences seemed to have an impact on treatment outcome for certain patient groups, due to e.g. more intensive supervision and fixed treatment schedules in the RCT. In RCTs, treatment forms are generally compared with other treatment forms, or with control groups that do not receive the intervention studied, but instead some background treatment such as treatment as usual. Therefore, non-specific therapy factors, time, and background interventions cannot be ruled out as possible explanations for overall improvement.

One form of naturalistic studies is register-based studies, which are suggested to be of great value for psychiatric research, due, for example, to the possibility of following individuals over long time periods. In Sweden, as in a few other countries, population-based registers of health data have existed for decades, and Swedish psychiatric quality registries in the health-care system have gathered data since the 1990s. SwEat is one of the oldest Swedish psychiatric quality registries, and as of 2003 it is internet-based.

Studies I and II were naturalistic studies based on data from SwEat, and the design implied some methodological strengths as well as limitations, affecting the internal validity. Strengths were, for example: 1) the large-scale naturalistic setting, which provided a natural treatment environment for patients and clinicians and secured a generalizability to a clinical environment, 2) the large number of participating units, which provided good national coverage, 3) the large sample sizes, providing good representation of the total population, and 4) the fact that subthreshold AN was included and adequate sub-groups analyses were conducted in order to determine treatment effects in the different diagnoses. Limitations with the study design were, for example: 1) the risk for selection bias, as the patients were not randomized, 2) considerable attrition at follow-up in SwEat and large differences in the proportion of registrations at the different units, which affected the generalizability of the results, 3) the missing data considering some of the variables in SwEat, 4) the lack of data on certain potential influencing factors, such as previous life events, 5) the large number of assessors, which decreased the reliability regarding different assessments, 6) the fact that height and weight in some cases were self-reported by the patients, 7) the lacked control over the assessments of symptoms and diagnoses, 8) the fact that some of the variables were assessed retrospectively, which may have led to memory bias, 9) the fact
that the procedure for establishing ED diagnoses varied over time as well as across units, 10) in some cases, the small cell sizes and wide confidence intervals, which increased the risk for Type II errors, 11) the low response rates regarding the patient-satisfaction questionnaire, which increased the risk for misrepresentative results, and 12) the fact that the patient-satisfaction questionnaire has not been validated.

Most of these limitations were factors over which we had no control when designing the study: for example, the loss of patients at follow up, the missing data considering some of the variables in SwEat and the low response rates regarding the patient-satisfaction questionnaire. Approximately 60% of initial registrations in SwEat are lost to follow up one year later 234, for uncertain reasons. However, in Study I, when comparing followed-up and non-followed up patients, no differences of clinical relevance were found. Missing data were most likely due to different technical issues. The patient-satisfaction questionnaire was sent home to the patients to fill in by themselves, manually, which might have affected the response rates negatively. However, although the patient-satisfaction questionnaire in SwEat has not been validated, it can be considered to have face validity since it was developed by clinicians who are well experienced in working with ED patients.

The use of self-reporting questionnaires entails particular considerations, involving the consequences of predesigned response options and the fact that the results often are presented in digits. Predesigned response options might lead to a situation where the participants do not find answers that correspond to their opinion, or where they feel obliged to give simple answers to complex questions. The fact that the results often are presented in digits tell us very little about the participants reasoning about the different questions and answers 235.

Another limitation of Study I was that in the group premature termination of treatment, even patients who were referred to another unit were included, as an aim was to examine all patients who did not complete their initial treatment. This might be considered a limitation, since the patients who were referred possibly completed their treatment somewhere else, although it was beyond our control. We could have used terms for further categories of premature termination, such as patient-initiated discharge and staff-initiated discharge, for example 152.

In Study II, cluster analysis was used for identifying subgroups of patients who received certain combinations, and various amounts, of treatment forms. Cluster analysis is a method in which the researcher has quite a great
influence, which entails certain limitations. In Study II, limitations were, for example: 1) the fact that variables used to classify the individuals might have been affected by bias, 2) the choice of the maximum number of clusters, which were somewhat subjective and affected the reported results, and 3) the fact that the method is data-driven, which decreased the generalizability of the results. However, cluster analysis is designed to generate hypotheses that can prompt future research, and is a beneficial method for its purpose. In addition, if well conducted, the method will generate results that are highly relevant for clinical practice.

From an ethical point of view, the information in Studies I and II was based on previously gathered data from young people who agreed to participate in SwEat when entering treatment at a specialized ED unit. In the cases where the adolescents were under the age of 15, the parents had given their permission. Since no data in the studies could be linked to specific individuals, the studies were conducted without contacting the young people for a study-specific consent. As the study sample was quite large and most of the adolescents most likely had ended treatment when the studies were conducted, the work with contacting them would have been extremely resource-intensive. We assessed that the gain from using this extensive and informative material in SwEat and making sure it could be of use for therapists and patients, outweighed the risk that anyone would be harmed by the project. Studies I and II were ethically approved by the regional ethical review board in Uppsala (Log No. 2011/160).

Studies III & IV
Qualitative studies may provide relevant in-depth understanding of different phenomena in the field of EDs and lead to greater knowledge about underlying factors to quantitative outcomes. In qualitative research, it is important to ensure trustworthiness, including credibility, dependability, confirmability, and transferability.

Credibility
Credibility in qualitative research has to do with whether or not a study measures what it intends to measure. In order to gather rich and varied material, data in Studies III and IV were analyzed on the basis of two different methods for data analysis – hermeneutic phenomenology in accordance with Max van Manen, and TA in line with Braun and Clark. During the interviews, the adolescents were encouraged to speak openly, and an interview guide, developed for this purpose, was used only when...
needed to move the story forward. In this way, the influence of my pre-understanding was most likely reduced. The interviews were audio-recorded and transcribed verbatim, and the participants who wanted to read their interviews had written copies sent to them and were given the opportunity to add or change things. Both analyses were conducted inductively, in close collaboration between two of my co-researchers and myself, in a “back and forth” process. In order to further enhance credibility, and in accordance to the methods for analysis, representative quotations were selected.

**Dependability**

Dependability in qualitative research has to do with how thoroughly the method is described a study, and the stability of data over time. In both studies, the analysis process was thoroughly described, step by step, and the findings were illustrated in tables and figures.

Using a hermeneutic phenomenological approach was an interesting entry into the field of qualitative research. As Study III was my first qualitative study, it was a difficult method to learn, although highly instructive. The method helped me realize that the interviews were about so much more than the young peoples’ actual words, and I believe the analysis really lifted their stories, even though some of van Manen’s ideas were hard to follow. It seems today like the field of qualitative research, previously dominated by methods with a strong connection to complex philosophical theories, are now moving towards an increased use of methods that are more robust and less dependent on a specific theory and/or epistemology. This may entail that qualitative studies become more accessible. When conducting Study IV, I chose to use TA, for the possibility of achieving a rich and detailed analysis, without being dependent on a specific theory and/or epistemology.

Regarding dependability, an obvious limitation with the studies was that the data collection went on for quite a long period of time, due to difficulties with the recruitment of participants, which possibly affected how I conducted the interviews.

**Confirmability**

Confirmability in qualitative research means to which extent the results reflect the participants’ experiences. Confirmability might be threatened by, for example, the researcher’s pre-understanding. According to Van Manen, as a researcher, one’s pre-understanding should be clearly described, in order to avoid any unconscious influences on the results. In
both studies, my pre-understanding, as well as my co-researchers’, was transparent throughout the process.

Transferability
Transferability in qualitative research corresponds to generalizability, that is, to what extent the results from one study can be applied to other situations. Although the results from Studies III and IV cannot be generalized to a larger population, they can be more or less recognized and be of importance for people who can apply them on their own context. In order to enhance recognition, we chose to collaborate with four different specialized ED units in the recruitment process, presented demographic data on the participants, and conducted the interviews in different stages of the adolescents’ recovery processes (1–3 years after end of treatment).

The procedure may have led to some information gathered during the interviews being affected by memory bias. The time that passed between treatment completion and the interviews may have made it difficult for the informants to remember details, but instead the young people got more distance and possibly could possibly remember the most important features of their treatment.

A strength of the studies was that the interviews were conducted by me, who, at that time, stood outside the context of treatment. Since the informants knew this, it is likely that this made it easier for them to speak openly about their treatment experiences. For me as an interviewer, it meant that it was natural to be genuinely curious and open-minded in the follow-up questions and comments.

Although the sample size was adequate to meet the purpose of the analytical methods, the homogeneity of the sample was an obvious limitation, considering gender as well as nationality. Additional limitations were the fact that we did not have any details about the treatment the young people received, or how they were diagnosed, and the possibility that the individuals who agreed to participate were influenced by a common motivation that was not shared by those who declined.

A limitation regarding Study IV was the fact that the interviews were not designed for the aim of that study. Instead, data was taken from the adolescents’ narratives that came up spontaneously during the interviews in Study III, about the young peoples’ time in treatment. A disadvantage of the spontaneous narratives was that I may have overlooked to ask some relevant follow-up questions, since the narratives were outside the actual
focus of the interviews. On the other hand, the spontaneous narratives indicate that the subjects that were presented in Study IV were of great importance for the adolescents. In addition, it can be considered an overall strength that all data were used.

Ethical issues with Studies III and IV involve the time aspect, since a research interview about treatment, after end of treatment, may cause unpleasant emotions and memories of the illness. There was also a risk of harmed integrity; the informants may have felt pressure to reveal more about themselves in the interviews than they actually wanted to. During the interviews, we offered the adolescents a possibility of talking with a therapist, if they felt that they needed to. We also emphasized that the informants could choose not to answer a question or choose to withdraw their participation at any time. The interviews were carried out at meeting-places chosen by the participants, in order to enhance their sense of security. On the other hand, an interview during which one are given an opportunity to reflect upon one’s experiences may seem rewarding to some people on a personal level. The presentations of the results were conducted with great respect for the informants’ integrity. Studies III and IV were approved by the regional ethical review board in Uppsala (Log No. 2011/478).
Conclusions and clinical implications

The findings in this thesis, based on an outside as well as an inside perspective, indicate that some areas that are important for adolescents with AN are not addressed sufficiently in treatment. This might mean that adolescents with AN do not receive the treatment they are most helped by, and that new approaches need to be applied in this field.

For an adolescent, suffering from AN means to put life on hold, in several respects. The illness and the time in treatment hinders life from continuing as usual. In the Background section, I presented the following question: how can we help these young people recover, while simultaneously trying to reduce the damage that may arise from such an interruption in life? In this section, I will present some suggestions, which are also potential clinical implications of the results.

- In most cases, if it is beneficial for the progress and the adolescents feel secure in such a constellation, the family should be involved in treatment. In all cases, support and psycho-education should be offered to parents and siblings, and individual sessions should be offered to the adolescents as a complementary intervention. For older adolescents, and in cases where the family-situation is too complicated, one might consider individual therapy as the main treatment. However, even older adolescents need extensive support in treatment, and will most likely benefit from having their parents at least partly involved.

- Treatment interventions for young people with AN should be broadened in their design and better adapted to both changed social structures and to patients' individual contexts. In treatment, therapists should reflect upon the possibility of reducing the negative effects of the illness through cooperation with different microsystems, such as the school environment or a sports organization. For older adolescents in particular, social activities - such as training or hanging out with friends - are of increased importance but might also cause stress and anxiety. Therefore, interpersonal relationships outside the family should have a greater role in treatment, and the inclusion of a peer group, for example, as partners in the treatment, might be considered. A so-called contextual model \(^{240-242}\), which implies a multifaceted
treatment program involving different professions, is to be preferred.

- The biopsychosocial perspective involves understanding the patient's subjective experience as an important contributor to accurate diagnosis, health outcomes, and a health care with greater warmth. In treatment, therapists should let the young people tell their story and reflect upon what it might imply. The adolescents need to be validated in their often quite complex emotions, and to be seen as competent persons. As a therapist, one should be kind and respectful, but not hesitate to be tough and uncomfortable, if needed. The adolescents might experience a strong ambivalence during the first few treatment sessions, that could be linked to a lack of personal insight and a wish for independence. In such cases, the therapist should not give up on the patients, but try to enhance their motivation.

- A dialogue between patients and therapists is of tremendous importance when approaching the completion of treatment, to ensure that the adolescents are prepared for the next step in the recovery process. The results in this thesis indicate a desired sensitivity among therapists, family members, friends and various actors to understand what might strengthen resilience in young people. After quite a long time in treatment, life after completion might seem somewhat scary, and the adolescents can be afraid to be left alone. As a therapist, one might consider ending treatment a bit earlier than planned, while offering the young people boosting sessions, and an opportunity for them to get in touch if they need to.

**Future research**

The intention of this thesis was to contribute to the clinical field of knowledge regarding illness, treatment, and recovery in adolescents with AN. However, the results point to some areas that are in need of additional research efforts, in order to further increase our understanding.
• Future research needs to investigate differences and similarities in patient characteristics (e.g. age, psychiatric comorbidity, and personal preferences) among individuals who are part of the same diagnostic group, in order to better predict who will best benefit from a certain treatment intervention.

• More longitudinal studies – quantitative as well as qualitative – with longer follow-up intervals are required to further examine the value of patient satisfaction and different treatment forms for clinical improvements.

• It has previously been stated that register-based studies are of great value for psychiatric research, but that there is an under-utilization of data from quality registries for research purposes in Sweden. Therefore, further research on the large amount of data gathered in the Swedish psychiatric quality registries within the health-care system, of which SwEat is one, is desirable.

• Future research needs to examine how sports activities and training are handled in treatment, and how negative consequences of restrictions on physical activities can be minimized.

• Future research is needed in the ED field in less-developed countries and among minorities (e.g. transgender individuals). The fact that most research is conducted on women in Western countries, and that it fails to accommodate diversity in the population within and across nations as well as genders, limits our understanding of risk factors.

• How patients perceive the therapist relationship might be dependent on many different factors, such as the physical environment, the therapists' personal attributes, and the therapists' bodily position in relation to the patients during the treatment session. Further research on such aspects is needed.
Summary in Swedish


De huvudsakliga resultaten i studie I visade att den genomsnittliga åldern vid behandlingsstart var 16,5 år och att ungdomarna då hade varit sjuka i genomsnitt två år (n=3997). En tredjedel av dem hade tidigare erfarenheter av ätstörningsbehandling och hos ännu några fler fanns försvårande psykiatriska, sociala eller somatiska faktorer, av vilka de flesta var psykiatriska. Separata analyser för dem som registrerades vid behandlingens slut (n=2195) visade att totalt cirka 55% var diagnosfria och cirka 85% var inom ett hälsosamt viktintervall när behandlingen avslutades. Av dem som fullföljde behandlingen enligt plan var cirka 70% diagnosfria (n=1564). Den genomsnittliga behandlingstiden var 15 månader. Sett över tid ökade andelen diagnosfria och andelen som hade en hälsohet vikt vid behandlingens slut, samtidigt som den genomsnittliga behandlingstiden minsikade. Detta tyder på att behandlingen för ungdomar med restriktiv ätstörning blivit mer effektiv under senare år, men resultaten behöver undersökas ytterligare för att kunna fastställas.

Resultaten i studie II visade att den enskilt vanligaste behandlingsinsatsen för ungdomar var individuell behandling, följt av familjebaserad behandling och somatisk behandling (n=1899). Andelen som fick individuell behandling ökade i takt med ökad ålder vid behandlingsstart, medan

I Studie III analyserades ungdomarnas egna berättelser om sin tid i behandling, och i analysen framkom att ungdomarna kände sig mer eller mindre tvingade in i behandling av sina föräldrar. Många av dem beskrev en stark ambivalens under den första tiden vilket kan kopplas till bristande sjukdomsinsikt och behov av frigörelse från familjen. De gemensamma faktorer som framkom i berättelserna samlades under två huvudteman: Betydelsen av familjens medverkan - på ett eller annat sätt och Progress i behandlingen - en fråga om tillit. Ungdomarna upplevde i efterhand att familjens medverkan i behandlingen var betydelsefull, men att individuell behandling var viktig som ett komplement eller som huvudbehandling när den familjebaserade behandlingen inte fungerade optimalt. Ungdomarna pekade på Vikten av att få möta en behandlare som de kände förtroende för, som kunde ta över i rätt läge och fatta viktiga beslut, men som i takt med tillfrisknandet gav huvudansvaret tillbaka till ungdomen.
I studie IV analyserades ungdomarnas egna berättelser om sin sjukdom och tid i behandling i förhållande till sociala kontexter utanför familjen. Ungdomarnas berättelser om detta följer en tydlig tidslinje som innehåller beskrivningar om när och hur problemen uppstod, tiden i behandling och tillfrisknandeprocessen. Tre huvudteman hittades: Problemen uppstod i vardagliga sammanhang (utanför familjen), Ett liv satt i pausläge och Att skapa nya livsförhållanden. Analysen visade att ungdomarna upplevde svårigheter med att balansera krav- och stressfyllda situationer i livet och skapa ordning i den förvirring som de upplevde föregick sjukdomen. Hur tillfrisknandet fortskred, och hur livet efter behandlingen blev berodde i stor utsträckning på kvaliteten i ungdomarnas interpersonella relationer med vänner och vuxna i sociala kontexter utanför familjen, som t.ex. i skolan och i idrottsammanhang.

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Appendices

Appendix A

DSM-IV Diagnostic criteria for Eating Disorders, AN and EDNOS

307.1 Anorexia Nervosa (AN)

A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g. weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).

B. Intense fear of gaining weight or becoming fat, even though underweight.

C. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

D. In postmenarcheal females, amenorrhoea, i.e. the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhoea if her periods occur only following hormone, e.g. oestrogen, administration.)

Specify type:

Restricting type: During current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behaviour.

Binge-eating/purging type: During the current episode of Anorexia Nervosa the person has regularly engaged in binge-eating or purging behaviour.

307.50 Eating Disorder Not Otherwise Specified (EDNOS), with a predominantly restrictive symptomatology

1. For female patients, all of the criteria for anorexia nervosa are met except that the patient has regular menses.

2. All of the criteria for anorexia nervosa are met except that, despite significant weight loss, the patient’s current weight is in the normal range.
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