

UMEÅ UNIVERSITY MEDICAL DISSERTATIONS  
New Series No 1098 - ISSN 0346-6612 - ISBN 978-91-7264-299-7

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RECOVERY FROM ADOLESCENT  
ONSET ANOREXIA NERVOSA

A LONGITUDINAL STUDY

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Umeå 2007

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ISBN 978-91-7264-299-7

Printed in Sweden by Print & Media, Umeå 2007  
Cover design: Maria Svallfors, [www.borea.nu](http://www.borea.nu)

*To my mother Ruth Elisabeth Holmlund*

## ABSTRACT

Anorexia Nervosa is a psychiatric illness with peak onset in ages 14-17. Most cases recover within a few years, but the illness can have a fatal outcome or long illness duration. Multifactor causes of anorexia nervosa include genetics, personality, family, and socio-cultural factors.

This study measures mortality, recovery from anorexia nervosa, and psychosocial outcome of patients with adolescent onset anorexia nervosa that were treated in Child and Adolescent Psychiatry in northern Sweden from 1980 to 1985. In addition, this study assesses the predictive value of background variables and studies perfectionism in relation to recovery. Finally, this study looks at how patients understand the causes of their anorexia nervosa and how they view their recovery process.

Follow ups were made 8 and 16 years after initial assessment at CAP. Quantitative and qualitative methods were used. These included a semi-structured interview, DSM diagnostics of eating disorders (including GAF), and the self-assessment questionnaires EDI and SCL-90. The interview also contained questions about causes and recovery.

Recovery increased from 68% to 85% from first to second follow-up and the mortality rate was 1%. Somatic problems and paediatric inpatient care during the first treatment period could predict long-term outcome of eating disorders. Most former patients had a satisfying family and work situation. At both follow-ups, individuals with long-term recovery had a lower level of perfectionism than those that recovered later. On individual levels, eating disorder symptoms and psychiatric symptoms decreased during recovery, whereas the levels of perfectionism stayed the same. Causes were attributed to self, family, and socio-cultural stressors outside of the family. The most common self-reported causes were high own demands and perfectionism. All recovered subjects could remember and describe a special turning point when the recovery started and 62% saw themselves as an active agent in the recovery process. Supportive friends, treatment, activities, family of origin, boyfriend, husband, and children were also helpful in the recovery process.

Compared to other outcome studies, the results were good. In spite of the good outcome, some individuals had a long duration of illness and were not yet fully recovered after 16 years of follow-up. Predictors of non-recovery were related to initial somatic problems. Levels of perfectionism were associated to recovery and patients with initial high levels of perfectionism may need more complex treatment strategies. Results from the study also implied that one should stimulate the patients' social contacts and their sense of self-efficacy in their recovery- process.

Keywords: anorexia nervosa, adolescent onset, long-term follow-up, outcome, causes, recovery, perfectionism, patient perspectives

## LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals. Reprints of original papers were made with approval from the publishers

- Paper I** Nilsson, K., & Hägglöf, B. (2005). Long-Term Follow-Up of Adolescent Onset Anorexia Nervosa in Northern Sweden. *European Eating Disorders Review*, 13, 89-100.
- Paper II** Nilsson, K., Sundbom, E., & Hägglöf, B. (2007). A Longitudinal Study of Perfectionism in Adolescent Onset Anorexia Nervosa. Submitted.
- Paper III** Nilsson, K., Abrahamsson, E., Torbiörnsson, A. & Hägglöf, B. (2007). Causes of Adolescent Onset Anorexia Nervosa: Patient Perspectives. *Eating Disorders: the Journal of Treatment and Prevention*, 15, 125-133.
- Paper IV** Nilsson, K., & Hägglöf, B. (2006). Patient Perspectives of Recovery in Adolescent Onset Anorexia Nervosa. *Eating Disorders: the Journal of Treatment and Prevention*, 14, 305-311.

## **ABBREVIATIONS**

AN	Anorexia nervosa
APA	American Psychiatric Association
BMI	Body Mass Index (the weight in kilogram divided by the square of the height in meters)
BN	Bulimia Nervosa
CAP	Child and Adolescent Psychiatry
CI	Confidence interval
CMR	Crude mortality rate
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Eating Disorders
EDI	Eating Disorders Inventory
DT	Drive for Thinness
B	Bulimia
BD	Body Dissatisfaction
I	Ineffectiveness
P	Perfectionism
ID	Interpersonal Distrust
IA	Interoceptive Awareness
MF	Maturity Fears
A	Asceticism
SOP	Self Oriented Perfectionism
SPP	Social Prescribed Perfectionism
EDNOS	Eating Disorders Not Otherwise Specified
GAF	Global Assessment of Functioning
NP	Not Participating
SCL-90	Symptom Check List -90
SDS	Standard Deviation Score
SMR	Standardized Mortality Rate

# CONTENTS

<b>PREFACE</b> .....	<b>1</b>
<b>INTRODUCTION</b> .....	<b>2</b>
History .....	2
Definitions of eating disorders .....	2
Epidemiology .....	5
Treatment .....	7
Assessment of recovery in adolescent onset eating disorders .....	7
Definitions and measurements .....	7
Patients' definitions of recovery .....	8
Outcome of anorexia nervosa .....	8
Mortality and Survival .....	8
Recovery .....	8
Mental health .....	9
Predictors of outcome .....	10
Perfectionism .....	10
Causes and risk factors .....	11
Patient perspectives on causes and recovery .....	11
Summary of introduction .....	13
<b>AIMS</b> .....	<b>15</b>
General aims for this thesis .....	15
Specific aims.....	15
<b>METHODS</b> .....	<b>16</b>
Procedure study I-IV .....	16
Subjects study I-IV.....	16
Dropouts .....	16
Instruments .....	17
Hospital records .....	17
Interview assessments.....	18
Procedure for the interviews.....	18
Interviewers .....	18
Semi-structured Interview at 1 <sup>st</sup> follow-up .....	18
Semi-structured Interview at 2 <sup>nd</sup> follow-up .....	19
Outcome of eating disorders .....	19
Global Assessment of Functioning (GAF) .....	20
Eating Disorders Inventory (EDI) .....	20
Symptom Checklist (SCL –90) .....	20
Study I.....	21
Study II .....	21
Study III.....	22
Study IV.....	23
Statistical methods.....	24
<b>ETHICAL CONSIDERATIONS</b> .....	<b>25</b>

<b>RESULTS .....</b>	<b>26</b>
Study I: Long-Term Follow-Up of Adolescent Onset Anorexia Nervosa .....	26
Mortality and survival.....	26
Eating disorders .....	26
GAF .....	27
EDI .....	27
SCL-90 .....	28
Psychosocial outcome .....	28
Physical and mental health .....	28
Predictors of outcome.....	29
Study II: A Longitudinal Study of Perfectionism .....	31
Perfectionism at 1 <sup>st</sup> and 2 <sup>nd</sup> follow-up.....	31
Comparison between recovered (R) and not recovered (NR).....	31
Differences between four recovery groups .....	32
Study III Patient Perspectives of Causes .....	33
Categories of causes .....	33
The most common causes.....	35
Study IV Patient Perspectives of Recovery .....	35
Sudden/gradual turning-point.....	35
Active-passive.....	35
Important persons .....	36
Most important in the recovery process .....	36
The long struggle towards recovery.....	36
Not Recovered .....	37
Summary of main findings.....	37
 <b>DISCUSSION .....</b>	 <b>38</b>
Originality of the study.....	38
Representativeness of the study group .....	38
Suitability of methods used.....	38
General discussion .....	39
Study I.....	39
Study II .....	40
Study III .....	41
Study IV.....	42
Strengths.....	43
Limitations.....	43
Clinical implications and conclusions.....	44
Implications for further studies.....	45
 <b>ACKNOWLEDGEMENTS.....</b>	 <b>47</b>
 <b>REFERENCES .....</b>	 <b>49</b>
 <b>SVENSK SAMMANFATTNING .....</b>	 <b>58</b>
 <b>APPENDIX I.....</b>	 <b>60</b>

## PREFACE

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### PREFACE

I have worked as a psychologist and family therapist in Child and Adolescent Psychiatry since 1983. Treatment of patients with anorexia nervosa and their families has during many years been a challenging and rewarding part of my daily work. This study started in 1991, as collaboration between clinicians working in CAP clinics in northern Sweden.

This was a time when both Swedish researchers and the Swedish public had a growing interest in the field of eating disorders (Norrington & Clinton, 2002). In Sweden, only a few studies had examined adolescent onset anorexia nervosa (Råstam, Gillberg & Garton, 1989; Isacson, Johnsson & Holmer, 1989) and the results of outcome-studies of patients treated in general Child and Adolescent Psychiatry were scarce and instead studies of anorexia nervosa patients treated in adult psychiatry (Theander, 1985), who reported 18% death rates were cited in newspapers. These reports were frightening for parents with anorectic children that came to Child and Adolescent Psychiatry for treatment. We could see that our patients' recovered but obviously more systematic information was needed about recovery of patients that were treated in Child and Adolescent Psychiatry. I was also an interest in treatment satisfaction and to find out how treatment could be developed. Studies on treatment satisfaction from our study were previously published (Nilsson et al., 1995) and have been used in the development of treatment programs in northern Sweden. This thesis has an interest in treatment but the interest is more on understanding how recovery can be fulfilled than comparing different treatments.

## INTRODUCTION

### History

Throughout history there have been individuals that have starved themselves and had difficulties maintaining their normal body weight. The explanations about why people have starved themselves have changed during the centuries (Vandereycken & Deth, 1994), and there are descriptions of individuals that could possibly have been anorexia nervosa cases long before AN was identified and explained. Early explanations were religious or dealt with possession or illness. In 1874, William Gull and Charles Lasège made the first modern description of anorexia nervosa (see Russell, 1995; Palmer, 2003a). Since their first descriptions, the physiological explanations and the psychological explanations have changed influencing how patients are treated. In addition, several sub-classifications of eating disorders have been identified in the DSM-system (Palmer, 2003b). Bulimia nervosa (BN) was distinguished as a disorder separate from AN by Russell (Russell, 1979). Before 1980, the term 'bulimia' in medical records denoted symptoms of heterogeneous conditions manifested by overeating, but it was not identified as a syndrome, a designation that researchers and health care providers use today.

### Definitions of eating disorders

The current classification systems used in this study is DSM-IV (American Psychiatric Association, APA, 1994). The DSM-IV identifies three major subgroups of eating disorders: anorexia nervosa (AN), bulimia nervosa (BN), and eating disorders not otherwise specified (EDNOS). The criteria for AN include a refusal to maintain normal body weight, an intensive fear of gaining weight, disturbance in the way in which one's body weight or shape is experienced, and amenorrhea for post-menarche females (Table 1). The major feature of anorexia nervosa is a body weight less than 85% of that expected from age, sex and length. Usually weight less than 85% is the result of weight loss but can also be the result of lack of expected weight gain. The amount of weight loss for children is usually determined from growth charts where the weight and heights is documented from school health services. For children and adolescents, there are special curves that provide the body mass index (BMI) reference values for Swedish children in different ages; these values differ for adults (Karlberg, Luo & Albertsson-Wikland, 2001).

## INTRODUCTION

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**Table 1.** Diagnostic criteria for Anorexia Nervosa according to DSM-III-R and DSM-IV.

### **DSM-III-R (APA, 1987)**

- A. Refusal to maintain body weight over a minimal normal weight for age/height; weight loss leading to maintenance of body weight 15% below that expected.
- B. Intensive fear of gaining weight or becoming fat even though underweight.
- C. Disturbance in the way in which one's body weight, size, or shape is experienced.
- D. In females' primary or secondary amenorrhoea (involving at least three menstrual cycles).

### **DSM-IV (APA, 1994)**

- 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, absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhoea if her periods occur only following hormone administration such as oestrogen).

### **Types**

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

The DSM-III-R (Table 1) allowed for a dual diagnose of AN and BN. DSM-IV identified a new sub-classification of AN in pure restricting or binge-purging subtypes. The rules in both of these sets of criteria represent different responses to the fact that low weight and bingeing occur commonly together; therefore, the cardinal features of AN and BN are closely related (Palmer, 2003b). For bulimia nervosa, the main symptoms are binge eating and inappropriate compensatory methods for preventing weight gain (Table 2). An essential feature of both diagnoses is a disturbance in perception of body shape and weight and undue influence of body weight or shape on self-evaluation.

## INTRODUCTION

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**Table 2.** Diagnostic criteria for Bulimia Nervosa according to DSM-IV.

- A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: (1) eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances; (2) a sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating during the episode – a feeling that one cannot stop eating or control what or how much one is eating).
- B. Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, enemas, or other medications, fasting, or excessive exercise.
- C. The binge eating and inappropriate compensatory behaviors both occur, on average, at least twice a week for 3 months.
- D. Self-evaluation is unduly influenced by body shape and weight.
- E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Types:

- Purging type: During the current episode of bulimia nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.
- Non-purging type: During the current episode of bulimia nervosa, the person has used inappropriate compensatory behaviors, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas. Eating disorders that do not fully meet all DSM-IV criteria for AN or BN are diagnosed in category, Eating Disorders Not Otherwise Specified (EDNOS).

## INTRODUCTION

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**Table 3.** Diagnostic criteria for EDNOS according to DSM IV.

Disorders of eating that do not meet the criteria for any specific eating disorder:

- A. For females, all of the criteria for anorexia nervosa are met except that the individual has regular menses.
- B. All of the criteria for anorexia nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
- C. All of the criteria for bulimia nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for duration of less than 3 months.
- D. The regular use of inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two cookies).
- E. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.
- F. Binge-eating disorder: recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviors characteristic of bulimia nervosa.

The main difference between DSM-III-R and DSM-IV was that DSM-IV provided two additional diagnoses, namely binge eating disorder (BED) and eating disorder not otherwise specified (EDNOS). Binge eating disorder was included only as a provisional category 'for further study'.

The diagnostic criteria within the DSM system tend to be based on clinical opinion and consensus, which sometimes don't fit a special individual. The EDNOS category can be problematic because it is a wide and residual category (Clinton, Button, Norring, & Palmer, 2004). Children and adolescents can be difficult to classify in the DSM-system (Nicholls, Chater, & Lask, 2000) although special assessment criteria for children are now being developed (Watkins, Frampton, Lask & Bryant-Waugh, 2005). In spite of serious eating disorders, children and adolescents might not fulfil all diagnostic criteria for a diagnosis according to the DSM-system (Chamay-Weber, Narring, & Michaud, 2005).

### Epidemiology

The rates of a disorder are expressed as incidence (new cases arising in a defined time period in a certain area) or prevalence (total cases existing at a point or in a period in time in a certain area) (Palmer, 2003a). Incidence rates

## INTRODUCTION

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are based on longitudinal data information and may indicate causes and various risk factors.

Anorexia nervosa has its peak onset in the mid to late teenage years (15-19 years) (Hoek, 2006), but it can have its onset in children as young as 8 years (Bryant-Waugh & Kaminski, 1993) and people older than 18 years. Most clinical series report a ratio of at least ten females to each male, but there is considerable uncertainty concerning the prevalence of boys with AN (Doyle & Bryant-Waugh, 2000). Råstam, Gillberg and Garton (1989) screened the total population of children in Göteborg that were born in 1970 for AN. At the age of 16, they found that the prevalence of AN was 0.47% (0.84% for girls and 0.09% for boys). At the age of 18, the cumulative prevalence was 0.58% (1.08% for girls and 0.09% for boys). In a register screening in Sweden of twins born between 1935 and 1958, the overall prevalence of AN was 1.20% for females and 0.29% for male participants (Bulik et al., 2006). The prevalence of AN in both sexes was higher among those born after 1945 than those born between 1935 and 1944. In westernized countries, studies of the overall incidence of anorexia nervosa have indicated an increase during the 1970s and 1980s, but a stabilization during the 1990s (Hoek & Van Hoeken, 2003; Hoek 2006). A Dutch study based on primary care patients (van Son et al., 2006) assessed changes in the incidence of eating disorders in the Netherlands from the 1980s and the 1990s. They found that the overall incidence of AN remained constant while there was an increase of the AN incidence from 56.4 to 109.2 per 100 000 among the high risk group (15-19 years old females). At the same time, the BN incidence rate did not rise as was expected from previous studies reported in van Son et al. (2006). The decrease in the occurrence of bulimia nervosa was also supported by Hoek (2006) and Keel, et al. (2006).

Screening surveys differ with regard to the objective psychometric properties and the methodologies used (Jacobi, Abascal & Taylor, 2004). Most surveys that identify cases with AN are not appropriate for the identification of at-risk behaviours; therefore, Jacobi, Abascal, and Taylor (2004) recommended screens to be used with caution. Jacobi, Abascal, and Taylor (2004) recommended a sequential procedure in which subjects identified as being at risk during the first stage that is followed by more specific diagnostic tests during the second stage, which might overcome some of the limitations of the one-stage screening approach. Keski-Rahkonen et al. (2006) tried another screening procedure. To screen current and life-time anorexia nervosa, they used the questions "Have you ever had anorexia?" and "Has anybody ever suspected that you might have an eating disorder?"; they also used three Eating Disorder Inventory (EDI) subscales and compared the results with a semi-structured interview. They found that simple screening questions, although less than ideal, were at least as good as other available instruments for community screening.

### **Treatment**

Guidelines about treatment of anorexia nervosa were earlier published by The Swedish Medical Research Council, (1993). There are now new guidelines for treatment of AN in Sweden (Svenska Psykiatriska föreningen, 2005) and in UK's National Institute for Clinical Excellence NICE guidelines (Wilson & Shafran, 2005).

### **Assessment of recovery in adolescent onset eating disorders**

#### ***Definitions and measurements***

Hsu (1988; 1996) defined criteria that should be fulfilled in outcome studies of anorexia nervosa. The criteria were (1) explicitly stated diagnostic criteria so that atypical cases are excluded, (2) more than 25 subjects in the study, (3) minimum follow-up of 4 years from the onset of illness, (4) failure-to-trace rate of less than 10%, (5) the use of direct interview in more than 50% of subjects, and (6) the use of multiple well-defined outcome measurements.

Mortality rates are also used as an indicator of the severity of anorexia nervosa (Herzog et al., 2000). The standard outcome measures for mortality are the crude mortality rate (CMR) and the standardized mortality rate (SMR). The CMR is the proportion of deaths within the study population. The SMR is the fraction of the observed mortality rate (CMR) compared with the expected mortality rate in the population of origin, for example, all young females (Hoek, 2006).

In the diagnostic procedure for anorexia nervosa it is possible to use interviews (e.g., Fichter, Herpertz, Quadflieg, & Herpertz-Dahlmann, 1998) or scales for assessment. The Morgan-Russel Scale contains both a global scale, which focuses on weight and menses (Ratnasurya, Eisler, Szmukler, & Russell, 1991), and a wider rating that include physical, psychological, and social aspects of functioning in defining outcome in AN (Morgan & Russel, 1975; Morgan & Hayward, 1988). Steinhausen and Seidel (1993) developed a follow-up interview of eating disorders with questions containing 12 topics such as symptoms of eating disorders, sexuality, and psychosocial situation, rated on 4-point scales (never, seldom, often, very often/absent, slight, moderate, severe) to reflect the intensity or frequency of the respective item. In Sweden, the Rating of Anorexia and Bulimia interview (RAB-R) was developed (Nevonen, Broberg, Clinton & Norring, 2003). There are several self-assessment questionnaires; the most widely used is EDI-2. It has been developed for adults (Norrington & Sohlberg 1988; Garner, 1994) and a research version has been developed for children (Thurfjell, Edlund, Arinell, Hägglöf, & Garner, 2004).

## INTRODUCTION

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### *Patients' definitions of recovery*

In addition to outcome measures, it can also be helpful to know how patients as well as the general population view prevention and treatment programs (Jorm 2000; Mont, Hay, Rodgers, Owen & Beumont, 2004). Noordenbos and Seubring (2006) studied what 41 previous patients considered relevant for recovery. From a list of 52 possible criteria for recovery, patients selected criteria that they viewed as important for recovery. Previous patients considered not only eating behaviour and weight as important, but also psychological, emotional, and social criteria. In a qualitative study of 48 women with experience from eating disorders, Pettersen and Rosenvinge (2002) found that recovery was not entirely dependent on symptom absence. The women also included improved acceptance of oneself, interpersonal relations, problem solving, and body satisfaction in their definition of recovery.

### **Outcome of anorexia nervosa**

#### *Mortality and Survival*

Steinhausen (2000b) found that CMR was 8.3% in a 11-year follow-up study of adolescent onset anorexia nervosa. In a review of 119 studies of anorexia nervosa, the mean CMR was 5% and increased with increasing duration of follow-up (Steinhausen, 2002). A number of studies have reported a CMR of zero after 10 years follow-up of adolescent onset anorexia nervosa (Herpertz-Dahlmann, et al., 2001; Strober, Freeman & Morrell, 1997; Råstam; Gillberg & Wentz, 2003). A Swedish register study of inpatients with anorexia nervosa (Lindblad, Lindberg & Hjern, 2006) found a decrease of deaths from 4.4% in patients hospitalized between 1977 and 1981 compared to 1.3% in patients hospitalized between 1987 and 1991. Signorini et al., (2007) reported 2.72 CMR in a retrospective study of 147 outpatients followed up for 8 years. Nielsen et al. (1998) reported SMR in between 3.6 and 9.9 for adolescent onset anorexia nervosa. Birmingham et al., (2005) found SMR=10.5 in 326 patients treated for anorexia nervosa in Canada. Hoek (2006) concluded that there is still a need to consider anorexia nervosa as a disorder that can be life-threatening and can include serious medical complications (Hägglöf, 2002; Katzman, 2005).

#### *Recovery*

Usually there is a distinction made between younger and older onset (Theander 1996; Rome et al., 2003). Outcome of adolescent onset anorexia nervosa concerning mortality, eating disorders, mental health, and psychosocial functions has generally been better compared to outcome of adult onset anorexia nervosa (Steinhausen, 2002). In a review of 119 outcome studies covering 5.590 patients of different ages it was found that for adolescent onset AN, the mean mortality was 1.8% compared to 5.9% for

## INTRODUCTION

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adult onset. Of patients with adolescent onset AN 57% recovered compared to 44% of the adult onset AN patients, improvement was 25.9 compared to 30.7 and 16.9% compared to 23.0% had a chronic course. The outcome also improved with longer follow-up periods. The better outcome of adolescent onset compared to later onset anorexia nervosa was questioned in a review by Fisher (2003) who found that the evaluation of age of onset as a predictor in anorexia nervosa remain inconclusive. However, during the 10-15 years course of recovery of 95 AN patients 12-17 years of age (Strober, Freeman & Morell, 1997) and in a 8-year follow-up comparing adult and adolescent onset (Casper & Jabine, 1996) it was found that adolescent patients, by virtue of starting at a younger age and thereby having greater developmental potential, may do somewhat better than adults in the first few years after illness and much better than adults in the long-term. Herpertz-Dahlmann et al. (2001) studied the course of adolescent onset inpatients with anorexia nervosa with repeated observations for 10-years and found that 69% were recovered, 3% had AN, and 5% had BN. In a 10-15 year follow-up of adolescents with anorexia nervosa, Strober, Freeman & Morell, 1997 found that 86% had partial recovery and 77% had full recovery. In a 8-year follow-up study of 51 patients treated in regular CAP-services Halvorsen, Andersen, and Heyerdahl (2004) found that 82% had no eating disorder at follow-up, 2% had AN, 2% BN, 14% EDNOS, and no deaths had occurred. In a 10-year population based follow-up study by Wentz (2000), 6% had AN, 4% BN, and 18% EDNOS.

Patients with pre-menarche onset of anorexia nervosa were found to have a less favourable outcome concerning physical development (Russell, 1992; Lask & Bryant-Waugh, 1992; Bryant-Waugh, Hankins, Shafran, Lask & Fosson, 1996; Cooper, Watkins, Bryant-Waugh, & Lask, 2002) and psychopathology (Fisher, 2003). Children can be different at initial evaluation (Peebles, Wilson & Lock, 2006) and may need special assessment (Watkins, Frampton, Lask, & Bryant-Waugh, 2005) and treatment (Rome et al., 2003; Gowers, & Bryant-Waugh, 2004).

### ***Mental health***

Johnson, Cohen, Kasen, and Brook (2002) found that eating disorders during adolescence could be associated with an elevated risk for physical and mental problems during early adulthood. An association between psychiatric comorbidity and eating disorder was found in Herpertz-Dahlmann et al. (2001) whereas long-term recovered patients were comparable to healthy controls. Ekeroth, Broberg, and Nevonen (2004) found increased psychopathology for 96 persons with eating disorders, aged 18-26 compared to 265 randomly chosen age matched controls. In Nolett and Button (2005) there were no differences concerning psychopathology between different eating disorders groups. Holtkamp et al. (2005) found that higher levels of depression, anxiety, and obsession were present in a sample of adults who had recovered from AN for 3 years compared to a matched healthy control group. Wentz, Gillberg, Gillberg, and Råstam (1999) found that 39% had a psychiatric disorder other

## INTRODUCTION

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than ED, in a 10-year follow-up of adolescent onset anorexia nervosa. In a register study of inpatients treated for adolescent onset anorexia nervosa, 8.7% had persistent psychiatric health problems demanded hospital care and 21.4% were dependent on society for their main income, 9-14 years after hospital admission (Hjern, Lindberg & Lindblad, 2006).

### **Predictors of outcome**

Strober, Freeman, and Morell (1997) analysed the degree to which individual predictors were associated with a chronic outcome of severe AN following discharge from a treatment programme. They found that extreme compulsive drive to exercise at discharge and a history of poor social relating preceding onset of illness could explain chronic outcome. Predictors of poor outcome in a study by Zipfel et al. (2000) were long duration of illness before first admission to hospital, low body mass index, an inadequate weight gain before first admission to hospital, and severe psychological or social problems. Binge-eating/purging type had a higher risk of developing a poor outcome than those classified as restricting-type. Herzog, Deter, Fiehn, and Petzold (1997) concluded in a 12-year follow-up of AN patients (age 15-36 years) that laboratory findings obtained at the initial examination may be helpful in predicting a fatal or chronic course of AN. Predictors of mortality included severity of alcohol use during follow up (Keel et al., 2003). Löwe, et al. (2001) found that a low body mass index and a greater severity of social and psychological problems were identified as predictors of poor outcome. Hjern, Lindberg, and Lindblad (2006) found that long duration of hospital care (>180 days compared to 0-28 days) and psychiatric co-morbidity were predictors of persistent psychiatric problems and financial dependency on society. Fichter, Quadflieg, and Hedlund, (2006) found several significant predictors of outcome for adults with AN: sexual problems, impulsivity, length of index inpatient treatment, and duration of eating disorder before index intake. Thurfjell (2006) found that factors related to gender ideals were related to outcome in a 3-year follow-up study of 100 ED patients treated in specialized CAP-clinics.

### **Perfectionism**

Perfectionism is defined as the tendency to set and pursue unrealistically high standards despite the occurrence of adverse consequences (Cassin & Ranson 2005). Perfectionism can precede, maintain, or be an effect of anorexia nervosa and sometimes persist after recovery (Halmi et al., 2000; Franco-Paredes et al., 2005; Lilienfeld, Wonderlich, Riso, Crosby & Mitchell, 2006). Perfectionism can be measured by self assessment instruments and the level of perfectionism has been associated with severity of anorexia nervosa (Sutandar-Pinnock, et al., 2003). A lower level of perfectionism at admission was associated with a better response to treatment, which was subsequently associated with better outcome at follow-up. Perfectionism has been associated with fasting behaviour when specific disordered eating behaviours

## INTRODUCTION

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were studied (Forbush, Heatherton, & Keel, 2007). There has also been empirical support for an association between perfectionism and obsessive-compulsive personality symptoms (Halmi, Tozzi, Thornton et al., 2005) and positive relationships between AN and obsessive compulsive symptoms in children and adolescents (Serpell et al., 2006).

### **Causes and risk factors**

The aetiology of anorexia nervosa is described as multi-factorial. Biological, psychological, and socio-cultural factors might contribute to the disease (Polivy & Herman, 2002; Schmidt, 2003). Jacobi, Hayward, deZwaan, Kraemer, and Agras (2004) found that pregnancy and birth-related complications, obsessive-compulsive disorder, perfectionism, and negative self-evaluation specifically were risk-factors for anorexia nervosa in comparison with a psychiatric comparison group. The main general risk factors for developing anorexia nervosa are being an adolescent female living in a western society (Fairburn & Harrison, 2003). Risk factors for different types of eating disorders involving individual-specific factors and premorbid experiences and characteristics have been identified (Fairburn, Cooper, Doll & Welch, 1999). For anorexia nervosa, there was considered to be a genetic predisposition and a range of environmental risk factors of which many are common risk factors for general psychopathology. Low self-esteem and perfectionism was a common antecedent of anorexia nervosa (Fairburn, Cooper, Doll & Welch 1999). Lindberg and Hjern (2003) found that the most important risk factors were related to the socio-cultural context of the individuals. Steiner et al. (2003) emphasized the importance to concomitantly study both risk and protective factors. He pointed to the possibility of early and preventive interventions if the knowledge from such studies can be used. Favaro, Tenconi, and Santonastaso (2006) found that specific types of obstetric complications and the total number of obstetric complications increased the risk for the child to develop anorexia nervosa. Swenne (2001) found that there were changes in body weight and body mass index (BMI) that differed from the usual pattern in teenage girls before the onset and diagnosis of an eating disorder. Swenne and Thurfjell (2003) found that clinical onset and diagnosis of eating disorders in premenarcheal girls were preceded by inadequate weight gain and growth retardation. There were differences in the patterns depending on ages, but both children and adolescents had changes that preceded an eating disorder.

### **Patient perspectives on causes and recovery**

Nevonen and Broberg (2000) found that a combination of interpersonal and weight-related problems together with dieting behavior constituted main reasons for the emergence of eating disorders according to adult outpatients newly admitted for treatment.

## INTRODUCTION

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D'Abundo and Chally (2004) used grounded theory when they interviewed 17 women that were recovered from eating disorders. In their study, the development of the disorder usually began with unhealthy attitudes favoring thinness and attitudes that sparked dieting and weight loss. The participants became obsessed with weight loss; as a result, the severity of the eating disorder increased. Thinking irrationally, struggling for control, and withdrawing from society were identified as important in the process. In a similar study of 15 inpatients with AN, Dignon, Beardsmore, Spain, and Kuan (2006) found unhappiness, control, being in a downward spiral, obsession, and perfectionism as causes. The spiraling behavior resulted in many patients describing their illness as an obsession. Several patients equated this obsession behavior with a perfectionist trait in their personalities. Weaver, Wuest, and Ciliska (2005) made a model of the development of anorexia nervosa from interviews of 12 recovered women where they used grounded theory. The development of anorexia nervosa was seen as a way to manage inner turmoil. The illness served to interrupt crises, provide recognition of others, and provide a distraction from different stresses and demands. The anorexia helped the women to gain a feeling that they had overcome their personal ineffectiveness.

Tozzi et al., (2002) interviewed patients with anorexia nervosa, mean age 32.3 years, about perceived causes of their anorexia nervosa. The most commonly mentioned self-reported causes were dysfunctional families, weight loss and dieting, stressful experiences and perceived pressure. Button and Warren (2001) found that loss of control and relationship problems was the most common causal themes when they interviewed adult patients.

In a review of qualitative research and questionnaire surveys with people who had experienced an eating disorder or received treatment for it Bell (2003) found that support and understanding were critical aspects of treatment that were perceived as helpful. Also experiences outside treatment had an impact on recovery in particular the presence of supportive relationships. It was also important to get help with wider psychological change and to have some degree of control over the process and pace of treatment.

In different treatments areas and in other diagnostics groups there are several studies describing turning points and experiences of changes. Böhm used "turning-point" to describe a momentary sudden change in quality, depth, or direction during psychoanalysis: "It is as if a metaphorical new door to a new unexpected room is opened. He described the centre of the turning point experience to be the feeling of having an inner life" (1992). Carlberg (1997) described turning points in psychotherapy with children from the perspective of psychotherapists. A few turning-points were "a sudden unexpected change that persisted" but there were also gradual changes. He proposed a model of change in which the turning point was a part of the recovery process. Schreiber (1996) described turning points in women's recovery from depression. She used the phrase "seeing the Abyss", a phase that reflects a

## INTRODUCTION

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woman confronting the fact of her depression. It represented a turning point and was for many a crisis situation. Interviewing patients with severe psychiatric disorders (schizophrenia) about factors contributing to turning-points and recovery (Topor, 2001; 2004) found that the patients themselves were a crucial factor in their own recovery. Throughout the whole course of the disorder, they struggled to find ways to manage both the symptoms and the factors that caused them. What appeared to others as symptoms could instead be the person's unsuccessful attempts to manage existential problems. Entering into and maintaining relationships with other people were crucial factors in recovery work. Professionals from a variety of backgrounds as well as family members and other laypersons could contribute to recovery (Topor, 2001; 2004).

In an interview-study (Tozzi, Sullivan, Fear, McKenzie, & Bulik 2002), the most commonly self-reported factors contributing to recovery of anorexia nervosa were interpersonal factors; partner 27%, maturation 24%, therapy 22%, children/pregnancy 18%, "waking up" 16%, and leaving home 16%. Keski-Rahkonen and Tozzi (2005) found that factors that were helpful varied due to the participant's stage of recovery but will power and ceasing to identify with an eating disorder were important for recovery. Pettersen and Rosenvinge (2002) found that professional treatment, non-professional care, and important persons in the women's lives were identified as important recovery factors. Beresin, Gordon, and Herzog (1989) interviewed 13 women who had recovered from anorexia nervosa. Life experiences from family, work, or school and meaningful relationships were considered as important as therapy in the recovery process. In a study of six recovered anorexic patients, Hsu, Crisp, and Callender (1992) found that psychotherapy, will power, marriage, children, and increased self-confidence were important recovery factors. Weaver, Wuest, and Ciliska (2005) studied 12 women recovered from anorexia nervosa: "finding me" was regarded as a turning-point at which these women began to distance themselves from the eating disorder, realizing that it no longer helped them to attain life goals and aspirations. They also described movement from victim to active participant during the recovery process. In Woods' (2004) study of untreated eating disordered adolescents, recovery was initiated through the empathic, participatory efforts of parents and friends or was self-initiated. In their study, respondents with the shortest disorder duration and most complete recovery reported early parental intervention as an important factor.

### **Summary of introduction**

Anorexia nervosa is a serious illness that affects 1% girls and 0.1% boys predominantly in adolescent ages and mostly in westernized societies. At the present time, there is not an increase of AN except for girls in the ages 14-19. Causes are unknown but models where physiological, psychological, and socio-cultural factors interact are proposed. There are numbers of risk factors identified of which many are similar for mental disorders in general. There is a

## INTRODUCTION

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high degree of other mental problems during the course of AN (depression, anxiety, obsessive-compulsiveness). The CMR has decreased according to a number of studies but there is still a need to consider AN as a disorder that can be life-threatening. Recovery of adolescent onset anorexia nervosa varies between 50-94%. In all studies 15-30% of patients with AN continue to have eating disorders, often in combination with other mental problems. Studies of patient perspectives on causes have shown an awareness of possible contributing factors that have preceded the illness. Patients usually consider more than “eating behaviour” as crucial for recovery and usually more factors than treatment can be important in the recovery process.

## AIMS

### General aims for this thesis

The research questions in this thesis were developed from clinical work. The general aim of this study was to gain knowledge about the recovery of patients with adolescent onset anorexia nervosa that were treated in child and adolescent clinics in northern Sweden. The knowledge was needed in order to provide information about prognosis and to improve treatment. We also wanted to find differences between patients with a short or long illness-duration. This study was inspired by White and Epstone (1989) and Andersen (1989) who highlighted the importance of the patient's knowledge. Therefore, patients' ideas about causes and recovery were important in this study.

### Specific aims

- I. The aim of the first study was to examine the long-term outcome of patients with adolescent onset anorexia nervosa treated in child and adolescent Psychiatry (CAP). The five main areas are mortality, recovery from AN, physiological and mental outcome, psychosocial outcome, and predictive value of background variables.
- II. For the second study, the aim was to study perfectionism in comparison with general psychiatric symptoms during the recovery process. The hypothesis was that higher levels of perfectionism could be related to time of recovery.
- III. The aim of the third study was to explore previous patients' ideas of the causes of their anorexia nervosa. We wanted to compare their view at 8 and 16 years after the onset of the disorder. We also wanted to compare perceived causes between those who were recovered compared to those who were still suffering from an eating disorder.
- IV. The aim of the fourth study was to find out whether the recovery process was characterized by some "turning-points": something important unpredictable or unusual happening such as a special moment of emotional meeting or striking event. Moreover, we wanted to know to what extent the patients described their own personal involvement as an active contribution to the recovery process as well as other contributing factors.

## METHODS

### Procedure study I-IV

This study started with an initial assessment made retrospectively on hospital records from subjects with 1<sup>st</sup> admission to CAP clinics in northern Sweden from 1980 to 1985. A 1<sup>st</sup> follow-up was accomplished in 1991 with a median of 8 years after 1<sup>st</sup> admission to CAP. The 1<sup>st</sup> follow-up was reported in Hägglöf et al. (1998). A 2<sup>nd</sup> follow-up was accomplished 1999 with a median of 16 years after 1<sup>st</sup> admission to CAP. The four studies in this dissertation were based on the results from these two follow-ups.

### Subjects study I-IV

All four studies were based on the same group of previous patients. The study group comprised all patients treated for adolescent onset anorexia nervosa at CAP clinics in northern Sweden from 1980 through 1985. The participating counties Jämtland, Västernorrland, Västerbotten, and Norrbotten provided child and adolescent services as inpatient and outpatient treatment. Since there were no specialised units for young patients with eating disorders at that time, these patients received treatment in ordinary CAP units; sometimes in co-operation with the local paediatric clinic. To be included in the study all criteria for AN according to DSM-III-R (American Psychiatric Association, 1987) had to be fulfilled. Additional criteria for inclusion were a restrictive type of AN according to the DSM IV criteria (American Psychiatric Association, 1994), and age below 18 when the treatment at CAP started. From the hospital records, 91 cases (90 girls, 1 boy) were identified that fulfilled the inclusion criteria. All patients (n=119) that did not meet the criteria were excluded such as BN, EDNOS, pica, eating problems due to depression, psychosis, gastric problems, or feeding-problems in young children. Of the 91 AN cases, 76 women participated in the 1<sup>st</sup> follow-up. Of these, 72 also participated in the second follow-up but only 68 (75%) had completed interviews and questionnaires at both follow-ups.

### Dropouts

There were 15 persons that did not participate (NP) at the 1<sup>st</sup> follow-up. They did not differ from the studied group concerning age of onset, weight reduction and other variables at initial assessment. At the 2<sup>nd</sup> follow-up another 8 persons dropped out; in four of these telephone numbers were not found and another four were excluded because the material was incomplete. According to analyses of the result from 1<sup>st</sup> follow-up, these additional 8 dropouts did not differ from the rest of the group on the variables SCL, EDI, GAF, and BMI at 1<sup>st</sup> follow-up. The total dropout rate at 2<sup>nd</sup> follow-up was 23 people (25%). One person had died during the study period. She died at 23

## METHODS

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years of age due to cardiac failure when she received intravenous nutrition. She was extremely low-weighted and had been treated at four different hospitals.

### Instruments

#### *Hospital records*

For the initial assessment, information from hospital records was collected retrospectively. All records from CAP and paediatric clinics were analysed by 2 different protocols. The CAP protocol included symptoms time before first treatment contact, age at onset of symptoms and age at 1<sup>st</sup> admission, weight and length at 1<sup>st</sup> admission, latest menstruation period, weight phobia, eating habits, psychiatric symptoms, and clinical diagnosis. Treatments as family and/or individual psychotherapy, inpatient care, psychopharmacological treatment, intravenous nutrition, and tube feeding were registered. The protocol for paediatric problems included somatic health problems during the treatment such as cardiac problems, liver function problems, need for electrolyte substitution, severe physical weakness, or generalised oedemas.

Age at 1<sup>st</sup> admission was median 15.0 years with range 10-17 years. Eleven (16%) had pre-menarche onset of AN. Different somatic problems besides typical somatic anorectic signs were seen during the treatment period in 22% of the patients.

There was not always an explicit diagnosis in the medical records but there were length and weight and weight curves from schools which made it possible to assess “refusal to maintain body weight over a minimal normal weight for age/height and if the body weight was 15% below that expected”.

The median weight was 37 kg and height was 1.62 m according to medical journals. Weight below 15% was calculated from age, length and previous weight curves. Weight reduction from highest to lowest weight was calculated as % weight reduction. Mean weight reduction was 29.0%, (sd 9.2, min 15% max 48%). BMI was calculated but was not used in the inclusion process. BMI values at initial assessment were statistically significantly lower than BMI values in Karlberg, Luo and Albertsson-Wikland (2001) when we compared mean BMI for individuals in the same age, (mean 13.95, sd 1.65 comp to mean 19.9, sd 1.11,  $p=.000$ ). At the initial assessment BMI (SDS) was mean -3.362 (sd 1.12, min -6 max -1.0).

At initial assessment there was usually explicit information about menses and amenorrhoea in the records. The criteria involving intensive fear of gaining weight or becoming fat, even though underweight and disturbance in the way in which one's body weight, size, or shape is experienced were also found out from the medical journals at initial assessment .

## METHODS

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Medical assessment and family therapy were provided as a base for treatment and was given to all patients. Individually oriented psychotherapy was provided for 40% of the cases. In-patient care was provided for 47% of the cases (paediatric inpatient care 35%, CAP 33%). Eight (10%) patients had received intravenous nutrition, 6 (8%) psychopharmacological treatment, and 4 (5%) tube feeding. Length of total CAP-treatment was median 12 months, length of inpatient treatment at CAP was median 7 (day and night), and length of inpatient treatment at paediatric clinic was median 2 (day and night).

### **Interview assessments**

#### ***Procedure for the interviews***

At both follow-ups there were written instructions for the procedure. After permission from the clinics and ethical committee a letter with information about the project was sent to the former patients. After some days, the interviewer made a telephone call to invite for an interview and if possible make an appointment. Most interviews took place at the clinics or in the subject's home. The interviews took about 2 hours, which included the time it took to fill out self-report inventories. The interviews were tape-recorded but the interviewers also filled in the semi-structured interview form during and after the interview. At the 1<sup>st</sup> follow-up, we met everybody for the interview. At the 2<sup>nd</sup> follow-up, 21 persons (31%) were interviewed by telephone. Self-report questionnaires were then sent by mail. The telephone interviews were mainly conducted because many of previous patients lived far away.

#### ***Interviewers***

The research group comprised 9 persons in 1991, all employed at CAP. All were active in the planning and interviews. In 1999, there were 4 people from the original group that planned and completed the 2<sup>nd</sup> follow-up including KN and BH.

#### ***Semi-structured Interview at 1<sup>st</sup> follow-up***

Before the construction of the interview we consulted AN researchers in Sweden that gave advices about the follow-up assessment and what instruments to use. The interview was intended to assess outcome with focus on assessment of eating disorders and recovery from anorexia nervosa. There were also questions about causes and recovery. The construction of the interview was done conjoint in the research group during several meetings. We had discussions about the contents and we used video-training to establish equal procedures and ratings.

## METHODS

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### *Semi-structured Interview at 2<sup>nd</sup> follow-up*

Since we wanted to compare the two follow-ups many of the questions at 1<sup>st</sup> follow-up were also used at 2<sup>nd</sup> follow-up (see appendix 1). Both interviews addressed physical and mental health, food and eating, worry about body and appearance and self-reported body weight and length. Due to developments in the field and new research questions we added some questions for the assessment of eating disorders outcome from a Swedish study (Nevonen, Broberg, Clinton & Norring, 2003) and questions for assessment of psychosocial outcome from Steinhausen and Seidel (1993), which contained 12 topics dealing with symptoms of eating disorders and psychosocial outcome (family, studies and work) each of which was rated on a 4-point scale (never, seldom, often, very often/absent, slight, moderate, severe) to reflect the intensity or frequency.

### **Outcome of eating disorders**

Outcome was defined as recovered from eating disorders (R) or not recovered (N-R), at 8 and 16 years follow-up. Recovery was defined as the absence of a diagnosis of any eating disorder – anorexia nervosa (AN), bulimia nervosa (BN), and eating disorder not otherwise specified (EDNOS) – at the time of the interviews according to DSM-IV (APA, 1994). The full recovery required “the sustained absence of weight deviation, compensatory behaviors, and deviant attitudes regarding weight and shape, including weight phobia” (Strober, Freeman & Morrell, 1997). Cases defined as eating disordered fulfilled DSM-IV criteria for AN, BN or EDNOS. Those who fulfilled AN in our study had BMI below 17.5 and no menstruation.

At initial measurements length and weight from medical records was used. Self-reported length, weight and menses were used in the follow-up interviews. Self-reported weight and menses in the age group 13-17 with ED has been studied by Swenne, Belfrage, Thurfjell & Engström (2005). They found that there were no tendency to underreport weight but 12% had a difference >3 kg between reported and measured weight, so that measured weight was higher than reported weight. In a study of 381 women with mean age 29.4 years all were found to underestimate their weight (Brunner Huber, 2007). Self-reported height and weight measures classified 84% of women into appropriate BMI categories. In a survey with 1703 participants (860 men and 843 women, 30 to 75 years old) Nyholm et al. (2007) found that mean difference between measured and self-reported weight were 1.8 kg underreport for women. Higher age and higher BMI were the major causes of bias in selfreport.

Other outcome measures were self-assessed physical and mental health rated on a 4-point scale. The Morgan Russell averaged scale scores were also assessed from the information in the 2<sup>nd</sup> follow-up. This is an averaged composite score summarizing outcome data on body weight, diet restriction,

## METHODS

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menstruation, attitude to sex and menstruation, social relationships, relationship with family and mental state. The score can vary between 0-12, where 12 is the best possible (Morgan, & Russel, 1975; Morgan, & Hayward, 1988).

### **Global Assessment of Functioning (GAF)**

The GAF scale was used to assess psychological, social and occupational functioning according to a hypothetical continuum of health-illness. GAF consists of a 100-point scale, ranging from 1-100: serious disability at the lower end (<50), and superior functioning with no clinical psychiatric symptoms at the other end of the scale (APA, 1994). At the 1<sup>st</sup> follow-up we used DSM-III (APA, 1987), which then had a scale from 0-90 for assessment of GAF.

### **Eating Disorders Inventory (EDI)**

The self-report questionnaire, "Eating Disorder Inventory" (Garner, Olmsted, & Polivy, 1983), measures an attitude or clinical traits related to eating disorders. It was used at both follow-ups. The original version has 64 items that are divided into eight sub-scales: Body Dissatisfaction (belief that specific parts of the body are too large); Bulimia (tendency to exhibit bulimic symptoms of binge eating and self-induced vomiting); Drive for Thinness (excessive concern with dieting in extreme pursuit of thinness); Ineffectiveness (feeling of not being in control of one's life); Interoceptive Awareness (lack of confidence in identifying one's emotions and sensations of hunger and satiety); Interpersonal Distrust (general reluctance to form close relationships); Maturity Fears (desire to return to the security of childhood), and Perfectionism (excessive need for superior achievement). At the 2<sup>nd</sup> follow-up, EDI-2 was used (Garner, 1994), which has 27 additional items that constitute three additional sub-scales: Asceticism (tendency to seek virtue through the pursuit of spiritual ideals such as self-discipline, self-denial, self-restraint, self-sacrifice, and control of bodily urges); Impulse Regulation (the tendency toward impulsivity, substance abuse, recklessness, hostility, destructiveness in interpersonal relationships, and self-destructiveness); Social Insecurity (measures the belief that social relationships are tense, insecure, disappointing, unrewarding, and generally of poor quality). We compared the original 8 scales between 1<sup>st</sup> and 2<sup>nd</sup> follow-up. Research has demonstrated the reliability and validity of EDI (Garner, Olmsted, & Polivy, 1983; Garner, 1994). The test has been validated with Swedish norm groups (Nevonen & Broberg, 2001; Nevonen, Clinton & Norring, 2006).

### **Symptom Checklist (SCL –90)**

The self-report inventory SCL-90, which measures general psychiatric symptoms was used at both follow-ups. SCL-90 is an extended version of the HSCL (Derogatis, Lipman, Rickels, Uhlenhuth & Covi, 1974; Derogatis, 1977), comprising 90 items, scored on nine underlying symptom dimensions:

## METHODS

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Somatisation, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. These dimensions have been identified in repeated factor analyses. The inventory has been widely used in clinical work and in research. SCL-90 has been validated and standardized for Swedish populations (Fridell, Cesarec, Johansson & Thorsen, 2002). For each of the nine scales or symptom dimensions there are a number of items (6-13), each of which are rated on a scale from 0-4. The measure is divided by the number of items on each scale and there is a score for each subscale. The total raw score of all scales can be between 0-360 which is the measure which we used as SCL-total.

### Study I

Study I gives a description of the information from semi-structured interview, DSM-diagnoses, GAF, EDI and SCL-90 and a comparison of the results between 1<sup>st</sup> and 2<sup>nd</sup> follow-up. From 2<sup>nd</sup> follow-up there was additional psychosocial information. The study also described results of predictions of outcome of eating disorders at 2<sup>nd</sup> follow-up from information at the initial assessment.

### Study II

In study II, we analyzed EDI Total (EDI-T, 8 subscales) and in particular the subscale perfectionism (EDI-P), which is defined as excessive need for superior achievement. This scale is considered as a multidimensional measure of perfectionism according to Sherry, Hewitt, Besser, McGee and Flett (2004). The six items from EDI-P scale were divided in self oriented perfectionism (SOP) and socially prescribed perfectionism (SPP), according to Sherry, Hewitt, Besser, McGee and Flett (2004). Items 36, 52 and 63 were used as SOP (I hate to not be the best; I feel that I have to do things perfect- if not, I won't try; I set up very high goals for myself) and items 13, 29, 43 were used as SPP (Only the best achievements are enough in my family; My parents have expected the best achievements from me; As a child I made great efforts to not make my parents and teachers disappointed). As a measure of psychiatric symptoms we used SCL-90.

In study II also time of recovery was analyzed from the question: Have you had any problems with food and eating during the last five years? We divided the individuals into four recovery groups (1-4) according to illness duration. This was an idea modified from Herpertz-Dahlmann et al. (2001) where patients were defined as recovered had not met the criteria for any kind of eating disorder during the last 6 months and long-term recovered when they had met criteria for "recovery" at the 7-year and 10-year follow-up and did not report any eating disorder symptoms during the last 3 years.

## METHODS

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The recovery groups in our study were:

1. recovered at 1<sup>st</sup> and 2<sup>nd</sup> follow-up, no relapse, n=25; (long-term recovered)
2. recovered at least 5 years before 2<sup>nd</sup> follow-up, n=18; (almost long-term recovered)
3. recovered at 2<sup>nd</sup> follow-up but had symptoms during the 5 years before 2<sup>nd</sup> follow-up, n=15; (newly recovered)
4. eating disorder at 1<sup>st</sup> and 2<sup>nd</sup> follow-up, n=10; (not recovered)

Approximate mean illness duration (years) for group 1-4 was: 2.1; 7.9; 10.0 and 16.4 years.

In this way we could get another estimate of the disappearance of eating disorder symptoms from the interview which we could compare with symptoms changes in SCL-90 and EDI during the recovery process. Our study had a recovered design (Lilienfeld, Wonderlich, Riso, Crosby & Mitchell, 2006) where we could identify individuals who were previously ill with anorexia nervosa, but no longer met the illness criteria at the follow-ups.

### Study III

In study III the patients' subjective view on the cause of their AN, was studied from the question:

- “What do you think today about the reasons why you got anorexia nervosa?”

The same question was used in the 1<sup>st</sup> and the 2<sup>nd</sup> follow-up. The question was open-ended in order to give an opportunity for the women to state their own opinions without being limited to predetermined concepts. The persons' own subjective perspectives were important since we wanted categories that were grounded in the answers, not in previous theories.

The answers were tape-recorded and transcribed. The answers could be of varying length (from 2 to 400 words) with one or more sentences. We used content analysis according to definitions developed by Kvale (1996). According to definitions developed by Graneheim & Lundman (2004), the content analysis used in our study focuses on manifest content describing the visible and obvious content. The categories were developed by review of the transcripts several times and developing categories from the content. Then explicit coding instructions were made which were used in the further categorization. The instructions contained three categories and eleven subcategories.

## METHODS

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The answers were scored for each subcategory as absent or present. One answer could contain more than one subcategory. The coding was done manually by the first (KN) and last author (BH) (interrater reliability according to Cohen's Kappa was mean 0.96, ranging from 0.89 to 1.0). We also counted the numbers in each category and subcategory.

### Study IV

For this study about the patients' subjective view on the course of their AN, the following questions were used:

- "Can you remember when there was a turning point?"
- "Can you tell me how the recovery started?"
- "Was there a person or event that was especially important?"
- "What do you think has been most valuable, important, or usable in your aim to feel well and recover from AN?"

The answers were tape-recorded and transcribed. A content analysis was done according to definitions by Graneheim & Lundman (2004) and Kvale (1996) where we focused on manifest content describing the visible and obvious content. Each question was coded according to categories that emerged from the answers and counted according to the numbers in the categories. Persons, activities and helpful things during recovery were counted for the different categories. We found that the answers contained information about the activities of the person as active, passive or both and the turning point as being sudden or gradual. We developed explicit coding instructions for type of own activity and type of turning point. For coding of own activity we used three categories. The active should include a statement of own decision e. g "it is up to yourself if you want to recover". If the answers were coded as passive it should have only statements like: "it just came by itself". We had a third category that include both active and passive which could include an active decision but also passive receiving of help from others. A sudden turning point should include information about something that initiated a change at a special moment or event. It could be an outside or inside change. Example of a sudden turning point could be: "My grandpa drew a picture of a tomb with the dates of my birth and death; this scared me so much that I realized what I was doing and I decided to start to eat." A gradual change should include some statement of gradual change and not contain information of a sudden change. We only had these two alternatives for turning-point experiences. An analyze of the answers of the four questions concerning if the subjects were active or passive and if the recovery process was sudden or gradual was done by the first and second author and a researcher with no previous knowledge of the material. In this analyze inter-rater reliability according to Cohen's Kappa was ranging from .74 to 1.0.

## METHODS

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### Statistical methods

In Study I-IV, the data was registered and statistical analysis was carried out using SPSS for Windows, version 14.0 (Field, 2005). Because the scale scores were not normally distributed we mainly used non-parametric statistics.

In study I, comparisons between groups were done using Mann-Whitney test, and the comparisons between 1<sup>st</sup> and 2<sup>nd</sup> follow-up were done using Wilcoxon signed-ranks test. Comparisons between diagnostic groups were made using the Kruskal-Wallis Test. Significance level was 0.05. Correlation was calculated by Spearman's correlation coefficient ( $\rho$ ). Logistic regression analysis was performed to analyse of the relationships between those recovered/not recovered and background factors (Odds Ratio). Logistic regression is a statistical technique that allows for analysis of relationship between a dichotomous dependent variable and one or more explanatory variables (Field, 2005). It can be used to determine the joint effect (including interaction) of the explanatory variables on the dependent variable and to adjust for the confounding effects of the remaining factors. The result of logistic regression is presented as odds ratios and 95% confidence intervals (CI). Odds ratio is an association of exposure to one or several factors among one group (cases) compared with another group (referents), i. e. the number of exposed individuals to non-exposed individuals among the referents. In our study logistic regression was performed for background variables and the cases that were recovered compared to those that were not recovered.

In study II, correlations between all measurements were determined by Spearman Rank correlation. Chronbach's alpha for internal consistency was used in order to measure the reliability of the tests in the study. Mann-Whitney signed ranked test was used to measure differences between the same individuals at follow-ups and Mann-Whitney U test to measure differences between recovered (R) and not recovered (NR). Kruskal-Wallis Test for differences between several independent groups was used to measure differences between the four recovery groups, for post hoc test Mann-Whitney U test was used. An alpha level of  $p < 0.05$  was used for overall effects, while an alpha level of 0.01 according to Bonferroni adjustment was used for pair wise comparisons between recovery groups to control for the relatively large numbers of tests conducted.

In study III and IV, Cohen's kappa (Cohen, 1960) was used to determine interrater reliability. In study III Spearman rank correlations were used to determine correlations between 1<sup>st</sup> and 2<sup>nd</sup> follow-up. Wilcoxon signed ranks test for two related samples was used to determine differences between 1<sup>st</sup> and 2<sup>nd</sup> follow-up. Fishers' exact test was used to determine differences between recovered and not-recovered.

## ETHICAL CONSIDERATIONS

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### ETHICAL CONSIDERATIONS

The study was approved from the ethical committee at Umeå University nr Dnr 91-007, dated 1991-02-12. The study was completed with informed consent from the participants in the study. The study was also approved from the heads of the participating Child and Adolescent Psychiatric Clinics (CAP) which included permission for the researchers to use information from the medical records. The research persons were all professionals that were employed at CAP in general health care. Before meeting with the previous patients we sent a letter with information about the project and informed that we were going to make a telephone call to ask if they wanted to participate, and if so, make an appointment for an interview. At the end of the 1<sup>st</sup> interview we asked about permission to contact for another interview. At the 2<sup>nd</sup> follow-up we used the same procedure with information letter and telephone call when we made an appointment for the interview. At both follow-ups we had permission from The Data Inspection Board (no 232100206-7). The data set did not contain any identifiable data like person numbers and it is not possible to detect any individuals in the presentations.

RESULTS

**Study I: Long-Term Follow-Up of Adolescent Onset Anorexia Nervosa**

*Mortality and survival*

From the group of 91 patients, one had died before the 1<sup>st</sup> follow-up. In 1999, we were able to trace the 76 people that participated in the 1<sup>st</sup> follow-up. They were all alive through 1999. Eleven people from the group of 91 that did not participate in 1<sup>st</sup> follow-up were alive in 1999 according to the Swedish national register. Three participants could not be traced because their birth numbers were not saved.

*Eating disorders*

According to DSM III-R and DSM IV, 2 subjects were diagnosed with AN (2, 3%) at both follow-ups. BN decreased from 4 (5.9%) at the 1<sup>st</sup> follow-up to 1 (1.5%) at the 2<sup>nd</sup> follow-up. EDNOS decreased from 16 (23.5%) at the 1<sup>st</sup> follow-up to 7 (10.3%) at the 2<sup>nd</sup> follow-up. Recovery from eating disorders increased statistically significant from 46 (67.6%) at the 1<sup>st</sup> follow up to 58 (85.3%) at the 2<sup>nd</sup> follow-up.

**Table 4.** Clinical diagnoses of eating disorders (T1= 1<sup>st</sup> admission, T2 = 1<sup>st</sup> follow-up, T3=2<sup>nd</sup> follow-up).

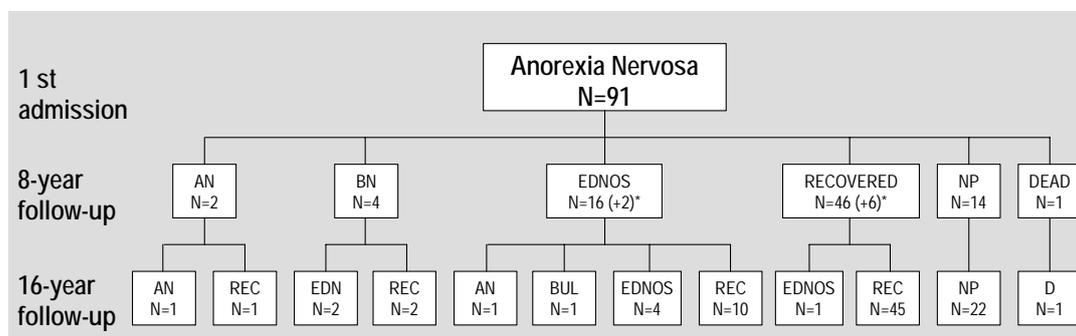
Diagnoses	T1	T2	T3	p-value*
AN	68	2	2	0.000
BN	0	4	1	
EDNOS	0	16	7	
No ED	0	46	58	

\*RxC contingency table, exact p-value

Those who were recovered by the time of the 1<sup>st</sup> follow-up were still recovered at the 2<sup>nd</sup> follow-up except for one person that had EDNOS at the 2<sup>nd</sup> follow-up. Ten of 16 individuals with EDNOS at the 1<sup>st</sup> follow-up were recovered while 6 were not recovered at the 2<sup>nd</sup> follow-up. Of these 6; one had AN, one had BN and four had EDNOS at the 2<sup>nd</sup> follow-up.

## RESULTS

**Figure 1.** Course of adolescent anorexia nervosa during a 16-year follow up (AN: anorexia nervosa; BN: bulimia nervosa; EDNOS: eating disorder not otherwise specified; REC: recovered; NP: not participating; D: dead).



Mean height increased significantly from initial assessment to 1<sup>st</sup> follow-up, from mean 1.62 to 1.67 m. Height did not change significantly between the two follow-ups. Weight increased significantly from initial assessment when it was mean 37.1 kg to 57.8 kg at 1<sup>st</sup> follow-up and 59.0 kg at 2<sup>nd</sup> follow-up.

At the 2<sup>nd</sup> follow-up Morgan-Russell (M-R) average outcome score (Morgan & Hayward, 1988) for the whole group was mean 10.72 (sd =1.69). The M-R average outcome score was statistically different for recovered and not recovered from eating disorders (m=11.14, sd=1.03 compared to m=8.30, sd=2.62, p=0.000) at the 2<sup>nd</sup> follow-up.

### ***GAF***

GAF significantly improved from 1<sup>st</sup> follow-up (mean =74.7, sd=12.31) to 2<sup>nd</sup> follow-up (mean=82.1, sd=10.87, p=0.000). GAF was significantly different also when it was corrected for the different scales used at 1<sup>st</sup> and 2<sup>nd</sup> follow-up.

### ***EDI***

EDI improved statistically significant from 1<sup>st</sup> follow-up (mean = 31.35, sd = 27.83) compared to 2<sup>nd</sup> follow-up (mean = 22.15, sd = 19.08, p=0.001). The strongest improvement was shown on the sub-scales “bulimia”, “drive for thinness”, and “body dissatisfaction”. All sub-scales except “maturity fears”, “perfectionism”, and “interoceptive awareness” had improved statistically significant. At both follow-ups, all scales except “ineffectiveness” were below clinical cut-off score suggested by Norring and Sohlberg (1988). A comparison with 602 non eating disorders controls from the general population (Nevonen, Clinton & Norring, 2006) at the 2<sup>nd</sup> follow-up showed that the subscale perfectionism was significantly higher for our group of 68 persons (m=4.04, sd 3.5 in comparison with m=2.6, sd=3.4, p=0.002). The control group had significantly higher (worse) scores on the subscales bulimia and body dissatisfaction in comparison with our study group at 2<sup>nd</sup> follow-up. The total score and the other subscales were not statistically significantly different.

## RESULTS

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### *SCL-90*

Result on SCL- 90 total score had improved from 1<sup>st</sup> follow- up (mean = 63.29, sd = 51.04) to 2<sup>nd</sup> follow-up (mean = 48.60, sd = 47.80,  $p=0.001$ ). The sub-scales “obsession-compulsion”, “interpersonal sensitivity”, “paranoid ideation”, and “psychoticism” showed the largest improvements. At 2<sup>nd</sup> follow-up our study population did not differ statistically significant from Swedish normative data (Fridell, Cesarec, Johansson & Thorsen, 2002) on all subscales except for the subscale Interpersonal Sensitivity which was statistically significantly higher for our study group ( $m=0.72$ ,  $sd=0.66$  compared to  $m=0.55$ ,  $sd=0.57$ ,  $p=0.044$ ).

### *Psychosocial outcome*

At the 2<sup>nd</sup> follow-up 91% had moved from the parents and 68% lived with a partner and additional 15% had a boyfriend. At the 1<sup>st</sup> follow-up, 25% had given birth to one or more children compared to 50% at the 2<sup>nd</sup> follow-up. Usually, the mothers felt comfortable as a mother. Only a few had experienced a crisis due to the pregnancy and childbirth. There were some women who wanted children, but were too concerned about the reactions the "big stomach" would have on their mental health. The total number of children was 66 in the group of 68 women at the 2<sup>nd</sup> follow-up which correspond to a fertility rate of 0.97. In 1997, total fertility rate of women (age 15-49) in Sweden was 1.5 children per women (SCB, 1999). According to self-evaluation at 2<sup>nd</sup> follow-up avoidance of sexual behaviour was absent in 64%, slight in 21%, moderate 13% and severe in 2%. Fifty-seven percent had a satisfactory relation to family of origin, 26% a slight unsatisfactory relation to family of origin, and 17% had moderate unsatisfactory relations with family of origin. Sixty-four percent had satisfactory social contacts, 28% had slightly unsatisfactory social contacts, and 8% had moderate unsatisfactory social contacts. Vocational career was good for 54%, slightly impaired for 29%, moderately impaired in 12%, and for 5% severely impaired. School career was good for 64%, slightly impaired for 26%, and moderately impaired for 10% of the participants. We found differences between the subjects recovered and those still having an eating disorder with statistically significant differences according to sexuality ( $p = .002$ ), number of children ( $p = .003$ ), and social contacts ( $p = .004$ ). Vocational situation during the last 5 years was close to significant ( $p = .069$ ).

### *Physical and mental health*

Physical health was estimated to be very good in 48 (70%) and good in 19 (28%). Only one (2%) estimated present physical health to be bad and none estimated physical health to be very bad at the 2<sup>nd</sup> follow-up. The main problems were teeth enamel problems and gastric-intestinal problems of different kinds. Mental health was estimated to be very good by 32 (47%), and

## RESULTS

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26 (38%) good. Eight persons (12%) estimated their present mental health to be bad, and 2 (3%) estimated their mental health to be very bad. During the 5 years prior to the 2<sup>nd</sup> follow-up 25 persons had experienced mental symptoms, of these were 14 (56%) depression, 7 (28%) anxiety, 3 (12%) compulsive symptoms and 1 (4%) phobic symptoms. Eight of 10 with eating problems had mental problems. Almost 50% of the individuals with EDNOS at the 1<sup>st</sup> follow-up had other mental problems at the 2<sup>nd</sup> follow-up.

### *Predictors of outcome*

Several variables recorded at initial assessment were analyzed in order to determine whether they were of value in predicting the 16 year outcome. As dependent variable a dichotomous variable was constructed with not recovered NR=0 and recovered R =1. The NR group included patients with AN, BN, and EDNOS (10 people). All others were assigned to the recovered group (58 people). A cross-tab statistics using Fisher exact test showed statistically significant associations between NR and somatic problems ( $p = 0.035$ ) and paediatric inpatient care ( $p = 0.018$ ). CAP inpatient care ( $p = 0.065$ ) and intravenous nutrition ( $p = 0.088$ ) were close to being statistically significant. Several variables such as age of onset of symptoms, symptom time before treatment and weight reduction (%) at initial assessment, total length of CAP treatment, length of inpatient treatment and length of follow-up at initial assessment did not show associations to recovery at 2<sup>nd</sup> follow-up. The variable NR/R was used as a dependent variable in a univariate and multivariate logistic regression model. Table 5 gives Odds-Ratios for univariate analysis and 95% confidence intervals for all independent variables entered. Significant predictors in the univariate model were somatic problems and paediatric inpatient care. In the multivariate model there were no significant predictors.

## RESULTS

**Table 5.** Odds ratio (OR) univariate and 95% confidence intervals (C.I.) to be recovered from eating disorders 1999 when background factors from initial assessment years 1980-1985 are grouped in yes-no or high-low.

Variable	OR	95% C.I.	
Somatic problems	no	1.0	0.05-0.86
	yes	0.21	
Paediatric inpatient care	no	1.0	0.04-0.77
	yes	0.18	
CAP inpatient care	no	1.0	0.07-1.11
	yes	0.28	
Psychopharmaca	no	1.0	0.05-1.89
	yes	0.30	
IV nutrition	no	1.0	0.04-1.13
	yes	0.22	
Tube feeding	no	1.0	0.05-5.25
	yes	0.49	
Age group	no	1.0	0.12-2.46
	yes	0.55	
Weight reduction	no	1.0	0.13-3.43
	yes	0.66	

SCL-90, EDI, and GAF were also used as outcome measures. Differences for means of SCL-90, EDI and GAF were tested between persons that were grouped according to information in initial assessment. Somatic problems, psychopharmacologic treatment, paediatric and CAP inpatient care were grouped according to the answers yes-no. Age and weight-reduction were grouped in high and low. Low age was defined as 10-13 years at initial assessment and high age was defined as 14-17 years at initial assessment. Definition of high weight-reduction was the high and low 25th percentile. Statistically significant differences were shown for the SCL-90 values for the groups with or without psychopharmacologic treatment, age groups and CAP inpatient care. EDI-8 significantly differed between age groups. There were no significant differences for the groups on GAF. High scores on SCL-90 were associated to psychopharmacological treatment, low age group at onset and CAP inpatient care. The low age groups had significantly higher values on EDI.

## RESULTS

### Study II: A Longitudinal Study of Perfectionism

#### *Perfectionism at 1<sup>st</sup> and 2<sup>nd</sup> follow-up*

Means on symptoms for the total group (measured by EDI-8, SCL-90 and GAF) showed significant decrease except for perfectionism (measured by EDI-P, SOP and SPP) that tended to increase at the 2<sup>nd</sup> follow-up compared to the 1<sup>st</sup> follow-up. This increase was not statistically significant. The values of SOP were numerically higher than the scores of SPP.

#### *Comparison between recovered (R) and not recovered (NR)*

Table 6 shows the means and standard deviation for recovered (R) and not recovered (NR) on EDI, SCL-90 and GAF at the 2<sup>nd</sup> follow-up. For eating disordered symptoms (EDI-8) and psychiatric symptoms (SCL-90) there were statistical significant differences between R and NR. For perfectionism (EDI-P, SOP and SPP) there was not a significant difference between R and NR. Table 6 also shows means of the subscale EDI-P for a non clinical group from Nevenon, Clinton and Norring, (2006), and on the obsessive-compulsive scale (O-C) from Fridell, Cesarec, Johansson and Thorsen (2002). The recovered group had numerically higher levels on EDI-P but lower on O-C in comparison with the non-clinical group.

**Table 6.** EDI, SCL-90 and GAF for Recovered (R) and Not Recovered (N-R) at 2<sup>nd</sup> follow-up.

	<b>2<sup>nd</sup> R n=58</b>	<b>2<sup>nd</sup> NR n=10</b>	<b>p-value</b>	<b>Non-Clinical m (sd)</b>
	<b>m (sd)</b>	<b>m (sd)</b>		
EDI				
EDI-8	18.50 (16.59)	43.30 (19.60)	0.001	
EDI-P	3.84 (3.56)	5.20 (3.01)	0.174	2.6 (3.4)
SOP	2.33 (2.52)	3.40 (2.22)	0.120	
SPP	1.52 (1.71)	1.80 (1.23)	0.346	
SCL-90				
Total	38.97 (34.82)	104.50 (72.56)	0.002	
O-C	0.50 (0.49)	1.20 (0.98)	0.028	0.65 (0.61) <sup>2</sup>
GAF	84.57 (9.33)	67.90 (8.14)	0.001	

<sup>1</sup> mean and (sd) for non clinical group age 18-30, n=602 from Nevenon et al. (2006)

<sup>2</sup> mean and (sd) for non clinical group age 20-40, n=707 from Fridell et al. (2002)

## RESULTS

### *Differences between four recovery groups*

Table 7 shows EDI, SCL-90 and GAF for the recovery groups. There were significant differences at both follow-ups. Table 7 also shows the groups that were different according to post hoc tests. The most common difference was between group 1 and 4 but usually also group 1 differed from group 3. At the 2<sup>nd</sup> follow up SOP was not significant different when  $p < 0.01$  was used in post hoc, but the tendency was that group 1 was lower than group 4 ( $p = 0.045$ ).

**Table 7.** Comparison between recovery groups (1, 2, 3, 4) at 1<sup>st</sup> and 2<sup>nd</sup> follow-up.

	1 n=25 m	2 n=18 m	3 n=15 m	4 n=10 m	p-value	post hoc test
<b>1<sup>st</sup> follow-up</b>						
EDI						
EDI-8	14.32	26.06	51.20	53.70	<0.001	1<3, 4; 2<4
EDI-P	1.40	3.72	5.27	6.00	<0.001	1<2, 3, 4
SOP	0.80	2.67	2.07	4.30	.001	1<2, 3, 4
SPP	0.60	1.06	3.20	1.70	.003	1<3
SCL-90						
Total	32.68	58.44	91.87	105.70	<0.001	1<3, 4
O-C	0.49	0.81	1.24	1.43	<0.001	1<3, 4
GAF	80.36	76.67	69.13	65.40	<0.001	1>3, 4; 2>4
<b>2<sup>nd</sup> follow-up</b>						
EDI						
EDI-8	10.16	22.89	27.13***	43.30	<0.001	1<2, 3, 4; 2<4
EDI-P	2.24	4.78	5.40	5.20	.001	1<2, 3, 4
SOP	1.56	3.11	2.67	3.40	.045	n.s
SPP	0.68	1.67	2.73	1.80	.001	1<3
SCL-90						
Total	24.76	46.33	53.80**	104.50	<0.001	1<3, 4
O-C	0.30**	0.61	0.72**	1.20	<0.001	1<3, 4
GAF	87.04***	83.89	78.33***	67.90	<0.001	1>3, 4

<sup>1</sup> 1. long-term recovered, recovered at 1<sup>st</sup> and 2<sup>nd</sup> follow-up, no relapse, n=25

2. recovered 5 years or more before 2<sup>nd</sup> follow-up, n=18

3. recovered at 2<sup>nd</sup> follow-up but had symptoms during the last 5 years before 2<sup>nd</sup> follow-up, n=15

4. not recovered from eating disorder, n=10

\*\*  $p < 0.05$  \*\*\*  $p < 0.01$

## RESULTS

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Table 7 also show how the individuals changed from 1<sup>st</sup> to 2<sup>nd</sup> follow-up. Group 1 decreased significant in obsessive-compulsive symptoms and increased in GAF while perfectionism had a tendency to increase. Also group 2 that did not change significantly between 1<sup>st</sup> and 2<sup>nd</sup> follow-up, had a tendency to increase the scores on perfectionism. This increase was within normality for both group 1 and 2. Group 3, that contained many individuals that recovered in between follow-ups, changed on all measurements but perfectionism. Group 4 did not change significant on any measurement between 1<sup>st</sup> and 2<sup>nd</sup> follow-up. To summarize: EDI P, SOP and SPP did not change statistically significant in any group. Numerically they increased in groups 1-3, and stayed high in group 4. The main findings were that EDI-P was dependent on recovery. There was a higher level of perfectionism if the person was not recovered or newly recovered. Those that recovered early (long term recovered) had a lower EDI-P than other groups and were within normal range at both follow-ups. Over time the EDI-P was stable in the different recovery groups and did not change on an individual level from 1<sup>st</sup> to 2<sup>nd</sup> follow-up.

### Study III Patient Perspectives of Causes

#### *Categories of causes*

Of the eleven subcategories, four dealt with self, three with the family, and four with socio-cultural aspects outside of the family (Table 8). The first four categories had to do with the person (self): demands/perfectionism; developmental crisis or physical or mental symptoms; dieting/body dissatisfaction; and low-self esteem. The family-categories were: difficulties in family interaction/communication; stressful life-events; and high demands from family-members. The four socio-cultural sub-categories were: problems with peer/bullying, bad situation at school; ideals; moving/separation; and sports. There could be more than one sub-category for each person. At the 1<sup>st</sup> follow-up, nine persons (13%) did not have any answer of causes, whereas at the 2<sup>nd</sup> there was only one (1.5%) with no answer.

## RESULTS

**Table 8.** Definitions and examples of categories.

Definition of Categories	Examples
<b>SELF</b>	
Own demands/high achievement, perfectionism/compulsory traits	“ambitious and high own demands”; “the goals were too high and difficult to achieve”; “a need to control and be perfect”
Developmental crisis or physical or mental symptoms	“changes in body and appearance were difficult”; “did not like when I grew and needed a bigger size”; “I stopped to eat because I wanted to die”; “I have always felt different, developed early”; “genetics”; “something in the brain”; “gastroenteritis”
High BMI, dieting, high degree of body dissatisfaction	“I was too heavy and decided to loose weight”; “I did not like my body”; “started to count calories in home-economics”
Low self esteem, negative self value	“poor self-confidence”; “low self esteem -uncertain about myself”
<b>FAMILY</b>	
Difficulties in family interaction and communication too little care or overprotection	“the parents did not talk openly with me or each other, no one showed any feelings, that was difficult when I was a teenager”; “my parents had no time with me and did not see that I was feeling bad”; “I wanted more attention and support from the parents”; “I was the first child of very young parents that overprotected me”
Stressful family-life; e g death of family member, illness or handicap, sexual abuse	“disappointed at mother’s alcohol problems”; “handicapped brother was born”; “a very difficult and traumatic childhood, with abusive relations”; “quarrels and rivalry between siblings”; “the parents were talking about divorce”; “sexual abuse from six years age”
High demands from family members for achievement or appearances	“heavy demands and expectations from my father”; “from 8 years of age, I had a lot of responsibility for my siblings”; “my mother was often on a diet”; “my grandmother said “what a fat girl” when I had got muscles from sports activities”
<b>SOCIOCULTURAL/ENVIRONMENTAL PRESSURES OUTSIDE OF THE FAMILY</b>	
Bad situation or incident/bullying at school and with peers	“a classmate that told me I was fat”; it was awful in school, I had no friends”; “rape at 13 years of age”
Ideals	“the ideals of society”; “I wanted to be like everybody else”
Moving to new place/separation	“moving to a new place at 10 years of age, was too old to move”; “my boyfriend broke up”
Sports	“I was in gymnastics and was told by coaches to loose weight before competitions”

## RESULTS

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### *The most common causes*

At both follow-ups high own demands/perfectionism had the highest value. There were statistically significant more answers concerning stress/event in the family ( $p=0.002$ ) and family interaction/communication ( $p=0.023$ ) at the 2<sup>nd</sup> compared to the 1<sup>st</sup> follow-up. Other subcategories were the same. Correlations between 1<sup>st</sup> and 2<sup>nd</sup> follow-up were significant for development crisis, problems with peers/bullying, ideals, moving/separation and sports. Self was the most common category with 164 answers, compared to 90 for family and 73 for socio-cultural. The most common subcategory was own demands/perfectionism, 62 (19%) of the totally 327, the other subcategories were in-between 11-35 (3%-11%). No categories differed statistically significant between recovered and un-recovered. There was a tendency that not recovered persons more often than recovered answered low self-esteem and problems with peers/bullying. We also noticed that only recovered mentioned moving/separation and sports in their answers of causes.

### **Study IV Patient Perspectives of Recovery**

#### *Sudden/gradual turning-point*

All recovered subjects could remember and describe a special turning point when the recovery started. The turning points were described as sudden by 38 subjects (65.5%) and more gradual by 20 subjects (34.5%). Unexpected commentaries or events were the most common things that contributed to the turning-point. For example, the seriousness with which the father of a boyfriend told a girl not to eat made a strong impression. These events were significant experiences that sometimes had to do with life and death, usually thinking that continued starvation would lead to death. The illness and death of a friend could encourage the subject to prefer life rather than death. An insight into the thinness of the body could be gained by looking in a mirror or comparing weight with a sister that previously was considered to be thinner. In other cases some body experiences like fainting, swelling of legs, and irregular heartbeats were frightening and could cause the subjects to re-evaluate their situation. Moving to a new place or leaving home was mentioned by 19%, and changing to a new school or entering high school was mentioned by 14% as important for the turning-point.

#### *Active-passive*

Analyzing the answers from all four questions, we found that 36 of the 58 answers of recovered subjects (62.1%) were coded as active. Own activity was described as important in the turning point and during the recovery process, activities that included will power and inner strength. Fifteen (25.9%) were coded as both active and passive. Seven (12.1%) were coded as passive, of these 5 (71.4%) recovered within the first two years.

## RESULTS

### *Important persons*

Persons that were especially important were family members (38%), persons related to treatment (35%), friends (33%) and boyfriends (24%).

### *Most important in the recovery process*

**Table 9.** The most valuable and important factors for recovery (n=58).

	n	%
Friends	25	43
Myself	23	40
Activities	19	33
Treatment	18	31
Family	10	17
Boyfriend/own family	7	12

Table 9 show that most useful in the recovery process were friends mentioned by 25 (43%). Friends could show alternative and normal life styles and how to enjoy life. Twenty-three (40%) of the recovered subjects, saw themselves as the active agent: own thoughts, will power, insights, maturation, decisions, persistence, and changes in the control and thinking of their well being instead of focusing on other people's needs. Next, activities 19 (33%), treatment 18 (31%), family of origin 10 (17%), and boyfriend/own family 7 (12%) were seen as the most useful tools in the recovery process.

In treatment, both treatment methods and special persons were mentioned as helpful. Often special persons and meetings during the treatment were seen as important. It could be a doctor that waited one more day with the intravenous nutrition because the girl needed some more time to get ready or a special doctor that cared and was honest. It could be a dietician that offered concrete information or a nurse that weighed or an understanding nurse at the school. It could also be an assistant nurse at inpatient treatment that was particular and confident in his way to assure that it was not dangerous to eat.

A wide variety of new activities were described as helpful such as: work, getting a pet (e.g. horses), travelling, reading books, dancing, writing, painting, and sculpting.

### *The long struggle towards recovery*

Getting well after a long time (mean 9.5 years, median 11 years) was demanding but could have its start in some special event (friends wedding), insight of damage of the body, longings for another life or a crisis situation. Most common was that different treatments and struggles over time finally turned out in a positive result. "A long process that gives result", "why you do

## RESULTS

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not recover is because you do not know anything about the alternatives, when you find alternatives that can fill the emptiness you use that instead of food". One person described that there was an early turning point but there were relapses but she had repeatedly made new decisions about recovery. Finally she had found herself and health during a trip abroad.

### ***Not Recovered***

Persons that were not recovered were still searching for things that would lead to recovery. In this process factors like own decision, family, friends and activities were important but treatment was seen as the most hopeful thing. Four of the 10 not recovered persons were currently in treatment and two wanted treatment. There were different explanations of the prolonged course of illness. Two persons mentioned genetic or social factors as an explanation of the prolonged course of illness. Two persons thought that difficulties in relations maintained their eating problems. One person held that her personality of perfectionism was the explanation and one person thought it was her extreme need to be seen that came from a strong feeling of not being loved. Two persons had difficulties to enter into new situations and changes, which resulted in very much anxiety that also maintained the symptoms of eating disorders. One was sometimes just overwhelmed by anorectic thoughts and could not ignore them. One person had for the first time decided to get well and was convinced that her decision now would lead to health.

### **Summary of main findings**

- The mortality rate was 1 (1%).
- Recovery increased from 46 (68%) to 58 (85%) from 1<sup>st</sup> to 2<sup>nd</sup> follow-up.
- AN were 2 (3%) in both follow-ups.
- Bulimia nervosa (BN) decreased from 4 (6%) to 1 (1.5%) from 1<sup>st</sup> to 2<sup>nd</sup> follow-up.
- EDNOS decreased from 16 (24%) to 7 (10%) from 1<sup>st</sup> to 2<sup>nd</sup> follow-up.
- 15% had depressive, anxiety, or compulsory symptoms at the 2<sup>nd</sup> follow-up.
- Somatic problems and paediatric inpatient care during the first treatment period could predict worse long-term outcome of eating disorders.
- The level of perfectionism was associated to recovery.
- Own demands/perfectionism was the most common self-reported cause of anorexia nervosa.
- 62% saw themselves as the active agent in the recovery process.
- Important for recovery were friends, activities, treatment and family.
- Persons with a long duration of eating disorders were continuously striving for recovery.

## DISCUSSION

### **Originality of the study**

This study had a longitudinal approach with a long follow-up time and repeated follow-up measurements in combination with descriptions of previous patients' own ideas of causes and recovery. The study group was clearly defined according to age and diagnoses and the previous patients were treated in regular Child and Adolescent Psychiatry (CAP). As much as 75% of the study group completed both follow-ups. The methods in this dissertation were both quantitative and qualitative. We have not found other 16-year follow up studies of adolescent onset AN treated in regular CAP services which have combined quantitative and qualitative information in a longitudinal study.

### **Representativeness of the study group**

The clinical group that was studied in the four papers is representative of AN patients treated in CAP in northern Sweden. This can be claimed since there were totally only 25% dropouts and because there was a careful screening procedure. Since we only included AN with restrictive type we cannot draw conclusions about other diagnostic groups of eating disorders. There was no control group but the main measurements were repeated and were compared for the same individuals. For the questionnaires used in the study there are population norms (Fridell, 2002; Nevonen, & Broberg 2001; Nevonen, Clinton & Norring, 2006) with which we compared our results.

### **Suitability of methods used**

Mortality rates were estimated on the basis of crude rates which is the most common measure of mortality (Steinhausen, 2002). Definition of recovery from eating disorders can be defined narrow, only including normalization of weight and menses or broadly which then include recovery of normal eating related cognitions and general psychological and social functioning. Couturier and Lock, (2006) found that the criteria of >85% body weight was fulfilled after mean 11.3 months whereas a recovery including also psychological recovery was fulfilled after 22.6 months. We considered the possibility that different criteria could give different results and therefore we choose a combination of measurements. As main criteria we choose the DSM-criteria which takes into account both weight, menses, fear of gaining weight or becoming fat, even though underweight and disturbance in the way in which one's body size is experienced. If we only had used the M-R outcome criteria of weight and menses we would have missed some persons with normal weight and menses that still had eating related problems. As additional outcome criteria we also used GAF, based on interviewer assessments and the self assessment instruments eating disorders inventory (EDI), and for

## DISCUSSION

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psychiatric symptoms (SCL-90). We used EDI-P as a measure of Self Oriented and Socially Prescribed Perfectionism and found that the psychometric properties of Self Oriented Perfectionism were better than for the whole EDI-P scales, which confirm the difference between SOP and SPP.

In the interview we used self-ratings of mental and physiological health at the time of the interview and during the 5 years prior to the 2<sup>nd</sup> interview. We also had additional questions about social situation which also made it possible to assess the combined scores according to Morgan and Hayward (1988). This kind of combined score have however been found difficult to interpret (Couturier & Lock, 2006) and therefore we decided to also report the outcome measures separately to increase the validity of the results. The questions comparable to those used in Steinhausen (1993) were compared with his outcome studies from different countries (Steinhausen, 1997; 2000a; 2000b; 2003). We could have included additional instruments for measuring psychopathology and personality disorders but since our main aim was to study survival and recovery from AN, additional measurement was beyond our aim. The self assessment of height and weight at follow-ups could be discussed. It would have been a more secure measure if the researchers had performed the assessments. From recent studies of self-reported weight (Swenne, Belfrage, Thurfjell, & Engström, 2005; Brunner Huber, 2007; Nyholm et al., 2007) one can conclude that the studied group at both follow-ups were in age and weight groups that did not underreport their weight since higher age and higher BMI were the major causes of bias in selfreport (Nyholm et al., 2007).

### General discussion

#### *Study I*

The aim of the first study was to examine the long-term outcome of patients with adolescent onset anorexia nervosa, treated in Child and Adolescent Psychiatry (CAP). The main areas were: mortality, recovery from AN, physiological and mental outcome, psychosocial outcome, and predictive value of background variables

In our study one death due to AN occurred in the early treatment period, a result comparable with Lindblad, Lindberg and Hjern, (2006) that found a death rate 1.3% in register data of patients hospitalized 1977-1981 in Sweden for AN. The low mortality rate in our study confirmed the result from other studies that mortality among young eating disorders patients has decreased.

The recovery from anorexia nervosa was 85.3% at the 2<sup>nd</sup> follow-up. Weight and menstruation were in 83% already normalized at 1<sup>st</sup> follow-up but there were 32.4% that were diagnosed with an eating disorder according to DSM-IV at 1<sup>st</sup> follow-up (Hägglöf et al., 1998).

## DISCUSSION

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When different studies are compared the characteristics of the study groups (age and duration of AN), duration of the follow-ups and the measurements that are used have to be considered.

The reported recovery rates of anorexia nervosa vary from 57% to 94% (Couturier & Lock, 2006). Many studies have a selection of cases that is biased due to special treatment programs. In Strober, Freeman and Morell (1997) their 95 patients with severe anorexia nervosa were treated in a special program. Their study showed that the time course of recovery was protracted until 10 years when it reached a plateau. The full recovery was reached in 76% of their sample after 10-15 years of follow-up. Studies of patients treated in general CAP services are rare, but the sample treated in general CAP services in the study by Halvorsen, Andersen and Heyerdal, (2004) had 82% recovery from eating disorders after 8 years of follow-up. Studies of Steinhausen (2000) that compared treatment and 5-years outcome of 138 AN patients in 3 countries showed that 20% maintained their anorexic symptoms. Those that were drug treated had a worse outcome. All patients in Herpertz-Dahlmann et al. (2001) were inpatients and 69% were recovered from eating disorders after 10 year follow-up, but 51% had a persisting psychiatric disorder. Our study also showed that it is important to consider other mental problems besides the eating disorder problems in the assessment of outcome. The impairment of functions that we found can be seen as serious consequences of AN. Approximately 17% had impairments that negatively influenced their work and other areas of life.

There is not enough knowledge about factors influencing the long term-outcome of AN. In our study somatic problems and paediatric inpatient care at first treatment period could predict eating disorders at the 2<sup>nd</sup> follow-up. Gowers et al. (2000) carried out a non-randomized, naturalistic comparison of adolescents with AN after treatment as inpatients and outpatients. They found those treated as inpatients did less well, with admission status being the main predictive variables. Their findings suggest caution in assessing the benefits of inpatient treatment, but care should be taken about conclusions drawn from their study in the absence of a randomized design.

### *Study II*

Perfectionism did not decrease between follow-ups and the levels of perfectionism were higher than in a normal control group. The hypothesis was that perfectionism could be related to time of recovery which we also found. Perfectionism did not change from 1<sup>st</sup> to 2<sup>nd</sup> follow-up although the levels of general psychopathology including obsessive-compulsive symptoms decreased concomitantly with decrease of eating disorders symptoms; also found in Fichter, Quadflieg & Hedlund (2006) in a 12 year follow-up of patients with severe AN. When we compared “recovery groups” in our study it was found that long term recovered had a lower perfectionism score than other groups and were within normal range at both follow-ups. Groups that recovered later

## DISCUSSION

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had a higher perfectionism score which did not decrease. The level of perfectionism was higher for persons that were not recovered or newly recovered but it did not change between follow-ups and can be seen as measuring a reluctant symptom. Nolett & Button (2005) found that higher levels of eating psychopathology measured by EDI-scales, except perfectionism, were associated with higher levels of psychological distress. Blatt (1995) found that more extensive therapy was necessary for many highly perfectionist, self-critical patients and patients with initial high levels of perfectionism may need more complex treatment strategies.

### *Study III*

The aim of the third paper was to explore previous patients' ideas of the causes of their anorexia nervosa. We wanted to compare their view at 8 and 16 years after the onset of anorexia nervosa. We also wanted to compare perceived causes between those who were recovered compared to those who were still suffering from an eating disorder.

The most common answers about causes of anorexia nervosa were things that had to do with self. High own demands/perfectionism were the most common sub-category at both follow-ups. In our study, this category included high ambitions, perfectionism, and compulsory traits. From a clinical point of view, it is well recognized that patients with anorexia nervosa often display rigid, stereotypic, ritualistic, or perfectionist behaviors (Jacobi, Hayward, Zwaan, Kraemer, & Agras, 2004). Fairburn, Cooper, Doll, & Welch (1999) showed that premorbid perfectionism was more common in adolescents with anorexia nervosa as compared to healthy comparison subjects and other subjects with psychiatric disturbances. Halmi, et al. (2000) found a positive correlation between perfectionism and eating disorder severity in a symptomatic group. Perfectionism has been shown to promote dieting behavior (Steiner, et al., 2003). Developmental crisis, overwhelming demands, different symptoms and low self-esteem preceding the onset of anorexia nervosa were also seen as causes.

When dieting was attributed as a cause of anorexia nervosa in our study, there was often a description of an active decision to loose weight. Longitudinal studies (Thompson, Covert, & Stormer, 1999; Lunner et al., 2000; Lunner, 2003) have proposed that BMI, weight related teasing, and body dissatisfaction can lead to restrained eating which later can lead to eating disorders. However we do not know why some people that diet develop anorexia while others do not. Identification of both factors associated with the emergence of anorexia nervosa and the failure to develop the disorder has implication for both detection and prevention of the disorder (Walsh et al., 2005).

There were more answers concerning stress/event in the family and family interaction/communication at the 2<sup>nd</sup> compared to the 1<sup>st</sup> follow-up. Among family factors, interaction/communication, stressful events, and high demands

## DISCUSSION

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from family members were described. Anorexia nervosa could be a result of difficulties in expressing feelings or pressure to achieve high grades in school. A chronic illness in the family could result in stress and too much burden of responsibility for the child. Sensibility for other persons' needs could result in doing too much without having been asked about it. Previous studies have shown that anorexia nervosa patients experienced higher expectations from parents in comparison with a control group (Fairburn, Cooper, Doll, & Welch, 1999). Other studies (Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2002; Beresin, Gordon, & Herzog, 1989) that asked patients about the causes of anorexia nervosa found family dysfunction to be the most common answer.

Socio-cultural pressure to be thin as well as peers/bullying, ideals and sports were also found among the answers. Media often idealize thinness and focus on body shape and size for women (Thurfjell, 2005). In our study, some of the recovered subjects (but none of the not recovered) attributed sports to be the cause of their anorexia nervosa.

No categories differed statistically significant between recovered and not recovered.

At the second follow-up the answers were more reflective and complex and there were combinations from the different categories. There were significant more answers about family causes. There were less "do not know" answers, and the answers contained more information. The combinations of categories can be due to an insight of the pressure coming from different sources. Other explanations could be that some subjects became parents and could see family perspectives in another way at the 2<sup>nd</sup> follow-up.

The most common explanations the young girls had about their development of anorexia nervosa were the demands they put on themselves. Some also experienced stresses and demands from their family and different socio-cultural life stresses.

### ***Study IV***

The aim of the fourth study was to find out whether the recovery process was characterized by some "turning-points", i.e. something important unpredictable or unusual happening like a special moment of emotional meeting or striking event. Moreover we wanted to know to what extent the patients described their own personal involvement as an active contribution to the recovery process as well as other contributing factors. All recovered subjects could remember and describe a special turning point when the recovery started and many saw themselves as the active agent in the recovery process. Almost as important were friends that could show alternative and normal ways of living, and how to enjoy life. Also treatment, activities, family of origin, and boyfriend, husband and children were important in the recovery process. In general, from these findings one may conclude that in order to

## DISCUSSION

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improve the treatment outcome in the long run, one should stimulate and support the patients' social contacts (developing a social network) and their sense of self-efficacy (being an active agent in their change process). Perhaps the combination of the two will – be it through treatment or the result of influential life events – will be the most powerful catalyser in the recovery process.

The importance of supporting different aspects of the patients' life was also shown in a study of patients' view on quality of life by de la Rie, Noordenbos, Donker, and van Furth (2007). Their results supported the importance of other persons. In spite of difficulties in caring for someone that has an eating disorder (Whitney, Murray, Gavan, Todd, Whitaker, & Treasure, 2005; de la Rie, Noordenbos, Donker, & van Furth, 2005) parents have been found to be very motivated to continue to give support to their children (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004).

### Strengths

The strengths of this study are the long follow-up period, large sample, and comparable methodology. Our study fulfilled most of the criteria outlined by Hsu (1988; 1996) for outcome studies of anorexia nervosa with explicitly stated diagnostic criteria, more than 25 subjects in the study, minimum follow-up of 4 years from the onset of illness, the use of direct interview in more than 50% of subjects, and the use of multiple well-defined outcome measurements.

The strengths of the qualitative studies were the previous patients' own words that were analyzed. Our findings agreed with other studies of causes and risk-factor research. This was also the implication of the external validity of the present study. We think it was valuable to distinguish between causes of self, the family, and socio-cultural causes. This makes our results more clear than previous reports of patient descriptions of causes.

### Limitations

At initial assessment all patients were children with median age 15.0, range 10-years and at the 1<sup>st</sup> follow-up they were median 23 years (range 18-25) and at 2<sup>nd</sup> follow-up they were median 30 years (24-36 years). BMI under the age of 18 are not comparable with BMI for adults. Therefore BMI has to be adjusted for age if it is used in comparisons. This was not done in paper one and therefore the value of the results where BMI is compared between follow ups are questionable. Usually BMI was not used at that time as a nutritional index (He, Albertsson-Wikland, & Karlberg, 2000) and body mass index reference values were published quite recently. Reference body mass index values for individuals more than 18 years of age are also lacking. We therefore later made calculations where we found that BMI values at initial assessment were statistically significantly lower than mean BMI values in He, Albertsson-Wikland & Karlberg (2000). We also calculated BMI (SDS) values which

## DISCUSSION

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showed that the study population was at a very low weight at initial assessment. In spite of this the BMI (SDS) initially was not significantly associated to recovery from eating disorders at 2<sup>nd</sup> follow-up.

One general problem when people get older is that they generally score lower scores on self-assessment mental health questionnaires. Therefore some of the decrease on the results on EDI and SCL-90 can also be attributed to higher age at the 2<sup>nd</sup> follow-up. For SCL-90 we could also have used the global (GSI) the General Symptom Index (GSI).

There was not a full medical examination and a full DSM evaluation of mental health was not done except for eating disorders. Results on questions of mental health mainly came from self-evaluation. It was not possible to meet everybody personally in the second follow-up. The dropout rate of 25% in the second follow-up is somewhat higher than the recommended 10%. There were three patients from the drop-out group that we could not trace because the birth-numbers were not saved. We did not have a control group, but we compared the same measurements between follow-ups, which made it possible to make comparisons for each individual and we used standardized measurements as reference values.

The interview was not validated and it could have been developed more but it was more important to compare between measurements. We added new questions at the 2<sup>nd</sup> follow-up which could not be compared to the 1<sup>st</sup> follow-up. These questions were mainly psychosocial aspects which also seemed more important to find out in the second follow-up. We did not have exact measurements for treatment received after the CAP treatment which could be related to outcome.

The GAF measure used in the 2<sup>nd</sup> follow-up was slightly changed due to the scale changed from 0-90 to 0-100. EDI-2 had three additional scales which we only used at the 2<sup>nd</sup> follow-up. These scales have been shown to have less good properties (Nevonen, Clinton, & Norring, 2006).

In the study of causes it was not possible to distinguish between factors – symptoms, maintaining factors, or consequences of the disorders – that preceded the onset as was done in risk factor research (Jacobi, Hayward, deZwaan, Kraemer & Agras, 2004). We could not control for how the answers were influenced by the present health status. There were some difficulties when deciding about the categories; more categories might need to be developed to compare results of different studies.

### **Clinical implications and conclusions**

This follow-up study has shed light on the process of recovery for patients treated in child and adolescent psychiatry with the diagnose anorexia nervosa.

## DISCUSSION

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The results concerning survival and recovery for a group of patients with adolescent onset anorexia nervosa show that the rate of recovery is better than previously estimated. At the same time the study shows that anorexia nervosa can be both a life threatening and protracted illness with one death and eating disorders symptoms for 10 years or more for 1/3 of the previous patients. Similar findings were found in a 10-15 year follow-up of adolescents with anorexia nervosa, (Strober, Freeman & Morell, 1997) that found similar high recovery rates but also a protracted course of anorexia nervosa.

The importance of careful treatment of medical complications is still an issue. Maybe the most important issue for the clinics is still the importance of being aware of the risk for development of a protracted illness that can last for many years. From the start of treatment it can be difficult to find individuals at risk for a longer duration of illness. If the patient does not recover during the first 2 years of treatments it is important to find out what might be hinder for recovery and maybe intensify and adopt treatment. By making clinical follow-ups of patients that have terminated treatment it can be possible to get knowledge about relapses and maybe make suitable interventions. Hypotheses that emerged from our study were caution about initial difficult somatic problems and high levels of perfectionism.

There are studies of patients with long illness duration that have shown positive treatment outcome. Rö et al., (2005) found that adult patients with eating disorders of more than five years duration and previous treatment could benefit from a multi component inpatient treatment program. From our study and other studies (e.g Noordenbos, Jacobs & Hertenberger, 1998; de la Rie, Noordenbos, Donker & van Furth, 2006) it is also possible to learn more about treatment that patients with anorexia nervosa consider as most helpful by making interviews. From all studies it seems that recovery involves more than changes in weight, eating behaviors and preoccupations with food and appearance. From an interview study (Bers, Blatt & Dolinsky, 2004 p. 310) found that many anorexia nervosa patients appeared “to be engaged in a desperate struggle to feel adequate, worthy, and effective, but in a way that leaves them feeling even more inadequate, unworthy and ineffective”. Therefore the nature of and changes in the sense of self was suggested as an important consideration of the treatment process with anorexia-nervosa patients.

### **Implications for further studies**

From this study it seems important to get more knowledge and understanding about patients with long duration of anorexia nervosa. The studies should also include thorough analyses of treatment attempts.

From our findings about different levels of perfectionism it seems important to further clarify the role of perfectionism in the development and

## DISCUSSION

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maintainance of anorexia nervosa and to develop measurements for different types of perfectionism for clinical use in Sweden.

Decision to diet was in this study sometimes attributed as a cause of the development of anorexia nervosa. The role of dieting and its possible connection to development of eating disorders is inconclusive and need further study.

## ACKNOWLEDGEMENTS

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### ACKNOWLEDGEMENTS

First and most I want to thank my supervisor Bruno Hägglöf. This dissertation would not have been written without you. Thank you for believing in the project, for your trust in my ability and for making it financially possible to finish this longitudinal project.

Also very important for the completion of this thesis was Birgitta Bäcklund administrator at the Division of Child and Adolescent Psychiatry. Thank you for help with all kinds of practical things and for arranging many nice meetings and social events during these 3 years. I also want to express my sincere gratitude to you for competent editing of the final manuscript.

I want to thank the following persons that have been most important and helpful for me in different aspects during the work with the thesis:

Anna Torbiornsson and Erik Abrahamsson for taking part in the planning and accomplishment of both follow-ups.

Statistician Hans Stenlund for teaching and for helping me to find the right statistical analyzes and how to communicate the results and Lars Dahlgren for valuable comments about my qualitative data analyses.

For help with coding of interviews and for support and information about the academic word I want to thank Gustav Ståhlberg.

For valuable comments at the mid-seminar: Bengt-Åke Armelius, Ulf Wallin and Elisabet Sundbom. To Elisabet also for fruitful cooperation and supervision after the mid-seminar.

The friendly and generous atmosphere at the Division of Psychiatry has provided an important and creative research context supported by Lars Jacobsson and Gunnar Kullgren. Especially I want to thank Ellinor Salander Renberg, PhD student coordinator and very supportive in both big and small problems during the dissertation work and Margaretha Lindh and Doris Cedergren for nice company.

The doctoral student colleagues at the Department of Clinical Sciences who helped by reading and commenting my papers during the dissertation work: Solveig Petersen, Mats Karling, Stephen Goldin, Jeanette Sigurdh, Krister Fredin, Spyridoula Lekkou, Anna Zashihina, Daniel Fekadu and Menelik Desta. Jeanette Sigurdh also for taking part in the planning of the second interview.

Barbro Thurfjell, thank you for interesting educational meetings and discussions and work with “three question of ideals” that still is left to do.

## ACKNOWLEDGEMENTS

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My thanks also go to helpful research colleges in the eating disorders field who chaired their knowledge and gave me advices: Inger Halvorsen, Walter Vandereycken and Greta Noordenbos.

My colleagues at Lycksele Child and Adolescent Psychiatry for doing all the other work when I was writing my thesis: Anneli Lindström and the whole team thank you for your work and for the supportive interest in my work. I also want to thank Lars Åström at Lycksele Psychiatric Clinic for supporting the research project. I want to thank my previous colleagues at Sundsvall Child and Adolescent Psychiatry for cooperative and developing work in the field of eating disorders. Thank you all for generously sharing of your knowledge.

For financial support I want to thank the county of Västerbotten, Hans Malker, FOU-centrum of Västernorrland, and Anna S Lindström, Child and Adolescent Psychiatry, Västerbotten.

My friends and my family have been important during these years. My mother Ruth Holmlund, thank you for support and interest during my work with the thesis which have continued in spite of your recent health problems and for all delicious meals and good bakery. My son Fritjof, sisters and brother with families; thank you for support and help with everything and thank you all for just being there.

Finally I would like to express my gratitude to the young women that participated in the interviews and shared their knowledge and experience with me. Knowledge that I hope will be of help in the field of eating disorders and shed light on some important issues.

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### SVENSK SAMMANFATTNING

Anorexia nervosa är en sjukdom som drabbar ca 1% flickor och 0.1% pojkar i länder med västerländsk livsstil. Sjukdomen debuterar vanligtvis i åldern 14-17 år och kännetecknas av en intensiv önskan att gå ner i vikt trots att kroppsvikten är lägre än den förväntade. Anorexia nervosa anses vara orsakad genom komplicerade samspel mellan biologiska, genetiska, individuella, grupp, familj och sociokulturella faktorer. Förekomsten av anorexia nervosa har varit stabil under 1990-talet men en ökning av förekomst i högrisk-gruppen 15-19 åriga kvinnor har beskrivits. Anorexia nervosa kan vara livshotande, innebära ett långdraget sjukdomsförlopp men tillfrisknande kan också ske inom 1-2 år. Initialt kan det vara svårt att förutsäga det individuella sjukdomsförloppet. Tidig diagnostik och behandling rekommenderas.

Denna avhandling fokuserar på att undersöka tillfrisknandet från anorexia nervosa, genom att studera överlevnad, ätstörningssymtom, fysisk och psykisk hälsa samt olika psykosociala aspekter 16 år efter sjukdomsdebut. Vi undersökte också om något vid behandlingsstart kunde predicera förekomst av ätstörningar efter 16 år. Förändringar av tendensen att försöka uppnå orealistiska höga mål trots att det ger negativa konsekvenser (perfektionism) undersöktes i relation till tillfrisknande. Slutligen undersöktes kvinnornas tankar kring orsaker till och tillfrisknande från anorexia nervosa.

De som ingick i studien var 68 unga kvinnor som sökte hjälp inom barn- och ungdomspsykiatri i norra Sverige under åren 1980-1985. För att ingå i studien skulle diagnostiska kriterier för anorexia nervosa vara uppfyllda.

Uppföljningar gjordes 8 och 16 år efter första kontakt med barn- och ungdomspsykiatri (BUP). Kvantitativa och kvalitativa metoder användes i studien. Metoderna var en semistrukturerad intervju, diagnostik av ätstörningar utifrån DSM-systemet och självskattningsskalorna EDI och SCL-90. I intervjun fanns också öppna frågor som handlade om åsikter om orsaker till varför man drabbats av sjukdomen och vad som varit till nytta för tillfrisknandet.

Resultatet efter 16 års uppföljning visade att alla utom en fortfarande levde och att 85% av de tidigare patienterna inte hade någon ätstörning. De som hade inte hade haft svåra kroppsliga problem och inte hade vårdats vid barnmedicinsk klinik var i högre grad tillfrisknade än de som haft svåra kroppsliga problem eller vårdats vid barnmedicinsk klinik. De flesta hade välfungerande socialt liv beträffande familj och arbete. Vid båda uppföljningarna befanns de som tillfrisknade tidigast ha en lägre nivå av perfektionism. Psykiatriska symptom minskade när ätstörningssymtomen minskade men nivåerna på perfektionsim var oförändrad.

## SVENSK SAMMANFATTNING

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De självrapporterade orsakerna kategoriserades i tre huvudkategorier (själv, familj och sociokulturella faktorer utanför familjen). Den mest vanliga orsaken var höga egna krav och perfektionism. Alla som tillfrisknat kunde komma ihåg och beskriva en speciell vändpunkt när tillfrisknandet startade och 62% beskrev sig själva som aktiva och betydelsefulla för tillfrisknandeprocessen. Vänner, behandling, aktiviteter, ursprungsfamilj och egen familj var också betydelsefulla för tillfrisknandet. För att tillfriskna var både egen aktivitet, behandling och sociala kontakter av stor betydelse.

I jämförelse med andra långtidsuppföljningar av patienter med anorexia nervosa som debuterat under ungdomsåren var resultatet bra. Trots att resultat kan ses som bra kan man notera i denna samt i andra jämförbara uppföljningsstudier att minst 15-20% har ett långdraget sjukdomsförlopp.

## APPENDIX I

### ANOREXIPROJEKTET NORRLAND

#### Frågeformulär för Semistrukturerad intervju II

Siffrorna inom parantes motsvarar siffror i intervjuformulär nr I. De som ej är numrerade är nya. Ett flertal av frågorna går att jämföra med Steinhausens formulär. Hänvisning görs även till LUAB-T.

KOD

LÄN

DATUM

INTERVJUARE

PLATS

TID

Datum och plats när formuläret ifyllts:

Intervjukommentarer:

## APPENDIX I

### I. Nu situation avseende hälsa

Hur mår du idag vad gäller fysisk hälsa? (24 a)	Mycket bra	Ganska bra	Ganska dåligt	Mycket dåligt
Kommentarer:	1	2	3	4
Hur mår du idag vad gäller psykiska hälsa?	Mycket bra	Ganska bra	Ganska dåligt	Mycket dåligt
Kommentarer:	1	2	3	4
Hur fungerar det för dig när det gäller mat och måltider?	Mycket bra	Ganska bra	Ganska dåligt	Mycket dåligt
Kommentarer:	1	2	3	4
Vad väger du? (24 b)	Antal kg:			
Kommentarer:				
Intervjuarens bedömning av uppgiven vikt. (Ringa in tillämpligt alternativ).	OK	Mer	Mindre	
Uppskattat antal kg om ingen vikt angetts?	Antal kg:			
Hur lång är du? (24 c)	Antal cm:			
Kommentarer:				
Försöker du förändra din kropp/vikt?	Ja	Nej		
Kommentarer:				
Har du menstruation? (24 d)	Ja	Nej		
Hur fungerar din menstruation?	Regelbunden	Något oregelbunden	Mycket oregelbunden	Upphört < 3 mån
Kommentarer:	1	2	3	4
Använder du för närvarande någon av dessa metoder för att gå ner i vikt?	(Intervjuarens bedömning med hjälp av LUAB-T)			
	Aldrig	Sällan	Ofta	Mycket ofta
Hetsätning (LUAB fråga 18)	1	2	3	4
Kräkning (LUAB fråga 25)	1	2	3	4
Laxermedel (LUAB fråga 26)	1	2	3	4
Överdriven motion (LUAB fråga 24)	1	2	3	4
Hur ofta motionerar du och med vad?				
Kommentarer:				

## APPENDIX I

Viktfofi och kroppsuppfattning (utifrån intervjuarens skattning)

Detta bedöms av intervjuaren utifrån ovanstående frågor om mat, ätande, önskan att gå ner i vikt samt hur betydelsefull kroppsformen är för personens självkänsla samt personens allmänna kroppsuppfattning.

Rädsla för att gå upp i vikt (LUAB fråga 8, 9, 10, 37)	Ingen viktfofi 1	Tendenser viktfofi 2	Tydlig viktfofi 3	Extrem viktfofi 4
Kroppsuppfattning (LUAB fråga 11, 35, 36)	Bra 1	Ganska bra 2	Ganska dåligt 3	Mycket dåligt 4

### II. Mellanperiod 1991-1996

Hur tycker du att de senaste 5 åren har varit avseende: (22)

Utbildning?	Bra 1	Ganska bra 2	Ganska dåligt 3	Dåligt 4
Vilken/vilka utbildningar har du gått?				
Kommentarer:				
Arbete?	Bra 1	Ganska bra 2	Ganska dåligt 3	Dåligt 4
Har du arbete? Vad?				
Kommentarer:				
Familjeliv?	Bra 1	Ganska bra 2	Ganska dåligt 3	Dåligt 4
Kommentarer:				
Har du under de senaste 5 åren haft problem kring mat och ätande? (23 a)	Ja	Nej		
Om ja, komplettera med följdfrågor för att fastställa typ av svårigheter, tidpunkt och omfattning.				
Typ?	AN	BUL	Annat	
När?				
Hur länge?				
Svårighet?				
Kommentarer:				
(Intervjuarens sammanfattande bedömning)	Inga problem 1	Lite problem 2	Ganska stora problem 3	Stora problem 4

## APPENDIX I

Har du haft andra psykiska svårigheter? (23 b)	Ja	Nej
Om ja, specificera:		
Kommentarer:		
Har du haft fysiska svårigheter?	Ja	Nej
Om ja, specificera:		
Kommentarer:		
Har du sökt hjälp för något eller några av dessa? (23 c)	Ja	Nej
Om ja, (23 d)		
Var?		
När?		
Vilken hjälp fick du? (t ex samtal, psykoterapi, psykofarmaka, hormoner, annan medicin etc)		
Vad tyckte du om denna hjälp? (23 e)		
Skulle du behöva mera hjälp?	Ja	Nej
Om ja, precisera vilken hjälp du skulle önska.		

### III. Nu situation avseende familj, arbete, fritid

Är det någon i din närmaste familj som fått eller haft ätstörningsproblematik, drogproblem eller psykiatrisk sjukdom?	Ja	Nej		
Om ja, precisera vem, vad samt ev behandling.				
Hur ofta träffar du din ursprungsfamilj idag? (25 d) (inkl syskon och tredje gen)	Dagligen	> 2 ggr/ vecka	< 2 ggr/ vecka	< 1 gång/ mån
Kommentarer:	1	2	3	4
Vad tycker du om kvaliteten på kontakten?	Bra	Ganska bra	Ganska dålig	Dålig
Kommentarer:	1	2	3	4
Hur bor du idag? (25 e)	Hos föräldrar	Egen bostad	Annat	
Kommentarer:				

## APPENDIX I

Civilstånd?	Ensamstående			
Kommentarer:	Gift	År:		
	Sambo	År:		
	Separerat	År:		
	Antal separationer?	Antal:		
Antal graviditeter?	Antal	År		
Antal aborter?	Antal	År		
Antal missfall?	Antal	År		
Kommentarer:				
Antal barn?	Antal			
	Kön	Ålder		
	Kön	Ålder		
	Kön	Ålder		
Hur tycker du att det fungerar för dig i modersrollen/föräldrarollen? (öppet svar)				
(Intervjuarens sammanfattande bedömning)	Bra	Ganska bra	Ganska dåligt	Dåligt
	1	2	3	4
Hur har det varit att amma och mata? (öppet svar)				
(Intervjuarens sammanfattande bedömning)	Bra	Ganska bra	Ganska dåligt	Dåligt
	1	2	3	4
Sexualitet				
Hur tänker du på och upplever sexualitet?	Med glädje	Något ambivalent	Mycket ambivalent	Undviker helst sex
	1	2	3	4
Kommentarer:				
Har du nära vänner? (25 b)	Ja	Nej		
Hur fungerar dina sociala kontakter?	Bra	Ganska bra	Ganska dåligt	Dåligt
Kommentarer:	1	2	3	4
Vilka fritidsintressen har du?				
Hur fungerar det för dig med fritidsintressena?	Bra	Ganska bra	Ganska dåligt	Dåligt
	1	2	3	4

## APPENDIX I

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### IV. Orsaker till sjukdomsdebut och tillfrisknande

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Varför just jag? Vad tänker du idag om orsakerna till att du blev sjuk? (9 a)

Vad tror du idag att man på barnpsykiatri trodde var anledningen till dina problem? (19)

Hur tror du idag att anorexi påverkat din hälsa och allmänna livssituation? (24 e)

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Om personen har tillfrisknat ställs följande frågor:

- Kan du idag komma ihåg när det vände?
  - Hur gick det till när tillfrisknandet startade?
  - Var det någon person eller händelse som var speciellt betydelsefull?
  - Vad tycker du har varit mest nytta för dig i din strävan efter att må bra och blir frisk från anorexi?
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Om personen mår dåligt:

- Vad tror du att det beror på att du fortfarande mår dåligt?
  - Vad tänker du idag om den behandling du fick på BUP? (13 a)
  - Om familjesamtalen? Bra ----- | ----- dåligt
  - Om de egna samtalen? Bra ----- | ----- dåligt
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### V. Råd till andra

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Vilka råd skulle du vilja ge till drabbade flickor?

Vilka råd skulle du vilja ge deras familjer?

Vi arbetar med unga flickor med ätstörningar. Har du något råd till oss?

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Får vi kontakta dig igen om en ny uppföljning skulle bli aktuell?	Ja	Nej
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