

Measuring Eating Disorder Outcome

To my family

Örebro Studies in Medicine 17



TABITA BJÖRK

Measuring Eating Disorder Outcome

– Definitions, dropout and patients' perspectives

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– Definitions, dropout and patients' perspectives

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Abstract

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Background: Despite a plethora of research, there are serious limitations in our knowledge of outcome in eating disorders. Almost all studies have been compromised by the problem of treatment dropout or non-participation in follow-ups. There exists a lack of consensus in definitions of outcome and choice of outcome measures, and there is a dearth of studies focusing on how patients subjectively perceive recovery. The overall aim of this thesis was to address problems in measuring outcome after treatment for eating disorders, with an emphasis on methodological issues. Specific areas of investigation included non-participation in long-term follow-ups, the role of self-image in treatment dropout, outcome among patients who drop out, patients' subjective perspectives of recovery, and the impact of different methods of measuring outcome.

Method: Four quantitative studies (I, II, III and V) were conducted within the framework of a large Swedish multi-centre study of eating disorders, which adopted a prospective, longitudinal and naturalistic design. Study IV was a qualitative investigation encompassing interviews with former ex-patients who were considered recovered.

Results: Study I suggested that the reasons for non-participation in research were mainly patient related (69%). Those declining further participation in follow-ups were reported significantly lower levels of obsession-compulsion and anxiety, while those not traceable reported significantly higher levels of hostility at admission. Study II suggested that patients who dropped out from treatment initially presented with less negative self-image and fewer psychological problems compared to those who remained in treatment. Low levels of self-blame discriminated dropouts from completers and remainers, and significantly predicted treatment dropout. Study III found no significant differences between dropouts and completers at follow-up, with the exception that dropouts were more dissatisfied with treatment. However, patterns of treatment response revealed that those who completed treatment made significantly greater changes in terms of reduced eating disorder symptoms, fewer psychological problems and a more positive self-image compared to dropouts. Study IV found that patients who had recovered from an eating disorder tended to describe other dimensions of outcome than those usually reported in follow-ups. Patients tended to view recovery in terms of being able to relate in a relaxed and accepting manner to food, their bodies, themselves as individuals, and their social environment. Some perceived recovery in terms of coping better with emotions, while others experienced themselves as healthier than people generally regarding food and weight. Study V applied some of the most frequently used outcome measures for eating disorders and found marked variations in the number of patients who could be considered in remission. Overall remission rates varied from 24.3% to 77.8%, depending on the outcome measure used.

Discussion: The results suggest that non-participation and dropout are not unitary phenomena. There is also a need for greater consensus on how eating disorder outcome should be measured. This is necessary in order to make comparisons between different outcome studies meaningful, and to elucidate the overall picture of eating disorders outcome.

Keywords: Eating disorders, non-participation, dropout, outcome definitions, patients' perspectives

List of Papers

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

- I Björk, T., Clinton, D., Norring, C. (2006). Reasons for non-participation in research on eating disorders. *Eating and Weight Disorders* 11: 147-153.
- II Björck, C., Björk, T., Clinton, D., Solberg, S., & Norring, C. (2008). Self-image and treatment dropout in eating disorders. *Psychology and Psychotherapy: Theory, Research and Practice* 81: 95-104.
- III Björk, T., Björck, C., Clinton, D., Sohlberg, S., & Norring, C. (2008). What happened to the ones who dropped out? Outcome in eating disorder patients who complete or prematurely terminate treatment. *European Eating Disorders Review* (Submitted).
- IV Björk, T., & Ahlström, G. (2008). The Patient's Perception on having recovered from an Eating Disorder. *Health Care for Women International* Vol 29:8 xx-xx (In press).
- V Björk, T., Clinton, D & Norring, C. (2008). The impact of using different outcome measures on remission rates in a three-year follow-up of eating disorders. (Manuscript).

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Abbreviations

AN	Anorexia Nervosa
ANP	active non-participator
APA	American Psychiatric Association
BED	Binge Eating Disorder
BN	Bulimia Nervosa
CO-RED	Co-ordinated evaluation and Research at specialist centres for Eating Disorders
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDI-2	Eating Disorder Inventory (version 2) (self-report measure)
EDNOS	Eating Disorder Not Otherwise Specified
GAF	Global Assessment of Functioning
PNP	passive non-participator
RAB	Rating of Anorexia and Bulimia (semi-structured interview)
SASB	Structural Assessment of Social Behavior (self-report measure)
SCL	Symptom Check List (self-report questionnaire)
TSS	Treatment Satisfaction Scale (self-report measure)

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Preface

To begin with, I'd like to briefly introduce the background of the present thesis. A decision was made by a group of enthusiastic researchers to carry out a longitudinal multi-centre project among specialised eating disorder units in Sweden. The Co-ordinated Evaluation and Research at Specialised Units for Eating Disorders in Sweden (CO-RED) project included the majority of the Swedish specialist units for treatment of adults with eating disorders. When the data had been collected I was offered the opportunity of using CO-RED data for my thesis, even though I had not been involved in the planning of the project or the work effort used to collect all the data. I was grateful for having access to such rich material, which in my opinion is like a gold mine.

My interest in recovery from an eating disorder was first aroused when a close friend of mine managed to recover from severe anorexia nervosa. Since then I have believed that it is possible to recover from an eating disorder. At the same time, I suspected that patients only recovered on the outside, and that they still experienced an ongoing struggle that they did not reveal to anyone. I therefore found it of special interest to use not only the data from the CO-RED project in my thesis, but also personally listen to those who were considered recovered and hear their stories. Ex-patients who participated in the qualitative interviews in this thesis kindly and willingly told me their personal stories and their thoughts about life as recovered. This gave me the opportunity to look upon recovery from a patient's perspective that otherwise would be missing in this thesis. I believe my inexperience of direct involvement in eating disorder treatment possibly was an advantage, in these interviews, since I could view recovery from their perspective rather than through the eyes of a therapist.

BACKGROUND

Eating disorders were earlier associated with Western culture, but are now seen all over the world, in all social and cultural contexts ⁴⁶. They are one of the most common mental disorders among young women ⁵⁶. There are reports of young children ⁶⁵, as well as middle-aged adults developing eating disorders, but they are still most common among younger women ⁵⁵. Only one of ten cases of AN or BN is male, while 50% of cases with BED are male ^{40, 55, 121}. Eating disorders are assumed to be difficult to treat and can seriously affect both the physical and psychosocial life. Still, approximately 25 to 50 percent of the cases are never detected in the health-care system, since many patients do not actively seek treatment ^{63, 122}. There are some evidence of spontaneous remission (i.e. recovery without treatment), but that is the case with other psychiatric disorders as well ⁸⁷. Still, studies have shown that patients receiving psychotherapy improve more than no-treatment controls and that the improvements achieved in therapy also tend to be stable ⁸⁷.

Research literature of recent decades has often covered the topic of outcome in eating disorders. Unfortunately, the latest review of the literature shows how this field still lacks a unified definition of recovery, and consensus of how to measure outcome ¹⁰. These methodological obstacles make results from outcome studies difficult to compare, and limits their clinical benefit. Therefore, much work is necessary, and is taking place around the world, in order to reach an agreement of what measures and definitions that should be used in the research of outcome of eating disorders. Patients, their families, researchers and clinicians all need to be aware of prognoses, if it is possible to fully recover, and what it means to be recovered from an eating disorder.

This thesis aims to address problems in measuring outcome for adults after eating disorder treatment, with an emphasis on methodological challenges in eating disorder research. Specific areas that are examined include: (I) non-participation in follow-ups; (II) the role of self-image in treatment dropout; (III) outcome for patients who drop out; (IV) patients' perspectives on recovery; and (V) the impact of different outcome measures on estimates of recovery.

What is an eating disorder?

Although the typical signs of both AN and BN are nowadays familiar to both clinicians and the general public, a definition of what constitutes an eating disorder per se has only recently been discussed. Fairburn ³¹ suggest a definition of eating disorder as follows:

“A persistent disturbance of eating behaviour or behaviour intended to lose weight, which significantly impairs physical health or psychosocial functioning. This disturbance should not be secondary to any recognized general medical disorder (i.e. a hypothalamic tumour) or any other psychiatric disorder (i.e. anxiety disorder).” (p.171)

Within mental health services, eating disorders are usually classified by one of two distinct diagnostic systems, namely the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV ², or the International Classification of Diseases (ICD-10) ¹²⁷. The diagnostic system most widely used for eating disorder research in Sweden, DSM-IV, divides the eating disorders diagnoses into three main categories; AN, BN and eating disorders not otherwise specified (EDNOS). Criteria for the DSM-IV eating disorder diagnoses are presented in Appendix A.

The characteristics of AN include a refusal to maintain normal weight (often calculated as a weight less than 85% of expected weight), intense fear of weight gain or becoming fat, disturbed body image, denial of the seriousness of their condition, and post-menarcheal amenorrhoea in females. The diagnosis is further divided into two subgroups: a *restrictive subtype* and a *binge eating / purging subtype*. A person with AN is frequently preoccupied with thoughts of food, and the condition is often associated with depressed mood, social withdraw, irritability, impulse-control problems, insomnia and decreased interest in sex. A high percentage of individuals with AN also meet criteria for other psychiatric disorders (DSM-IV Axis I), such as Major Depressive Disorder, Obsessive-Compulsive Disorder or the personality disorders (DSM-IV Axis II). The prevalence of AN is estimated to be below 1% in young women, and the female-to-male ratio is more than 10:1⁵⁵.

The characteristics of BN include regular episodes of binge eating, with a sense of lack of control, followed by compensatory behaviour to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics or other medications, fasting or excessive exercise. Self-evaluation is excessively influenced by body shape or weight. BN is divided in two subgroups: a *purging subtype* (which includes those who misuse laxatives, diuretics or enemas) and a *non-purging subtype*. There is an increased frequency of mood and anxiety disorders in patients with BN ². A sizeable proportion of these patients also meet criteria for one or more personality disorders. The prevalence of BN is estimated to be 1% in young women and 0.1% in young men; one of ten cases of BN are male ⁵⁵.

The DSM-IV manual also provides a third category (EDNOS) for coding disorders that do not fulfil the rather stringent criteria for AN or BN, but are nevertheless suffering from a disabling eating disorder of clinical severity. EDNOS is the most common eating disorder seen in outpatient settings ²⁷. The prevalence of EDNOS has been estimated to be between 2.4 to 5.4% among young women ^{55, 73, 115}. DSM-IV gives six examples of EDNOS. The first two examples are similar to AN, but patients still have functioning menstruation or a weight greater than 85% of expected. The third example describes symptoms similar to BN, but characterised by binge-eating or compensatory behaviours to a lesser degree than in BN. Examples four and five include compensatory behaviours after eating small amounts of food, and repeatedly chewing and spitting out large amounts of food. The sixth example of EDNOS includes those who binge-eat in the absence of compensatory behaviours. This sixth group is presented as a distinct provisional diagnosis named binge eating disorder (BED). The prevalence of BED has been estimated to be between 1.2% ⁴⁵ and 6.6%, distributed equally

between men and women ⁴⁸. BED is still provisional, since it has not yet been empirically established and more research is needed. More work also needs to be done in order to delineate the boundaries between EDNOS and the normal population, since there is no clear definition of what constitutes an eating disorder of clinical severity ²⁶.

Outcome studies have unfortunately focused mainly on the diagnoses of AN or BN and very little is subsequently known about outcome for patients with EDNOS. One reason is possibly the lack of a clear definition of what an eating disorder is, that raises difficulties when measuring outcome. In the present thesis all eating disorder diagnoses are included. The diagnoses are based on the DSM-IV criteria. BED has been separately analysed from the other types of EDNOS when it was possible due to group sizes (in study I, II and V). The subtypes of AN and BN (i.e. AN, restricting or binge eating/purging type, and BN, purging or non-purging type) are not included here (with the exception of study V, in the construction of specific outcome criteria). Other disorders related to disturbed eating, like night eating syndrome or obesity, has not been addressed in this thesis, neither has co-morbidity with other Axis I or II diagnoses. The relatively low prevalence of eating disorders requires screening of many individuals before finding a true case of eating disorder. Quantitative research studies often needs large samples of eating disorder patients to answer their specific questions. In this thesis, the use of the multi-centre database in the CO-RED project made it possible to get a sample large enough to examine the methodological problems in measuring eating disorder outcome.

What do we know about prognosis?

The course of an eating disorder is difficult to foretell, since it varies considerably from person to person. There are individual prognostic factors, such as treatment factors, diagnostic factors, as well as factors relating to the social environment that can influence course and outcome. Some recover after a short duration of illness, while others have trouble over long periods and struggle with symptoms that come and go. About 2-5% of patients die as a consequence of their eating disorder. However, most patients tend to show substantial improvement during treatment, as well as further improvement and stabilisation ten to twelve years later, when about 70% of patients no longer fulfil criteria for an eating disorder ^{33, 35, 105, 115}. Patients with BED seem to have a more favourable outcome than those with BN, with 79% of patients not fulfilling criteria for an eating disorder 6 years after treatment ³⁴. Adolescents appear to lack eating disorder diagnoses at follow-up to a greater extent than adult patients ^{112, 122}. Studies using shorter follow-up times (i.e. up to five years) tend to yield recovery rates of about 50% for AN, while 30% demonstrate improvement, and 20% remain ill ^{37, 105}. Similar recovery rates of about 50% have been reported for BN in a five year follow-up ²⁹. Longer duration of follow-up increases both estimated rates of recovery, as well as rates of mortality ^{33, 105}. About a third of the patients relapse after showing clinical improvement ¹⁰⁷. It is, however, unusual to relapse after achieving full recovery ⁶⁶.

In summary, recovery appears to be a process going on for several years, with gradual improvement and temporary relapses ¹⁰⁷. Most patients recover, however, during the first 12 years; after that only few manage to recover ⁵³.

There is nevertheless a case report of recovery after 50 years with an eating disorder ⁸⁸. So the three-year outcome used in this thesis is definitely no final end point. It is status at a specified time point during the course of the eating disorders, and progress can fortunately still be expected.

What is measured in follow-ups and how?

Outcome in eating disorders is measured in many different ways, but traditionally the focus has been on changes in key behaviour and symptoms, rather than levels of functioning or qualitative aspects of life.

Eating related outcome

The majority of outcome studies focus on eating related outcome and measure symptom reduction quantitatively using a range of approaches. According to recent reviews of treatment outcome, improvement in terms of core symptoms is generally considered to be the outcome variable of primary interest ^{13, 14, 101}. Primary outcome variables in AN are weight gain and resumption of menstruation ¹⁴. In BN primary outcome variables reflect the core behavioural features of the disorder, i.e. reduction of and abstinence from binge eating and purging ¹⁰¹. Primary outcome variables in BED concern reduction of and abstinence from binge eating and weight loss¹³.

Outcome studies that focus on normalisation of core symptoms often measure outcome categorically. The most common way of measuring categorical outcome in eating disorder research since the 1970's is through the use of the Morgan Russell Scales, which measure nutritional status, menstrual functioning, mental state, as well as sexual and social adjustment. Outcome is categorised as “good”, “intermediate” or “poor” ^{81, 82, 114}. Alternatively, stepwise gradations may be used to describe the severity of the disorder and the degree of symptom improvement ^{51, 52, 107}. Other methods use a combination of degree of symptom improvement and changes in attitudes concerning weight and appearance ⁹⁴. One of the most common methods of measuring outcome since 1980 is to simply consider a patient as recovered if she no longer meets diagnostic criteria for an eating disorder ¹⁰.

Another way of measuring outcome is to evaluate the effectiveness of treatment. This is normally done by comparing pre- and post-treatment scores on a given measure in order to establish whether there has been a significant decrease in scores from baseline ^{3, 84}. Such change is often considered clinically significant when patients have improved with at least 50% reduction of symptoms from baseline scores toward the normal population mean ⁵⁷. An additional approach involves measuring whether the individual has returned to a normal level of functioning. This is estimated by noting whether the patient's score (on any psychometric outcome instrument) falls within the range of the normal population at follow-up (i.e. the normal mean plus or minus one or two standard deviations) ^{11, 23}. These diverse ways of measuring eating related outcome raise the question of how the different methods impact on estimates of remission.

Other dimensions measured in eating disorder outcome

Secondary outcome variables concern reductions in the associated psychological features of eating disorders (e.g. self-image, perfectionism, alexithymia), as well as reductions of depression and anxiety. Irrespective of the dimension concerned (e.g. eating disorder symptoms, psychological features, improvement of depression or anxiety), variables tend to be measured by established questionnaires or by applying predefined categories of remission^{11, 23}. Some studies report mortality data as an outcome variable. By calculating standardised mortality ratios, it becomes possible to make comparisons with other studies.

An alternative approach to assessing outcome involves the use of qualitative interviews, which can widen the concept of recovery, and measure dimensions that otherwise risk being lost in quantitative research^{8, 43, 93}. Unfortunately, it is still uncommon to ask patients who consider themselves recovered, how they perceive recovery, and what constitutes life without an eating disorder.

Generally speaking, the diversity of methods for measuring outcome makes it difficult to compare different studies. Sometimes it is only the number of patients not fulfilling diagnostic criteria for eating disorders that are comparable between studies.

What are the methodological challenges?

Even if there were consensus on an optimal measure of outcome, several methodological challenges remain to be dealt with. The utility of the outcome studies are limited unless these issues are addressed.

Non-participation is an important problem in eating disorder research that has not received much attention. Increasing numbers of outcome studies tend to report data on non-participation, which is important. The frequency of successful follow-ups can vary considerably, from only a quarter of the original sample to the entire sample^{16, 94, 96, 105}. Patients may not want to participate in research, or they chose to break off their participation in ongoing projects. This lack of participation or withdraw from follow-ups can seriously bias outcome estimates, since results will only concern those who remained in the study until the point of follow-up¹². Non-participation in follow-ups may also generate a risk for over-estimating treatment effects, since there may be an over-representation of patients in follow-up samples who have been helped by treatment¹¹¹. Unless the effect of non-participation is carefully explored and the reasons for non-participation are known, the results may lack validity.

Dropout from treatment is another methodological challenge that is in need of being addressed. Every third patient treated for BN has been reported to drop out, and even higher figures have been given for AN. Similar results have been reported for patients in treatment for depression⁸⁷. It is imperative to investigate why these patients decide to leave treatment. It is also important to examine the impact dropout has on estimates of recovery, by examining the initial status of these patients and establishing whether they run the risk of more negative outcome¹². What's more, it is necessary to clearly define dropout,

since there are many different ways of bringing treatment to a close. Claussen¹⁶ distinguishes between: attrition (i.e. a patient leaves a study), dropout (i.e. a patient decides to interrupt treatment based on an own decision), premature termination (i.e. interruption of a patient's treatment based on a decision of the therapist), and finally withdrawal or transfer (i.e. a joint decision on the part of a patient and a therapist to prematurely end treatment).

Lack of research considering the patient's perception of recovery

It is well known that eating disorders seriously affect, not only the physical health, but also cognitive functioning, self-awareness and interpersonal interaction. However, outcome studies tend to focus on the assessment of diagnosis-specific symptoms. Everyday functioning and subjective experiences are not considered.

Previous qualitative studies of eating disorders have investigated the patients' experience of relapse⁵⁰, the process of recovery^{62, 64, 80, 83, 102} and have evaluated helpful elements in the social, family or therapeutic context^{88, 120}. Studies that have focused on the meaning of improvement and recovery from the patient's point of view^{67, 89, 91, 93, 98} have delineated other aspects of life that are not usually measured in follow-ups. In these studies recovery from the patient's perspective was often related to psychological and social changes. More specifically, recovery meant acceptance of themselves and their feelings, along with the acquisition of new social skills that can change a reticent person into a more direct and self-confident individual. Recovery also meant being more accepting of their bodies and not being so rigid in relation to food, which are variables recognised more often in quantitative follow-ups. Researchers that have given patients the opportunity of telling their own stories of recovery suggest that such perspectives provide important information on components of recovery that otherwise tend to be absent if only approaches focusing more narrowly on diagnostic symptom are used. Investigating the patient's perspective on recovery was, therefore, seen as an important part of this thesis.

Impact of outcome measures and definitions

The European eating disorders research project (TR-EAT), which has been described by Kordy et al.⁶⁶, defined full remission as when the individual is asymptomatic (i.e. has no more than minimal symptoms). The definition was inspired by depression research⁶⁸, where remission was achievement of a complete asymptomatic response that lasts from two weeks to six months³⁶, argued that an indication of recovery would be an absence or decline of those factors that increase risk of relapse. A relevant definition of recovery should therefore include changes in several dimensions (i.e. physical, psychological and social improvements). Others argue for inclusion of cognitive symptoms, such as body dissatisfaction and fear of gaining weight²¹ when defining recovery. A meaningful construct should also consider the severity of symptoms and the duration of the observed improvements^{38, 52}. There are a great number of ideas about how to measure eating disorder outcome. Unfortunately, we still lack a unified definition of recovery and consensus on how to measure it¹⁰. Results of outcome studies are therefore difficult to compare with each other, and the clinical benefits of this research are also limited.

Another problem is the poorly described operationalisations used in defining behavioural and cognitive symptoms, making it difficult to replicate outcome studies ⁶⁰. Diagnostic criteria for eating disorders are used frequently as a measure of outcome, but there are divergences in categorizing patients at follow-up. One particular problem concerns deciding when a patient meets criteria for EDNOS and when that person no longer fulfills criteria for an eating disorder, since no distinct limit exists between normal concerns with body and weight and the diagnosis of EDNOS. In clinical practice some clinicians diagnose patients as EDNOS during the phase of improvement, while others label patients as AN- or BN- in remission without giving them a diagnosis of EDNOS. A logical consequence is that patients with a multitude of divergent conditions are compared and categorized as having improved to the same level. Even studies using the same measure, such as the PSR, may define recovery considerably differently when requiring varying levels of functioning on the measure to define recovery ^{52, 60, 72}. Likewise, frequently used categorisations, such as good, intermediate and poor outcome ⁸², are often defined in considerably different ways ^{5, 24, 97}. General conclusions, such as that reached by Steinhausen¹⁰⁵, that good outcome indicates recovery from substantial clinical symptoms, or that intermediate outcome designates improvement with some remaining symptoms, or that poor outcome can be considered a chronic state or death, all designate semantic rather than empirical agreement on how these categories should be defined and measured. In other words, there is little more than general agreement between studies that good, intermediate and poor designate gradations of some (undefined) quality.

AIMS

This thesis aims to address problems in measuring outcome after treatment for eating disorders, with an emphasis on methodological issues. Specific areas of investigation included non-participation in follow-ups (Study I), the role of self-image in treatment dropout (Study II), outcome among patients who drop out (Study III), patient's perceptions of recovery (Study IV), and the impact of different methods of measuring outcome (Study V). More specific aims of the individual studies were as follows:

Study I

This study aimed to illuminate non-participation in follow-up research by systematically exploring the problem in a large longitudinal naturalistic study of eating disorders. The study attempted to delineate reasons for non-participation in a 36-month follow-up, achieve a relevant classification of non-participants, and explore factors associated with different reasons for non-participation.

Study II

The aim of this study was to examine whether SASB self-image and interpersonal theory could help to explain treatment dropout in a heterogeneous sample of eating disorder patients. In particular, it compared patients who dropped out with patients who completed treatment and with those who were still actively receiving treatment at 12-month follow-up.

Study III

In this study the aim was to explore outcome three years after intake for patients, who dropped out of treatment, and compare within-group changes from baseline to follow-up, as well as make between-group comparisons with patients who completed treatment.

Study IV

This study aimed to describe how ex-patients perceive having recovered from an eating disorder.

Study V

The aim of this study was to examine the impact of using different outcome measures on estimates of remission rates at 3-year follow-up in a large clinical sample including the entire spectrum of eating disorders.

METHODS AND MATERIAL

Design

This thesis comprises five studies based on both quantitative and qualitative methods, since the use of mixed methods is assumed to be more efficient in answering research questions than the use of only one method alone ⁶¹. Four quantitative studies (I, II, III and V) were conducted within the framework of the Co-ordinated Evaluation and Research at Specialized Units for Eating Disorders in Sweden (CO-RED) project ^{19, 90}. The CO-RED project was a multi-centre study applying a prospective, longitudinal and naturalistic design. One paper (IV) is a qualitative study encompassing interviews with ex-patients who perceive themselves as recovered.

The CO-RED project

The CO-RED project followed patients seeking treatment at specialist units for eating disorders in Sweden. The project had two main scientific objectives:

- To evaluate short- and intermediate-term outcome in a large unselected sample of eating disorder patients treated at specialist units for adult eating disorder patients.
- To relate aspects of treatment and patient characteristics (and combinations thereof) to differential features of outcome.

The clinics that took part in the CO-RED project were both public and private clinics. About 85% of the clinics in Sweden who offered treatment for adults with eating disorders decided to take part in the project (a total of 15 units). They offered different forms of inpatient, day-patient and outpatient treatments, as well as individual psychotherapy, family and group therapy, psychoactive drugs, and expressive forms of treatment such as dance and art. Interview-based and self-report measures were used, administered at intake and subsequently after 6, 12, 18 and 36 months. Data collection commenced in August 1995 and ended in December 2001. Patients included were required to be 18 years of age or older and to have an eating disorder according to DSM-IV. If clinics found it troublesome to include patients consecutively or to conduct all follow-ups, due to heavy work laden, they were asked to include, for example, every fourth patient and to prioritise the 36-month follow-ups. When data collection ended in December 2001, the clinics were asked to describe the inclusion process, in order to assure that patients had been included without selection biases, for instance excluded due to serious illness. Based on this information, all units but one were included and a total of 56 patients were excluded. The total sample for this thesis, therefore, comprised eating disorder patients ($n = 840$) from fourteen specialist treatment units. A descriptive overview of the studies is presented in Table 1.

Table 1. Overview of the five papers presented in this thesis

Study	Participants	Data collection
I	n = 840 from CO-RED, 14 units included	Semi-structured interview, self-report questionnaires: EDI-2, SCL-63 & BaT
II	n = 162 from CO-RED, 12 units included	Semi-structured interview, self-report questionnaires: EDI-2, SCL-63, SASB & BaT
III	n = 82 from CO-RED, 9 units included	Semi-structured interview, self-report questionnaires: EDI-2, SCL-63, SASB & BaT
IV	n = 14 ex-patients from a specialist unit	Qualitative interview
V	n = 334 from CO-RED, 12 units included	Semi-structured interview, GAF assessment, self-report questionnaire: EDI-2

The qualitative study

The patients included in Study IV were recruited from one local specialist eating disorder unit. A total of 18 patients were asked during 2003-2004 to participate in the qualitative study, if they perceived themselves to be recovered or at least markedly improved at one-year follow-up. Participants were required to be 18 years of age or older, to have a history of an eating disorder according to DSM-IV, and to have completed their treatment. Of the 18 prospective participants, two could not be reached by phone and two chose not to participate. Fourteen agreed to participate, all of whom viewed themselves as recovered at the time of the interview.

Phenomenographic approach

The phenomenographic approach used in Study IV has people's experiences as its object of study. The focus is on how people experience, conceive of and talk about a phenomenon, as well as their knowledge and skills related to the phenomenon ⁷⁸. Phenomenography has its roots in cognitive, gestalt and developmental psychology. It was developed in educational studies during the 1970's by Marton and colleagues at Gothenburg University, Sweden, as a way of investigating learning, but has subsequently been used with advantage in health care research ⁴¹.

Phenomenography makes a distinction between what something *is* (the first-order perspective), and what it is *perceived to be* (the second-order perspective). In the first case, people learn about the environment and make statements about it; in the second, they orient themselves in relation to their experiences of the environment⁷⁵. This means a total focus on how the individual looks upon the phenomenon, how that person thinks the specific phenomenon works, and how it is understood and remembered. Although the individual's perceptions are central in phenomenography, the analysis provides a description at a collective level in the form of distinct descriptive categories that capture the variation within and between the individuals⁷⁵. Phenomenography permits variation in methodology depending on the aim of the specific research^{41, 103}. Phenomenographic analysis results in logical hierarchical categories between conceptions and descriptive categories, as well as variation of descriptive categories⁷⁸. The method has similarities with phenomenology, since both approaches aim to capture the nature of the human consciousness and experiences. Phenomenology focuses, however, on capturing the essence of a phenomenon, while phenomenography seeks to discriminate, understand and conceptualize variation in how people conceive of a phenomenon or the logical hierarchy of their conceptions⁷⁶⁻⁷⁸.

Participants

Descriptive details of the participants included from the CO-RED project (i.e. studies I, II, III and V) are given in a flow-chart, Figure 1.

Participants in **Study I** comprised all patients included in the CO-RED database when data collection was concluded in December 2001, $n = 840$ (827 females and 13 males). Distribution of DSM-IV diagnoses were: AN ($n = 152$), BN ($n = 334$), BED ($n = 51$) and EDNOS ($n = 303$). Age at initiation of treatment ranged from 18 to 54 years ($M = 25.2$, $SD = 6.3$). Body Mass Index (BMI) ranged from 10.4 to 50.6 ($M = 21.0$, $SD = 5.4$). Mean duration of eating disorders at treatment start was 8.6 years ($SD = 6.3$).

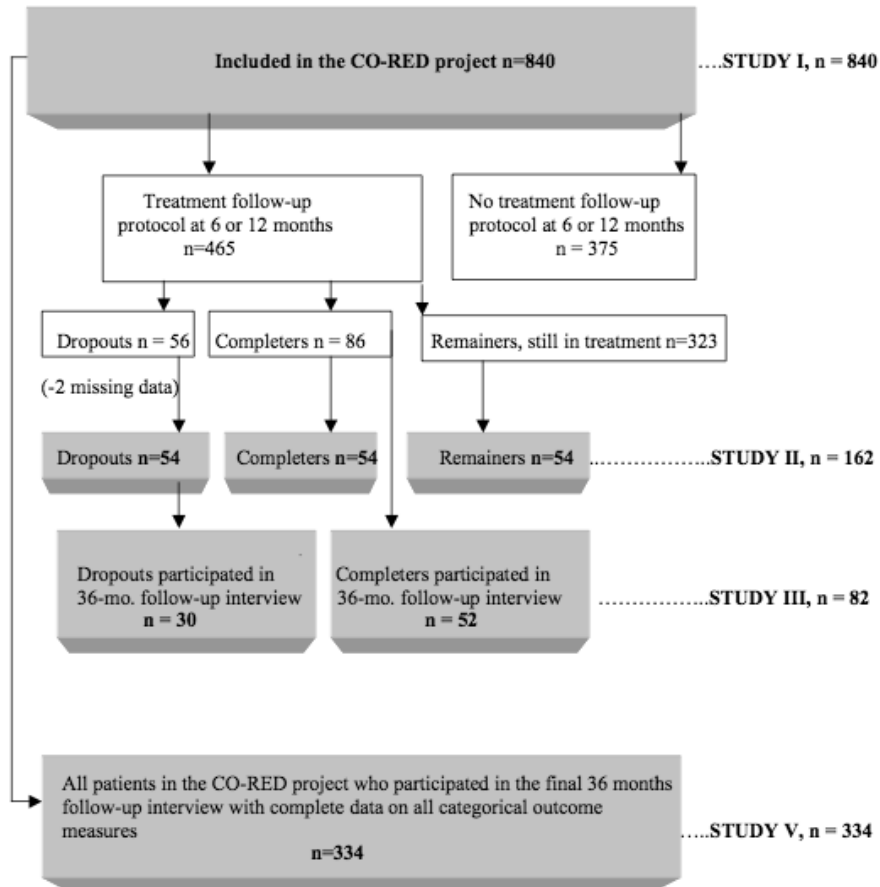
Participants in **Study II** comprised three equally sized groups that were identified at 6- or 12-month follow-up. The groups were: 1) actively engaged in treatment at 12 month follow-up ($n = 54$, one was male), 2) had completed treatment according to treatment plan ($n = 54$, two were male), or 3) had dropped out of treatment ($n = 54$, all women). The two comparison groups (i.e. groups 1 and 2) were randomly selected from all patients engaged in treatment ($n = 323$) and all completers ($n = 86$) at 6- or 12-month follow-up. Groups of equal size were chosen following recommendations by Hair and colleagues⁴⁹ to avoid the risk of overestimating prediction accuracy in the largest group. The mean age of dropouts was 23.4 years ($SD = 5.7$), in completers 25.5 years ($SD = 6.9$) and in remainders 24.8 years ($SD = 6.5$). No initial significant differences at intake were found between the three groups in terms of age, BMI or distribution of eating disorder diagnoses. The average length of treatment in completers was 9.3 months ($SD = 5.4$), and average length of treatment prior to dropout was 5.5 months ($SD = 3.2$).

Participants in **Study III** comprised two groups: patients who dropped out of treatment ($n = 30$), or patients who had completed treatment according to plan ($n = 52$). All participated in 36-month follow-ups, and all but two were women, with one man in each group. Mean length of treatment was 5.3 months ($SD = 2.9$) for dropouts, and 9.2 months ($SD = 4.5$) for completers. Age ranged from 18 to 47 years ($M = 22.4$, $SD = 5.8$) in the dropout group, and from 18 to 49.5 years ($M = 25.2$, $SD = 7.4$) among completers. Mean duration of eating disorder at admission was 6.1 years ($SD = 5.9$) among dropouts, and 7.8 years ($SD = 7.0$) among completers.

Participants in **Study IV** consisted of 14 women who were ex-patients treated for eating disorders at one local specialist unit. The median duration of eating disorders until termination of treatment was 5.5 years (range from 1.5 to 12 years) and the median duration of treatment was 11 months (range from 1 to 41 months). Diagnoses at treatment start were AN ($n = 4$), BN ($n = 4$) and EDNOS ($n = 6$). The median age was 27 years (range from 22 to 34 years). Seven participants were married or co-habiting, four were single, and three were in steady relationships. Seven were working, four were studying, and three were on parental leave.

Participants in **Study V** comprised 334 eating disorder patients. This included all patients with complete data on the chosen outcome measurements who participated in the final 36-month follow-up. Distribution of DSM-IV eating disorder diagnoses at start were: AN ($n = 54$), BN ($n = 126$), BED ($n = 23$) and EDNOS ($n = 131$). Age ranged from 18 to 51.5 years ($M = 25.2$, $SD = 6.4$). BMI at intake ranged from 10.4 to 49.8 ($M = 20.7$, $SD = 5.0$). Most participants were female with exception of five males. Mean duration of eating disorder at treatment start was 8 years ($SD = 6.0$) ranging from 3 months to 30.5 years.

Figure 1. Flow-chart showing the inclusion of participants to study I, II, III and V



Instruments

Rating of Anorexia and Bulimia (RAB), was used in Studies I, II, III and V, to assess eating disorder and related psychopathology at admission and at follow-up. The RAB is a semi-structured interview comprising 56 items covering a wide range of eating disorder and related psychopathology, as well as background variables. The internal consistency, inter-rater and test-retest reliability, and validity of the instrument been found to be good^{19, 85}. Diagnoses at admission and follow-up were based on RAB data together with expert ratings (clinicians in consensus with researchers) of specific DSM-IV criteria.

The Background and Treatment (BaT) Questionnaire for Anorexia and Bulimia. The BaT is a 63-item self-report questionnaire developed for the CO-RED project. It was used in studies I, II and III to provide measures of basic socio-demographic variables and treatment variables relating to eating disorders²⁰.

Treatment Satisfaction Scale (TSS)

Satisfaction with treatment was measured in Study III using the TSS, a short questionnaire developed for the CO-RED project. Patients were asked to rate five questions on a three-point scale concerning treatment satisfaction. The overall inter-item consistency has been reported to be high (Chronbach's $\alpha = .87$)¹⁸.

The Eating Disorders Inventory, version 2 (EDI-2)

EDI-2 was used in Studies I, II, III and V to measure self-reported eating disorder symptoms and psychological correlates^{42, 86}. This 91-item questionnaire is widely used in the study of eating disorders, and generates three subscales of central symptoms (i.e. drive for thinness, bulimia, body dissatisfaction), often collapsed into a symptom index, and eight subscales of psychological correlates of eating disorders (i.e. ineffectiveness, interpersonal distrust, interoceptive awareness, asceticism, perfectionism, social insecurity, maturity fears and impulse regulation). The EDI subscales were analysed separately in Studies I and III. In Study II the EDI-2 was divided in two parts; the central symptom index and the psychological correlates. In Study V only the symptom index was used.

The Symptom Check List-63 (SCL-63) was used in Studies I, II and III to measure self-reported psychiatric symptoms. This constitutes a shortened, 63-item version of the SCL-90²⁵. In the CO-RED project the subscales for Phobic Anxiety, Paranoid Ideation and Psychoticism were removed since these subscales can be assumed to be of less relevance for eating disorder patients. A further reason for shortening the questionnaire was to limit the total length of the assessment battery. Three items assessing sleeping problems were kept from Additional Subscales to constitute a separate subscale used in Study I.

The Structural Analysis of Social Behaviour SASB, (Intrex version, 3rd surface, self-image). SASB was used in Studies II and III to assess self-image^{6, 7}. The questionnaire comprises 36 self-referential statements, some framed positively and others negatively. The questionnaire forms eight clusters of self-image: (1)

Self-emancipation, (2) Self-affirmation, (3) Active self-love, (4) Self-protection, (5) Self-control, (6) Self-blame, (7) Self-hate, and (8) Self-neglect. Empirical work supports the reliability of the SASB self-image questionnaire with a total $\alpha = .74$ ^{7, 71 4}.

Global Assessment of Functioning (GAF), Axis V of DSM-IV, was used in Study V to measure the staff's overall assessment of the patient's level of functioning at follow-up. A GAF score is a value between 1 and 100, where 1 represents the most severe symptoms or problems in functioning and 100 represents an extremely well functioning individual. The reliability of GAF has been shown to be satisfactory when used in routine clinical work¹¹⁰.

Documentation of Participation, a protocol used in Study I was developed for the CO-RED project to document whether or not patients attended follow-ups and, if follow-ups did not take place, to document the reasons why.

Treatment Follow-up Protocol was used in Study II to delineate dropout. This short protocol documented basic aspects of the treatment process. Units used the protocol, amongst other things, to note if, when, and under what circumstances patients terminated treatment.

The qualitative interview guide used in Study IV, covered four questions: what patients think about when they hear that someone has recovered from an eating disorder; whether they perceived themselves as recovered; in what areas; and in what ways recovery was evident in their own lives. If the participant did not spontaneously cover different dimensions of life, open-ended questions were asked about physical, mental and social aspects of recovery.

Procedure

Overall procedure (in the CO-RED-project Studies I, II, III and V)

Eating disorder and associated psychopathology was measured at initial assessment and subsequently at all follow-ups. Staff at participating units collected data. Diagnostic and clinical assessment prior to the commencement of treatment took place within, at the latest, two (for inpatients) to four (for outpatients) weeks after the patient's first visit to the unit.

Systematic assessment of eating disorder diagnoses was made using a rating scale covering specific diagnoses (AN, BN, BED and EDNOS). Clinical raters working at the specialist units were asked to rate each diagnostic criterion on a three-point scale (not present, not fully verified, fully verified). Only those patients who presented with fully verified symptoms on all criteria were classified as AN or BN. These assessments, based on clinical ratings, were subsequently compared with the operational eating disorder diagnoses generated from specific items on the semi-structured clinical interview (RAB). If results of the two procedures were dissimilar, the two CO-RED project leaders independently diagnosed the patient in question based on an examination of all available data for a given patient. If the two project leaders were not in agreement, the case was discussed until consensus was reached¹⁹. The same procedures were applied at 36-month follow-up.

Study-specific procedures and definitions

In **Study I** *Non-participation* was defined as initial agreement to take part in the CO-RED project, and attendance at the first diagnostic assessment, but missing from the 36-month follow-up. Patients were initially categorised as either *participants* or *non-participants* at 36-month follow-up. Non-participants were further divided into groups based on reasons for not taking part in the final follow-up: 1) patient-related non-participants (i.e. patients declined to participate, failed to attend scheduled follow-ups, or could not be traced); 2) organisational-related non-participants (i.e. administrative changes at the units or lack of time and/or heavy workloads); or 3) uncertain non-participants (i.e. reasons for non-participation were not documented). Patient-related non-participants were further analysed and divided into two subgroups, based largely on an active-passive distinction. Active non-participants (ANP) were defined as patients who initially agreed to participate in follow-ups, but at the time of their 36-month follow-up either refused to participate or did not attend previously agreed follow-up meetings. Passive non-participants (PNP) were defined as patients who initially agreed to participate in follow-ups, but later could not be traced at follow-up.

In **Study II** the Treatment follow-up protocol was used to identify patients who dropped out from treatment, completed treatment or who were still in treatment at 6- or 12-month follow-ups. *Dropout* was defined as termination of treatment by the patient during the first 12 months of treatment prior to completion of the treatment plan. All patients that dropped out prior to follow-ups at either 6- or 12-months were selected for the study ($n = 54$). Treatment completers were defined as patients who had terminated treatment according to the treatment plan prior to 6- or 12-month follow-ups. Patients who still remained in treatment at 12-month follow-up were defined as remainers. Random samples of equal size for completers ($n = 54$) and remainers ($n = 54$) were selected as comparison groups, and for discriminant analysis.

In **Study III** the Treatment follow-up protocol was used with the same procedure and definitions as in Study II; however, this time the protocol was only used to identify patients that dropped out or completed treatment. An additional inclusion criterion required dropouts and completers to have participated in the semi-structured interview (RAB) used at 36-month follow-up.

In **Study IV**, recovery was defined on the basis of patients' subjective perceptions of having recovered. The focus on recovery instead of remission in this study is in line with suggestions by Kordy and co-workers⁶⁶, who contend that the only distinction between remission and recovery is in terms of stability over time. If no essential eating disorder symptoms were present for at least three months they considered the patient to be in remission; if no key eating disorder symptoms were present for a year or more, the patient was considered to be recovered. Most of the participants already considered themselves as recovered one year prior to the interview. This suggests maintenance of their status for more than a year and that use of the word recovery was suitable.

In conjunction with the unit's standard one year follow-up, patients who considered themselves recovered were asked if they could consider taking part in a qualitative interview with the aim of focusing on their thoughts and experiences regarding recovery. Patients who expressed an interest in participating were contacted by post one year later to set up an interview (i.e. when approximately two years had passed since ending treatment). An appointment for the interview was made by phone within 10 days. Special attention was given to ensuring that all diagnostic groups were represented in the sample, and that participants represented a varied sample in terms of diagnoses, duration of illness and age. Face-to-face interviews were conducted 18 to 26 months after completion of treatment (median = 22.5 months). The interviews were conducted in the patient's home ($n = 2$), at the patient's place of work ($n = 1$) or in the research facility used by the study ($n = 11$) and lasted from 33 to 86 minutes (median 52 min). The interviews were conducted using an interview guide. The audio-taped interviews were transcribed prior to phenomenographic analysis.

In **Study V**, the use of the word *remission* was based on the proposals made by Kordy and colleagues ⁶⁶. They defined remission as the absence of essential eating disorder symptoms (e.g. has no symptoms of binge eating, vomiting or laxative abuse, and a BMI of at least 19) for at least three months. In the semi-structured interview (RAB) used at the 36-month follow-up in Study V, questions concerning patients' symptomatic status were with reference to the last three months. We therefore found it appropriate to use the concept of remission in study V.

Remission was operationally defined using six distinct measures of outcome (see appendices A, B, C and D for details), and patients were judged as either meeting or failing to meet specific definitions of remission according to each measure. Definitions of remission were based on:

- I. Eating disorder diagnoses according to the DSM-IV ². Patients were regarded as in remission if they no longer met criteria for any eating disorder at follow-up.
- II. Psychiatric Status Rating Scale; PSR ⁵². Patients were regarded as in remission if they received a rating of PSR level 1 or 2. A modified version was constructed in order to make the PSR appropriate for patients with EDNOS and BED.
- III. Outcome definitions by Kordy et al ⁶⁶. A modified version was constructed in order to make Kordy et al's definitions appropriate for patients with EDNOS and BED.
- IV. The diagnosis-specific primary outcome measures identified by Berkman ¹⁰.

- V. The symptom index (the three symptom scales) of the EDI-2. Patients were regarded as in remission if they scored within one (conservative criterion) or two (liberal criterion) SD from a published normal group mean.
- VI. The Global Assessment of Functioning scale. Patients were regarded as in remission if they scored within one (conservative criterion) or two (liberal criterion) SD from a published non-clinical group mean.

Analyses

SPSS for Windows (version 12.0, 13.0 and 14, SPSS, 2003-2006) was used to analyse data in Studies I, II, III, and V. An alpha level of $p < .05$ was considered as significant throughout these studies. In Study IV a phenomenographic approach was used to analyse the interviews. In the coding process the material was imported and analysed using the program NVivo⁹⁵.

In **Study I** participators and all non-participators were compared using t-tests for parametric data and chi-square tests for categorical data. Comparisons between participators, ANP and PNP on parametric data were made using one-way ANOVA, followed by pair-wise Scheffé tests when F was significant using a 95% confidence interval. If the dependent variables did not fulfil assumptions for normality and equal variances, non-parametric tests were carried out instead (i.e. Kruskal Wallis test followed by the Mann-Whitney for pair-wise comparisons). Chi-square tests were used in the three-group comparisons for categorical data.

In **Study II** comparisons on continuous variables were made using one-way ANOVA, with post hoc Scheffé tests of pair-wise differences when overall F was significant. Distribution of eating disorder diagnoses and specific diagnostic criteria for AN and BN were analysed with Chi-square tests. Effect sizes for pair-wise comparisons were evaluated using Cohen's d ²². A stepwise multiple discriminant analysis was used to predict group membership. SASB-variables together with age and BMI were used as independent variables. To test if sample size was sufficient for comparative purposes, a power analyses was calculated using G Power PPC version 2.1.2.

In **Study III** comparisons between groups were made using chi-square tests for categorical data, applying Fischer's exact test when appropriate. Independent two-tailed t-tests were used when comparing groups on parametric outcome data, as well as when comparing the groups mean changes (pre-test scores minus post-test scores) from admission to follow-up. Within-group comparisons were made using paired t-tests. Effect sizes for changes from admission to follow-up were computed using Cohen's d in relation to both within group changes and between group changes. All effect sizes are described as a positive value (i.e. d is independent of the original measurement's point-system); all d values stand for degrees of improvement²². An inspection of the results was made by checking the correlations between the individual's mean values (admission + follow-up / 2), along with their change from admission to follow-up in order to control the risk of regression to the mean¹.

In **Study IV**, the qualitative interviews were analysed using a phenomenographic approach ⁷⁷. The interviews generated 345 pages for analysis. In the first step of the analysis, the text was verified by listening to the recorded interview and then read several times again in an open-minded manner. Thereafter, statements of essential content were identified in compliance with the aim (i.e. the participants were describing their thoughts and experiences of recovery) and coded in the data program NVivo ⁹⁵. In the second step, all 240 statements about recovery were compared and grouped into conceptions and preliminary non-overlapping descriptive categories. In the third step, analyses of similarities and differences between the preliminary descriptive categories were performed, resulting in four descriptive categories containing 14 conceptions about recovery. To assure reliability of the results, the second author (GA) independently scrutinized the resultant statements in relation to both conceptions and categories. These results were discussed until agreement was reached between the two authors ⁶⁹.

In **Study V** all patients were judged as either meeting or failing to meet the specific criteria for remission for each one of the chosen measures. The number of patients thereby judged to have attained remission was noted. Cut-off scores of 1 and 2 SD from published normal group means ⁸⁶, were used to calculate remission rates based on the symptom index of EDI-2; one more conservative (normal mean + 1 SD) and one more liberal (normal mean + 2 SD). Likewise, cut-off scores of 1 and 2 SD respectively, were calculated for GAF based on earlier published non-clinical group means ¹⁰⁹. Pair-wise analyses of agreement among outcome measures were calculated using Kappa ¹.

Ethical considerations

All studies were approved by appropriate professional ethics committees. Patient participation was strictly voluntary, and failure to participate affected in no manner whatsoever treatment offered at the individual units.

RESULTS

Brief summaries of the results of each study are presented below. More detailed results are available in the papers themselves (I-V).

Study I: Reasons for non-participation in follow-up research on eating disorders

When non-participation was delineated it was found that 40% of patients were missing at 36-month follow-up. Reasons for not participating were mostly patient-related (69%). A fifth of the patients were missing due to organisational difficulties (20%). The remaining reasons for non-participation were judged to be uncertain (11%). Patients who later became non-participants had, at intake, higher BMI, were younger and reported lower asceticism compared to participants.

Patient-related non-participation was further classified as active (ANP), if they refused participation/failed to attend scheduled appointments, or passive (PNP), if they could not be traced. See Table 2 for details. ANP were found to differ significantly in terms of lower levels of obsession-compulsion and anxiety compared to PNP and participants. ANP also differed from participants in terms of lower levels of asceticism. PNP reported significantly higher levels of Hostility compared to ANP and participants, as well as higher BMI compared to participants. PNP were more often employed or engaged in studies, compared to participants. No differences were found between ANP, PNP and participants in terms of age at onset of treatment, duration of illness, weight fluctuations, amenorrhoea, laxative misuse, vomiting, distribution of diagnoses or incidence of previous treatment.

Study II: Self-image and treatment dropout in eating disorders

When dropouts, completers and remainers were compared on DSM-IV diagnoses, age of onset, age at admission, BMI, compensatory behaviours and amenorrhoea, no significant differences emerged. Dropouts were found to report significantly lower levels of the psychological correlates of eating disorders on the EDI-2, as well as lower levels of psychiatric symptoms on the SCL compared to remainers. Significant differences were also found on self-image measured by SASB. Dropouts reported more Self-emancipation and Self-affirmation and less Self-blame compared to remainers. Dropouts also reported less Self-blame and Self-hate compared to completers. No significant differences were found between completers and remainers.

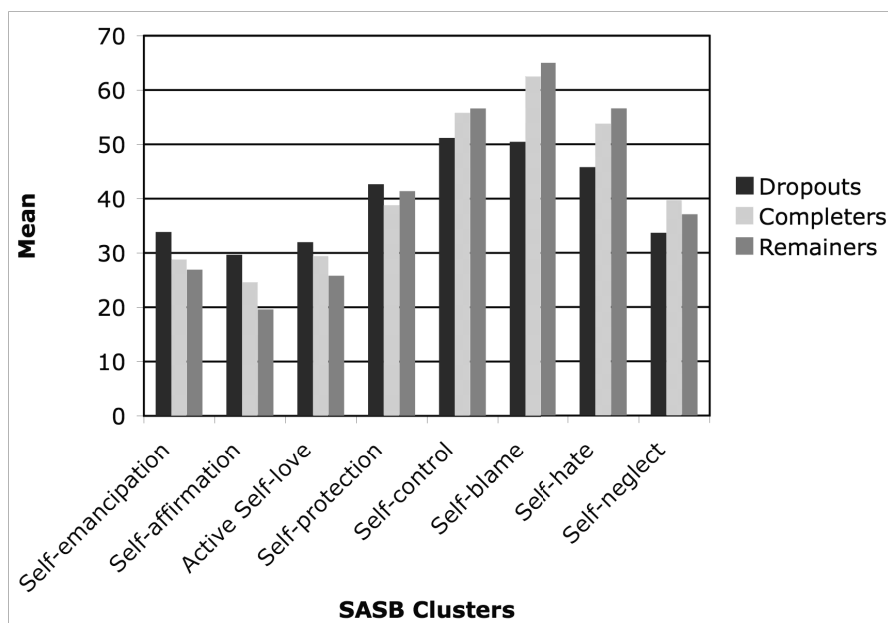
Table 2. Initial between-group differences on EDI-2 and SCL-63 with ANOVA, significance of F, and post-hoc Scheffé tests

	Follow-up participants n = 508	Active Non- Participants n = 88	Passive Non- participants n = 141	Post Hoc Scheffé tests p<.05	
Measure:	Mean (SD)	Mean (SD)	Mean (SD)	F	p
EDI-2:					
Drive for thinness	14.0 (5.2)	13.1 (5.6)	13.2 (5.7)	1.5	ns
Bulimia	7.6 (6.1)	7.1 (5.5)	8.5 (5.6)	1.5	ns
Body dissatisfaction	17.9 (7.2)	16.9 (7.3)	17.5 (7.7)	0.7	ns
Ineffectiveness	12.5 (6.6)	12.0 (7.3)	11.1 (6.6)	2.0	ns
Perfectionism	6.2 (4.2)	5.6 (4.4)	6.2 (3.9)	0.7	ns
Interpersonal distrust	4.9 (4.2)	4.9 (3.6)	4.3 (4.0)	0.9	ns
Interoceptive awareness	13.0 (6.6)	12.1 (6.2)	12.0 (6.4)	1.6	ns
Maturity fears	5.3 (4.6)	5.2 (4.3)	5.1 (4.6)	0.1	ns
Asceticism	7.4 (4.0)	6.1 (3.4)	6.8 (4.2)	4.6	.018 a
Impulse regulation	6.1 (5.0)	6.4 (4.9)	6.8 (5.5)	0.9	ns
Social insecurity	8.1 (4.3)	7.7 (4.4)	7.3 (4.5)	1.8	ns
SCL-63:					
Somaticism	1.42 (0.8)	1.26 (0.8)	1.42 (0.8)	1.5	ns
Obsession-compulsion	1.7 (0.8)	1.5 (0.8)	1.8 (0.8)	4.4	.025 a, .021 b
Interpersonal sensitivity	1.8 (0.8)	1.6 (0.8)	1.8 (0.9)	2.7	ns
Depression	2.1 (0.8)	1.9 (0.9)	2.1 (0.8)	1.9	ns
Anxiety	1.7 (0.8)	1.5 (0.8)	1.7 (0.8)	3.6	.050 a, .039b,
Hostility	0.9 (0.8)	0.8 (0.7)	1.1 (0.9)	5.6	.003 b, .031c
Sleeping problems	1.9 (1.1)	1.8 (1.2)	1.8 (1.2)	0.7	ns
Symptom index	1.7 (0.7)	1.5 (0.7)	1.7 (0.7)	3.3	ns
BMI	20.7 (5.0)	21.6 (6.8)	22.0 (5.1)	3.5	.002 c
Age at onset	16.9 (4.5)	16.5 (4.1)	15.8 (3.9)	3.2	.042 c

a= follow-up participants vs active non-participants, b= active non-participants vs passive non-participants, c= follow-up participants vs passive non-participants

Stepwise multiple discriminant analysis was used to predict group membership, with all SASB clusters together, and age and BMI as independent variables. This resulted in correct classification of 44% of the sample. The equation classified dropouts best (67%), while classifying correctly 54% of remainders but only 9% of completers. SASB self-blame was the only significant discriminating variable, with low levels of SASB self-blame significantly predicting treatment dropout.

Figure 2. SASB self-image profiles among Dropouts, Completers and Remainders at initial presentation.



Study III: What happened to the ones who dropped out? Outcome in eating disorder patients who complete or prematurely terminate treatment

Dropouts and completers started treatment at similar levels on all variables except SASB self-image. At intake dropouts presented with significantly higher levels of Self-empowerment as well as lower levels of Self-blame and Self-hate, compared to completers. At follow-up, no significant differences were found between dropouts and completers in self-rated symptoms and self-image, or in a number of interview-rated eating disorder and psychosocial aspects. No eating disorder diagnosis was found among 47% of dropouts, and 52% of completers. Dropouts did, however, report significantly higher levels of dissatisfaction with treatment (i.e. suitability of treatment approach and their therapists' ability to listen and understand). When patterns of change were examined (Table 3), both groups had made significant changes. Results suggested, however, that those who completed treatment, compared to dropouts, had made significantly greater changes in terms of lower levels of

eating disorder symptoms and psychological problems, along with a more positive self-image.

Table 3. Descriptive statistics for dropouts and completers on the EDI-2, SCL-63 and SASB at intake (T1) and follow-up (T5), significance of change using paired t-tests calculated for each group separately and effect sizes.

Measure:	Dropouts T1 Mean (SD)	Completers T1 Mean (SD)	Dropouts T5 Mean (SD)	Completers T5 Mean (SD)
EDI-2				
Drive for thinness	12.9 (5.4)	13.4 (5.8)	5.4(4.9)**	6.6 (6.2)**
Bulimia	5.3 (5.9)	7.25 (6.6)	3.3 (5.4)	2.1 (3.6)**
Body dissatisfaction	16.5 (7.1)	17.1 (7.4)	8.2 (7.2)**	8.1 (7.4)**
Ineffectiveness	9.25 (5.5)	11.3 (5.9)	6.0 (6.4)*	4.2 (5.1)**
Perfectionism	5.3 (5.1)	6.4 (3.5)	4.3 (3.7)	4.0 (3.4)*
Interpersonal distrust	4.8 (4.6)	4.8 (4.2)	2.3 (2.8)*	1.4 (2.0)**
Interceptive awareness	12.1 (5.5)	12.5 (6.9)	5.3 (5.4)**	4.0 (5.0)**
Maturity fears	5.1 (4.2)	5.4 (4.5)	2.9 (2.6)*	1.8 (3.1)**
Asceticism	7.0 (4.2)	7.8 (4.5)	4.1 (4.0)*	3.5 (3.9)**
Impulse regulation	5.7 (3.6)	6.3 (4.7)	3.5 (4.1)*	2.4 (3.2)**
Social insecurity	6.4 (4.9)	7.8 (3.9)	3.9 (5.1)	3.9 (3.2)**
SCL-63				
Somaticism	1.4 (0.8)	1.4 (0.9)	0.9 (0.7)*	0.7 (0.7)**
Obsession-compulsion	1.5 (0.8)	1.6 (0.8)	1.1 (0.9)	0.7 (0.6)**
Anxiety	1.4 (0.8)	1.4 (0.7)	0.8 (0.6)**	0.8 (0.7)**
Interpersonal sensitivity	1.6 (0.8)	1.6 (0.8)	1.0 (0.9)*	0.8 (0.9)**
Depression	1.8 (0.9)	1.8 (0.7)	1.3 (1.0)*	1.0 (0.9)**
Hostility	0.9 (0.6)	0.8 (0.6)	0.5 (0.6)*	0.3 (0.4)**
SASB				
Self-emancipation	34.3 (14.1)	26.1 (14.4)	37.8 (13.8)	40.0 (17.8)**
Self affirmation	30.0 (21.2)	21.5 (20.4)	40.6 (25.5)(*)	52.1 (27.8)**
Active self-love	33.3 (17.3)	26.6 (15.4)	46.2 (22.0)*	50.6 (22.8)**
Self-protection	44.0 (15.6)	38.1 (13.8)	48.6 (14.1)	52.9 (17.2)**
Self-control	55.7 (17.9)	58.9 (18.5)	49.1 (14.7)	51.4 (14.7)(*)
Self-blame	46.4 (21.8)	63.8 (18.9)	37.4 (24.0)	33.4 (26.1)**
Self-hate	43.3 (20.3)	54.7 (20.5)	33.4 (19.4)(*)	26.8 (25.3)**
Self-neglect	34.9 (17.6)	37.0 (17.3)	28.0 (17.8)	23.2 (19.2)*

(*) Significantly change from T1 to T5, small effect size

* Significantly change from T1 to T5, moderate effect size

** Significantly change from T1 to T5, large effect size

Study IV: The patient's perception of having recovered from an eating disorder

On the bases of interviews with ex-patients, four descriptive categories emerged, which covered the patients various conceptions of recovery. The first category was termed *Relaxed in relation to food*, and described a new way of perceiving eating, whereby an earlier irrational fear or compulsion had been replaced by a more relaxed attitude. Conceptions in the first category included: *Eating everything*, *Having a regular eating pattern*, *Eating together with others* and *Not relapsing into eating disorders*. The second category was termed *A healthy relationship to the body*. This new view of taking care of the body was described by three conceptions: *Accepting the body*, *A relaxed relationship to weight* and *Cooperating with the body*. In the third category; *Self-esteem*, participants described a change in their way of relating to themselves, such as

listening to their own wishes, allowing different moods, allowing space for themselves, and expressing opinions without fear of criticism. This category comprised four conceptions: *Achieving self-acceptance*, *Thoughtful about oneself*, *Having self-respect*, and *Permitting and dealing with emotions*. In the fourth category; *Social interaction*, participants described a new and active opinion toward social relations. Instead of withdrawing or interacting in a superficial or anxious way, they felt natural, experienced responsiveness, and felt pleasure in social relationships. This category contained three conceptions: *Being active to create a social life*, *Attaching great importance to social relations* and *Listening to others*.

Table 4. Categories and conceptions of recovery

Relaxed in relation to food	A healthy relationship to the body	Self-esteem	Social interaction
Eating everything	Accepting the body	Achieving self-acceptance	Being active to create a social life
Having a regular eating pattern	A relaxed relationship to weight	Thoughtful about oneself	Attaching great importance to social relations
Eating together with others	Cooperating with the body	Having self-respect	Listening to others
Not relapsing into eating disorders		Permitting and dealing with emotions	

Study V: The impact of using different outcome measures on remission rates in a three-year follow-up of eating disorders

The results are presented according to *who* assessed the outcome (experts or patients) and *which* outcome was assessed (i.e. eating disorder or global). Table 5 shows the remission rates resulting from the four expert-rated outcome measures of eating disorder symptoms. The remission rates in the total sample varied from 24.3% to 49.1%. The lowest remission rate was found for PSR (the strict definition requiring level 1) and the highest for the Primary outcome variables described by Berkman et al.¹⁰.

When the sample was divided according to initial eating disorder diagnosis, the variation in remission rates between outcome measures was even larger for AN (18.5% to 48.1%) and EDNOS (19.8% to 58.5%), but smaller for BN (30.2% to 44.4%) and BED (21.7% to 39.1%). This indicates that the outcome measures not only estimates eating disorder outcome differently, but also that they function differently depending on the patient's symptom setup.

The two other outcome measures, the EDI-2 symptom index (patient rated eating disorder outcome) and the GAF (expert rated global outcome) resulted in higher proportions of patients in remission. 77.8% of the patients reported scores within 1 SD of the mean of a normal group on the symptom index of the EDI-2. The same cut-offs used for the GAF resulted in 70.4% of the patients estimated as in remission. In the study we also used cut-offs for the EDI-2 symptom index and the GAF based on 2 SD from the normal mean. These cut-offs, however, resulted in remission rates that were clearly unrealistic, and they were thus not further used.

Table 5. Proportion of patients “in remission” as a result of different expert ratings of eating disorder symptoms, n = 334*

Remission Criteria	Total n=334	AN n=54	BN n=126	EDNOS n=131	BED n=23
PSR level 1	24.3%	18.5%	31.7%	19.8%	21.7%
PSR level 1 and 2	32.9%	29.6%	44.4%	23.6%	21.7%
Kordy's definitions	40.4%	44.4%	30.2%	48.9%	39.1%
Primary outcome measures	49.1%	40.7%	44.4%	58.5%	39.1%
DSM-IV criteria (No ED-diagnosis)	44.3%	48.1%	41.3%	46.6%	39.1%

* For details of Remission Criteria see Appendices A, B, C and D.

The pair-wise analyses of agreement between the different remission classifications showed results varying from no agreement at all to good agreement. Good agreement was found between the Primary outcome measures and Kordy's definitions ($\kappa = 0.74$), and moderate agreement among the other pairs of expert-rated outcome measures of eating disorder symptoms ($0.41 < \kappa < 0.60$). The classifications based on the EDI-2 symptom index showed no agreement at all with the PSR classifications, the Primary outcome variables and Kordy's definitions ($\kappa < 0.20$), and weak agreement with the DSM-IV based classification ($\kappa = 0.27$). In addition, the GAF based classification showed no agreement with the PSR classifications, and only weak agreement with the Primary outcome variables ($\kappa = 0.27$), Kordy's definitions ($\kappa = 0.27$), and the DSM-IV based classification ($\kappa = 0.29$).

Summary of main findings

- There was a substantial variation in remission rate, from 24.3% to 77.8%, depending on which outcome measure that was used. The pair-wise agreement between outcome measures in classifying patients as in remission or not varied from none ($\kappa < 0.20$) to good ($\kappa = 0.74$).
- A large amount of non-participation in long-term follow-ups was patient related. Patients missing at follow-up were distinct in a number of aspects but did not, however, show any signs of more severe psychopathology, rather the opposite.
- A similar pattern could be seen among treatment dropouts, who initially presented fewer psychological problems and less negative self-image compared to those who remained in treatment. Low levels of self-blame predicted treatment dropout.
- No significant differences were found between dropouts and completers at follow-up except that dropouts were reported to be more dissatisfied with treatment. Patterns of change, however, showed that treatment completers made significantly larger changes towards less eating disorder symptoms, less psychological problems and a more positive self-image compared to dropouts.
- Recovered women described a relaxed and accepting way of relating to food and the body. Recovery was also described as accepting themselves as individuals and interacting confidently with their social environment.

DISCUSSION

The focus of this thesis was to address problems in measuring outcome after eating disorder treatment, including non-participation in follow-ups, the role of self-image in treatment dropout, outcome among patients who drop out, patient's subjective perspectives of recovery, and the impact of different methods of measuring outcome. Results and methodological considerations of each study, along with conclusions and implications, will now be discussed.

Reflections on the results

The rate of **non-participation** in the 36-month follow-up (Study I) was 40% and the reasons for non-participation mainly patient-related. The successful follow-up rate of 60% is low, but still within the range of 23-100% earlier reported in the eating disorder literature ^{16, 94, 96, 105}. The non-participation was found to be mainly patient-related. Some of the non-participants (i.e. those who declined participation in further follow-ups or failed to attend scheduled follow-ups) initially presented with less psychopathology than the passive non-participants and those participating in follow-up. A common notion is that a high amount of non-participation automatically jeopardizes the reliability of the results, since participants may be healthier or may have found the treatment to be more helpful than non-participants ^{12, 111}. Studies investigating the impact of non-participation in health surveys found non-participants to smoke or use alcohol significantly more often than participants ⁵⁴, and to have more sickness benefit days ⁹. In contrast to such earlier studies of non-participation, we found an apparently healthier status with less psychopathology at intake among active non-participants compared to passive non-participants and participants. There was also an initially higher BMI among passive non-participants compared to participants. Since research has shown patients with low BMI to risk a poor prognosis ^{106, 129}, this raises the question whether the non-participants also were healthier at follow-up and therefore failed to see the rationale for follow-up. Often patients with eating disorders feel a need to please others, which may result in difficulties to say no ¹²⁴. The fact that some patients decline follow-up can thus possibly be interpreted as a sign of healthy changes towards greater autonomy, resulting in the ability to listen to their own wishes instead.

The non-participation was to some degree also caused by organisational difficulties, resulting in substantially different follow-up rates among participating units. This shows how organisational factors play an important role in follow-up non-participation. Organisational reasons for non-participation could probably in many cases have been prevented by supplying the units with research resources to lessen the burden of data collection on the clinicians. However, such resources are seldom available. Participation in research projects thus requires a great deal of leadership and organisational ability from the clinical unit.

The results in Study I underline the importance of not viewing non-participation as a unitary phenomenon. A systematic exploration of non-

participation in research is needed in order to lessen the problems of indistinct results due to missing data.

Treatment **dropout** might not be such a pathological sign as assumed in earlier research^{32, 39, 104, 108, 116, 119, 126}. Given the lesser degree of psychopathology at treatment start among dropouts in our Study II, and how dropout tended to take place relatively late in treatment, it could reflect a healthy decision to end treatment at a stage when patients felt they had received sufficient help and could continue to manage on their own. Patients, who drop out, may also have more limited treatment goals. Together with less self-blame, it may have been easier for these patients to disengage from treatment when they experienced symptom improvement. As Mahon⁷⁴ has pointed out, patients who are registered as dropouts might consider themselves as “completers”, although their therapists wanted to achieve more. This may be the case in our Study III as well since the dropouts did not differ significantly from completers at follow-up. This is also in line with a study that followed patients who dropped out of psychiatric care in the public mental health system¹²⁸. Using interviews they found that the dropouts had recovered from their presenting problems and needed no further treatment.

There may, however, be important differences in the treatment goals of dropout patients and their therapists. Previous research found subsequent dropout patients to have greater expectations of help by insight-related interventions than their therapists¹⁷. The treatment interventions generally offered, focussing on the eating disorder symptoms, may fit the majority of the patients, but may also be inappropriate for patients with disparate needs. This seems to be the case in our study. Compared to completers dropouts experienced significantly more frequent feelings of not being understood by their therapists and considered the treatment approach to be less suitable. It is a challenge for therapists to early discern who these patients are in order to prevent dropout due to treatment dissatisfaction.

When patterns of change were examined in our study, treatment completers were found to have made significantly greater changes towards less eating disorder symptoms, less psychological problems and a more positive self-image compared to dropouts. One possible interpretation of this is that the dropouts could have improved even more had they stayed in treatment according to plan.

The **patient's perceptions of recovery** is often missing in outcome studies^{8, 44, 56, 79, 93, 100, 113}. In accordance with other similar studies^{44, 89, 91-93}, results from Study IV, the qualitative interview study, revealed that several areas of life are included in recovery after an eating disorder. In addition to a relaxed attitude towards food and weight, the patients also emphasized a strengthened self-esteem that was expressed through increased self-respect, ability to handle difficult emotions, and courage to express their opinions without fear of criticism. The strengthened self-esteem experienced by the recovered patients in this study is in line with previous studies that have found self-esteem to be an important factor in outcome. Low self-esteem has been found to be involved in dieting awareness and the development of eating problems, while high self-esteem has been found to be an important predictor of better outcome among patients with BN^{28, 30}.

Another important sign of recovery was an active social life. Some of the women also viewed recovery in ways similar to feminist theory⁵⁸. Since an ongoing struggle with emotions and thoughts about food and body image has become an integral part of the social and personal life of women today, feminist theory sees it as a natural part also of being recovered from an eating disorder. Other women assumed that special maintaining factors first need to be solved before recovery is possible. Some women comprising this perspective of recovery maintained that their earlier difficulties with loving themselves had been solved, and as a result they felt a total freedom from their eating disorder⁵⁸.

Our results point out the unique characteristics of recovery from eating disorders, quite different from those of recovery from other mental disorders. This finding is in line with that of other researchers⁶⁷, who found that those recovered from eating disorders no longer identify themselves as a person with an eating disorders, while the opposite was true for recovery from other mental illnesses. Something new in our results, not generally reported in qualitative studies of eating disorders, are the recovered women's new and thoughtful caring for themselves. They acquired greater well-being through kindness towards themselves and through allowing themselves to experience pleasure. As recovered persons they wanted to make sure they were listening to the needs of the body as well as their innermost wishes or dreams. This pattern has been reported in studies of chronically ill women with cancer or heart disease⁵⁹. When these chronically ill women came to a point where they accepted the body as an essential part of themselves, they also became respectful of the demands of their bodies in a new way⁵².

Results in this Study V clearly point out the impact of using different outcome measures on the remission rates. The remission rates are highly dependent on how remission is defined in the outcome measure, who the evaluator of remission is (experts or patients) and which type of outcome that is assessed (eating disorder or global). The remission rate varied from 24.3% to 49.1% in the total sample when expert-rated outcome measures based on eating disorder symptoms were used. It is therefore equally true to state that experts rated approximately a quarter of the patients as being in remission at the three year follow-up, as to declare that almost 50% were in remission. Further, the outcome measures seem to function differently depending on what combination of eating disorder symptoms (i.e. what eating disorder diagnosis) the patients have. It was also noted that outcome measures that only required behavioural improvements to define remission classified a larger amount of patients as in remission.

When remission was calculated based on patient-rated eating disorder symptoms at follow-up, it resulted in a much higher remission rate, 77.8%. It is however important to consider that the rating of the EDI-2 was a single post measurement, not informed by possible improvement since treatment start. Post hoc analyses showed that about 20% of all patients scored within 1 SD of the normal population mean already at treatment start, which probably should be interpreted as a sign of symptom denial rather than normal concerns about weight and shape. This indicates that patient-rated endpoint measures, used

without considering initial symptom levels, are highly unreliable as outcome measures.

Remission rates based on expert-rated global functioning also classified a much larger proportion of patients (70.8%) as in remission than the expert-rated eating disorder outcome measures. The fact that remission rates based on patient-rated eating disorder symptoms and expert-rated global functioning were much higher suggests that these two outcome measures have very little in common with the expert-rated outcome measures based on eating disorder symptoms. This interpretation is confirmed by the absent or weak agreements found for these two measures in the analyses of agreement between the different outcome measures. In addition, the moderate to good agreements among the expert-rated eating disorder based outcome measures suggest that they capture roughly the same dimensions.

These results clearly demonstrate the need of a consensual measure of eating disorder outcome in order to make comparisons between outcome studies meaningful and to reliably elucidate the picture of outcome after eating disorders.

Methodological considerations

General aspects

Important strengths of the studies using the CO-RED material are the naturalistic and prospective approaches. The naturalistic approach because it gives a sample that is representative for adult patients seeking specialised eating disorder treatment in Sweden, with the ensuing mix of diagnoses, ages, illness severity and duration typical of patients in every-day clinical practice. The prospective approach because it gives reliable pre-treatment data to compare with follow-up data collected at several time points. In addition, the use of interviews and self-report measures covering eating disorder symptoms, general psychopathology, psychosocial situation and functioning, and self-image, together with measures for treatment satisfaction, gives a broad impression of the patients' problems.

Since there is no consensus about which aspects should be measured in order to be able to define recovery after eating disorders, knowledge emerging from the qualitative interviews about the variation in the patient's own conceptions of recovery is of great value. The qualitative interviews took place two years after the end of treatment. The interviewed women thus had quite long experiences of improvement from their eating disorder, assuring that they knew what they were talking about in the interviews¹⁰³.

The complementary combination of quantitative and qualitative approaches gives extra strength to this thesis by adding subjective experiences to well-researched dimensions of recovery¹⁵.

The primary methodological concern in the studies using the CO-RED material is questions of reliability and validity in the data collection phase. Firstly, a new

and previously untested semi-structured interview (the RAB) was used by a rather large number of interviewers, some of them without previous training in the use of the interview. Internal consistency, inter-rater and test-retest reliabilities, as well as concurrent and discriminant validities have, however, been found to be good ^{19, 85}. Secondly, a number of factors – like e.g. organisational changes, lack of staff motivation, a time pressed work schedule, and uncertainties regarding documentation of non-participation – contributed to a substantial frequency of non-participation and lack of information about reasons for non-participation. Not all of the participating units did, however, allow the shortage of time to seriously flaw the data collection. They realised early during the project that they would not be able to follow-up all patients they intended to treat, and decided, together with the research group, to only include some of their patients. By doing this randomly, e.g. every third or fourth patient, systematic selection biases were avoided. This decision probably prevented an even higher frequency of missing data or non-participating patients due to organisational factors.

Study-specific considerations

Study I showed that most non-participation was patient-related, while organisational factors accounted for only a small part of non-participation and were thus not further analysed.

It would have been interesting to know why the patients chose not to fulfil their follow-up commitments. We are, however, only aware of the motives of a few patients. Among them were some patients who moved to other cities or countries. Information about mortality was not available when Study I was written. We now know that four of the missing patients were deceased at follow-up.

Questions have arisen during investigating both research non-participation and treatment dropout. Who are these patients? Do the patients who withdraw from research or treatment present with more denial of eating disorder symptoms? Or do these patients feel forced into treatment by relatives and thus feel that they have their rights violated? Could withdrawal be a way to demonstratively claim their right not to fulfil the agreement to take part in treatment or follow-ups? The initial analyses did not show less severity in self-reported eating disorder symptoms among non-participants or dropouts that could indicate denial of their problems. In order to obtain further clarity, we examined how many patients that scored in the normal range when self-evaluating their symptoms at treatment start. There were, however, no between-group differences in the proportion of “denying” patients or in any other “signs” of denial. Furthermore, the groups did neither differ in proportion of patients who sought treatment on their own initiative, nor in motivation to overcome the eating disorder. These findings are in accordance with the results presented in the studies, once again suggesting that both non-participation and dropout may be related to other factors than denial, severity of symptoms or feelings of being forced into treatment. The decision not to participate in follow-ups or to withdraw from treatment could even be interpreted as a good sign in previously “nice girls”, who have learnt to listen to their own wishes and

acquired the ability to say no, or at least to act a no by not appearing for treatment or follow-up.

Strengths of **Study II** include the use of a three-group design that allowed dropouts to be contrasted with both patients who remained in treatment longer than 12 months and those who had completed treatment by the 12-month follow-up. There were many patients in Study II with either missing data at the 6- and 12-month follow-ups or who were excluded for procedural reasons. In order to investigate possible systematic differences between those included and those excluded, we did post-hoc comparisons. No significant differences were, however, found between those included ($n = 162$) and those without treatment follow-up protocols at 6 or 12 months ($n = 375$) or those excluded for procedural reasons ($n = 301$) (see figure 1; flow-chart).

Though **Study III**, to our knowledge, is the first study to report medium term outcome for eating disorder treatment dropouts, a possible problem is that outcome was studied only for some of the dropouts in the CO-RED project, i.e. those who participated in the final follow-up. Comparisons of initial data from missing dropouts and those participating in the final follow-up did, however, not indicate any substantial differences between the groups at treatment start. Another problem may concern the use of several t-tests that can increase the risk of type-1 errors. We therefore attempted to explore the patterns of results and report the effect sizes together with p-values in order to confirm the strength of differences found. Yet another methodological concern is that the completers started significantly worse off than the dropouts regarding self-image and subsequently made greater changes. This could be a sign of regression to the mean. The fact that completers continued to progress and ended up even better than dropouts might, however, be a sign of true progress. In order to scrutinize the risk of regression to the mean in our results, we investigated the correlations between the individuals' mean values and their change from admission to follow-up, as recommended by Altman ¹. Two significant improvements, EDI Ineffectiveness and SCL Obsession-compulsion among completers, were found to be significantly correlated with the individual's mean values and must therefore be interpreted with caution. No other signs of regression to the mean were found. The influence on outcome of the initial differences (i.e. levels of self-image, age and duration) between the two groups was investigated post hoc, using multivariate analyses. The differences were, however, not shown to have any effect on the proportions of patients with an eating disorder diagnosis at outcome. Another concern in this study is that we do not know if the significantly greater improvement among completers at 36-month follow-up can be attributed to the treatment. Since follow-ups were pre-planned to fixed time-points, we do not have data from the exact dates when treatments were terminated. The greater improvement among completers could thus possibly be due to support from important persons outside of treatment or other extra-therapeutic circumstances. The results should therefore be interpreted with caution and the conclusion that it is better to complete treatment than to dropout should be regarded as tentative.

In **Study IV** a phenomenographic approach was found to suite the aim to describe the patients' ideas of recovery and their various ways of experiencing it.

Since I on a regular basis meet patients at our local eating disorder unit in Örebro for one-year follow-ups, it was practical to include patients from this unit in Study IV. In phenomenographic studies it's important that participants are included in a way that maximises variation, often by strategic selection^{75 78}. Such a selection was not necessary in the present study, since the consecutively included patients showed a satisfying variation in terms of eating disorder diagnoses, age and illness duration. This variation increases the possibility to apply the found descriptive categories to other groups⁷⁸.

Since very few males seek eating disorder treatment, there were unfortunately no males included in the qualitative interviews. It is thus possible that males who recover from an eating disorder perceive recovery differently. A question of credibility is whether some recovered patients deny remaining illness and thus incorrectly present themselves as recovered⁶⁹. It is well known that patients with AN tend to deny their illness. However, research has shown that the kind of denial where patients 'fake good' is primarily not a question of lack of insight, but is better understood as a part of an overvalued idea linked to perfectionism. Denial is often also a sign of poor motivation and such patients rarely seek treatment^{117, 118}. In addition to a decreased perfectionism, the patients in our study clearly expressed changed attitudes in direction of accepting their appearance instead of adhering to a thin ideal. This indicates that the patients had experienced a true improvement.

The labels and descriptions of the categories and conceptions are direct results of the patient's expressions and special care has been taken to keep as close as possible to the original text from the interviews. It should be emphasized that the interviews took place two years after the end of treatment. The conversation did not focus on the process of recovery, but rather on the patients' perceptions of recovery at the current point in time. The fact that they ended treatment approximately two years before the interviews guarantees own experience of the topic under study, which is essential in qualitative studies¹⁰³.

To secure credibility of the results, the second author scrutinized the patients' statements in relation to the conceptions and categories. Using a number of quotes from the interviews when presenting the results also strengthened the dependability of the categories⁶⁹. The present conceptions of recovery can be merged with results from other qualitative studies. Qualitative similarities and shared characteristics can be disclosed even though results come from various cultures or time periods in different parts of the world. The present views of recovery are probably transferable to other women in stable remission from an eating disorder. It is, however, possible that more recently recovered patients, as well as adolescents or males who have had an ED, think differently about recovery. Nevertheless, our results increase the knowledge about the patients' perspectives on recovery from eating disorders, and reveal important dimensions that should be measured in follow-ups.

Other approaches than the phenomenographic that possibly could have been used in the qualitative study are the Phenomenologic hermeneutical approach⁷⁰ or Qualitative content analysis⁴⁷. By using these approaches we could have captured the real essence of recovery or found the patients' underlying meaning

of recovery, but we would probably also not have detected the full variation in the patients' experiences of recovery maybe had lost the variations of patient's experiences.

The outcome for men and women were analysed together in **study III** and **V**, due to few cases of men. Research has however shown no reason to expect a different outcome for men. The same rates of treatment response and similar long-term prognoses as in women, have earlier been found among men ¹²⁵. Outcome studies have shown that the journey to recovery from eating disorders begins in treatment, but continues for a long time, with most patients recovering within twelve years ^{33, 35}. The outcome presently measured at 36 months should consequently not be thought of as a final outcome, but rather as a status snapshot taken somewhere on the road to recovery.

Future research

- In order to clarify treatment related aspects of non-participation and dropout, future research should try to measure patients' improvement until the point of withdrawing from research or treatment.
- To increase the knowledge about long-time experiences of recovery and to clarify if conceptions of recovery are stable over time, future qualitative research should study patients who have been recovered for a longer time than two years.
- Another line of qualitative inquiry could investigate if males with eating disorder have different conceptions of recovery than females.
- Further investigation of treatment dissatisfaction is badly needed. By qualitatively evaluating treatment from the patients' perspective, factors preceding the decision to interrupt treatment could be disclosed.
- Continued research regarding how to best measure outcome independent of eating disorder diagnosis is also needed.

CONCLUSIONS

This thesis does not focus on which measure is best for assessing outcome in eating disorders. Instead it focuses on the problems researchers encounter when studying eating disorder outcome, and suggests possible solutions to some of these problems. Accordingly, one of the most important conclusions of this work is that it is important not to ignore methodological questions. Instead, these problems should be scrutinized closely in order to see whether they tend to skew results beyond the point of plausibility.

What's more, our analyses suggest that it is important to question the assumption that patients who choose not to participate in follow-ups will necessarily have had less use of treatment or be less healthy than those who participate in follow-ups. There were no signs of greater psychopathology among patients who were missing at follow-up, nor did post-hoc analyses show non-participation to be associated with less motivation for change, denial of illness, or that these patients had been pressured into seeking help.

The studies of treatment dropouts led us to similar conclusions. Quite simply, it should not be assumed that patients with greater eating disorder or psychiatric psychopathology are the ones who are most likely to drop out, and that these individuals are at greater risk for negative outcome. Instead, the present work suggests that it is in fact patients with less psychopathology and less negative self-image at the start of treatment who terminated treatment prematurely, and that the outcome of these individuals is virtually identical to those who complete treatment. Nevertheless, results did suggest that there was greater dissatisfaction with treatment among those who dropped out, especially in terms of how well suited the treatment was to their own needs, and how well therapists tended to listen and understand. These results indicate the importance of the therapist and the patient together continuously evaluating their treatment experiences. In our study, the patients dropping out remained in treatment for an average of five months. When treatment has been going on for some time and certain improvements has been reached, it may thus be especially important to identify necessary changes in the treatment approach to prevent the patient from interrupting treatment due to dissatisfaction.

There was considerable variation in the number of patients who could be judged to be "in remission" when different outcome measures were used. This indicates how important it is to achieve greater consensus about acceptable methods of measuring outcome in eating disorders. There is a large number of outcome studies in the field, mostly as regards AN and BN. The problem today is not primarily lack of knowledge regarding outcome, but an inability to use this knowledge optimally, since the available knowledge is described and measured in such divergent ways. Ultimately knowledge of outcome cannot be based on single studies, but rather on the cumulative effect of a number of studies that together indicate important patterns of outcome. In order to achieve this goal, individual studies will need to become more comparable.

Another important conclusion of this thesis is that ex-patients' perceptions of recovery only partially involve attitudes to food, weight and whether or not they continue to show disordered eating behaviour. These are areas that are often measured in outcome studies. However, in interviews ex-patients tended to also talk about other aspects of recovery, such as greater self-esteem, acceptance of oneself as an individual, and being able to interact with others in a more positive way. These aspects of recovery need to be addressed in research in order to achieve a more holistic picture of outcome.

Even if it was not the primary aim of this thesis to investigate whether full recovery from an eating disorder is possible, two of the studies indicate this possibility. The most stringent definition of remission used in study V required no remaining signs of the eating disorder; either behavioural (e.g. binge-eating, vomiting), physiological (e.g. underweight, amenorrhoea) or cognitive (e.g. body image disturbances, weight phobia). When it was applied on the three-year follow-up data, almost a fourth of the patients were classified as in remission. Also in the qualitative study (IV), some of the ex-patients described themselves as recovered, not only in their way of handling food and weight, but also in terms of freedom from eating disorder cognitions. This is an important message for patients, relatives, therapists and researchers to bring into the struggle against eating disorders: It is possible to become completely free from an eating disorder.

EPILOGUE

On the basis of the definition of an eating disorder by Fairburn and Walsh ³¹, and the time frame proposed by Kordy et al ⁶⁶, definitions of remission and recovery from an eating disorder, could be expressed as follows:

“Remission from an eating disorder is attained when an earlier persistent disturbance of eating behaviour (i.e. weight-loss related behaviour, eating related cognitive disturbances, or concerns about weight or shape) has decreased to an extent that it no longer significantly impairs physical or mental health, or psychosocial functioning. Recovery is achieved when remission has been stable for a year or more”.

Over the past five years, my perception of recovery has of course changed while listening to the patients I have interviewed, and when analysing the results of this thesis. My decided opinion today is that it is possible to fully recover from an eating disorder, not only in a behavioural sense, but cognitively and emotionally.

I believe that a patient's view of the possibility of full recovery tends to become modified during their journey. I have often heard those who are still struggling state, in resignation, that they will always be plagued with thoughts about weight and eating; but at the same time their eating behaviour is relatively normal and they regard themselves as recovered. Therapists may not believe in full recovery, and may therefore tend to influence their patients in such a way as to make them accept that they may always be struggling with eating disordered thoughts.

Years later many former patients, who have maintained normal eating behaviour, may finally notice how these disturbed thoughts are gone, and that they have started to think differently about food, their bodies and themselves. The recovered women in our study emphasized that their new way of relating to themselves was demonstrated by greater self-acceptance, self-respect, and by listening to their own wishes and dreams. Greater self-acceptance has also been reported as the most important protective factor hindering the development of body dissatisfaction and dysfunctional eating attitudes ¹²³.

I therefore believe that former eating disorder patients who feel totally free from their eating disorder may view recovery in ways different than the definition above. As Reindl ⁹⁹ has put it:

“The opposite of an eating disorder is accepting and respecting oneself as one is, and yet striving to develop one's potential as an increasingly whole complex person” (p. 290)

SAMMANFATTNING PÅ SVENSKA (SUMMARY IN SWEDISH)

Det finns en mängd utfallsstudier inom ätstörningsforskningen och nästan alla dessa studier har påverkats av problem med att patienter avbryter behandlingen eller sitt deltagande i forskningen. Ett annat problem i dessa studier är att det saknas en gemensam syn på hur man ska definiera och mäta utfall. Det är också ovanligt att utfallsstudier orienteras mot hur patienterna själva uppfattar tillfrisknandet från ätstörning.

Det övergripande syftet i denna avhandling var att fokusera på problem med att mäta utfall efter ätstörningsbehandling. Fokus har särskilt varit på följande specifika metodologiska utmaningar: patienter som avbryter sin medverkan i långtidsuppföljningar, självbildens betydelse för patientens beslut att avbryta behandling, utfallet för patienter som avbrutit behandlingen, patienternas egen syn på tillfrisknande, samt effekten av att använda olika definitioner och mätmetoder för utfall.

De fyra kvantitativa studierna (I, II, III och V) genomfördes inom ramen för projektet *Samordnad utvärdering och forskning vid specialenheter för anorexi/bulimi (SUFSA)*. Detta projekt använde en prospektiv, longitudinell och naturalistisk forskningsdesign med datainsamling från ett flertal deltagande ätstörningsenheter. En studie (IV) var en kvalitativ studie som, med hjälp av fenomenografisk metod, analyserade intervjuer med ex-patienter som upplevde sig som friska.

Studie I visade att orsakerna till bortfall från forskningsuppföljningar främst var patientrelaterade (69 %). De som avböjde fortsatt deltagande i uppföljning rapporterade signifikant lägre nivåer av obsession-kompulsion och ångest, medan patienter som inte gick att hitta vid uppföljning rapporterade signifikant högre nivåer av ilska-fientlighet vid inskrivning.

I **Studie II** visade patienter som avbröt behandlingen en lägre grad av negativ självbild och färre psykologiska problem i jämförelse med patienter som stannade kvar i behandling. Låg nivå av självkritik särskiljde patienter som avbröt behandling från dem som fullföljde sin behandling och från dem som fortfarande var kvar i behandling och predicerade alltså avbrytande av behandling.

Vid uppföljning efter 3 år (**Studie III**) fanns inga signifikanta skillnader mellan dem som avbröt behandling och dem som fullföljde sin behandling förutom att de som avbröt rapporterade mer missnöje med behandlingen. När mönster av behandlingsrespons studerades visade det sig att patienter som fullföljde sin behandling hade förbättrats signifikant mer sedan start avseende ätstörningssymtom och psykologiska problem. De uppvisade också större positiva förändringar av sin självbild jämfört med patienter som avbrutit behandlingen.

I de kvalitativa intervjuerna i **Studie IV** beskrev kvinnorna som upplevde sig som friska delvis andra dimensioner av utfall än de som vanligtvis mäts vid uppföljningar. Som friska hade de nu ett avspänt och accepterande förhållande

till mat, till kroppen, till sig själva som individer och i sin sociala miljö. Vissa uppfattade tillfrisknande som en effekt av att de lärt sig hantera känslor, medan andra upplevde sig själva som friskare än människor i allmänhet i sitt förhållande till mat och vikt.

I **Studie V** användes några av de vanligast förekommande utfallsmåtten vid uppföljning efter 3 år. Beroende på utfallsmått varierade andelen förbättrade patienter från 24.3 % till 77.8 %. Överensstämmelsen mellan de olika utfallsmåtten varierade också kraftigt.

Sammanfattningsvis: Resultaten pekar på vikten av att inte uppfatta bortfall från uppföljning eller avbrytande av behandling som enhetliga problem. Vidare tydliggörs behovet av att enas kring hur vi ska definiera och mäta utfall för att jämförelser av resultaten från utfallsstudier ska bli meningsfulla, men också för att klarlägga bilden av utfall efter ätstörning.

Nyckelord:

Ätstörning, bortfall, avbrytande av behandling, utfallsdefinitioner, patientperspektiv

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APPENDICES

Appendix A

DSM-IV Diagnostic Criteria for Eating Disorders

307.1 Anorexia Nervosa (AN)

- A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g. weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to a 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 body weight.
- D. In post menarcheal females, amenorrhea, i.e. the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g. oestrogen administration.)

Specify type:

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

Binge-Eating/Purging Type: during the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behaviour (i.e. self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

307.51 Bulimia Nervosa (BN)

- A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both 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 what or how much one is eating)
- B. Recurrent inappropriate compensatory behaviour 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 behaviours occur, on average, at least twice a week for 3 months.
- D. Self-evaluation is unduly influenced by body shape and weight.
- E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Specify type:

Purging type: during the current episode of Bulimia Nervosa, the Person has regularly engaged in self-induced vomiting or the misuse of Laxatives, diuretics or enemas.

Non-purging type: during the current episode of Bulimia Nervosa, the Person has used other inappropriate compensatory behaviours, such as fasting or excessive exercise but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics or enemas.

307.50 Eating Disorder Not Otherwise Specified (EDNOS)

1. For females, all of the criteria for Anorexia Nervosa are met except that the individual has regular menses.
2. All of the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
3. All of the criteria for Bulimia Nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
4. The regular use of inappropriate compensatory behaviour by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two cookies).
5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.
6. Binge-eating disorder: recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviours characteristic of Bulimia Nervosa.

Appendix B

Psychiatric Status Rating Scale¹

Psychiatric Status Rating Scale for Anorexia Nervosa (AN)		
6	Definite / severe AN	Meets DSM-IV criteria for AN and BMI< 16.3 and presents with a severe disturbance in level of functioning (i.e. GAF <= 50)
5	Definite Criteria	Meets DSM-IV criteria for AN but does not present with a severe disturbance in level of functioning (i.e. GAF > 50)
4	Marked	Does not meet DSM-IV criteria for AN, but shows obvious evidence of this disorder (e.g. more than 10% below normal body weight BMI<17, AND some of following symptoms: amenorrhea / restricted eating / afraid of gaining weight / pathologically disturbed body image, compulsive exercise). Does not present with a severe disturbance in level of functioning (i.e. GAF > 50)
3	Partial remission	Does not meet DSM-IV criteria for AN, shows less psychopathology than full criteria and 'Marked' criteria, but shows obvious evidence of the disorder (e.g. within 10% of normal body weight : BMI 17-27, AND same symptoms as in 'Marked' criteria, but less frequent or intense). Level of functioning no more than moderately impaired (i.e. GAF > 60).
2	Residual	Does not meet DSM-IV criteria for AN, shows no evidence of disordered eating behaviour, but shows clear evidence of disordered thoughts concerning shape and weight. Within 5% of normal body weight: BMI 17.5 to 26.25.
1	Usual self	Does not meet DSM-IV criteria for AN, shows no evidence of disordered eating behaviour (i.e. no restricted eating, no compulsive exercise) Shows no evidence of disordered thoughts concerning shape and weight (i.e. not afraid of gaining weight and normal body image). BMI between 18.5 to 25, for females: regular menstruation

Psychiatric Status Rating Scale for Bulimia Nervosa (BN).		
6	Definite criteria / severe	Meets DSM-IV criteria for BN and presents with a severe disturbance in level of functioning (i.e. GAF <= 50)
5	Definite criteria	Meets DSM-IV criteria for BN but does not present with a severe disturbance in level of functioning (i.e. GAF > 50)
4	Marked	Does not meet DSM-IV criteria for BN, but shows clear evidence of the disorder (e.g. continues to binge and purge, but less than twice a week)
3	Partial remission	Does not meet DSM-IV criteria for BN, shows considerably less psychopathology than full criteria (e.g. bingeing occasionally, without purging)
2	Residual	Does not meet DSM-IV criteria for BN, but still has to fight disordered thoughts concerning shape and weight
1	Usual self	Does not meet DSM-IV criteria for BN, shows no evidence of BN, no evidence of disordered thoughts concerning shape and weight

¹ A time frame of three months was used for all measures.

Modified Psychiatric Status Rating Scale, suitable EDNOS diagnoses

6	Definite criteria / severe	Meets DSM-IV criteria for any eating disorder diagnosis and presents with a severe disturbance in level of functioning (i.e. GAF \leq 50)
5	Definite criteria	Meets DSM-IV criteria for any eating disorder diagnosis but does not present with a severe disturbance in level of functioning (i.e. GAF $>$ 50)
4	Marked	Does not meet DSM-IV criteria for a primary eating disorder (i.e. AN or BN), but shows clear evidence of eating disorder (e.g. bingeing / purging but less than twice a week, BMI $<$ 17, amenorrhea / restricted eating / afraid of gaining weight / pathologically disturbed body image / compulsive exercise). No more than moderate impairment in level of functioning (i.e. GAF $>$ 50)
3	Partial remission	Does not meet DSM-IV criteria for AN or BN, shows clear evidence of eating disorder (same symptoms as 'Marked' criteria but less frequent or intense.). BMI not lower than 17. Level of functioning GAF $>$ 60.
2	Residual	Does not meet DSM-IV criteria for any eating disorder, but still has to fight disordered thoughts concerning shape and weight. BMI $>$ 17.5
1	Usual self	Does not meet DSM-IV criteria for any eating disorder, shows no evidence of disordered eating behaviour, and shows no evidence of disordered thoughts concerning shape and weight. BMI $>$ 17.5

Appendix C

Kordy et al's original definitions and modifications for EDNOS²

Original criteria according to Kordy et al (2002)

AN Restrictive type	Partial Remission (if former AN restricting type (1 month*))	Weight: BMI > 17.5. No weight reduction by vomiting or laxative abuse. No binges.
AN Binge/Purging type	Partial Remission (if former AN BingePurge Type) (1 month*)	Weight: BMI > 17.5, no weight reduction by vomiting or abuse of laxatives. Binges ≤ 1 / week.
BN	Partial Remission (1 month*)	Binge /purge attacks, vomiting or abuse of laxatives ≤ 1 / week.
AN Restrictive type	Full remission (3 months)	Weight: BMI > 19. No extreme fear of gaining weight, no weight reduction by vomiting or laxative abuse. No binges.
AN Binge/Purging type	Full remission (3 months)	Weight: BMI > 19, no extreme fear of gaining weight, no weight reduction by vomiting or laxative abuse. No binges.
BN	Full remission (3 months)	No binge/purge attacks, no extreme preoccupation with figure, no weight reduction by vomiting or laxative abuse.

Modified Kordy criteria, suitable for DSM-IV EDNOS

EDNOS	Partial Remission	Weight: BMI > 17.5. Binge/purge attacks, vomiting or abuse of laxatives ≤ 1 / week if these symptoms were present earlier, otherwise no occurrence of binge/purge attacks, vomiting or abuse of laxatives.
EDNOS	Full remission	Weight: BMI > 19. No binge/purge attacks, no weight reduction by vomiting or laxative abuse, no extreme preoccupation with figure, no extreme fear of gaining weight

² Time criterion of 3 month was applied for full remission criteria.

Appendix D

The diagnosis-specific primary outcome measures identified by Berkman et al. 2007.

Initial AN	Criteria	BMI >18.5, regular menstruation, no bulimic symptoms (i.e binge/purging)
Initial BN	Criteria	No binge/purging
Initial BED	Criteria	Weight-loss (i.e. BMI lower at follow-up than at treatment start), no binge eating
Initial EDNOS	Criteria	BMI >18.5, no binge eating, no purging behaviour

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