Measuring Eating Disorder Outcome
To my family
Tabita Björk

Measuring Eating Disorder Outcome
– Definitions, dropout and patients’ perspectives
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Title: Measuring Eating Disorder Outcome – Definitions, dropout and patients’ perspectives

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Abstract


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:


The studies presented in this thesis have been reprinted with the kind permission of the publishers concerned.
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. They are one of the most common mental disorders among young women. There are reports of young children, as well as middle-aged adults developing eating disorders, but they are still most common among younger women. Only one of ten cases of AN or BN is male, while 50% of cases with BED are male. 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. There are some evidence of spontaneous remission (i.e. recovery without treatment), but that is the case with other psychiatric disorders as well. 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.

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. 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 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) or the International Classification of Diseases (ICD-10). 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 amenorrhea 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 10:1.

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. 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.

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. The prevalence of EDNOS has been estimated to be between 2.4 to 5.4% among young women. 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% and 6.6%, distributed equally.
between men and women. 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.

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. 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. Adolescents appear to lack eating disorder diagnoses at follow-up to a greater extent than adult patients. 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. Similar recovery rates of about 50% have been reported for BN in a five year follow-up. Longer duration of follow-up increases both estimated rates of recovery, as well as rates of mortality. About a third of the patients relapse after showing clinical improvement. It is, however, unusual to relapse after achieving full recovery.

In summary, recovery appears to be a process going on for several years, with gradual improvement and temporary relapses. Most patients recover, however, during the first 12 years; after that only few manage to recover.
There is nevertheless a case report of recovery after 50 years with an eating disorder. 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. Primary outcome variables in AN are weight gain and resumption of menstruation. In BN primary outcome variables reflect the core behavioural features of the disorder, i.e. reduction of and abstinence from binge eating and purging. Primary outcome variables in BED concern reduction of and abstinence from binge eating and weight loss.

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”. Alternatively, stepwise gradations may be used to describe the severity of the disorder and the degree of symptom improvement. Other methods use a combination of degree of symptom improvement and changes in attitudes concerning weight and appearance. 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.

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. 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. 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). 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. 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. 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 is it 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. 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-up. 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 treatment. 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 has been reported for patients in treatment for depression. 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 outcome. What’s more, it is necessary to clearly define dropout,
since there are many different ways of bringing treatment to a close. Claussen\textsuperscript{16} 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).

\textit{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 relapse\textsuperscript{50}, the process of recovery\textsuperscript{62, 64, 80, 83, 102} and have evaluated helpful elements in the social, family or therapeutic context\textsuperscript{88, 120}. Studies that have focused on the meaning of improvement and recovery from the patient’s point of view\textsuperscript{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.

\textit{Impact of outcome measures and definitions}

The European eating disorders research project (TR-EAT), which has been described by Kordy et al.\textsuperscript{66}, defined full remission as when the individual is asymptomatic (i.e. has no more than minimal symptoms). The definition was inspired by depression research\textsuperscript{68}, where remission was achievement of a complete asymptomatic response that lasts from two weeks to six months\textsuperscript{36}, 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 weight\textsuperscript{21} when defining recovery. A meaningful construct should also consider the severity of symptoms and the duration of the observed improvements\textsuperscript{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 it\textsuperscript{10}. 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. 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. Likewise, frequently used categorisations, such as good, intermediate and poor outcome, are often defined in considerably different ways. General conclusions, such as that reached by Steinhausen, 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.
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. 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.

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

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Data collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>n = 840 from CO-RED, 14 units included</td>
<td>Semi-structured interview, self-report questionnaires: EDI-2, SCL-63 &amp; BaT</td>
</tr>
<tr>
<td>II</td>
<td>n = 162 from CO-RED, 12 units included</td>
<td>Semi-structured interview, self-report questionnaires: EDI-2, SCL-63, SASB &amp; BaT</td>
</tr>
<tr>
<td>III</td>
<td>n = 82 from CO-RED, 9 units included</td>
<td>Semi-structured interview, self-report questionnaires: EDI-2, SCL-63, SASB &amp; BaT</td>
</tr>
<tr>
<td>IV</td>
<td>n = 14 ex-patients from a specialist unit</td>
<td>Qualitative interview</td>
</tr>
<tr>
<td>V</td>
<td>n = 334 from CO-RED, 12 units included</td>
<td>Semi-structured interview, GAF assessment, self-report questionnaire: EDI-2</td>
</tr>
</tbody>
</table>
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 environment. 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 individuals. Phenomenography permits variation in methodology depending on the aim of the specific research. Phenomenographic analysis results in logical hierarchical categories between conceptions and descriptive categories, as well as variation of descriptive categories. 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 conceptions.

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 colleagues 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 remainers 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

Included in the CO-RED project n=840

- Treatment follow-up protocol at 6 or 12 months n=465
  - Dropouts n=56
  - Completers n=86
  - Remaining, still in treatment n=323

- No treatment follow-up protocol at 6 or 12 months n=375
  - Dropouts n=54
  - Completers n=54
  - Remaining, still in treatment n=54

- Study II, n=162
  - Dropouts participated in 36-mo. follow-up interview n=30
  - Completers participated in 36-mo. follow-up interview n=52

- Study III, n=82
  - All patients in the CO-RED project who participated in the final 36 months follow-up interview with complete data on all categorical outcome measures n=334

- Study V, n=334
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. 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 disorders.

*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 α = .87).

*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. 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-90. 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. The questionnaire comprises 36 self-referential statements, some framed positively and others negatively. The questionnaire forms eight clusters of self-image:

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 work.

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 reached. 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 participators or non-participators at 36-month follow-up. Non-participators were further divided into groups based on reasons for not taking part in the final follow-up: 1) patient-related non-participators (i.e. patients declined to participate, failed to attend scheduled follow-ups, or could not be traced); 2) organisational-related non-participators (i.e. administrative changes at the units or lack of time and/or heavy workloads); or 3) uncertain non-participators (i.e. reasons for non-participation were not documented). Patient-related non-participators were further analysed and divided into two subgroups, based largely on an active-passive distinction. Active non-participators (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-participators (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-workers, 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. 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. 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. 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. 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.
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 NVivo

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. 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 improvement. 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 mean.
In Study IV, the qualitative interviews were analysed using a phenomenographic approach. 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. 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.

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, 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. Pair-wise analyses of agreement among outcome measures were calculated using Kappa.

**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 participators.

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 participators. ANP also differed from participators in terms of lower levels of asceticism. PNP reported significantly higher levels of Hostility compared to ANP and participators, as well as higher BMI compared to participators. PNP were more often employed or engaged in studies, compared to participators. No differences were found between ANP, PNP and participators 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

<table>
<thead>
<tr>
<th>Measure:</th>
<th>Follow-up participators n = 508</th>
<th>Active Non-Participators n = 88</th>
<th>Passive Non-participators n = 141</th>
<th>Post Hoc Scheffé tests p&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDI-2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drive for thinness</td>
<td>14.0 (5.2)</td>
<td>13.1 (5.6)</td>
<td>13.2 (5.7)</td>
<td>F = 1.5</td>
</tr>
<tr>
<td>Bulimia</td>
<td>7.6 (6.1)</td>
<td>7.1 (5.5)</td>
<td>8.5 (5.6)</td>
<td>p = ns</td>
</tr>
<tr>
<td>Body dissatisfaction</td>
<td>17.9 (7.2)</td>
<td>16.9 (7.3)</td>
<td>17.5 (7.7)</td>
<td></td>
</tr>
<tr>
<td>Ineffectiveness</td>
<td>12.5 (6.6)</td>
<td>12.0 (7.3)</td>
<td>11.1 (6.6)</td>
<td></td>
</tr>
<tr>
<td>Perfectionism</td>
<td>6.2 (4.2)</td>
<td>5.6 (4.4)</td>
<td>6.2 (3.9)</td>
<td></td>
</tr>
<tr>
<td>Interpersonal distrust</td>
<td>4.9 (4.2)</td>
<td>4.9 (3.6)</td>
<td>4.3 (4.0)</td>
<td></td>
</tr>
<tr>
<td>Interoceptive awareness</td>
<td>13.0 (6.6)</td>
<td>12.1 (6.2)</td>
<td>12.0 (6.4)</td>
<td></td>
</tr>
<tr>
<td>Maturity fears</td>
<td>5.3 (4.6)</td>
<td>5.2 (4.3)</td>
<td>5.1 (4.6)</td>
<td></td>
</tr>
<tr>
<td>Asceticism</td>
<td>7.4 (4.0)</td>
<td>6.1 (3.4)</td>
<td>6.8 (4.2)</td>
<td></td>
</tr>
<tr>
<td>Impulse regulation</td>
<td>6.1 (5.0)</td>
<td>6.4 (4.9)</td>
<td>6.8 (5.5)</td>
<td></td>
</tr>
<tr>
<td>Social insecurity</td>
<td>8.1 (4.3)</td>
<td>7.7 (4.4)</td>
<td>7.3 (4.5)</td>
<td></td>
</tr>
<tr>
<td>SCL-63</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somaticism</td>
<td>1.42 (0.8)</td>
<td>1.26 (0.8)</td>
<td>1.42 (0.8)</td>
<td>F = 1.5</td>
</tr>
<tr>
<td>Obsession-compulsion</td>
<td>1.7 (0.8)</td>
<td>1.5 (0.8)</td>
<td>1.8 (0.8)</td>
<td>p = 0.025 a, 0.021 b</td>
</tr>
<tr>
<td>Interpersonal sensitivity</td>
<td>1.8 (0.8)</td>
<td>1.6 (0.8)</td>
<td>1.8 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>2.1 (0.8)</td>
<td>1.9 (0.9)</td>
<td>2.1 (0.8)</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>1.7 (0.8)</td>
<td>1.5 (0.8)</td>
<td>1.7 (0.8)</td>
<td></td>
</tr>
<tr>
<td>Hostility</td>
<td>0.9 (0.8)</td>
<td>0.8 (0.7)</td>
<td>1.1 (0.9)</td>
<td></td>
</tr>
<tr>
<td>Sleeping problems</td>
<td>1.9 (1.1)</td>
<td>1.8 (1.2)</td>
<td>1.8 (1.2)</td>
<td></td>
</tr>
<tr>
<td>Symptom index</td>
<td>1.7 (0.7)</td>
<td>1.5 (0.7)</td>
<td>1.7 (0.7)</td>
<td></td>
</tr>
<tr>
<td>BMI</td>
<td>20.7 (5.0)</td>
<td>21.6 (6.8)</td>
<td>22.0 (5.1)</td>
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<tr>
<td>Age at onset</td>
<td>16.9 (4.5)</td>
<td>16.5 (4.1)</td>
<td>15.8 (3.9)</td>
<td></td>
</tr>
</tbody>
</table>

a= follow-up participators vs active non-participators, b= active non-participators vs passive non-participators, c= follow-up participators vs passive non-participators
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 remainers 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 Remainers 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-emancipation 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.

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

( * ) Significantly change from T1 to T5, small effect size
<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>*</td>
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</tbody>
</table>

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

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

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

*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-participators (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-participators 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 participators may be healthier or may have found the treatment to be more helpful than non-participators 12, 111. Studies investigating the impact of non-participation in health surveys found non-participators to smoke or use alcohol significantly more often than participators 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-participators compared to passive non-participators and participators. There was also an initially higher BMI among passive non-participators compared to participators. Since research has shown patients with low BMI to risk a poor prognosis 106, 129, this raises the question whether the non-participators 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. 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 Mahon 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 system. 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 therapists. 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. In accordance with other similar studies, 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.
Another important sign of recovery was an active social life. Some of the women also viewed recovery in ways similar to feminist theory. 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 disorder.

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 researchers, who found that those recovered from eating disorders no longer identify themselves as a person with an eating disorder, 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 disease.

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 way.

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 interviews.

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

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. 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-participators 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. 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. 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 groups.

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 recovered. 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. 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 studies.

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 categories. 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 approach or Qualitative content analysis. 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. 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. 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 have 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 in 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 behandlingen 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
TACK TILL PERSONER SOM BIDRAGIT (ACKNOWLEDGEMENTS)

Ett stort och varmt tack till var och en av er som på olika sätt har stöttat mig under de senaste fem åren så att arbetet med denna avhandling gått att genomföra.

Ett särskilt tack till:
Alla patienter som delade med sig av sina erfarenheter av åtstörning, all personal på åtstörningsenheterna som genomförde datainsamlingar i SUFSA-projektet och projektgruppen som noggrant planerade genomförandet av multi-centerstudien och som gav mig möjlighet att använda materialet. Utan alla dessa insatser skulle detta avhandlingsarbete inte ha varit möjligt.

Alla tillfrisknade patienter som så villigt deltog i de kvalitativa intervjuerna för att ge sin bild av att vara frisk från en åtstörning. Utan deras insats hade denna avhandling saknat det viktiga patientperspektivet på tillfrisknande.

Till min huvudhandledare Claes Norring, för support och outtröttlig passion i att hjälpa mig att omvandla mina idéer till riktig forskning, att hitta och fokusera på den röda tråden, genomföra forskning av hög kvalitet, för tålmodigt ställa frågor om hur jag resonerat, vilket tvingat mig att utvecklas och tänka självständigt, för god vänskap, uppmuntran och mycket skratt.

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Min handledare Gerd Ahlström, för hängivet engagemang och noggrannhet, för professionell hjälp i att förstå den kvalitative forskningsansatsen och för all väntlig uppmuntran.

Min medförfattare och vän Caroline Björck, som bidragit till mycket glädje, entusiasm och kunskap i samarbetet och många trevliga stunder tillsammans.

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Mona Wilhelmsson-Göstas för noggrann korrekturläsning

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Mina barn Esther, Hannah, Viktoria och Johannes för att ni finns och för all humor, tålamod och kärlek ni visat i alla de situationer som kan uppstå när en fyrobarnsmamma ger sig på utmaningen att skriva en avhandling.
Mina fantastiska föräldrar som uttröttligt stöttat och uppmuntrat på de bäst tänkbara sätt, för att möjliggöra fullföljandet av arbetet.
Min Bosse, för att du gjorde de sista månaderna av avhandlingsarbetet till en glädjefylld och spännande tid.
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.

Appendix B

Psychiatric Status Rating Scale

<table>
<thead>
<tr>
<th>Psychiatric Status Rating Scale for Anorexia Nervosa (AN)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychiatric Status Rating Scale for Bulimia Nervosa (BN)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

1 A time frame of three months was used for all measures.
<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Definite criteria / severe</td>
<td>Meets DSM-IV criteria for any eating disorder diagnosis and presents with a severe disturbance in level of functioning (i.e. GAF &lt;= 50)</td>
</tr>
<tr>
<td>5</td>
<td>Definite criteria</td>
<td>Meets DSM-IV criteria for any eating disorder diagnosis but does not present with a severe disturbance in level of functioning (i.e. GAF &gt; 50)</td>
</tr>
<tr>
<td>4</td>
<td>Marked</td>
<td>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&lt;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 &gt; 50)</td>
</tr>
<tr>
<td>3</td>
<td>Partial remission</td>
<td>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 &gt; 60.</td>
</tr>
<tr>
<td>2</td>
<td>Residual</td>
<td>Does not meet DSM-IV criteria for any eating disorder, but still has to fight disordered thoughts concerning shape and weight. BMI &gt; 17.5</td>
</tr>
<tr>
<td>1</td>
<td>Usual self</td>
<td>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 &gt; 17.5</td>
</tr>
</tbody>
</table>
Appendix C

Kordy et al’s original definitions and modifications for EDNOS²

Original criteria according to Kordy et al (2002)

<table>
<thead>
<tr>
<th></th>
<th>AN Restrictive type</th>
<th>AN Binge/Purging type</th>
<th>BN</th>
<th>AN Restrictive type</th>
<th>AN Binge/Purging type</th>
<th>BN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partial Remission</td>
<td>Partial Remission</td>
<td></td>
<td>Full remission</td>
<td>Full remission</td>
<td></td>
</tr>
<tr>
<td>(if former AN restricting type)</td>
<td>(if former AN BingePurge Type)</td>
<td>(1 month*)</td>
<td></td>
<td>(3 months)</td>
<td>(3 months)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No weight reduction by vomiting or laxative abuse. No binges.</td>
<td>no weight reduction by vomiting or abuse of laxatives</td>
<td></td>
<td>No extreme fear of gaining weight, no weight reduction by vomiting or laxative abuse. No binges.</td>
<td>No extreme fear of gaining weight, no weight reduction by vomiting or laxative abuse. No binges.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(1 month*)</td>
<td>(1 month*)</td>
<td></td>
<td>≤ 1 / week.</td>
<td>≤ 1 / week.</td>
<td></td>
</tr>
</tbody>
</table>

Modified Kordy criteria, suitable for DSM-IV EDNOS

<table>
<thead>
<tr>
<th>EDNOS</th>
<th>Partial Remission</th>
<th>Weight: BMI &gt; 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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDNOS</td>
<td>Full remission</td>
<td>Weight: BMI &gt; 19. No binge/purge attacks, no weight reduction by vomiting or laxative abuse, no extreme preoccupation with figure, no extreme fear of gaining weight.</td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Initial AN</th>
<th>Criteria</th>
<th>BMI &gt;18.5, regular menstruation, no bulimic symptoms (i.e binge/purging)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial BN</td>
<td>Criteria</td>
<td>No binge/purging</td>
</tr>
<tr>
<td>Initial BED</td>
<td>Criteria</td>
<td>Weight-loss (i.e. BMI lower at follow-up than at treatment start), no binge eating</td>
</tr>
<tr>
<td>Initial EDNOS</td>
<td>Criteria</td>
<td>BMI &gt;18.5, no binge eating, no purging behaviour</td>
</tr>
</tbody>
</table>
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Reasons for non-participation in follow-up research on eating disorders

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ABSTRACT. OBJECTIVE: Lack of participation in follow-ups is thought to be a serious bias in outcome research on eating disorders; however, little systematic knowledge exists about the problem. The present study aimed to delineate non-participation in long-term follow-up research, and explore the reasons for non-participation. METHOD: Eating disorder patients (N=840) entering a naturalistic, longitudinal multi-centre study were divided into participators (N=508) and non-participators (N=332) in 36-month follow-ups. Non-participators were further classified as either active (i.e. refused participation or failed to attend scheduled appointments) or passive non-participators (i.e. could not be traced). RESULTS: Active non-participators exhibited significantly lower levels of general and eating disorder psychopathology at intake compared to participators, while passive non-participators reported higher levels of hostility. DISCUSSION: Systematic exploration of non-participation in longitudinal research can help to mitigate the problem of indistinct results due to missing data. Barriers to successful longitudinal research and how to overcome non-participation at endpoint are discussed.


INTRODUCTION

Despite a plethora of material on outcome in eating disorders, virtually all follow-up studies have, to some extent, been biased by the problem of dropout or non-participation. The problem is by no means specific to the field of eating disorders, and has been discussed within other areas of mental health research (1) as well as in relation to clinical trials (2). For a long time the problem was largely ignored. Now, an increasing number of outcome studies report figures on non-participation. Within the eating disorders literature the frequency of reported successful follow-ups varies considerably, and has been estimated to lie between 23 to 100 percent of patients entering studies (3-6). Fichter and Quadflieg (7) managed to reassess as much as 91% of their patients with binge eating disorder (BED) at 12-year follow-up. A Japanese study stands out as one of few who within the field to have successfully followed-up all 61 patients entering the study, with the exception of those who died (8). This was achieved by conducting telephone interviews with those who were not willing to participate in face-to-face interviews.

Non-participation in follow-up studies is an important problem since it means that outcome and long-term course of illness remain unclear. External validity is compromised in longitudinal research, since results pertain only to those patients who remained in the study until the point of follow-up (9). What’s more, as (10) has argued, non-participation in follow-ups may mean a risk for over-estimated treatment effect, due to an over-representation of patients in the follow-up samples who have been helped by treatment.

Although non-participation in follow-ups is a serious problem, there has been a paucity of research into the question. The empirical work that has been done has tended to focus on the separate, albeit related, question of treatment dropout. These studies can help us to better understand treatment and related issues that may be involved in a particular patient’s decision to terminate treatment prematurely, but they cast only limited light on the larger group of patients who fail to take part in follow-ups. Reasons for non-participation in follow-up research may be many. Some of the missing follow-ups may, of course, be due to the high death rate associated with eating disorders (16). Patients may withdraw from treatment prematurely, and therefore fail to be followed-
up. Others may be impossible to trace. Still others may simply not wish to participate, despite having largely positive treatment experiences.

Several studies have struggled with the problem of non-participation in follow-ups. The most common method of dealing with non-participation is to simply report the number of missing subjects without further examining any of the reasons for non-participation (6). Others allocate missing patients at follow-up their most recent value on the measure in question, and assume that no change has taken place. By doing so they attempt to deal with the risk of bias due to non-participation (17). Other researchers have allocated all missing patients the most positive outcome in a first analysis, and the most negative in a second analysis. If both these analyses yield similar results, and are comparable with analyses without missing patients, results are judged to be reliable (18). However, it must be emphasised that none of these retrospective procedures actually solve the problem of non-participation. Instead the problem needs to be considered prospectively. As Ross et al. (2) argue, there is a need in the planning stage of research to identify possible barriers that could constitute hindrance to successful follow-ups.

Systematic investigation of non-participation in follow-up research is needed not only in order to improve our knowledge of course and outcome in eating disorders, but also in order to aid the development of more effective longitudinal research strategies. Information on reasons for non-participation may shed light on whether a particular follow-up sample is representative of the original sample (17). Steinhausen (19), who divided non-participants into three groups: those who actively refused to participate (11% of total sample), those who had died (8%), and those still alive who could not be traced (5%). However, the researchers subsequently chose to group all non-participants together finding no significant differences between participants and non-participants on intake data. Since patients who actively refuse to participate in follow-ups may have had quite different treatment experiences to patients who cannot be traced, it would make sense to analyse such groups separately.

The present study aimed to illuminate non-participation in follow-up research by systematically exploring the problem in a large longitudinal naturalistic study of eating disorders. More specifically, we 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. Data were collected within the framework of the Co-ordinated Evaluation and Research at Specialized Units for Eating Disorders in Sweden (CO-RED) project. This longitudinal naturalistic study has followed patients treated at 14 specialist treatment centres for eating disorders across Sweden. Participating units offer a wide variety of treatment forms such as inpatient, day-patient, and outpatient forms of treatment, individual psychotherapy, family and group therapy, psychoactive drugs, expressive forms of treatment using dance and art, etc. A battery of self-report and interview-based measures is used to assess eating disorder and comorbid psychopathology at initial assessment, and subsequently after 6, 12, 18 and 36 months.

METHOD

Participants

The sample comprised 840 eating disorder patients (827 females and 13 males) taking part in the CO-RED project. All participants had a diagnosed eating disorder according to DSM-IV (20): Anorexia Nervosa (AN)=132, Bulimia Nervosa (BN)=334, Eating Disorder Not Otherwise Specified (EDNOS)=303, and Binge Eating Disorder (BED)=51. Age ranged from 18 to 54 years of age (M=25.2 years, SD=6.32). Body mass index (BMI) ranged from 10.4 to 50.6 (M=21.0, SD=5.37). Mean duration of eating disorder at presentation was 8.6 years (SD=6.35). All participants provided informed consent and information was treated confidentially. Ethical approval was obtained from relevant professional bodies. Data were collected between August 1996 and December 2001. In all cases, treatment units had declared their “intent to treat” participating patients. All participants had agreed to take part in CO-RED’s schedule of follow-ups.

Measures

The Rating of Anorexia and Bulimia (RAB)

It was used to assess eating disorder and related psychopathology (21). 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, and has shown good internal consistency, as well as inter-rater and test-retest reliability (21, 22). The interview was used at both initial assessment and 36-month follow-up. Diagnoses were based on RAB data together with expert ratings of specific DSM-IV criteria.

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

It was used to measure self-reported eating disorder symptoms (23). This instrument is a
widely used questionnaire in the study of eating disorders, and generates measures of central symptoms and the psychological correlates of eating disorders.

**The Symptom Check List (SCL)**

It was used to measure self-reported psychiatric symptoms. A shortened (63-item) version of the SCL-90 (24) was administered. The SCL-90 was shortened by removing the subscales for Phobic Anxiety, Paranoid Ideation, Psychoticism and Additional Scales.

**Documentation of participation**

It was made using a protocol developed for this purpose. Participating units agreed to document whether or not patients attended follow-ups, and, if follow-ups did not take place, to state the reasons why.

**Procedure**

Staff at participating treatment units collected data. For the most part these were either qualified psychiatrists or clinical psychologists with experience in the assessment and treatment of eating disorders, although other professionals, such as experienced nurses and social workers, also took part. Administration of intake measures took place at initial diagnostic assessment prior to treatment, or within two (inpatient) to four (outpatient) weeks of commencing treatment at the latest. Patients were contacted for follow-ups by letter or phone if they were no longer in treatment, and an appointment for a follow-up interview at the unit was made. Questionnaires were posted to patients with a request to return them prior to the interview. In those cases where patients were unable to attend personal interviews, telephone interviews were conducted. Patients were initially categorised as either participators or non-participators in 36-month follow-ups. Non-participators were defined as having initially agreed to participate in longitudinal follow-ups, but not participating in the final 36-month follow-up of the study.

**Statistical analysis**

Data were analysed using SPSS for Windows version 12.0 (SPSS, 2003). Two-sample tests were made using t-test for parametric data and chi-square test for categorical data. Multiple-sample tests 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 dependent variables did not fulfill assumptions for normality and equal variances, non-parametric tests were carried out (i.e. Kruskal Wallis test followed by the Mann-Whitney for pair-wise comparisons). Chi-square tests were used in the multiple-sample tests for categorical data.

**RESULTS**

**Delineation of non-participation**

A total of 508 (60%) patients participated in 36-month follow-ups, while 332 patients (40%) did not participate. Among non-participators, 88 patients (26.5%) were classified as active non-participators (ANP), while 141 patients (42.5%) were classified as PNP. Frequency of non-participation varied substantially between the 14 participating units. Two units had ceased to exist, and another two had consolidated into one, while one unit had left the CO-RED project at the time of final follow-up. Among the ten units that were not heavily affected by organisational changes, the range of successful follow-ups ranged from 44-87%, while variation in the degree of ANP ranged between 3-37% and PNP ranged between 3-42%.

**Reasons for non-participation**

Cases were reviewed and protocols documenting participation were examined. One known death could be found among the non-participants. Reasons for non-participation among the remaining patients were categorised as: patient-related (n=229, 69%), organisational (n=66, 19.9%), or uncertain (n=36, 11%). In the case of patient-related non-participation, 70 patients declined to participate, 18 failed to attend scheduled follow-ups, and 141 could not be traced. Organisational reasons for non-participation involved administrative changes made at units prior to follow-ups, which influenced the unit’s ability to conduct follow-ups, such as the unit closures and amalgamations mentioned above. Another organisational reason for non-participation was the unit’s ability to conduct follow-ups, such as the unit closures and amalgamations mentioned above. Another organisational reason for non-participation was the unit’s ability to conduct follow-ups, such as the unit closures and amalgamations mentioned above.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Participators (n=508)</th>
<th>Non-participants (n=332)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>25.3 (6.4)</td>
<td>25.1 (6.1)</td>
<td>0.63</td>
</tr>
<tr>
<td>Age at onset (years)</td>
<td>16.9 (4.5)</td>
<td>16.1 (4.1)</td>
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<tr>
<td>Body mass index (BMI)</td>
<td>20.7 (5.0)</td>
<td>21.5 (6.0)</td>
<td>0.05</td>
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<tr>
<td>Duration of eating disorder (years)</td>
<td>8.4 (6.3)</td>
<td>9.0 (6.5)</td>
<td>0.21</td>
</tr>
<tr>
<td>Weight fluctuation* (kg)</td>
<td>18.0 (11.6)</td>
<td>18.8 (13.5)</td>
<td>0.41</td>
</tr>
</tbody>
</table>

*Weight fluctuation was defined as the difference between highest and lowest weight in kg since onset of eating disorder.
participation in follow-ups involved participating units deferring calling patients to follow-ups due to lack of time and/or heavy workloads. When the reason for non-participation was classified as uncertain it was largely due to units neglecting to register the reason.

**Classification of non-participators**

Classification of non-participators was based on the patient-related reasons for non-participation mentioned above. Using participation protocol reasons for patient-related non-participation were further differentiated, and patients with similar motives for non-participation were merged into the same group. This procedure resulted in patient-related reasons for non-participation being divided into two groups, based largely on an active-passive distinction: active non-participants (ANP) were defined as patients who either refused to participate in follow-ups or did not attend previously agreed follow-up meetings, while passive non-participants (PNP) were defined as patients who could not be traced. Patients who failed to attend scheduled follow-ups were grouped with patients who expressly declined follow-ups since these patients either missed repeated appointments or neglected to get in touch with the unit to find new times. Although these patients were less active in an explicit sense than those who
decidedly declined to be followed-up, we reasoned that even those who failed to attend had made an active decision not to. Patients who could not be traced were considered to be passive non-participants since they did not decline or avoid follow-up. If reasons for non-participation were organisational or unknown, patients were excluded from the active-passive classification. The elimination of such cases allowed for more conceptually distinct comparisons to be made in subsequent analyses.

**Factors associated with non-participation: two-sample tests**

In order to explore differences between the two groups in terms of background, demographic and clinical variables, t-tests were computed for continuous variables (Table 1) and chi-square tests were used with categorical variables (Table 2). Non-participation was equally common among the four diagnostic groups. However, non-participants were significantly younger at onset, had a higher BMI at treatment start, and were more often living without partner. There was a non-significant tendency for a higher frequency of non-participants to present binge eating. On the EDI-2 and SCL-63 at baseline the only significant between-group difference to emerge was lower Asceticism among non-participants: t(787)=2.66, p=0.01. There was also a non-significant tendency toward lower Social Insecurity among non-participants.

**Factors associated with non-participation: multiple-sample tests**

Multiple-sample tests between participators, ANP and PNP at intake on parametric data were made using one-way ANOVA, followed by pairwise Scheffé tests when F was significant using a 95% confidence interval. Since SCL Hostility and BMI did not fulfill the assumptions of ANOVA, non-parametric Kruskal Wallis analysis of variance was computed followed by paired comparison with the Mann-Whitney test. Results are presented in Table 3, and suggested that the two groups of non-participants were distinct in a number of respects. On the SCL-63, ANP reported significantly lower levels of Obsession-compulsion and Anxiety compared to both PNP and participators. On the EDI-2, ANP reported significantly lower levels of Asceticism compared to participators. PNP were significantly younger at onset compared to participators. Using the Kruskal Wallis test, PNP reported significantly lower levels of Obsession-compulsion and Anxiety compared to both ANP and participators. PNP also presented with significantly higher BMI compared to participators. No significant differences were

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**TABLE 2**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Participators (n=508)</th>
<th>Non-participants (n=332)</th>
<th>p</th>
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<tr>
<td><strong>DSM-IV Diagnosis:</strong></td>
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<tr>
<td>AN</td>
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<td>BN</td>
<td>196</td>
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<td>BED</td>
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<td>EDNOS</td>
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<td><strong>Clinical feature:</strong></td>
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<tr>
<td>Binge-eating</td>
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<td>0.08</td>
</tr>
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<td>Laxative abuse</td>
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<td>Vomiting</td>
<td>231</td>
<td>168</td>
<td>0.15</td>
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<td>Amenorrhoea</td>
<td>118</td>
<td>74</td>
<td>0.86</td>
</tr>
<tr>
<td>Previous treatment</td>
<td>337</td>
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</tr>
<tr>
<td>Marital status</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Married/with partner</td>
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<td>75</td>
<td>0.04</td>
</tr>
<tr>
<td>No partner</td>
<td>340</td>
<td>234</td>
<td>0.00</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Working/Studying</td>
<td>319</td>
<td>198</td>
<td>0.62</td>
</tr>
<tr>
<td>Unemployed/On the sick-list</td>
<td>169</td>
<td>113</td>
<td>0.34</td>
</tr>
</tbody>
</table>

1 Figures apply to number of patients who presented with binge eating, vomiting or abuse of laxatives during the three months prior to initial interview regardless of frequency. 2 Figures apply to number of patients who reported amenorrhoea during the three months prior to initial interview.

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Non-participation in follow-ups

found on age at start of treatment, duration of illness or weight fluctuations. Chi-square tests indicated no significant differences as regards amenorrhoea, laxative abuse, vomiting, distribution of diagnoses or incidence of previous treatment. There was, however, a significant result for bingeing: $X^2(2, N=709) = 6.25, p=0.04$. Binge eating was more common in PNP (62%), than ANP (52%) and participators (50%). PNP were more often employed or studying (75%), compared to ANP (58%) and participators (65%): $X^2(2, N=703) = 7.83, p=0.02$.

**DISCUSSION**

The present research investigated the problem of non-participation in longitudinal naturalistic research on eating disorders by comparing patients who participated in 36-month follow-ups with those who did not, on relevant measures from intake. More specifically, the study aimed at delineating reasons for non-participation, relevantly classifying non-participants, and exploring factors that may help to explain non-participation. Our findings suggest that the reasons for non-participation were predominantly patient-related (e.g. patients declined to participate, did not attend scheduled follow-ups or could not be traced). Organisational factors at participating units were considerably less common reasons for non-participation (e.g. lack of time or resources for follow-ups, unit closures). Patient-related non-participation was classified as either active (i.e. patients who refused to participate in follow-ups or did not attend previously agreed follow-ups) or passive (i.e. patients could not be traced).

When two-sample tests were carried out between participators and non-participators few differences emerged. However, when results were analysed in terms of the active-passive classification of patient-related non-participation, interesting differences emerged. Multiple-sample tests suggested that active non-participants initially presented with less psychopathology than both participants and passive non-participants. On the one hand, active non-participants presented with lower levels of Obsession-compulsion and Anxiety on the SCL-63. They also reported significantly lower levels of Asceticism on the EDI-2 compared to participants. On the

<table>
<thead>
<tr>
<th>TABLE 3</th>
<th>One-way ANOVA, F, significance of F, and pair-wise post-hoc Scheffé tests, multiple-sample tests of differences at intake on EDI-2 and SCL-63.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow-up</td>
<td>Active non-participants</td>
</tr>
<tr>
<td>Participators</td>
<td>(n=508)</td>
</tr>
<tr>
<td>Age at onset</td>
<td>16.9 (4.5)</td>
</tr>
<tr>
<td>EDI-2:</td>
<td></td>
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<tr>
<td>Drive for thinness</td>
<td>14.0 (5.2)</td>
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<tr>
<td>Bulimia</td>
<td>7.6 (6.1)</td>
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<tr>
<td>Body dissatisfaction</td>
<td>17.9 (7.2)</td>
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<td>Ineffectiveness</td>
<td>12.5 (6.6)</td>
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<td>Perfectionism</td>
<td>6.2 (4.2)</td>
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<td>Interpersonal distrust</td>
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<td>Interoceptive awareness</td>
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<td>Maturity fears</td>
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<tr>
<td>Asceticism</td>
<td>7.4 (4.0)</td>
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<td>Impulse regulation</td>
<td>6.1 (5.0)</td>
</tr>
<tr>
<td>Social insecurity</td>
<td>8.1 (4.3)</td>
</tr>
<tr>
<td>SCL-63:</td>
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<tr>
<td>Somatism</td>
<td>1.42 (0.8)</td>
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<td>Obsession- compulsion</td>
<td>1.7 (0.8)</td>
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<tr>
<td>Interpersonal sensitivity</td>
<td>1.8 (0.8)</td>
</tr>
<tr>
<td>Depression</td>
<td>2.1 (0.8)</td>
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<td>Anxiety</td>
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<tr>
<td>Hostility</td>
<td>0.9 (0.8)</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>1.9 (1.1)</td>
</tr>
<tr>
<td>Symptom index</td>
<td>1.7 (0.7)</td>
</tr>
<tr>
<td>BMI*</td>
<td>20.7 (5.0)</td>
</tr>
</tbody>
</table>

*Kruskal Wallis test, followed by Mann Whitney paired comparisons. a=participators vs ANP. b=ANP vs PNP. c=participators vs PNP.
other hand, passive non-respondents reported higher levels of Hostility on the SCL-63 and binge eating compared to both ANP and participants; they also presented with higher BMI, were younger at onset of their eating disorder, and were more often employed or studying. This latter finding may help to explain why these patients were difficult to trace. Patients in the group of active non-participants may have been expressing dissatisfaction with treatment by failing to attend follow-ups. The between-group differences in initial status found in our multiple-sample tests raise the question of whether these patients had different treatment needs compared to the other two groups. Alternatively, the apparently healthier status of active non-participants at intake also raises the question of whether these patients were in fact healthier at follow-up. If so, these patients may have been choosing not to participate because they failed to see the rationale of follow-ups.

Although our study casts light on the question of non-participation in follow-up research, it does have a number of limitations. We lacked information from the national death registry. It is entirely possible that the death rate among patients participating in the project was higher than the one case noted. If so, it could help to explain why some patients were not traceable or why reason for non-participation were unknown. What’s more, the study would have benefited from knowledge of why patients declined follow-up; unfortunately this information was not available. An additional limitation was that the treatment units conducted their own follow-ups. Although necessary from the standpoint of the practicalities involved in conducting multi-centre research, this procedure increased the risk of participating units documenting non-participation in dissimilar ways, as well dealing with difficulties in tracing patients differently. Strengths of the present study included its prospective design, which decreased the risk of recall bias. It also used the full spectrum of eating disorder diagnoses from a large unselected sample, and can be assumed to be representative of eating disorder patients treated at specialist units in Sweden. Moreover, as far as we know, this study is the first to investigate the sub-grouping of non-participation in relation to those patients who participated in follow-ups.

Our scheme of classification casts light on the problem of non-participation, but it is not necessarily the most optimal solution. In analysis of participant-related non-participation we focused on the reasons for not participating in follow-ups. An alternative approach in longitudinal research, that might help to clarify treatment-related aspects of non-participation could focus on categorising patients in terms of levels of improvement that were achieved up to the point of non-participation. Such a classification scheme would reduce the risk of over-estimating treatment effect. Since there may be an over-representation of patients who have been helped by treatment in follow-up samples (10) such an approach could be of considerable value. Although other approaches to categorising non-participants could prove more useful, our findings underline the importance of not viewing non-participation as a unitary phenomenon. Significant differences emerged when non-participants were differentiated, which in turn emphasises the importance of studying non-participation more closely. Traditional approaches that fail to differentiate between non-participation and follow-up group may obscure important findings and limit the possibility of dealing with the problem more constructively.

Non-participation in the present study was predominantly patient-related; however, organisational factors also played an important role. There were substantial differences in frequency of successful follow-ups among participating units. At some units, more than half of their cases from intake were missing at 36-month follow-up, while other units managed to follow-up all but 10% of cases from intake. Nevertheless, it should be noted that the degree of non-participation in our study was within the bounds found in Steinhausen’s (6) review of the literature where non-participation ranged between 0-77%. Three of our units accounted for 65% of passive non-participation. Common characteristics of these units included leadership changes resulting in failing commitment to the value of conducting follow-ups, and the fact that these units were located in metropolitan areas with a high degree of urban mobility.

Finally, our study raises the question of how participation in follow-up research can best be facilitated. In accordance with Steinhausen (6) we would argue that organisational factors such as leadership, decision-making structure, and research enthusiasm among staff, are essential for long-term follow-up success. In the present study, some units may have been considerably more skilful in communicating the rationale and importance of follow-ups for patients, not to mention organising administration of follow-up work. However, other factors may also be involved. In a review of treatment follow-ups Ross et al. (2) maintain that the nature of specific research questions and
the procedure of collecting data, can be a hindrance to successful follow-ups. They argued that research questions must be seen as relevant in order to convince participating clinicians to engage in the project. They also argued that the procedure for collecting data must be as demanding as possible for both staff and patients. These points may help to explain some of the non-participation in the present multi-centre study. Our design involved a battery of measures administered on five different occasions, which some clinicians could have experienced as demanding in terms of time and resources. Rates of successful follow-ups could also have been affected by differences in how units interpreted the relevance of the project’s stated aims and methods. Some units appeared to experience participation in the project as outwardly imposed and lacking in meaningfulness. Other units were particularly successful in integrating project methodology with their own clinical routines, using results of questionnaires and interviews as means for formulating individual treatment aims, providing feedback, monitoring treatment provision, and providing a basis for systematically reflecting on how treatment could be improved. These units took advantage of the research procedures and made repeated follow-ups part of their regular routine following termination of the research project. Such steps not only increased knowledge about how their patients progressed, but also established a productive base for quality assurance. This underscores the importance of integrating systematic research and clinical practice. To this end, continued research into establishing a productive base for quality assurance. This underscores the importance of integrating systematic research and clinical practice. To this end, continued research into non-participation in follow-ups will be important to increase knowledge of course and outcome in eating disorders, and to stimulate more effective ways of integrating research and clinical practice.

REFERENCES

Self-image and treatment dropout in eating disorders
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May 2007

Running head: Eating disorders and dropout

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Abstract

Introduction: Dropout from treatment is a serious problem in eating disorders that remains poorly understood. The present study investigated whether self-image and interpersonal theory could help to explain why eating disorder patients drop out of treatment.

Method: Intake data on eating disorder patients who terminated treatment prematurely (n = 54) were compared with patients who had completed treatment (n = 54) and those who were still in treatment after 12 months (n = 54). Self-image was assessed using the Structural Analysis of Social Behavior (SASB), and comparisons were made on demographic and clinical variables.

Results: Patients who dropped out had initially presented with less negative self-image and fewer psychological problems compared to remainers. Low levels of SASB self-blame discriminated dropouts from completers and remainers and significantly predicted treatment dropout.

Discussion: Dropout in eating disorders appears to be a complex phenomenon, not necessarily as pathological as often assumed. There may be important differences in the treatment goals of dropouts and therapists; patients who drop out may be choosing to disengage at a time when symptom improvement creates space for closer examination of interpersonal issues.
Introduction

Dropout from treatment is considered a serious problem in eating disorders (Agras, Crow, Halmi, Mitchell, Wilson & Kraemer, 2000). Up to 57% of patients terminate treatment prematurely (Di Pietro Valoroso, Fichele, Bruno & Sorge, 2002). Dropout has been associated with poor long-term outcome (Baran, Weltzin & Kaye, 1995) and relapse among anorexics (Strober, Freeman & Morrell, 1997). A number of patient characteristics have been associated with dropout, such as bulimia (Woodside, Carter & Blackmore, 2004; Surgenor, Maguire & Beumont, 2004; Waller, 1997; Franzen, Backmund & Gerlinghoff, 2004), longer duration of illness (Vandereycken & Pierloot, 1983), greater drive for thinness (Fassino, Abbate-Daga, Piero, Leombruni & Rovera, 2003), borderline personality (Waller, 1997), impulsivity and anger problems (Fassino et al., 2003), depression, hopelessness and external locus of control (Steel, Jones, Adcock, Clancy, Bridgford-West & Austin, 2000). Other patient characteristics impacting on dropout have included low levels of self-directedness and cooperativeness (Fassino et al., 2003; Fassino, Daga, Piero & Rovera, 2002).

Although research on patient characteristics has shed some light on the problem, such work tends to be limited to information gathered at assessment for general research or clinical purposes and does not necessarily help to explain why a patient chooses to remain in treatment or not (Mahon, 2000). Other factors relating that may help to explain dropout include parental break-up (Mahon, Winston, Palmer & Harvey, 2001), divergence in treatment expectations between patients and therapists (Clinton, 1996), discrepancies between what patients expect of treatment and what they receive (Walsh, Fairburn, Mickley, Sysko & Parides, 2004), lack of motivation to change (Geller, Cockell & Drab, 2001), difficulties trusting and relating to others (Blouin, Schnarre, Carter, Blouin, Tener, Zuro et al. 1995), and social insecurity (Fassino et al., 2002). All of these factors have an important interpersonal underpinning; however, they have not been explored within the context of an empirically valid interpersonal theory.

The Structural Analysis of Social Behavior (SASB) developed by Benjamin (1974; 2000) provides such a theory, and could be used to investigate dropout in ways that are both clinically and theoretically meaningful. Unlike methods that focus on a single dimension, the SASB model is built upon two axes, interdependence and affiliation, which are measured in terms of three aspects (or surfaces as they are termed within the theory). The theoretical basis of the model is to be found in Sullivan’s (1953) interpersonal theory, where self-image (i.e. how an individual views him- or herself) is seen as constituting a guiding force in a person’s perceptions of interactions with others, and reflecting how important others have treated the individual. Since negative self-image appears to be typical of eating disorders (Björck, 2006), it may increase the risk for negative therapeutic reactions and premature termination of treatment.

Investigating self-image in relation to dropout could, therefore, help us to understand an important clinical problem more fully. How such work is carried out is important, since previous studies have suffered from problems with the definition of dropout and use of appropriate comparison groups. Patients who are classified as having dropped out may have done so early in treatment (Clinton, 1996) or relatively late (Vandereycken & Pierloot, 1983). Other studies have combined early and late dropout (Eivors et al., 2003), or have failed to report data on time in treatment prior to dropout (Tasca et al, 2004, Blouin et al 1995; Franzén et al, 2004; Surgenor et al, 2004; Walsh et al 2004; Favaro & Santonastaso 2000). Such differences make between-study comparisons problematic. Furthermore, dropouts tend to be compared with those who have not dropped out when data is collected. However, it is not known whether those
who remained in treatment dropped out at a later stage. If dropouts are not compared with remainers they tend to be compared with patients who have completed treatment, and the question of comparisons with those remaining in treatment is ignored. A more robust design would be to compare dropouts with both those who remain in treatment and those who have completed treatment.

The present study adopts such a design and explores the relationship of self-image to dropout. In particular, the study aimed to examine whether SASB self-image and interpersonal theory could help to explain treatment dropout in a heterogeneous sample of eating disorder patients that could be divided into: dropouts (i.e. patients who terminated treatment prematurely), completers (i.e. patients who had completed treatment according to plan) and remainers (i.e. patients who were still actively receiving treatment at 12 month follow-up). We anticipated that initial negative self-image would be significantly greater among patients who later dropped out compared to those who completed or remained in treatment. The study was conducted within the framework of the Co-ordinated Evaluation and Research at Specialized Units for Eating Disorders in Sweden (CO-RED) project, a longitudinal and naturalistic study following eating disorder patients treated at 14 specialist treatment centres across Sweden over a 6-year period. Participating centres offer a wide variety of treatment such as inpatient, day-patient, and outpatient care, individual-psychotherapy, family and group therapy, psychoactive drugs, as well as expressive forms of treatment using dance and art, etc. Psychotherapeutic treatment was individually designed for each patient, depending on both the patient's needs and the treatment approaches offered at each centre. Standard symptom-focused interventions of cognitive-behavioural character were almost always present; these were often complemented by supportive interventions, and, to a lesser extent, psychodynamically based interventions focusing on, for example, problems with interpersonal relationships, self-image, as well as the identification and expression of affect. A battery of self-report and interview-based measures is used to assess eating disorder and concomitant psychopathology at initial assessment, and subsequently after 6, 12, 18 and 36 months. Data collection commenced in August 1995 and ended in December 2001. No exclusion criteria were applied; simply having an eating disorder and being treated at the unit provided the basis for inclusion in the project.

Method

Participants

Three equally sized groups of eating disorder patients who were randomly selected following the recommendations of Hair, Anderson, Tatham, and Black (1998) to avoid the risk of overestimating prediction accuracy in the largest group (total n = 162). This comprised 35% of the 465 patients who were followed up after 12 months. The groups studied were:

Remainers: A random sample (n = 54) was selected from 323 patients who were still actively receiving treatment at 12-month follow-up: 16 patients were receiving psychotherapeutic treatment in outpatient settings, 21 patients were receiving inpatient treatment, and 17 patients were receiving a combination of in- and outpatient treatment. 

Completers: A random sample (n = 54) was selected from 86 patients who had completed treatment according to plan (one patient was excluded due to missing data). Average length of treatment was 9.3 months (SD = 5.4): 27 patients had completed
treatment in outpatient settings, and 27 had received a combination of in- and outpatient treatment.

**Dropouts:** All documented cases of dropout prior to follow-ups at either 6 or 12 months were selected (n=54). Dropout was defined as termination of treatment by the patient prior to completion of the treatment plan. A total of 56 patients were initially classified accordingly as dropouts; two were excluded due to missing data. Treatment lasted on average for 5.5 months (SD = 3.2): 45 patients had received outpatient treatment, and 9 had received a combination of in- and outpatient treatment.

**Measures**

*The Rating of Anorexia and Bulimia (RAB)* was used to assess eating disorder and related psychopathology (Clinton & Norring, 1999). 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, and has shown good internal consistency, as well as inter-rater and test-retest reliability (Clinton & Norring, 1999; Nevonen, Broberg, Clinton & Norring, 2003). Diagnoses were based on RAB data together with expert ratings of specific DSM-IV criteria.

*The Eating Disorders Inventory, version 2 (EDI-2)* was used to measure self-reported eating disorder symptoms (Garner, Olmsted & Polivy, 1983; Garner, 1991; Nevonen & Broberg, 2001). This questionnaire is widely used in the study of eating disorders, and generates measures of central symptoms and the psychological correlates of eating disorders.

*The Symptom Check List (SCL)* was used to measure self-reported psychiatric symptoms. A shortened, 63-item version of the SCL-90 (Derogatis, Lipman & Covi, 1973) was utilised by removing the subscales for Phobic Anxiety, Paranoid Ideation, Psychoticism and Additional Scales.

*The Structural Analysis of Social Behavior SASB, (Intrex version, 3rd surface, self-image)* was used to assess self-image (Benjamin, 1974, 2000). The questionnaire comprises 36 self-referential statements, some framed positively and others negatively. Responses are given on a scale from 0 to 100 with 10-point increments. Responses of 40 or above represent confirmation of the statement, whereas responses below 40 designate non-confirmation. 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. Cluster scores are obtained by dividing the sum of the items comprising the cluster by the number of items in the cluster. Recent empirical studies support the reliability of the SASB self-image questionnaire with a total $\alpha = .74$ (Lorr & Strack, 1999; Benjamin, 2000).

**Procedure**

Data were collected at intake by staff at participating treatment units. For the most part these were either qualified psychiatrists or clinical psychologists with experience in the assessment and treatment of eating disorders, although other professionals, such as experienced nurses and social workers, also took part. Administration of measures took place at initial diagnostic assessment prior to treatment, or within two (in-patient) to four (out-patient) weeks of commencing treatment at the latest.
Results

In order to test whether sample sizes were sufficient for comparative purposes, a power analysis was calculated with an alpha level of .05. The lowest power value was .81, which suggests that the samples were of sufficient size.

*Between-group comparisons*

The distribution of eating disorder diagnoses across groups along with the number of patients fulfilling specific diagnostic criteria for bulimia nervosa and anorexia nervosa are presented in Table 1. Using chi-square tests there were no significant deviations from expected frequency distributions on these variables. Between-group comparisons on continuous variables were made using one-way ANOVA, and conducting post hoc Scheffé tests of pair-wise differences when overall F was significant (i.e. \( p < .05 \)). Effect sizes for pair-wise comparisons were evaluated using Cohen’s \( d \) (Cohen, 1988). When dropouts, completers and remainers were compared on DSM-IV diagnoses, age, age of onset, BMI, compensatory behaviours (i.e. bingeing, purging and use of laxatives) anorexic weight (i.e. BMI < 18) and amenorrhoea, no significant differences emerged. However, significant between-group differences were found on SASB Self-emancipation, Self-affirmation, and Self-blame. Dropouts reported more Self-emancipation \( (d = .53) \) and Self-affirmation \( (d = .56) \), as well as less Self-blame \( (d = -.67) \) compared to remainers, while they expressed less Self-blame \( (d = -.66) \) compared to completers. Dropouts reported significantly lower levels of the psychological correlates of eating disorders on the EDI-2 \( (d = -.57) \), as well as lower levels of psychiatric symptoms on the SCL \( (d = -.64) \) compared to remainers. No significant differences were found between completers and remainers. Detailed results are presented in Tables 1 and 2.

**Table 1.** Frequencies of eating disorder diagnoses, and numbers of patients fulfilling specific diagnostic criteria relating to BN (binge eating, compensatory behaviour) and AN (anorexic weight, amenorrhoea) across groups with results of Chi-square tests.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Dropouts n=54</th>
<th>Completers n=54</th>
<th>Remainers n=54</th>
<th>Chi-2</th>
</tr>
</thead>
<tbody>
<tr>
<td>DSM-IV diagnoses:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>9</td>
<td>10</td>
<td>13</td>
<td>ns</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>18</td>
<td>18</td>
<td>19</td>
<td>ns</td>
</tr>
<tr>
<td>EDNOS</td>
<td>24</td>
<td>22</td>
<td>17</td>
<td>ns</td>
</tr>
<tr>
<td>Binge Eating Disorder</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>ns</td>
</tr>
<tr>
<td>Specific DSM-IV criteria:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Binge eating</td>
<td>24</td>
<td>28</td>
<td>25</td>
<td>ns</td>
</tr>
<tr>
<td>Compensatory behaviour</td>
<td>23</td>
<td>27</td>
<td>26</td>
<td>ns</td>
</tr>
<tr>
<td>Anorexic weight</td>
<td>15</td>
<td>12</td>
<td>19</td>
<td>ns</td>
</tr>
<tr>
<td>Amenorrhoea</td>
<td>14</td>
<td>16</td>
<td>14</td>
<td>ns</td>
</tr>
</tbody>
</table>
Table 2. Means and standard deviations on age, age at onset, BMI, SASB, EDI-2 and SCL-63 with ANOVA, significance of F and post hoc Scheffé tests.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Dropouts n=54</th>
<th>Completers n=54</th>
<th>Remainers n=54</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>23.4 (5.7)</td>
<td>25.5 (6.9)</td>
<td>24.8 (6.5)</td>
<td>1.0</td>
<td>ns</td>
</tr>
<tr>
<td>Age at onset (years)</td>
<td>16.7 (2.8)</td>
<td>17.8 (4.8)</td>
<td>17.3 (5.9)</td>
<td>0.9</td>
<td>ns</td>
</tr>
<tr>
<td>Body Mass index (BMI)</td>
<td>20.4 (3.3)</td>
<td>22.1 (6.3)</td>
<td>20.5 (6.1)</td>
<td>1.5</td>
<td>ns</td>
</tr>
</tbody>
</table>

SASB

<table>
<thead>
<tr>
<th>Clusters</th>
<th>Dropouts n=54</th>
<th>Completers n=54</th>
<th>Remainers n=54</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-emancipation</td>
<td>33.9 (13.1)</td>
<td>28.8 (15.7)</td>
<td>26.9 (13.5)</td>
<td>3.4</td>
<td>b*</td>
</tr>
<tr>
<td>Self-affirmation</td>
<td>29.7 (20.3)</td>
<td>24.6 (22.1)</td>
<td>19.6 (16.1)</td>
<td>3.5</td>
<td>b*</td>
</tr>
<tr>
<td>Active self-love</td>
<td>32.0 (16.5)</td>
<td>29.4 (19.7)</td>
<td>25.8 (15.3)</td>
<td>1.7</td>
<td>ns</td>
</tr>
<tr>
<td>Self-protection</td>
<td>42.7 (16.0)</td>
<td>38.8 (16.5)</td>
<td>41.4 (15.1)</td>
<td>0.8</td>
<td>ns</td>
</tr>
<tr>
<td>Self-control</td>
<td>51.2 (16.2)</td>
<td>55.8 (19.7)</td>
<td>56.6 (20.1)</td>
<td>1.3</td>
<td>ns</td>
</tr>
<tr>
<td>Self-blame</td>
<td>50.5 (21.1)</td>
<td>62.5 (21.2)</td>
<td>65.0 (22.0)</td>
<td>6.8</td>
<td>a*, b**</td>
</tr>
<tr>
<td>Self-hate</td>
<td>45.8 (20.3)</td>
<td>53.8 (23.0)</td>
<td>56.6 (20.1)</td>
<td>3.6</td>
<td>b*</td>
</tr>
<tr>
<td>Self-neglect</td>
<td>33.7 (16.5)</td>
<td>39.7 (19.5)</td>
<td>37.1 (16.2)</td>
<td>1.6</td>
<td>ns</td>
</tr>
</tbody>
</table>

EDI psychological subscales: 51.8 (22.8) 62.2 (26.2) 67.1 (30.5) 4.4 b*

EDI eating disorder subscales: 35.2 (14.8) 38.8 (15.2) 39.1 (14.6) 1.1 ns

SCL Symptom Index: 1.4 (.63) 1.6 (.64) 1.7 (.62) 3.9 b*

a = Dropouts vs. Completers, b = Dropouts vs. Remainers, c = Completers vs. Remainers
* = p < .05, ** = p < .01

Prediction of dropout

Stepwise multiple discriminant analysis was used to predict group membership. Since the primary focus of the study was to investigate the relationship between self-image and dropout, all SASB clusters were used as potential predictors. Together with age and BMI, this resulted in a total of 10 independent variables, in a three-group stepwise discriminant analysis. The stepwise method was used in order to evaluate the distinct discriminatory effect of each SASB cluster. Prior to computation of discriminant analysis all independent variables were tested for normality and outliers were examined on both univariate and multivariate levels. A recommended cut-off score of +/- 2.5 for

1 MANCOVA was also carried out, using age and BMI as covariates, with similar results being found.
standardized residuals was used (Hair, Anderson, Tatham & Black, 1998). SASB clusters displayed normal distributions and no outliers were found. Overall, the resultant discriminant function classified 44% of the sample correctly. Dropouts were classified best (36 of 54, or 67%). The equation classified 54% of remainers correctly (29 of 54), but only 9% of completers (5 of 54).

SASB Self-blame was the only significant variable that discriminated between the three groups (Wilk’s Lambda = .92, Chi-square = 13.2, p = .001). The validity of these results was further tested using a split-sample procedure with two independent discriminant analyses. Self-blame was the only significant discriminating variable in both the first sub-sample (Wilk’s Lambda = .89, Chi-square = 10.8, p = .005) and second sub-sample (Wilk’s Lambda = .69, Chi-square = 24.2, p < .001).

**Figure 1.** SASB self-image profiles among dropouts, completers and remainers at initial presentation.

![SASB Clusters](image)

**Discussion**

The present study aimed to examine whether SASB self-image could help to explain treatment dropout in a heterogeneous sample of eating disorder patients. Our most important finding was a significant relationship between SASB and dropout, but not in the expected direction. Compared to patients who remained in treatment, patients who dropped out had presented with a considerably more positive self-image at intake (i.e. significantly lower levels of Self-blame and Self-hate, and significantly higher levels of Self-emancipation and Self-affirmation). They also presented with lower levels of the
psychological correlates of eating disorders on the EDI-2, along with fewer psychiatric symptoms on the SCL compared to patients who remained in treatment. Patients who dropped out also reported significantly less self-blame compared to patients who completed treatment.

Strengths of the present study include the use of a large heterogeneous sample of eating disorder patients, and the use of a three-group design that allowed dropouts to be contrasted with both patients who remained in treatment and those who completed treatment. There are, nevertheless, also limitations to the study. The total dropout rate of 12% may be an underestimation, since the CO-RED project did not systematically assess dropout after 12-month follow-up. Neither was it possible to ascertain exactly how many sessions each patient had completed, even though data on time in treatment suggests that results concern patients who prematurely terminate treatment relatively late. Nor was it possible to analyse results in relation to type of treatment, which could be an important mediating variable. Although the dropout group was classified with 67% accuracy using discriminant analysis, the overall rate was only 44%, which is low. Finally, although systematic analysis of dropout in relation to diagnostic groups was not possible due to small group sizes, analyses of DSM-IV diagnoses and diagnostic symptoms using chi-square techniques suggested no significant between-group differences on these variables.

The present results may seem surprising compared to those of others who have found that eating disorder patients who drop out tend to have more severe symptoms at presentation (Vandereycken & Pierloot, 1983; Coker et al. 1993; Baran et al., 1995; Waller, 1997; Fassino et al., 2003; Woodside et al., 2004; Surgenon et al., 2004). There are, however, studies suggesting that dropout may be unrelated, or even inversely related, to symptom severity (Palmer, 2000; Kahn & Pike, 2001), social functioning (Mitchell et al., 2002) and factors associated with poor prognosis (Di Pietro et al., 2002). This leads to the most important implication of our findings, namely that dropout in eating disorders must be studied more systematically. Discrepancies between studies may be largely due to research design (e.g. naturalistic vs. experimental, single centre vs. multicentre), research aims, the particular treatment programmes that have been studied, or relevant to specific diagnostic groups, all of which makes generalisation problematic. In order to better understand dropout it will be important to pay closer consideration to how it is defined, as well as who these patients are compared with.

When SASB was used to discriminate between patients who had been divided into dropouts, completers and remainers, it provided important information for predicting dropout. However, it was less successful in predicting who remained in treatment, and largely immaterial in predicting who actually completed treatment. Self-blame was most important for discriminating dropouts from completers and remainers. We distinguish three basic interpretations of these findings.

The first interpretation concerns how treatment practitioners and researchers tend to view the nature of dropout. It must be borne in mind that all groups in the present study presented with negative self-image, although patients who later dropped out had initially presented with significantly less negative self-image compared to those who remained in or completed treatment. They also reported fewer psychological problems and fewer psychiatric symptoms. Between-group differences, therefore, tended to be of degree rather than kind. Dropout might not, therefore, be as pathological as therapists may assume. Given the lesser degree of psychopathology among dropouts, 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. As Mahon (2000) has pointed out, a patient
who is registered as a dropout might consider herself a “completer”, although the therapist wanted to achieve more. Here there may be important differences in the treatment goals of dropouts and therapists.

The second interpretation of our results concerns interpersonal dynamics. It could be argued that less negative self-image, as found among dropouts in our study, does not necessarily indicate a lesser degree of interpersonal problems. The pattern of self-image found among dropouts could be indicative of interpersonal difficulties centring on a tendency to avoid relationships that demand change. This could be especially relevant later in the treatment process, when symptoms of disordered eating have improved and focus often shifts to examining underlying interpersonal relationships and problems. At this point, emotionally laden issues about opening up and trusting the therapist may tend to come to the fore, as there is a shift away from focus on eating behaviour. Patients with an avoidant interpersonal style may find this anxiety-provoking, leading to a flight reaction. Empirically, there is support for such an interpretation. Patients with avoidant attachment patterns have been found to be less sensitive to positive therapeutic interactions and more likely to disengage from a help provider (Chen & Mallinckrodt, 2002). Similarly, anorexics (bulimic subtype) with high avoidant attachment are more likely to drop out than patients reporting high anxious attachment (Tasca, Taylor, Bissada, Ritchie & Balfour, 2004).

Our third line of interpretation, which may be the most viable, combines the aforementioned lines of reasoning. Patients who later drop out, may have more limited treatment goals. Together with less self-blame, it may have been easier for these patients to disengage from treatment when they experience symptom improvement. At the same time, they may be choosing to disengage when symptom improvement creates space for closer examination of interpersonal issues. When questions of opening up and trusting the therapist come to the fore, separation anxiety may be awakened. Instead of choosing to engage in this new phase of therapy such patients may decide to terminate in order to maintain their psychological equilibrium.

Our work underscores the potential of using interpersonal theory and SASB for better understanding dropout in eating disorders. SASB could be used to help identify eating disorder patients with interpersonal profiles who are at risk for dropout. By identifying such patients and alerting therapists to important interpersonal dynamics, such as issues of trust and separation anxiety, it may be possible to improve interpersonal functioning. Future research could focus more directly on what happens with patients who drop out by collecting outcome data on patients who complete treatment and those who terminate prematurely. This is currently the focus of on-going research within our project.

References


STUDY III
What happened to the ones who dropped out?

Outcome in eating disorder patients who complete or prematurely terminate treatment

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and Claes Norring4

January 2008

Running head: Follow-up of dropouts

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Abstract

Introduction: There is a lack of knowledge about the outcome of eating disorder patients who terminate treatment prematurely. The present study followed-up eating disorder patients who had previously dropped out of treatment and examined clinical status 36 months after intake.

Method: Dropouts (n = 30) were compared with treatment completers (n = 52) on diagnostic status, clinical symptoms, psychosocial adjustment and treatment satisfaction at follow-up. Patterns of change from intake to follow-up within groups, as well as between groups, were explored.

Results: No significant differences were found between groups at follow-up, except for more treatment dissatisfaction reported among dropouts. When patterns of change were examined between groups, patients who completed treatment were found to have made significantly greater changes (less eating disorder symptoms, less psychological problems and more positive self-image) compared to dropouts.

Discussion: Although no significant differences in outcome were found between dropouts and completers, greater clinical improvement was found among those who completed treatment. The dropouts examined in this study did well despite premature termination of treatment. Clinical and research implications are discussed.
INTRODUCTION

Dropout from psychotherapeutic treatment is a common phenomenon in mental health services in general (Lyons, Howard, O’Mahoney, & Lish, 1997), as well as in eating disorder treatment. A review covering psychological treatments for eating disorders (Mahon, 2000) suggests overall dropout rates of approximately 30% for patients in treatment for Bulimia Nervosa (BN), while dropout rates of about 50% have been reported from inpatient treatment for Anorexia Nervosa (AN). This empirical work, which mainly focused on the characteristics of dropout patients at intake, found the bulimic subtype of AN to be associated with increased risk for dropout. Further characteristics associated with dropout were more severe bulimic symptoms, longer duration of illness and a stronger drive for thinness. In other studies, borderline personality (Waller, 1997), impulsivity and anger problems (Fassino, Abbate-Daga, Piero, Leombruni, & Rovera, 2003), as well as depression, hopelessness and external locus of control (Steel et al., 2000) have all been related to dropout. Other researchers have found difficulties among dropouts in trusting and relating to others (Blouin et al., 1995), along with a lack of congruence in treatment expectations between patients and therapists (Clinton, 1996). A recent study that compared dropouts, treatment completers and patients who were discharged as a decision by the treatment team (due to non-compliance), found no differences between dropouts and completers at admission (Masson, Perlman, Ross, & Gates, 2007). The patients who were discharged due to non-compliance were, however, significantly more likely to present with Axis-I co-morbidity. Usually, the premature termination of treatment is viewed as something negative (Eivors, Button, Warner, & Turner, 2003), and it is assumed that its occurrence must be limited since it may negatively confound outcome (Masson et al., 2007).

However, the truth is that we know virtually nothing about the long-term outcome of patients who do drop out. As a consequence of premature termination, these patients are often missing at follow-up, and normally, outcome studies report data only for those patients who completed treatment (Blouin et al., 1995). One study comparing treatments for BN managed to include dropouts at both 3- and 6-month follow-ups (Chen et al., 2003). This study found dropouts to report more self-harm and suicidal behaviour than completers at 3-month, but not at 6-month, follow-up. However, only one study has specifically addressed the topic of outcome among eating disorder patients who terminated treatment prematurely. Di Pietro and co-workers (2002) reported an unexpected improvement in diagnostic symptoms (BMI, vomiting, amenorrhea) among 71% of dropout patients, and emphasised the need for further studies of outcome among dropouts. The study found that what patients perceived as a partial recovery as one important motive for termination. Initial changes in behaviour may be a sign of treatment response (Pike, 1998); however, this will only tend to be so if a significant change from base-line values occurs (Couturier & Lock, 2006). The study by Di Pietro et al (2002) unfortunately has methodological shortcomings. It used a retrospective design, and focused almost exclusively on diagnostic features assessed during telephone interviews without the use of standardised ratings. There is, therefore, a need to prospectively address the issue of dropout using established self-report measures and interviews, while taking care to investigate whether treatment responses are present among dropouts and assessing status after premature termination.
Findings from our previous work on dropout and self-image (Björck, Björk, Clinton, Sohlberg, & Norring, in press) suggests that dropout is not necessarily associated with initial negative patient characteristics. We found that patients who dropped out had in fact initially presented with less negative self-image and fewer psychological problems, compared to those who completed treatment and those who still remained in treatment at one-year follow-up. However, it was unclear whether the dropouts also had more positive outcome. In the present study we, therefore, examine changes from baseline to follow-up (i.e. treatment response) among dropouts and treatment completers. Our 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.

**METHOD**

**Design**
The study was conducted within the framework of the Co-ordinated Evaluation and Research at Specialized Units for Eating Disorders in Sweden (CO-RED) project. The CO-RED project is a longitudinal naturalistic study that has followed eating disorder patients treated at 14 specialist treatment centres across Sweden. Data collection commenced in August 1995; it ended in December 2001 and included 840 patients. In all cases, treatment units had declared their “intent to treat” participating patients. Participating centres offer a wide variety of treatment forms such as inpatient, day-patient, outpatient forms of care, individual, family and group psychotherapy, psychoactive drugs, as well as expressive forms of treatment using dance and art, etc. A battery of self-report and interview-based measures was used to assess eating disorder and concomitant psychopathology at initial assessment, and subsequently after 6, 12, 18 and 36 months. Data from initial assessment and final 36-month follow-up were used in the present study. The naturalistic approach in the CO-RED project, where patients often received several forms of treatment during their contact with the specialist centres, made it impossible to examine the effects of any specific treatment.

**Participants**
Two groups of eating disorder patients who had either dropped out of treatment (n = 30) or who had completed their treatment (n = 52) were studied. The method of selecting participants is shown in a flow-chart in Figure 1.

*The dropout group*
Dropout was defined as termination of treatment by the patient prior to completion of the treatment plan during the first 12-months. A total of 56 (12%) of the 465 patients terminated the treatment by own decision and met definition criteria. Thirty of them (i.e. 54%) participated in the final 36-month follow-up interview and were selected for the study. There were no significant differences with respect to eating disorder symptoms, general psychiatric symptoms, self-image, duration of illness or BMI at admission between dropouts who were followed-up and dropouts who were not followed-up, although age at admission was significantly lower (p < .05) among dropouts who were followed-up (M = 22.4 years M = 26.4 years, respectively).
Figure 1. Flow chart showing breakdown of inclusion for patients participating in the study (shaded boxes).

The completer group
Completers were defined as patients who had completed treatment according to their treatment plan by 12-month follow-up. A total of 86 (18.5%) of the 465 patients had completed treatment during that time and fulfilled definition criteria. Fifty-two of them (i.e. 60%) participated in the final 36-month follow-up interview and were selected for participation in the present study. The completer group examined in the present study did not differ from completers who were missing at 36-month follow-up with respect to eating disorder symptoms, general psychiatric symptoms, self-image, duration of illness, BMI or age at admission.

All participants were female with the exception of two males, one in each group. Age ranged from 18 to 47 years (M = 22.4 years, SD = 5.85) among dropouts, and from 18 to 49.5 years (M = 25.2 years, SD = 7.4) among completers. Mean duration of eating disorder at admission was 6.1 years (SD = 5.9) in the dropout group, and 7.8 years (SD = 7.0) in the completer group. The treatment form was predominantly outpatient treatment (90% of dropouts and 78% of completers). The remaining participants had received inpatient treatment, or a combination of in- and outpatient treatment. Mean length of treatment prior to dropout was 5.3 months (SD = 2.92), and mean length of treatment among completers was 9.2 months (SD = 4.54). Previous treatment experiences were reported among 47% of dropouts and 54% of completers.

Measures
The Rating of Anorexia and Bulimia (RAB)
The RAB was used to assess eating disorder psychopathology. It is a semi-structured interview comprising 56 items covering a wide range of eating disorder and related psychopathology, as well as background variables. It has shown good internal consistency, as well as good inter-rater and test-retest reliability (Clinton & Norring,
Diagnoses were based on RAB data together with expert ratings of specific DSM-IV criteria.

**The Eating Disorders Inventory, version 2 (EDI-2)**
The EDI-2 was used to assess self-reported eating disorder symptoms (Garner, 1991; Nevonen, Clinton, & Norring, 2006). This 91-item questionnaire is widely used in the study of eating disorders, and generates 11 subscales: three subscales of central symptoms (i.e. drive for thinness, bulimia, body dissatisfaction) 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 Background and Treatment (BaT) Questionnaire for Anorexia and Bulimia**
The BaT is a self-report questionnaire developed for the CO-RED project. Its 63 items provide measures of fundamental socio-demographic and treatment variables relating to eating disorders (Clinton, Norring & Eriksson, 1995).

**The Treatment Satisfaction Scale (TSS)**
Treatment satisfaction was measured using the Treatment Satisfaction Scale, a self-report measure comprising five questions (Clinton, Björck, Sohlberg, & Norring, 2004). Patients were asked to rate their experiences of initial reception at the treatment unit, suitability of the treatment programme, ability of staff to listen and understand, confidence in staff, and agreement on treatment goals. A categorical measure of treatment satisfaction was computed by classifying patients as ‘highly satisfied’, ‘satisfied’ or ‘not satisfied’. Patients were classified as ‘highly satisfied’ if they answered with the most satisfied alternatives to all questions. Patients who gave at least one intermediate answer were classified as ‘satisfied’, while patients, who gave at least one of the least satisfied alternatives, were classified as ‘unsatisfied’.

**The Symptom Check List (SCL-63)**
The SCL-63 was used to measure self-reported psychiatric symptoms (Derogatis, 1973). A shortened, 63-item version of the SCL-90 was constructed by removing subscales assumed to be of less relevance for eating disorder patients. The subscales of the SCL-63 that were used were Somaticism, Obsession-Compulsion, Interpersonal Sensitivity, Depression, Anxiety and Hostility.

**The Structural Analysis of Social Behavior SASB, (Intrex version, 3rd surface, self-image)**
The SASB was used to assess self-image (Benjamin, 1974, 2000). 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 studies support the reliability of the SASB self-image questionnaire with a total $\alpha = .74$ (Benjamin, 2000; Lorr & Strack, 1999).

**Procedure**
Participating staff used a treatment follow-up protocol to document whether patients were still in treatment after 6 and 12 months. If treatment had been terminated, the staff reported when it occurred and the reason for termination. Patients were contacted for follow-up by letter or phone if they were no longer in treatment, and an
appointment for an interview at the unit was scheduled. Questionnaires were posted to patients with a request to return them prior to the interview. In those cases where patients were unable to attend personal interviews, telephone interviews were conducted.

**Statistical analysis**
Data were analysed using SPSS for Windows version 14.0 (SPSS, 2006). Between group comparisons were made using chi-square tests for categorical data, with Fischer’s exact test where appropriate. Independent two-tailed t-tests were used when comparing groups on parametric data, as well as when comparing mean changes between groups (i.e. pre-test scores at intake minus post-test scores at follow-up). Within group comparisons were made using paired t-tests in order to test for significant changes within each group on separate dimensions of self-report measures. Effect size for change from admission to follow-up was computed using Cohens $d$ in relation to both within- and between-group changes. All effect sizes are given as pure values according to Cohen (1988), i.e. a positive $d$ designates an improvement. Following the recommendations of Altman (2003) the risk of regression to the mean was controlled for by computing the correlation between each individual’s mean values on a given measure (i.e. $[\text{intake} + \text{follow-up}] / 2$) and their change from intake to follow-up on the same measure. A value of $p <0.05$ was considered significant in all analyses.
RESULTS

Diagnoses, clinical symptoms and psychosocial functioning

At intake
No significant between-group differences were found on distribution of diagnoses, frequency of compensatory behaviour (i.e. bingeing, purging and use of laxatives), occurrence of amenorrhoea, BMI, occupational status or marital status. Neither were there any significant between-group differences in terms of age, EDI-2 or SCL-63. On the SASB, however, dropouts had initially presented with significantly more Self-emancipation ($d = .58^1$), as well as less Self-blame ($d = .80$) and Self-hate ($d = .51$) compared to completers.

At follow-up
At follow-up, 14 (47%) of the dropouts and 27 (52%) of the completers had no eating disorder diagnoses according to DSM-IV criteria. A further 6 (20%) of the dropouts and 8 (15%) of the completers, who shifted from AN or BN to EDNOS, had improved and reported no presence of compensatory behaviour. These patients reported no amenorrhea or anorectic weight levels (i.e. BMI < 18).² No significant between-group differences were found on distribution of diagnoses, compensatory behaviour, amenorrhoea, BMI, occupational status or marital status, eating disorder symptoms (EDI-2), psychiatric symptoms (SCL-63) or self-image (SASB).

Treatment satisfaction
Dropouts expressed less satisfaction than completers with the suitability of treatment approach that was offered ($\chi^2 (2, n = 75) = 9.3, p<.05$) and with their therapists’ ability to listen and understand ($\chi^2 (2, n=73) = 6.25, p < .05$). Using the categorical measure of satisfaction with treatment, 8 (28%) of the dropouts were classified as ‘highly satisfied’. Among completers, 24 (52%) were found to be highly satisfied. Nine (31%) of the dropouts and 14 (30.4%) of the completers were classified as ‘satisfied’, while 12 (41%) of dropouts and 8 (17%) of completers were ‘unsatisfied’ ($\chi^2 (2, n = 75) = 6.3, p < .05$). One of the dropouts and 6 of the completers failed to answer the TSS questions.

Patterns of changes from base-line to follow-up

Within-group comparisons
Comparisons within groups were performed in order to estimate treatment response, i.e. whether significant changes had occurred from baseline to follow-up. Dropouts reported significantly less self-reported eating disorder symptoms (i.e. all EDI-2 subscales except ‘Bulimia’, ‘Perfectionism’ and ‘Social insecurity’). Further significant improvements were reported on psychiatric symptoms (i.e. all SCL subscales except ‘Obsession-Compulsion’). Significant positive changes were also reported in terms of self-image on the SASB (i.e. more ‘Active self-love’, less ‘Self-hate, and more ‘Self-affirmation’). Detailed results are presented in Table One. At

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¹ According to Cohen (1988) $d < 0.2$ indicates no difference, $d = 0.2-0.49$ indicates a small difference, $d = 0.5-0.8$ indicates a moderate difference, and $d > 0.8$ indicates a large difference.

² Moving from a diagnosis of AN or BN to EDNOS does not necessarily mean that the eating disorder can be considered less serious. Only those patients who had changed diagnosis as a result of a healthier weight (AN), lack of amenorrhea (AN) or the absence of compensatory behaviour (BN) were classified as improved.
follow-up completers reported significantly less eating disorder symptoms on all EDI-2 subscales, and less psychiatric symptoms on all subscales of the SCL-63. Significant improvements were reported on all SASB clusters.

**Table 1.** Within group comparisons for changes (paired t-test calculated for each group separately), on the EDI-2, SCL-63 and SASB from intake (T1) to follow-up (T5).

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

(*) Significantly change from T1 to T5 with small effect size
* Significantly change from T1 to T5 with moderate effect size
** Significantly change from T1 to T5 with large effect size

**Between groups comparisons**

The magnitude of change between groups was examined by computing mean change scores (i.e. intake scores minus follow-up scores). Table Two presents the results of these analyses with the significance of independent t-tests and effect sizes.
Table 2. Comparisons between dropouts and completers on their mean changes from admission to follow-up on the EDI-2, SCL-63 and SASB. Columns show significance of independent t-tests (p) and effect sizes (d) for changes.

<table>
<thead>
<tr>
<th>Measure</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDI-2:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drive for thinness</td>
<td>.70</td>
<td>.10</td>
</tr>
<tr>
<td>Bulimia</td>
<td>.053</td>
<td>.47</td>
</tr>
<tr>
<td>Body dissatisfaction</td>
<td>.77</td>
<td>.07</td>
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<td>Ineffectiveness</td>
<td>.013*</td>
<td>.61</td>
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<td>Perfectionism</td>
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<td>Interpersonal distrust</td>
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<td>Interoceptive awareness</td>
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<td>Maturity fears</td>
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<td>Impulse regulation</td>
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<td>.40</td>
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<td>Social insecurity</td>
<td>.034*</td>
<td>.51</td>
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<td>SCL-63</td>
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<td>Somaticism</td>
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<td>.54</td>
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<td>Anxiety</td>
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<td>.03</td>
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<td>Interpersonal sensitivity</td>
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<tr>
<td>Depression</td>
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<td>.28</td>
</tr>
<tr>
<td>Hostility</td>
<td>.58</td>
<td>.13</td>
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<td>SASB</td>
<td></td>
<td></td>
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<tr>
<td>Self-emancipation</td>
<td>.020*</td>
<td>.59</td>
</tr>
<tr>
<td>Self-affirmation</td>
<td>.008*</td>
<td>.68</td>
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<td>Active self-love</td>
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<td>.56</td>
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<td>Self-control</td>
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<td>.67</td>
</tr>
<tr>
<td>Self-hate</td>
<td>.007*</td>
<td>.69</td>
</tr>
<tr>
<td>Self-neglect</td>
<td>.168</td>
<td>.34</td>
</tr>
</tbody>
</table>

* Significantly larger change in the completer group with a moderate effect size

Completers reported significantly greater changes compared to dropouts on EDI-2 Social Insecurity and Ineffectiveness, SCL-63 Obsession-Compulsion, as well as significantly more positive SASB Self-emancipation, Self-affirmation, Self-protection and less Self-blame and Self-hate compared to dropouts (Fig. 4). No significant differences in the amount of change were found between dropouts and completers on the remaining scales. These results are presented graphically in Figures 2 – 4.
Figure 2. T-test on mean changes for EDI-2 from T1 (admission) to T5 (follow-up) in the dropouts and the completers. The bars represent the mean change (not raw score from the measurement).

![Graph showing mean changes for EDI-2](image)

Note: * indicate a significantly larger change in the COMP group compared to the DO group with $d > .50$.

Figure 3. T-test on mean changes for SCL-63 from T1 (admission) to T5 (follow-up) in the dropouts and the completers. The bars represent the mean change (not raw score from the measurement).

![Graph showing mean changes for SCL-63](image)

Note: * = Significantly larger change ($p < .05$) in the completer group compared to the dropout group with an ES > .50.
DISCUSSION

The present study looked at the question of what happens with the patients who prematurely terminate treatment. Our main finding was that dropouts, who were subsequently successfully followed-up, and treatment completers, were in fact clinically similar at follow-up. This was found to be the case in regard to diagnostic characteristics, eating disorder and psychiatric symptoms, and self-image. These results raise the question of whether or not treatment dropout should necessarily be considered as indicative of treatment failure, as is often assumed in clinical practice.

One possible interpretation of our findings could be that the similarity of the two groups at follow-up obscures important relative gains make by completers. Dropouts initially presented with less negative self-image (i.e less self-blame and self-hate, more self-emancipation). A healthier self-image at intake among dropouts compared to completers is in keeping with the findings of Granberg and Armelius (2002), who found that psychiatric patients who prematurely terminate treatment tend to have a more positive self-image than those who remain in treatment. Perhaps this is not surprising. A person with marked deficits in self-image may be more highly motivated to engage in treatment and work toward change. This could be one reason why the completers stayed in treatment and made greater progress, resulting in a lack of significant between-group differences in status at follow-up. On the one hand, it might therefore be argued that dropouts were not sufficiently disordered to motivate them to take part in treatment. On the other hand, such an interpretation is mitigated by the fact that dropouts received considerable treatment, 5.3 months on average, before terminating treatment, and that they showed a clear positive response to treatment (i.e. significant positive changes from baseline). Dropout might, therefore, reflect a
rational decision on the part of these patients to terminate treatment after attaining meaningful improvement.

Nevertheless, the seemingly positive results for dropouts could also be indicative of underlying clinical problems. There may be implicit differences in the treatment goals of patients who drop out and their therapists. Such an interpretation is in keeping with Clinton’s (1996) finding that treatment dropout in eating disorders is related to discrepant expectations about specific treatment strategies on the part of patients and therapists. It may be that if expectations or goals diverge and are not made explicit during the stage of treatment planning, the scene may be set for future antagonisms between patient and therapist. Such an interpretation is supported by our analysis of treatment satisfaction. Dropouts reported greater dissatisfaction with the suitability of the treatment and their therapists’ ability to listen and understand compared to completers.

Important patterns also emerged when change from baseline to follow-up was explored. Not surprisingly, the greatest treatment response was shown by patients who completed treatment according to plan. In particular, completers expressed a significantly higher degree of positive change in their self-image and ability to relate to others (i.e. significantly greater changes in social insecurity, ineffectiveness, obsessive-compulsive behaviour, self-blame and self-hate, as well as self-emancipation, self-affirmation and self-protection). The fact that those who completed treatment also made relatively greater changes in their way of relating to themselves and others suggests that it is important for patients with negative self-image to complete treatment. This may act as a protective factor, improving chances of positive long-term outcome and reducing the risk of relapse. In other words, patients who have learned to care for themselves and stopped criticising themselves may be better prepared to cope with the societal pressure of a thin body ideal. Such an interpretation is supported by recent research by the senior author (Björk & Ahlström, 2007). In this qualitative interview study, patients emphasized that an essential aspect of recovery from eating disorders was their newly acquired ability to care for and accept themselves. These patients had a strong belief that they would not relapse into an eating disorder again. As such, their treatment gains, in terms of reduced symptoms, can be seen as being founded on firm self-psychological ground. Nevertheless, further long-term follow-ups of these patients would be beneficial in order to investigate just how protective these changes are in relation to risk for relapse.

Although the present study sheds light on the question of what happens with the eating disorder patients who drop out, it does have some methodological weaknesses. The lack of data on all 840 patients in the CO-RED project means that the dropout rate of about 12% is probably an underestimation; results should therefore be interpreted with caution. Nevertheless, to our knowledge this is the first prospective follow-up of dropout patients in the field of eating disorders that includes all eating disorders diagnoses. Other methodological problems concern the use of multiple t-tests, which can increase the risk of type-1 error. We are aware of this problem, but have chosen not to correct the alpha-level. Instead we have reported effect sizes together with p-values in order to confirm the strength of differences found. We also attempted to explore patterns of results rather than single p-values. Overall, the pattern of change was clear; on all measurements but one (drive for thinness) the magnitude of pre-post differences was smaller compared to completers. Taken together the significantly larger effect-sizes for degree of pre-post change along with the significant p-values for completers, suggest that the pattern we found likely reflects true results, and are not a consequence of different group sizes. Unfortunately, we do
not have follow-up data at the exact time-point for treatment termination, so the change we describe as treatment response could possibly also be the result of other positive factors such as support or circumstances not directly related to the treatment.

Another methodological problem concerns the risk of regression to the mean, a common problem with repeated measurements (Altman, 2002). This could be argued to have affected completers, who began treatment with a more negative self-image compared to dropouts. Following Altman’s recommendations for analysing such phenomena we found no evidence of regression towards the mean on SASB measures of self-image or EDI-2 Social Insecurity. However, the changes among completers toward less EDI-2 Ineffectiveness and SCL-63 Obsession-compulsion were significantly correlated with the mean value (i.e. \([\text{admission} + \text{follow-up}] / 2\)), which could suggest regression to the mean, and must therefore be interpreted with caution.

The strengths of the present study include the use of multiple aspects of outcome for patients who dropped out over two years after leaving treatment, the use of both self-report interview measures, as well as the use of an appropriate comparison group of patients that had completed treatment. Together, our results present an informative picture of outcome among eating disorder patients who drop out of treatment.

From a clinical perspective, our results suggest that dropout is a complex and multifaceted phenomenon. It may not only be about problems accepting a treatment plan, or a patient’s resistance to therapy. Dropout may also have important interpersonal aspects that could be more closely examined in future research. One such interpersonal aspect concerns the therapeutic alliance, which may have an impact on the decision to prematurely terminate treatment. Work by de la Rie, Noordenbos, Donker, and van Furth (2006) emphasises how treatment goals may need to be renegotiated at different points in time, in order to maintain a good therapeutic alliance. In order to better understand dropout it may, therefore, be important to also follow how patients and therapists concur on treatment goals over time. Another important future step will be to differentiate the outcome of patients who drop out, in order to better understand which patients run the risk of negative outcome and what factors might influence such events.
REFERENCES


The Patient’s Perception of Having Recovered from an Eating Disorder

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Abstract

Our aim in this study was to describe how ex-patients perceive having recovered from an eating disorder. A qualitative method with a phenomenographic approach was used to identify various ways of experiencing recovery. Four categories emerged, describing how the subjects now relate in a relaxed and accepting manner to food, the body, themselves as individuals, and their social environment. Some perceived recovery as coping with emotions, while others experienced themselves as healthier than people in general regarding food and weight. Different aspects were emphasized as important for recovery. As long as patients perceive themselves as recovered, it is not necessary that they fulfill all conceivable criteria for recovery.
Eating disorders are the third most common mental disorder among young women. These long-lasting disorders with disturbed eating or weight-controlling behavior seriously affect both physical health and psychosocial functioning (Fairburn, 2002; Lamoureux & Bottorff, 2005). In the literature, authors give an ambiguous picture of the long-term prognosis for eating disorders. In a review were researchers addressing short- and long-term course and outcome of Anorexia Nervosa (AN) (the follow-up period ranging from less than 1 year to 29 years) they found that the recovery rate ranged from 0 to 92%. A higher recovery rate was seen with increased follow-up time. The same authors reported a mean of 20% chronicity and 5% mortality (Steinhausen, 2002). Even though the mortality is lower in Bulimia Nervosa (BN) than in AN, the chronicity shown in outcome reviews of BN is high as well. Approximately 25% of patients were still suffering from BN at a 10-year follow-up (Quadflieg & Fichter, 2003). There are also reports of spontaneous recovery where no treatment was involved (Woods, 2004). This warrants a critical examination of the long-term prognosis for eating disorders. Despite the considerable number of outcome studies, an established definition of recovery is lacking. Consequently, rates of recovery vary immensely depending on how improvement and recovery is measured (Jarman & Walsh, 1999).

When diagnostic criteria were used to define recovery, approximately 50% of patients with AN, 75% of patients with BN, and a majority of patients diagnosed as having a binge eating disorder (BED) had recovered by the time of the 5-year follow-up (Ben-Tovim, Walker, Gilchrist, Freeman, Kalucy & Esterman, 2001). In previous follow-up studies regarding AN researchers used resumption of menses and maintaining an acceptable weight as physical criteria of recovery (Pike, 1998). With regard to BN the usual measure of recovery has been the absence of binge eating and purging, but the utility and sufficiency of physical and behavioral aspects of recovery has been questioned (Jarman & Walsh, 1999). Others suggest the inclusion of measures of psychological and cognitive aspects in a definition of recovery (Cogley & Keel, 2003; Norring & Sohlberg, 1993). Several researchers have begun by focusing on recovery from a patient perspective, to enable a deeper understanding of the process of recovery and patients’ thoughts regarding the causes of eating disorders as well as factors important for recovery (Beresin, Gordon & Herzog, 1989; Garrett, 1997; Hsu, Crisp & Callender, 1992; Keski-Rahkonen & Tozzi, 2005; Lamoureux & Bottorff, 2005; Redenbach & Lawler, 2003; Rorty, Yager & Rossotto, 1993; Tozzi, 2003). A majority of these authors investigated recovery from AN. Recovered patients considered for example overcoming self-loathing, body dissatisfaction, developmental stagnation, eating behavior problems, and detachment from other people as essential elements in the process of recovery (Garrett, 1997). This is consistent with the findings of Peters & Fallon (1994), who describe recovery as a process that involves a multidimensional change in relation to one’s self, body, family, and culture. In an attempt to establish criteria of recovery from a patient perspective some have focused on how patients perceive recovery (Noordenbos & Seubring, 2006; Pettersen & Rosenvinge, 2002). In a comparison between ex-patients’ and therapists’ opinions regarding criteria of recovery, Noordenbos & Seubring (2006) found a high degree of consensus but also divergences. Ex-patients accentuated self-esteem, a positive body attitude, and being able to express emotions as important criteria for recovery, while therapists accentuated physical recovery and normalized eating behavior. By using qualitative approaches researchers can complement the concept of recovery on several dimensions that otherwise risk being lost in quantitative research (Beresin et al., 1989; Garrett, 1998; Pettersen &
Rosenvinge, 2002). Therefore our aim in this study is to describe how ex-patients perceive having recovered from an eating disorder.

**Method**

A qualitative phenomenographic approach was used to guide the interviews and analyses. When formulating the questions during the interviewing and when analyzing the data, the first author (TB) adopted the perspective of the participant and tried to observe the phenomena from her point of view and thereby experience the situation through her understanding (Marton & Booth, 1997). When using phenomenography, researchers potentially disclose similarities and differences in how people understand a specific phenomenon (Marton, 1981, 1992). By using this approach in present study, the authors were able to identify and describe various ways in which ex-patients conceive and experience recovery from eating disorders. Phenomenography can be seen as a complement to other approaches. With the focus on the description and analysis of people’s experiences, the researcher deals with how a phenomenon is perceived and how it is lived as well as with individually developed ways of relating to the environment (Marton, 1981). Using phenomenography, one 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 environment (Marton, 1981). The second-order perspective is the central focus in phenomenography (Marton & Booth, 1997). Phenomena can be perceived in a number of ways that are qualitatively different. The individual’s different ways of experiencing a particular phenomenon are the central factor, but analyses generate a description on the collective level. In phenomenography, it is believed that phenomena, as an aspect of reality, are experienced in a restricted number of qualitatively different ways. The results deriving from this approach are a limited number of distinct descriptive categories that capture the variations within or between individuals (Marton, 1981). Since a researcher using a phenomenographic approach always derives the descriptive categories from a fairly small group of people, the sample has to represent a variation in the interview answers within the studied population to increase the ability to later apply the descriptive categories to other groups (Marton & Booth, 1997). The Regional Ethical Review Board in Uppsala approved the study (15th December 2004, D. no: M-433).

**Participants**

The setting of the study was a middle-sized Swedish town. The prevalence of eating disorders is estimated to be the same in Sweden as in other European countries (Hoek & van Hoek, 2003; Nielsen, 2001; Rastam, Gillberg & Garton, 1989). Usually patients with eating disorders are treated at special units run by public or private clinics. The participants were recruited from the special unit for eating disorders at the university hospital in the town. At the one-year follow-up the first author (TB) asked the patients whether they looked upon themselves as recovered. Those who felt recovered or markedly improved, had finished their treatment and were 18 years old or older, were asked whether they were willing to take part in the study. Additionally, special attention was given to ensuring that all diagnostic groups were represented and that the participants represented a variation of illness duration and age. A letter of invitation was sent to those patients who fulfilled the inclusion criteria. The letter indicated the aim of the study, the voluntary nature of participation and the freedom to exit the interview
whenever they wanted, as well as giving an assurance that the data would be handled with secrecy. A total of 18 letters were sent. Within ten days, the first author (TB) called them to further inform them about the study and to ask if they still wanted to participate. Two patients were inaccessible (phone numbers were not known). All but two of the contacted patients wanted to participate. Agreement was reached as to a place where the participant felt comfortable about being interviewed. Each of a total of 14 former eating disorder patients, females aged between 22 and 34 years (Md 27 years), participated in a face-to-face interview. Their duration of illness (i.e., from start of serious eating disorder problems until finishing treatment) ranged from 1.5 to 12 years (Md 5.5 years), and their earlier diagnoses according to the 4th ed. of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) were distributed as follows: 4 AN, 4 BN and 6 eating disorder not otherwise specified (EDNOS). Marital status was as follows: seven were married or lived with a partner, four were on their own, and three had a boyfriend. On the occupational level, seven were working, four were studying, and three were on parental leave.

**Interviews**

Face-to-face interviews occurred 18 to 26 months after the end of treatment (Md 22.5 months) and were conducted in the patient’s home (2), at the patient’s work (1) or in an administrative center (11). The interviews were in conversational form and concerned how the patients experienced recovery from an eating disorder. A question about how they felt when they heard that somebody had recovered from an eating disorder started the interview. The ensuing questions concerned whether they perceived themselves as recovered and in what areas it was evident in their own lives, and in what way. If the participant did not spontaneously cover different dimensions of life, open-ended questions were asked about how recovery was physically, mentally, and socially evident. The interviews took 33 to 86 minutes (Md 52 min), were recorded on a mini-disc, and were transcribed verbatim.

**Data analysis**

The data analysis was carried out in accordance with the phenomenographic approach (Marton, 1994). Firstly, the text was verified by listening to the recorded interview. To obtain an overall impression of the content, the text was read several times in an open-minded manner. Thereafter, statements of essential content were identified in compliance with the author’s aim in the study and coded in the data program NVivo (QSR-International, 2002). Secondly, conceptions were compared and grouped into preliminary non-overlapping descriptive categories. Thirdly, analyses of similarities and differences between the preliminary descriptive categories were performed, resulting in descriptive categories and conceptions about recovery. To assure trustworthiness of the results, the second author (GA) scrutinized the statements in relation to the conceptions and categories.

**Results**

The participants were very willing to share their thoughts and feelings about being recovered. Most of them had a lot to tell, and a rich volume of material emerged. A few of them, though, answered more briefly. They just lived their new lives and did not devote much thought to recovery. All participants reported regular eating behavior. None reported dieting, using diuretics or doing extreme workouts. One still reported binge eating and vomiting, but of rare occurrence (i.e. once a month) and not involving
a feeling of loss of control. When the women were reminiscing, they thought about the eating disorder as a trauma they had overcome but which had clearly affected their entire existence. Even though they grieved about the loss of an important period in their lives, several women were thankful for the trauma in that it had caused a personal development that they considered would never have occurred otherwise. Regarding their present lives, the participants expressed hope, pleasure, and a sense of freedom. It was clear that they separated life in the present from life in the past. Recovery meant dealing with the eating disorder that had earlier filled their lives, rejecting disordered eating behavior, and no longer having the identity of a person with an eating disorder. They now felt they belonged to the healthy instead. Even though the participants realized that there was a risk of their relapsing, they did not see themselves as going back to a life dominated by an eating disorder. The reason was that they now valued their new life very highly, as worth caring about.

The participants’ 240 statements about recovery generated four descriptive categories containing 14 conceptions. Some of the women perceived recovery as being a question of being able to handle feelings, even if they still sometimes found themselves thinking in terms of an eating disorder. Others experienced themselves as healthier than ordinary people when it came to food and weight. They realized that they no longer thought the same way as they used to when they had an eating disorder.

**Relaxed in relation to food**

In this category the participants’ new approach to eating is described, whereby the earlier irrational fear or compulsion had been replaced by a relaxed attitude. Now that the question of food was not dominant in their daily lives, they felt a sense of freedom. The category contains four conceptions: ‘eating everything’, ‘having a regular eating pattern’, ‘eating together with others,’ and ‘not relapsing into eating disorders’.

**Eating everything.**

This conception has to do with eating a variety of food in everyday life without avoiding high-calorie ingredients. It also means being able to permit oneself to eat even unhealthy foods like candy, cookies, and rich desserts, or indeed whatever one fancies. This conception also includes eating normal-sized portions without counting calories or balancing the intake with purging or other compensational behavior.

I feel healthy and feel I can eat anything at all and needn’t be afraid to have whatever I fancy. Oh, it’s lovely to just go and sit down and look at the menu and choose something without having to go and worry about how they’ve done it. Nowadays I can enjoy a proper meal — what a difference that makes! I believe in eating everything and in normal portions. (Amanda)

Now I eat everything and I’m very interested in food — not special low-calorie but varied, with fruit and vegetables, and candy at the weekend. Not that I cut out fatty food so much — I have candy and I have a snack with my coffee and that, and I can handle it and I feel fine. (Lisa)

**Having a regular eating pattern.**

This conception has to do with regular eating patterns, without removing any meals. It means usually eating breakfast, lunch, and dinner and additionally having something to eat between meals. A regular eating pattern also allows an opportunity for spontaneity, where the routines can be changed if necessary. If a meal is missed, it is because of practical circumstances and not a way of eating less.
I suppose I hardly thought about anything except food and training. I was freezing cold and I was ever so hungry all the time. That’s about how it was. But nowadays I think about completely different things, and food I have several times a day. It tastes really lovely — but sometimes not so lovely. I have about the same for breakfast every day, then I have lunch — and I think it’s fun to cook too. (Sarah)

I have breakfast, lunch, dinner, and two snacks in between, and it’s always the food plate model. I eat very well — often too well, perhaps.... [later in the interview:] A lot of times I feel this regular pattern of mine isn’t healthy. It’s not normal that it always has to be twelve o’clock, three o’clock, six o’clock or whatever — you need to be able to modify things a bit now and then, and I suppose that’s what I’m working at most at the moment. When you have children, as I do, it’s anyway very hard to say that at three o’clock I eat and everything else can wait, because it doesn’t work like that. (Kim)

*Eating together with others.*

This conception is about allowing eating to be a social function. Even if they cannot control what ingredients are included in the food when invited to friends’ homes, they still can eat together with others. It also means a freedom to say no thanks, if they do not want to eat or are not hungry, because they do not have to prove that they have recovered by eating everything someone offers.

Well, I’ve just had lunch with a pal of mine and that was great. And I didn’t have to pay the price by feeling bad after — I don’t feel bad at all. (Alex)

If you’re offered something it’s OK to say no thanks just as much as it’s OK to say yes please. You don’t need to say yes please, eat up and then leave as fast as hell. You can eat, you can enjoy eating and you can eat a bit less, and you can see it as OK to enjoy your food. There doesn’t have to be a frenzy when it comes to food, the way there used to be (and which was exceptionally dangerous), and there’s no more need to worry a whole week if you’ve been invited somewhere and have no control over the food that’s to be offered. (Amanda)

*Not relapsing into eating disorders.*

By this conception ex-patients show a strong will to remain recovered, even if they at the same time have an insight into the risk of relapse. It also includes not having an identity as a person with an eating disorder, but as a recovered person. They now see eating disorders as a closed chapter in their lives. Some of the women were quite convinced that they were going to remain recovered: the healthy life was highly valued and they could not allow themselves to relapse. Others supposed they would remain recovered but said that crises in the future would show whether they could manage it or not.

Once you’ve been in a bad state you don’t want to return to it for anything in the world. I don’t want to land there again. Now it feels as if it can’t happen, because it’s all somehow a bit further away than it used to be. The only thing I think about when it comes to being ill again is what’s going to happen when I start gaining weight. I certainly *shall*, some time, but I think somehow anyway that if I like myself — as indeed I do at the moment — I’ll be able to handle it without too much trouble. (Sandra)

No, I don’t think that I’d go back to an eating disorder. I really can’t be sure, but I don’t think so, because I hope I’m clever enough, or that there are people around me that will help, at least it feels that way. It depends what happens in life. But... — but, yes, I hope I have enough resources to see if I’m beginning to get myself in to something... If
something really bad happens, I need people around that I can unload myself on, I need to be able to feel bad, otherwise I’d go crazy. Because I think a person can survive it without becoming self-destructive again. (Anne)

A healthy relationship to the body
In this category, the participants revealed their new way to relate to their body. They have stopped criticizing or neglecting their bodies. Instead they accept their body-size, take care of and enjoy their bodies and as a result experience bodily well-being. This category contains three conceptions: ‘accepting the body’, ‘a relaxed relationship to weight’ and ‘cooperating with the body’.

Accepting the body.
This conception concentrates on having an acceptable attitude to the appearance of one’s body, a feeling of looking good enough, without demanding any changes. It means accepting the size of one’s body and buying clothes that fit. Some of the participants said that they could now accept their body, while others sometimes felt beautiful and could understand that people could be affectionate to them.

Yes, I’ve accepted my body. Not that I think I’m so fine — I wouldn’t say I’m fine and pretty, but I’ve accepted it. My body works and it’s good enough, that’s what I think. Well, I’m not a slender little person, but that’s the way it is, so be it. (Lisa)

But anyway, yes, I’m pretty satisfied with my body really, or at least I know I have a good basis in my body. It’s my body and it’s nice to me, it’s adaptable again and so I think it’s pretty fantastic. (Emma)

A relaxed relationship to weight.
This conception has to do with no longer focusing on weight. Some women considered that weight had become less important, while others avoided weighing themselves. If they gained weight they reacted with acceptance, instead of fear and relapsing into an eating disorder. To have a relaxed relationship to weight also included a critical attitude to the body ideal promoted by the media.

You don’t get fat just because you can’t train, it’s a question of your whole lifestyle. If your weight does go up, it’s not the end of the world either. It’s not so deadly serious. (Isabell)

We don’t have a scale at home now. It’s banned anyway. But there’s one at the public baths I can weigh myself on. My weight’s been very steady, but now after Christmas I’d gone up more than three pounds, and it felt like it! But anyway I felt I was in very good health, because I don’t intend to change, go on a diet — I think more, well, you eat, we’re back to normal, you eat like a normal person and sooner or later it’ll be as it’s been before, I suppose. Let it take as long as it needs to. (Lisa)

Cooperating with the body.
This conception has to do with valuing one’s health and giving it priority, which is shown by listening to the signals of the body and taking care of it. The participants reported that their bodies felt strong and functioned normally, and that their weights were more stable. They had an insight into their body-size, knew where the body began and where it ended. They had a feeling of bodily well-being and felt that their bodies were reliable and strong enough to meet challenges. Sleeping well and having mental energy was also seen as a consequence of cooperating with the body and fulfilling the body’s needs. Cooperating with the body includes allowing and enjoying intimacy.
A very big difference is that I’m aware of my body, I hear signals. When I was ill I thought my head was completely separated from my body. I couldn’t hear what it wanted — or I didn’t listen. I was never aware of being tired or thirsty or hungry. There was something lacking in my basic instinct for survival. Now we’re more of a piece, me and my body. We work as a team, quite simply, and I listen to how my body’s feeling. (Helen)

I can manage living with... having a boyfriend I love, sort of. It’s as if I just enjoy being near him. It’s been quite a process, learning to be like this, but I have a patient boyfriend, I really do — because I had a long way to go. I had so much self-contempt because of my body and... — well, if I didn’t feel at home in my own body, things were difficult. Nowadays I feel more at one with my body, if you can put it that way. (Anne)

**Self-esteem**
In this category participants described a change in their way of relating to themselves as individuals that clearly influences their interaction with others. They now listen to their own wishes, give free play to different moods, give themselves space and express their opinions without fear of criticism. This category contains four conceptions: ‘achieving self-acceptance’, ‘thoughtful about oneself’, ‘having self-respect’ and ‘permitting and dealing with emotions’.

**Achieving self-acceptance.**
This conception has to do with the participants’ acceptance of themselves as good enough. Some of them had come to accept their personality, others felt that they in fact liked themselves and did not want to be someone else. Accepting themselves also meant finding themselves, their personal style, and allowing themselves to be as they were. Even when they recognized their weaknesses, the participants did not blame themselves; instead they either accepted these weaknesses or tried to change them. Accepting oneself also included asking less of oneself and accepting one’s limitations. This was possible because they now felt loved and good enough as they were.

Now I feel I’m an emotional person and it’s just marvelous, really lovely. The glass is half-full now, or whatever they say. I’m aware of my shortcomings and I can handle them, and that’s why I can feel esteem for who I am. I can appreciate — well, that this is the way I am. I’m intense, but I can keep it within certain limits. (Alex)

In the past I wasn’t aware of how much I disparaged myself. Nowadays I think I have more worth, I’m more satisfied with myself than I used to be. (Emma)

**Thoughtful about oneself.**
This conception has to do with being kind-hearted and caring about oneself, with an attitude of approval toward spontaneity, pleasure, and happiness. It also has to do with permitting oneself to live here and now without stress or over-activity. It furthermore means a willingness to take responsibility for how life turns out, listening to one’s own wishes and letting dreams direct choices. There is a determination to enjoy life, involving the courage to try new activities and interests.

I have a new job now, for example, that I put a lot of energy into and that I feel very involved in and enjoy and all that. I don’t think I would have had the self-confidence before. Now I know I fill a place I feel good about and... — well, it’s not just to do with this job: at home, too, I try to do things for my own sake in another way, I think. Not that I’m a super-egoist and always put myself first and think I have a right to everything and so on. It’s more like, say, “I don’t feel like doing anything this
Sunday, I’ll just read a book in the bath.” So that’s what I do now and then, treat myself to a bit of relaxation in a way I couldn’t before. (Elizabeth)

It’s a question of getting what I want, getting where I want to get in one way and another. More and more of what I want to accomplish has to do with work and a career and where I want to go with it. I want to raise new challenges, I’ve noticed, and want to try to meet them. I try to reach goals I’ve set up, try to make my dreams come true — and I work at it. When it comes to leisure, too — I try to have things the way I’ve wanted them on every level. (Susan)

_Having self-respect._
This conception involves setting boundaries. With self-respect the women can say no and do not feel forced to do what others want or need. When they have self-respect, they do not allow people to disparage them. Instead the self-respect gives them the courage to stand up for themselves and express opinions and feelings. They are no longer frightened of conflicts, because they feel confidence, self-esteem, and an inner strength.

I feel much more secure in myself. I’m not afraid to say no and I have the courage of my convictions. If I think one thing and another person thinks another thing I just have to accept it, but I’m not afraid to stand up for my opinion. You’ve just got to accept that people think differently. So in this way I should think I’m tougher than I used to be. (Emilie)

I used to find it hard to say what I thought to certain people, but I think I’ve become much better at it now. I do what I feel like doing a bit more, what I want to do myself. I pay a bit more attention to my own feelings. (Isabell)

_Permitting and dealing with emotions._
This conception has to do with handling emotions, thoughts or problems. The participants perceived their feelings to be more noticeable and genuine. Now that they have recovered they have the ability to recognize different kinds of emotions and can also find ways to handle unpleasant emotions without blaming themselves or starting to behave destructively, this as a result of accepting feelings and allowing them to come forth. Some of the participants considered their emotional life to be steadier. They have achieved an inner harmony and well-being. Other participants sometimes felt overwhelmed by feelings that earlier were repressed, experiencing a more rapid fluctuation of emotional level than before.

I allow myself to be sad. I cry, and there’s nothing dangerous about being sad any more. There’s that strong emotion and it’s not dangerous because it doesn’t have to be my fault. There doesn’t have to be anything wrong with me because I feel sad. Or rather ... I can feel that of course it made me sad to hear him say what he did, or her say what she did, because I’d expected something different from that person. I’m allowed to feel sad — I suppose that’s one of the big changes. It’s lovely to see the difference — it wasn’t very long ago I didn’t allow myself to be sad. It’s not self-destructive to be sad, it’s natural — I can see that now. It’s taken years of training, but I do cry, quite often. (Anne)

It’s as if your feelings go up and down, up and down all the time. I don’t think it was ever really like that before, because I used to sort of turned my feelings off. So in a sense I could almost say I feel worse now. Maybe I feel in quite a good mood some morning, say, and then Bang! I’m down in the dumps instead. So it can swing. (Linda)
Social interaction
In this category, participants describe their new move toward social relations. Instead of withdrawing or just interacting in a superficial or tense way, they now feel natural and present and get pleasure from social relationships. This category contains three conceptions: ‘being active to create a social life’, ‘attaching great importance to social relations’ and ‘listening to others’.

Being active to create a social life.
This conception means both being open to others’ suggestions and taking one’s own initiatives for social interaction. It also means being active in making new friends. This implies an ability to give to and receive from others and not to let an earlier eating disorder be a hindrance to social intercourse. This conception includes a wish to have one’s own family and having the courage to let someone be close to one.

I’d say I have a social life. There are a few people I sometimes go and have a cup of coffee with or have lunch with or study with or something. I’m perhaps a bit more open to suggestions. I’m perhaps more ready to say something like, ‘Shall we meet and have a cup of coffee?’ I perhaps wasn’t quite like that before. A lot more effort was required for that sort of thing in the past. (Linda)

Yes, it’s easier to get in touch with new people, of course. I’m not afraid to let people get close to me, which I was before. Now I can arrange to meet somebody so that we can do something together. Before, I sort of just used to go to work and then go home and do keep-fit. I mean, there wasn’t time for anything else. But now I find the time, spend it with friends and all that. (Amanda)

Attaching great importance to social relations.
This conception has to do with not taking social relations for granted but giving them priority and being careful about them. It means feeling important to others and letting others be important to oneself. It also means sometimes keeping one’s distance, when relationships do not fulfill one’s expectations.

Nowadays I can see that people mean an awful lot to me. I see them. I’ve come to understand, too, that I’ve neglected them — not in such a way that I have a bad conscience about it, but I do understand now that, God, they mean a lot to me. I hadn’t seen it before, or anyway hadn’t properly realized it. I hadn’t realized how important it was, which I do now. (Helen)

I value being important to people and having people I can let be important to me. It has to do with daring to believe in yourself.... I’ve never found it difficult to have close friends, it’s just all that about not being afraid they’re going to disappear. It’s about being ready to take life as it comes, knowing you can cherish relationships but they can change. I mean, it’s not something you can own, it’s something it’s a privilege to have. (Sandra)

Listening to others.
This conception is about being able to join in a conversation, focusing on and being receptive to somebody’s ideas or thoughts and evaluating what somebody is saying, instead of dismissing it. It also means feeling comfortable and relaxed when relating to others, because there is no feeling of inferiority in the social interaction. This conception also concerns acquiring an opportunity to adopt a wait-and-see attitude and just listen, without feeling any demand to entertain and make others happy.
I reflect on what people say in another way. It sort of goes in now. There can be a dialogue. I feel a direct response arising in me, in contrast with how it used to be — it’s got to do with my having the energy to take in the world around. I see the world around. I’ve got more focus, more concentration. I can take part in a conversation, I’m affected by what’s said. (Anne)

I used to be very much the stereotype of the anorexic girl, very clever and very cheerful. I used to joke and I was sort of always in top form. I saw it as my role, entertaining everybody around me and all that. Nowadays I leave it to others — they can get on with the talking for a bit now. I perhaps don’t care as much what they think of me. I don’t need to be amusing all the time, I don’t have to have intelligent things to say; sometimes I just sit and listen. (Helen)

Discussion

In the study we describe how ex-patients perceived recovery from eating disorders. Our results showed differences between the participants’ conceptions of recovery, but several similarities as well. Statements with reference to recovery constituted four descriptive categories, describing how the ex-patients now related to food, to the body, to themselves as individuals and to the social environment, in a relaxed and accepting manner. We verify, in our results, a number of aspects of recovery previously described in the literature. Factors found both in the present study and in earlier research — for instance self-acceptance, accepting one’s body, having a relaxed attitude to food, having a functioning social life, and being in contact with and having the courage to express emotions — are all believed by ex-patients to be important manifestations of recovery (Lamoureux & Bottorff, 2005; Noordenbos & Seubring, 2006; Pettersen & Rosenvinge, 2002).

Of particular interest, not generally reported in recovery studies, was a new thoughtful caring for themselves. They acquired greater well-being through kindness toward 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. Participants described how a positive emotional relationship to themselves diminished the stress of trying to please others as well as achievement anxiety. It can perhaps be assumed that their recently acquired self-esteem had an influence on their entire life-situation and that self-esteem offered a firm foundation for them to assume responsibility for their well-being and the shape of their lives.

Our results are in line with those of other researchers (Lamoureux & Bottorff, 2005) who have pointed out the unique characteristics of recovery from eating disorders, quite different from those of recovery from other mental disorders. To regard themselves as recovered, the ex-patients no longer acknowledged eating disorders as a part of their identity, while the opposite was true concerning recovery from other mental illnesses. However, an interestingly comparable pattern has been reported in studies of chronically ill women with cancer or heart disease (Kearney, 1999). Even though these women remained ill, their way of coping with their trauma was very much like that which the recovered women in our study had used. It was a question of finding ways to accept and value themselves, by rediscovering their individuality on the basis of their persisting qualities. When the 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 way. Thus there are close points of similarity between
how women seek to overcome eating disorders and how chronically ill women deal with their illness. It is therefore imaginable that part of the recovery from eating disorders implies an ability to cope with the previously experienced trauma of being seriously weakened in the body by these disorders.

One strength of our study is that all eating disorder diagnoses were represented, which resulted in a broadening of the previous picture of the patient’s perspective on recovery. Our results corresponded to those of earlier studies on recovery from Anorexia Nervosa (Lamoureux & Bottorff, 2005), from Bulimia Nervosa (Rorty et al., 1993), and from either (Pettersen & Rosenvinge, 2002). This suggests that variations in patients’ conceptions of recovery are not dependent on earlier diagnoses but on individual variations in how patients perceive recovery. A further strength of the study is the choice of a phenomenographic approach, where we gave an opportunity for the participants to freely express themselves, not limited by questions formulated in advance. In a recently published study where participants were requested to fill in a pre-formulated criteria-list for recovery, patients pointed out that some important criteria were lacking (Noordenbos & Seubring, 2006). The procedure used in our study admitted a certain guidance of the interview, but only if the participant did not spontaneously cover different dimensions. In our judgment this did not involve any influencing of the answers, but in some cases helped the persons being interviewed to remember experiences of change since recovery. With a phenomenographic approach, the researchers have an opportunity to use different procedures and different ways of analyzing the material. It is the norm that the aim in a study and the content of the material determine how researchers organize the results. Some researchers focus on finding variation, others on finding the logical hierarchy of categories and conceptions (Fridlund & Hildingh, 2000). In accordance with our aim in this study, we chose to describe the variation in how ex-patients perceive recovery from an eating disorder. An additional strength of our study is that the interviews were carried out when roughly two years had passed since patients finished their treatment. Authors have shown in a previous study that significant improvement occurred up to two years after treatment and that some criteria for recovery (i.e., psychosocial functioning) took longer to evaluate in ex-patients with Anorexia Nervosa (Noordenbos & Seubring, 2006). There are limitations to our study as well. The recovery status was established only on the basis of what the participants themselves experienced, without objective measurement. At least the participants had verified improvement on the basis of the Eating Disorder Inventory scale (Garner, 1991) at their one-year follow-up, and it may be assumed that the achieved progress was maintained up to the time of the study.

Some researchers have questioned whether former eating-disordered patients are able to fully recover (Noordenbos & Seubring, 2006) and if their extremely controlled cognitive patterns ever change (Redenbach & Lawler, 2003) or whether it is perhaps time for clinicians and researchers to modify their expectations of full recovery (Windauer, Lennerts, Talbot, Touyz & Beumont, 1993). In contrast, other researchers claim that it is incorrect to say that patients never recover (Palmer, 2000), or that the variation of weight and food concerns seen in people in general must be accepted in recovered eating-disordered patients as well (Pettersen & Rosenvinge, 2002). It is indefensible to expect former eating-disordered patients to be less concerned about food and weight than people in general.
Conclusion

In the present study we suggest that it is possible to achieve recovery that includes changes in both behavioral and cognitive patterns. Nevertheless, as the participants also described, an individual variation in the concern about food or weight should be admitted when assessing recovery, as long as patients see themselves as recovered in such a way that they can handle thoughts and feelings without resorting to eating-disordered behavior. One can also discuss whether the participants who perceived recovery as an ability to handle emotions even though they still had thoughts in line with an eating disorder, had reached the same level of recovery as those with no such thoughts. It is possible that these women will still progress in recovery. Certain researchers doing long-term studies indicate that recovered patients still report this kind of variation 20 years after onset (Hsu et al., 1992), while others indicate that patients’ conceptions of recovery changed with their illness status (Keski-Rahkonen & Tozzi, 2005). Further qualitative research on the long-term recovered is necessary to gain a greater understanding of this issue and elucidate whether the pattern seems to remain in the case of the fully long-term recovered or if it is to be interpreted as a sign of an ongoing recovery process.

References


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

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Running head: Impact of different outcome measures

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Abstract

**Introduction:** There is a lack of consensus concerning definitions of outcome and choice of outcome measures in eating disorder research. As a consequence, many different definitions of outcome are used, reported remission rates vary considerably and comparisons between studies are problematic.

**Aim:** 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.

**Method:** Remission from eating disorder was operationally defined using six different measures of outcome and the patients (n = 334) were judged as either meeting or failing to meet remission criteria according to each measure. Pair-wise analyses of agreement between outcome measures were also calculated.

**Results:** The remission rates varied from 24.3% to 93.1% depending on which outcome measure was used. Measures based on expert-rated eating disorder symptoms generated lower remission rates (24.3 – 49.1 %), while higher rates (77.8 - 93.1%) were found when measures based on patient-rated eating disorder symptoms (EDI-2) and expert-rated global outcome (GAF) were used. Calculation of agreement between outcome measures showed moderate to good agreement between the outcome measures based on expert-ratings of eating disordered symptoms. Two outcome measures, the EDI-2 and the GAF, showed no or weak agreement with the other measures.

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

Estimates of remission rates in eating disorders vary considerably. In adolescent Anorexia Nervosa (AN) estimates range from 3% to 96% depending on the definition of remission used (Couturier & Lock, 2006b). Although it is often assumed that the situation is similar across eating disorder diagnoses, no systematic comparisons have been made of the impact of different outcome measures on estimates of remission rates across the entire diagnostic spectrum of eating disorders. What’s more, the use of different and poorly defined outcome measures makes it difficult to interpret and compare outcome studies, rendering conclusions about prognosis largely remain unclear. Major contributing factors are lack of consistency in the choice of outcome measures and lack of consensus in the definitions of important outcome terms (Couturier & Lock, 2006b; Jarman & Walsh, 1999).

A recent review (Berkman, Lohr & Bulik, 2007) found that the most commonly used outcome measure is diagnosis (i.e. whether patients fulfil criteria for an eating disorder at follow-up). Outcome also tends to measured using categorical scales, the Morgan-Russell Outcome Assessment Schedule (Morgan & Hayward, 1988; Morgan & Russell, 1975), which categorises patients in terms of ‘good’, ‘intermediate’ or ‘poor’, is a widely used measure (Freeman, Walker & Ben-Tovim, 1996; Ratnasuriya, Eisler, Szmukler & Russell, 1991). Some studies have used the Psychiatric Status Rating Scale (PSR)(Herzog, Sacks, Keller, Lavori, von Ranson & Gray, 1993), with graded outcome in six categories varying from ‘Definite Severe AN / Definite Severe BN’, to ‘Usual self’. It is also common to use different definitions of recovery, taking into account weight, menstrual disturbances, bingeing/purging behaviour, body-image disturbance or other eating disturbances, that are assessed at different points in time (Pike, 1998; Strober, Freeman & Morrell, 1997). In addition to patients’ changes in symptoms the Global Assessment of Functioning (GAF), axis V of the DSM-IV (American Psychiatric Association, 1994), is widely adopted as a tool for measuring change and outcome in mental health. It has also repeatedly been used in eating disorder research (Halvorsen, Andersen & Heyerdahl, 2004; Nilsson & Hagglof, 2005; Thurfjell, Eliasson, Swenne, von Knorring & Engstrom, 2006; Wentz, Gillberg, Gillberg & Råstam, 2001).
Definitions of outcome

Although research that explores concepts of remission and recovery in other psychiatric disorders is extensive (Frank, Prien, Jarrett, Keller, Kupfer, Lavori, Rush & Weissman, 1991; Nierenberg & DeCecco, 2001), there has been a dearth of studies in the field of eating disorders (Kordy, Kraemer, Palmer, Papezova, Pellet, Richard & Treasure, 2002). This has resulted in a lack of critical discussion of key concepts pertaining to outcome, such as what is meant by response, partial remission, full remission, relapse, recovery and recurrence, with each study using its own definitions (Strober et al., 1997). Kordy et al (2002) followed the recommendations from depression research (Frank et al., 1991) and defined patients with partial remission as those who no longer are fully symptomatic, but who continue to exhibit more than minimal symptoms. Full remission was defined as asymptomatic, i.e. no more than minimal symptoms, and the maintenance of this state for a considerable time was defined as recovery. Relapse was defined as a return of symptoms to full syndrome criteria during a period of remission, but before recovery. These concepts were then operationalised using a minimum asymptomatic period of 3 months for remission and one year for recovery. The concepts were applied to a German sample in the TR-EAT project of 1690 eating disorder patients (Kordy et al., 2002).

What do we know about the rates of remission in outcome studies?

Studies using diagnostic criteria to measure outcome often report remission for approximately 50% of patients with Anorexia Nervosa (AN) and about 70% of patients with Bulimia Nervosa (BN) at a ten year follow-up (Berkman et al., 2007; Quadflieg & Fichter, 2003; Steinhausen, 2002). Studies using the Morgan-Russell outcome categories (in five to ten year follow-ups) report a good outcomes for 27% to 50% of AN (Ben-Tovim, Walker, Gilchrist, Freeman, Kalucy & Esterman, 2001; Fichter & Quadflieg, 1999; Gillberg, Råstam & Gillberg, 1994; Wentz et al., 2001), 76% of BN, and 65% of EDNOS (Ben-Tovim et al., 2001). PSR outcome rates for BN at 4-year follow-up have reported good outcome for 32.5% of BN (Hagedorn Bøgh, Rokkedal & Valbak, 2004). When Kordy and co-workers (2002) applied their outcome definitions in a large German patient sample, they found 34% of the patients with BN and 13% of the patients with AN to have achieved full remission or
recovery at a 2.5-year follow-up. The most common outcome in their study was partial remission, achieved by 30% of BN patients and 20% of AN patients.

**The impact of different outcome measures**

The lack of standardised measures (Morgan & Hayward, 1988) and the potential effect of different definitions of remission have been highlighted earlier (Herzog et al., 1993; Jarman & Walsh, 1999; Steinhausen, 2002). The range of patients with good outcome after treatment for bulimia nervosa was found in a review to vary between 24 to 74% (Clausen, 2004). The author emphasised the need to further investigate this large range of outcome rates to find explanations of the variance. In a study of adolescent AN-patients, the authors clearly illustrated the magnitude of various recovery definitions; recovery rates varied from 57% to 94%, when examining definitions of recovery (Couturier & Lock, 2006a). In another article they examined different conceptualisations of remission and found that remission varied from 3% to 96% depending on the used construct of remission (Couturier & Lock, 2006b). These two studies by Couturier et al inspired us to examine the different rates of remission in a larger sample of adult eating disorder patients with all eating disorder diagnoses represented, by applying some of the most frequently used outcome measures.

As for most aspects of eating disorders, studies on outcome have so far focused almost exclusively on patients with Anorexia Nervosa (AN) and Bulimia Nervosa (BN). The well known problem of defining the border between EDNOS symptoms and “normal” concerns for weight, food and body (Engström & Norring, 2002) extends to problems defining improvement for EDNOS patients, and is probably one main reason for the paucity of outcome studies of atypical eating disorders. The lack of knowledge about outcome in EDNOS (including BED) is therefore even more marked than in AN and BN (Fairburn & Bohn, 2005).

The aim of this study was to examine the impact of different definitions of outcome on estimates of remission rates in a large clinical sample including the entire spectrum of eating disorders.
Method

The study was conducted within the framework of the Co-ordinated Evaluation and Research at Specialized Units for Eating Disorders in Sweden (CO-RED) project. The CO-RED project is a prospective longitudinal naturalistic study that has followed eating disorder patients treated at 14 specialist treatment centres across Sweden. Follow-ups from twelve of these units are included in present study. Patients were included consecutively during three years and followed up during three years (i.e. at 6-, 12-, 18- and 36-month) after treatment start. Data collection commenced in August 1995 and ended in December 2001.

Participating centres offered a wide variety of treatment forms such as inpatient, day-patient and outpatient forms of care, individual psychotherapy, family and group therapy, psychoactive drugs, as well as expressive forms of treatment using dance and art, etc. The naturalistic approach in the CO-RED project, where patients often received several treatment efforts during their contact with the special units, prevented examination of the effects of any specific treatment or treatment unit. In all cases, treatment units had declared their “intent to treat” participating patients.

Participants

Of the 840 eating disordered patients included in the CO-RED project, it was possible to describe the outcome for 512 (60.5 %) at 36-month follow-up. Non-participation analysis is described elsewhere (Björk, Clinton & Norring, 2006). Four (0.8%) women of the 512 patients were deceased at their time point for 36-month follow-up according to information from the Swedish National Cause-of-Death Register. Since inclusion in the present study required complete data on all categorical outcome measurements, 334 patients (65.7%) were included in the study. To insure that the participating patients did not differ from those excluded due to missing data (n=174), comparisons were made between the two groups. Chi-square tests showed no significant deviations from expected frequency on the distribution of eating disorder diagnoses. T-tests were computed and effect size for differences on continuous variables were evaluated by computing Cohen’s $d$ (Cohen, 1988). No significant differences in duration of illness and age at admission were found.
Significant differences were found at admission on age at onset, EDI-2 total and SCL-63 symptom index (i.e. included patients were younger at onset, reported higher mean on EDI-2 total and SCL-63 symptom index), but the effect sizes of differences between groups were shown to be low (from $d = 0.19$ to $d = 0.28$), indicating only a very small difference between groups.

Almost all the participants were female with the exception of five males. At admission the age ranged from 18 to 51.5 years ($M = 25.2$ years, $SD = 6.4$), the mean duration of eating disorder was 8 years ($SD = 6.0$) with a range from 3 months to 30.5 years. Body mass index (BMI) ranged from 11.6 to 49.8 ($M = 21.0$, $SD = 5.1$). At treatment start all participants had a diagnosed eating disorder according to DSM-IV (American Psychiatric Association, 1994); AN = 54 (16.2%), BN = 126 (37.7%), EDNOS = 131 (39.2%), and BED = 23 (6.9%). There were no significant differences in follow-up frequency between the diagnoses.

**Measures**

A battery of self-report and interview-based measures was used to assess eating disorder, concomitant psychopathology and global functioning. The measures from the 36-month follow-up were used to calculate rate of remission according to six distinct outcome measures.

**The Rating of Anorexia and Bulimia (RAB).** The RAB, developed for the CO-RED project, was used to assess eating disorder and related psychopathology, at admission and 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. RAB has shown good internal consistency, as well as good inter-rater and test-retest reliability (Clinton & Norring, 1999; Nevonen, Broberg, Clinton & Norring, 2003) Diagnoses at admission and follow-up were based on RAB data together with ratings by clinical and research experts of specific DSM-IV criteria. Information about BMI, menstrual status, fear of gaining weight, thoughts about food and weight and the occurrence of binge eating and purging were also derived from the RAB.
The Eating Disorder Inventory, version 2 (EDI-2). EDI-2 was used to measure the self-reported central eating disorder symptoms (i.e. symptom index of drive for thinness, bulimia and body dissatisfaction) (Garner, 1991). Cut-off scores of 1 (i.e. symptom index ≤ 27.6) and 2 standard deviations (SD) (i.e. symptom index ≤ 41.8) from a published normal group mean (Nevonen, Clinton & Norring, 2006), were used to calculate one more conservative and one more liberal remission rate.

Global Assessment of Functioning (GAF). GAF, i.e. axis V in the DSM-IV (American Psychiatric Association, 1994), was used to report the staff’s assessment of the patient’s overall level of functioning at follow-up. The GAF was chosen as an example of a measure of non eating disorder specific outcome. 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. Cut-off scores of 1 SD (i.e. GAF ≥ 67) and 2 SD (i.e. GAF ≥ 58) from a published non-clinical group mean (Söderberg & Tungström, 2006) were used to calculate one more conservative and one more liberal remission rate. GAF scores were also used to define “level of functioning” in the Psychiatric Status Rating Scale (PSR) (for details see appendix B). The reliability and validity of the GAF has been proved to be satisfactory (Mirandola, Baldassari, Beneduce, Italo, Segala & Tansella, 2000; Söderberg & Tungström, 2006).

Procedure
Staff at participating treatment units collected data. Administration of intake measures took place at initial diagnostic assessment prior to treatment or at the latest within two (inpatient) to four (outpatient) weeks of commencing treatment. When 36 months had passed since initial assessment, patients were contacted for follow-ups, by letter or phone if they were no longer in treatment, and an appointment for a follow-up interview at the unit was made. Questionnaires were posted to patients with a request to return them prior to the interview. In those cases where patients were unable to attend personal interviews, telephone interviews were conducted.

Based on the findings from previous outcome studies, we operationally defined remission from eating disorders using six different measures of outcome to compare the resulting rates of remission. All patients were judged as either meeting or failing
to meet the criteria for remission according to each measure. The measures were expert ratings of eating disorder symptoms, expert ratings of functioning and patient ratings of eating disorder symptoms in order to obtain three perspectives of outcome. In accordance with three recent reviews of Randomized Controlled Trials (Brownley, Berkman, Sedway, Lohr & Bulik, 2007; Bulik, Berkman, Brownley, Sedway & Lohr, 2007; Shapiro, Berkman, Brownley, Sedway, Lohr & Bulik, 2007) a measure of primary outcome for each diagnosis also was defined. The primary outcome measures of AN was weight gain and returning of menses. The primary outcome measures of BN focused on core behavioural features (i.e. reduction of and abstinence from binge eating and purging) and the primary outcome measures of BED were reduction in binge eating, abstinence from binge eating and weight loss.

We applied the following outcome measures (see appendices A, B, C and D for details):

I) Eating disorder diagnoses according to the DSM-IV (American Psychiatric Association, 1994). 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 (Herzog et al., 1993). 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 (2002). 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 et al. (2007).

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.
In addition, the agreement between the remission classifications resulting from the use of different outcome definitions was calculated using Kappa (κ). A value of 1 indicates perfect agreement and a value of 0 indicates no agreement better than chance (Altman, 1991).

In this study, ‘remission’ is used as a synonym to ‘full remission’ (Kordy et al., 2002) and ‘full recovery’ as defined by PSR level 1 or 2 (Herzog et al., 1993). Care was taken to make the definitions of the outcome measures as true to the originals as possible.
Results

The results are presented in three parts, based on who the estimator of outcome was (experts or patients) and which dimension that was measured (i.e. eating disorder symptoms or global functioning).

Expert-rated outcome measures for eating disorder

Comparisons between the expert-rated definitions of remission from eating disorder symptoms are shown in table 1. The remission rate for the whole group varied from 24.3% to 49.1% depending on chosen remission definition. The largest variation in remission rate through all measures was found in AN and the smallest variation was found in patients with BED. The outcome measure that gave the largest variation in remission rates was seen when using level 1 and 2 in PSR, while the smallest variation in remission rates between diagnostic groups was seen when remission was defined using DSM-IV. Definitions of remission that required a total absence of binge /purging behaviour (i.e. Kordy et al’s definitions) decreased the remission rate in patients with BN, but not in the other diagnose groups, while the definition that was more stringent regarding eating behaviour and weight (PSR level 1 and 2) decreased remission rate in the all diagnose groups, but BN. Definitions of remission that required no disordered thinking or behaviour, gave the lowest rates of remission in AN, EDNOS and BED, and the second lowest rates for BN. Primary outcome measures, that only measured absence of diagnose specific symptoms, gave the highest rates of remission.
Table 1. Proportion of patients “in remission” resulting from the use of different outcome measures based on expert ratings of eating disorder symptoms, n = 334.

<table>
<thead>
<tr>
<th>Remission Criteria</th>
<th>Total n=334</th>
<th>AN n=54</th>
<th>BN n=126</th>
<th>EDNOS n=131</th>
<th>BED n=23</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSR level 1</td>
<td>24.3%</td>
<td>18.5%</td>
<td>31.7%</td>
<td>19.8%</td>
<td>21.7%</td>
</tr>
<tr>
<td>PSR level 1 and 2</td>
<td>32.9%</td>
<td>29.6%</td>
<td>44.4%</td>
<td>23.6%</td>
<td>21.7%</td>
</tr>
<tr>
<td>Kordy’s definitions</td>
<td>40.4%</td>
<td>44.4%</td>
<td>30.2%</td>
<td>48.9%</td>
<td>39.1%</td>
</tr>
<tr>
<td>Primary outcome measures</td>
<td>49.1%</td>
<td>40.7%</td>
<td>44.4%</td>
<td>58.5%</td>
<td>39.1%</td>
</tr>
<tr>
<td>DSM-IV criteria (No eating disorder diagnosis)</td>
<td>44.3%</td>
<td>48.1%</td>
<td>41.3%</td>
<td>46.6%</td>
<td>39.1%</td>
</tr>
</tbody>
</table>

**Patient-rated outcome measure for eating disorder**

A total of 77.8% of the patients reported scores within 1 SD of a normal group mean on the symptom index of EDI-2. The highest rate of remission was seen in AN and the lowest in BED. When 2 SD from the mean was used as cut-off for remission, the rate increased to 93.1% (see table 2).

Table 2. Proportion of patients “in remission”, based on EDI symptom index scores within 1 SD or 2 SD of normal comparison group at follow-up, n = 275.

<table>
<thead>
<tr>
<th>EDI-2 Symptom index</th>
<th>TOTAL n = 275</th>
<th>AN n = 48</th>
<th>BN n = 101</th>
<th>EDNOS n = 108</th>
<th>BED n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal mean + 1 SD</td>
<td>77.8%</td>
<td>83.3%</td>
<td>76.2%</td>
<td>77.8%</td>
<td>72.2%</td>
</tr>
<tr>
<td>Normal mean + 2 SD</td>
<td>93.1%</td>
<td>100%</td>
<td>93.1%</td>
<td>91.7%</td>
<td>83.3%</td>
</tr>
</tbody>
</table>
Expert-rated outcome measures for global functioning

A total of 70.4% of the patients were categorised as “in remission” since their GAF-scores were within 1 SD of the non-clinical mean at follow-up and increased to 88% when 2 SD was used as cut-off. The rates of remission ranged between diagnoses with the lowest rates for EDNOS (see table 3).

Table 3. Proportion of patients “in remission”, based on GAF scores within 1 SD and 2 SD of a non-clinical comparison group at follow-up, n = 334.

<table>
<thead>
<tr>
<th>GAF-score</th>
<th>TOTAL n = 334</th>
<th>AN n = 54</th>
<th>BN n = 126</th>
<th>EDNOS n = 131</th>
<th>BED n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-clinical mean + 1 SD</td>
<td>70.4%</td>
<td>75.9%</td>
<td>71.4%</td>
<td>65.6%</td>
<td>78.3%</td>
</tr>
<tr>
<td>Non-clinical mean + 2 SD</td>
<td>88%</td>
<td>90.7%</td>
<td>88.9%</td>
<td>86.3%</td>
<td>87.0%</td>
</tr>
</tbody>
</table>

Measure of agreement between outcome definitions

The pair-wise analyses of agreement in remission classification between outcome definitions varied from no agreement at all to good agreement. Good agreement was found between the Diagnosis-specific primary outcome measure and “Kordy’s definitions” (κ = .74). Moderate agreements were found between the other pairs of expert-rated outcome measures of eating disorder symptoms (0.41 < κ < 0.60) (see table 4). When classifications were based on the patients’ self-rated eating disorder symptoms (EDI-2 symptom index), no agreement at all was found with the PSR classifications, the Primary outcome variables and Kordy’s definitions (κ < 0.20), and weak agreement with the DSM-IV based classification (κ = 0.27). In addition, the GAF based classification showed no agreement with the PSR classifications, and only weak agreement with the Primary outcome variables (κ = 0.27), Kordy’s definitions (κ = 0.27), and the DSM-IV based classification (κ = 0.29).
Table 4. Strength of agreement between the measures of remission\(^1\).

<table>
<thead>
<tr>
<th></th>
<th>PSR 1</th>
<th>PSR 1 &amp; 2</th>
<th>Kordy</th>
<th>POM*</th>
<th>No Dx**</th>
<th>EDI-2 1 SD</th>
<th>EDI-2 2 SD</th>
<th>GAF 1 SD</th>
<th>GAF 2 SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSR 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSR 1 &amp; 2</td>
<td>.80</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kordy</td>
<td>.55</td>
<td>.52</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>POM*</td>
<td>.47</td>
<td>.60</td>
<td>.74</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Dx**</td>
<td>.49</td>
<td>.50</td>
<td>.53</td>
<td>.46</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EDI-2 1 SD</td>
<td>.13</td>
<td>.14</td>
<td>.20</td>
<td>.15</td>
<td>.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EDI-2 2 SD</td>
<td>.04</td>
<td>.05</td>
<td>.06</td>
<td>.05</td>
<td>.11</td>
<td>.41</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GAF 1 SD</td>
<td>.18</td>
<td>.19</td>
<td>.27</td>
<td>.27</td>
<td>.29</td>
<td>.10</td>
<td>-.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GAF 2 SD</td>
<td>.08</td>
<td>.10</td>
<td>.11</td>
<td>.11</td>
<td>.15</td>
<td>.09</td>
<td>-.01</td>
<td>.49</td>
<td></td>
</tr>
</tbody>
</table>

* The diagnosis-specific primary outcome measures
** No eating disorder diagnosis according to DSM-IV

Discussion

The present study aimed to examine the impact of different definitions of outcome on estimates of remission rates in a heterogeneous sample of eating disorders. It utilised six different measures of outcome based on expert-rated and patient-rated measures, covering eating disorder symptoms and global functioning. Remission rates assessed by these common outcome measures vary largely, depending on how remission is defined in the outcome measure, but also on who the evaluator is (experts or patients) and which type of outcome that is assessed (eating disorder or global). The outcome measures also seem function differently depending on the patient’s eating disorder diagnosis. Use of expert-rated global functioning (not eating disorder specific) and patient-rated eating disorder symptoms resulted in similar rates of remission (i.e. 70.4% and 77.8% respectively), while use of expert-rated eating disorder outcome gave much lower remission rates (i.e. 24.3% to 49.1%). When cutoffs on the EDI-2 and the GAF were based on 2 SD from the non-clinical mean, almost all patients (GAF: 88% and EDI-2: 93%) were classified as in remission. Since these figures clearly are unrealistically high, such definitions of remission are useless. Good to moderate strength of agreement was seen among all of the expert-rated outcome measures of eating disorder symptoms, which is an indication that they capture roughly the same variation. No or weak agreement was seen between the GAF and the EDI-2 on the one hand, and all other measures on the other hand.

\(^1\) Strength of agreement: \(\kappa<0.20\) No, 0.21-0.40 Weak, 0.41-0.60 Moderate, (grey) 0.61-0.80 Good (dark grey), 0.81-1.00 Very good
Strengths of the present study include the use of a large unselected sample of patients with the full range of DSM-IV eating disorders, and the use of a long-term prospective design enabling proper dropout analyses. Earlier study of the present sample suggested that followed-up patients did not differ from those missing at follow-up in any important respect (Björk et al., 2006). The studied sample can therefore, in spite of the fairly large dropout rate, be assumed to be representative for adults in specialist treatment for an eating disorder in Sweden.

A potential problem concerns the reliability of some of the variables used to define outcome. Many persons were involved in the ratings of the RAB variables. Though training and checks of inter-rater reliability were performed, they did not include all subsequent raters. In addition, there is a possibility of rater drift over time and development of local rating norms. However, these possible problems affect the outcome measures fairly similarly, and there is no reason to believe that variation within or between outcome measures would be systematically influenced by possible reliability problems. Thus, even if levels of remission rates might have been different, the present results and conclusions are not threatened.

**Interpretations of outcome results**

In order to correctly interpret results from other outcome studies, the reader needs to considerate not only the characteristics of the sample studied and the duration of follow-up, but also what kind of measure that has been used. In the present study, measures of core behavioural symptoms resulted in higher remission rates than if cognitive symptoms were also added to the assessment. If reviews and meta-analyses of eating disorder outcome do not deal with these kinds of methodological challenges, results must be interpreted with caution.

In the present study, the patient-rated eating disorder symptoms resulted in a much higher remission rate than the expert-rated eating disorder symptoms. It is important to consider that these patient ratings did not take into account status at treatment start and possible improvement since then. In post-hoc analyses we found that about 20% of the patients rated themselves within 1 SD of the normal group mean already at treatment start. This is probably due to initial symptom denial, and it indicates that patient-rated outcomes are highly unreliable without considering initial symptom levels. Expert-rated global functioning also resulted in much higher remission rates
than expert-rated eating disorder symptoms. The two outcome measures based on patient-rated eating disorder symptoms (EDI-2) and expert-rated global functioning (GAF) thus seems to have very little in common with the outcome measures based on expert-rated eating disorder symptoms. This interpretation is also confirmed by their absent or weak agreement with the other outcome measures, while the moderate to good agreement among the measures based on expert-rated eating disorder symptoms suggests that they capture roughly the same dimensions.

Our results are in line with earlier published studies highlighting the variation in remission rates resulting from the use of different outcome measures (Couturier & Lock, 2006b). Even though we do not know exactly how other studies defined remission, a comparison with studies using the PSR (Hagedorn Bøgh et al., 2004), and Kordy’s concepts of remission (Kordy et al., 2002), show that our remission rates for BN are similar, while those for AN are much higher, than reported in those studies. Our results clearly demonstrate the need of a consensual measure of eating disorder outcome in order to make comparisons between studies meaningful and to reliably elucidate the picture of outcome after eating disorders.
References


Publikationer i serien Örebro Studies in Medicine


