# Defining recovery in Anorexia Nervosa

## - The importance of concept clarification

## Kristin Aaserudseter



Levert som hovedoppgave ved Psykologisk institutt Universitet i Oslo April 2007

ISBN:

#### **SUMMARY**

**Title of dissertation:** Defining recovery in Anorexia Nervosa- the importance of concept

clarification

**Author:** Kristin Aaserudseter

**Supervisor I**: prof. Bryan Lask

Supervisor II: Vigdis Wie Torsteinsson

**Objective**: The purpose of this dissertation is to identify major problems that obscure understanding of recovery in Anorexia Nervosa, to differentiate recovery from other closely related concepts, and to highlight the importance of reaching a consensus on the use of terminology.

**Method**: Literature review based on papers that address the concepts of recovery, remission and outcome in Anorexia Nervosa. Relevant literature included in this review was identified by searching the electronic databases Cochrane library, PubMed, Medline, Embase, and Psychinfo. Searches were made on literature published between the years 1996-2007, to provide and overview of the field from the past decade. 42 articles were included in the final selection.

**Findings**: Recovery rates varied between 6% and 83% depending on the definitions used.

**Conclusions**: The research literature on outcome and recovery in AN provides enormous variability and great confusion when defining terms such as outcome, remission and recovery. Recovery is a term frequently used, but less frequently defined, in outcome studies. Multiple interpretations and measures make evaluating research difficult. The need to clarify concepts, develop theory, and enhance communication is significant if one is to move the field forward.

### **ACKNOWLEDGEMENTS**

I would like to thank my two supervisors, dr. Bryan Lask and Vigdis Wie Torsteinsson, for their superior help and guidance throughout the process of writing this dissertation. They have given excellent advice on structure and content, not to mention the valuable moral support and motivation they have provided along the way.

I would also like to thank my co-workers at RASP for supporting me through this whole journey, for their academic advice, and for always believing in my abilities.

For the tremendous dedication in helping me with a though rough literature search I would like to extend my gratitude towards Sonja May Amundsen, at the medical library, Ullevål University Hospital.

A special thanks goes out to all of my family and friends who have been incredibly understanding and supportive along the way. Without their help I wouldn't have been able to complete this task.

## TABLE OF CONTENTS

INTRODUCTION	4
Aims of dissertation	5
Anorexia Nervosa	6
Outcome	8
Treatment response	9
Remission	10
Recovery	11
METHOD	13
FINDINGS	14
DISCUSSION	
Lack of consistent definitions	
Lack of consistent measures	27
Assessment	29
Global vs. specific measures	31
Physical measures	31
Psychological measures	32
Physical vs. psychological measures	33
Time required for symptom abstinence	34
Self-report vs. interview	35
Face to face vs. telephone interviews	35
Comorbidity	36
Young vs. adult patients	37
Characteristics of participants	37
Patients' perspectives	38
The therapeutic negotiation of the recovery process	40
The international eating disorder conference	41
SUGGESTIONS FOR FUTURE RESEARCH	45
CONCLUSION	48
REFERENCES	50

### INTRODUCTION

What is recovery in Anorexia Nervosa? What does it mean to be "well" or "cured" from a long lasting illness like anorexia? Does it mean that the person suffering from Anorexia Nervosa is no longer meeting the diagnostical criteria for the disorder? Does it mean that the person is functioning on a normal level both psychologically, physically, emotionally and socially? If so, what is "normal" functioning? Who can decide if a person has recovered? Is it the clinicians working with the person, is it researchers having conducted studies over several years, is it the people in close contact with the person, or is it simply the person itself? What time period of symptom abatement or "normal" functioning is needed in order to classify a person as recovered? Where do we draw the line for recovery? What is "enough" recovery to actually be recovered? Is it good enough for us that a patient who previously only ate one apple a day now eats two ham and cheese sandwiches, or do we expect the recovered patient to be comfortable around Christmas dinner? Do we need to have a universal consensus on what it means to be recovered from Anorexia Nervosa? Or is it up to the patient and the clinical team to agree on treatment goals and hence decide when recovery is achieved? And how are we supposed to measure all this? What kind of assessments are we to use to be able to capture the concept of recovery? Is it important to define what recovery from Anorexia Nervosa is, and if so-why?

## AIMS OF DISSERTATION

The purpose of this dissertation is to identify major problems that obscure understanding of recovery in Anorexia Nervosa, to highlight the difficulties associated with defining recovery, to differentiate recovery from other closely related concepts such as outcome and remission, and to highlight the importance of reaching a consensus on the definition of the concept. Based on a review of the literature, between 1997-2007, this dissertation aims to provide the reader with the current standings on the matter, and to offer suggestions for further development in order to reach a consensus on a definition of the concept of recovery.

This dissertation is divided into four sections and is structured as follows. The first section of the dissertation attempts to briefly introduce the reader to a description of Anorexia Nervosa as a disorder. In addition a short elucidation will be given on the terms outcome, treatment response, remission, and recovery as the definition of these terms have been interchangeably used in the literature to describe the possible development of the disorder. The second section provides a critical review of the definition and measures of recovery that has been defined, by researchers, in eating disorder outcome research. This section also examines the impact of variable definitions and measures on reported recovery rates. The third section focuses on one important limitation in the outcome literature, the frequent absence of clients' views on the recovery process. Finally, the fourth section of the article offers several proposals for development in the field, suggesting the use of methods and measures that acknowledge the widespread diversity of anorectic clients, and of clients' experiences of recovery, while remaining informative to both the researcher and the clinician.

### ANOREXIA NERVOSA

Anorexia Nervosa (AN) is a serious eating disorder characterized by a refusal to maintain normal weight, an intense fear of weight gain, a disturbed body image, and amenorrhea (American Psychiatric Association, APA, 2000). The criteria for diagnosis of AN listed in the Diagnostic and Statistical manual of Mental Disorders (4<sup>th</sup> edition) (DSM-IV) are: a) refusal to maintain weight at or above the minimal normal weight for height and age, b) intense fear of gaining weight or becoming fat even though underweight, c) disturbance in body image, and d) amenorrhea. Two specified types of anorexia are the restricting type and binge-eating/purging type. The restricting type means the person has not engaged in any binge-eating/purging activity, but simply restricts food. The binge-eating/purging type means that the person has had episodes of bingeing and purging between episodes of restricting food (APA, 2000).

Anorexia Nervosa is a relatively common eating disorder, considered a complex and long lasting illness, with substantial mortality and high morbidity rates (Mc Master, Beale, Hillege, & Nagy, 2004). Adolescent girls and young adult women between the ages of 15 and 35 are most commonly affected by this disorder (Lask & Bryant-Waugh, 2007). It is estimated that approximately 0.5% to 1% of American women, will struggle with AN at some point in their lives (Sokol, Steinberg, & Zerbe, 1998). Population studies indicate that the annual prevalence of Anorexia Nervosa among young women is up to 370/100,000 (Crisp et al., 2006). Death through starvation or suicide of 1:200 patients who has undergone treatment illustrates the seriousness of this disorder (Gilchrist et al., 1998, in McMaster et al., 2004), and it does in fact show the highest mortality rates of all psychiatric disorders (Fichter, Quadflieg, & Hedlund, 2006).

Descriptions of patients suffering from AN, are characterized by several psychological, physical and behavioral abnormalities (Sokol et al., 1998). Psychological symptoms of AN include disturbed body image, low self-esteem, fear of gaining weight or becoming fat, perfectionism, obsessionality, anxiety, depression, and an impaired stress response. Physical abnormalities can be seen in cardiac, gastrointestinal, kidney, and reproductive function. Hormonal and metabolic imbalances can also be found, along with central nervous system abnormalities. Behavioral

problems include dieting, strict dietary patterns, bingeing, purging and over-exercise. Abuse of over the counter substances, such as diet pills and laxatives, diuretics, thyroid supplementation, and other prescription medications, as well as fluid restriction is also occurring quite frequently.

The cause of eating disorders is not fully understood, but is probably multidimensional, including psychological, genetic, familial, sociocultural, neuroendocrine, and hypothalamic factors.

Anorexic patients exhibit a spectrum of eating disorder symptoms, and can move in and out of the different clinical and sub clinical diagnostic categories over time. Eating disorders require careful assessment and comprehensive treatment. Treatments can and do work, but it is unclear whether treatment is able to remove the risk of recurrence completely (Sokol et al., 1998). When studying eating disorders such as AN, long-term follow up studies are essential. Findings from these outcome studies have indicated a tendency towards dichotomy over time: recovery for some and severe chronicity or even death for the rest (Fichter et al., 2006). It is currently impossible to predict with certainty which individuals eventually recover from AN completely (Bachner-Melman, Zohar, & Ebstein, 2006). Despite considerable attention devoted in research to the identification of prognostic factors, clear predictors of recovery from AN have proven elusive. Knowledge of the course and outcome of AN is needed for evaluation of different treatment methods, and for development of future treatment studies (Herzog, Sacks, Keller, Lavori, von Ranson, & Gray, 1993).

Information on outcome patterns of the degree and duration of eating disorder symptom reduction is also necessary when establishing the most meaningful definition of recovery from AN. A detailed and specified definition of recovery, used consistently and globally, would allow for comparable research findings across studies (Frank et al., 1991, in Herzog et al., 1993). For more than half a century extensive research has been conducted in order to find out how well patients with eating disorders do over time (Fisher, 2003). The literature has yielded mixed results, and definite answers are still lacking. At present, there is no internationally accepted definition of recovery in eating disorders. Most research groups take account of information about weight and height, but pay less attention to equally, if not more, important features, such as physical and psychological health and social functioning. The need to determine and reach a consensus on a definition of recovery from Anorexia Nervosa applies to many areas. Patients,

families, clinicians and researchers all want to know what recovery is, how often and when to expect it and the best possible way to achieve it. In the same way, categories of recovery are important to researchers as they often serve as clinical endpoints for intervention (Couturier & Lock, 2006a). A range and variety of definitions of recovery exists, and as such it is the most frequently reported outcome in studies of AN (Couturier and Lock, 2006a). Steinhausen (2002) found recovery rates varying between 0% and 92% within 119 studies. This enormous range of reported recovery rates likely has many origins, including age at onset, time to follow up, sample characteristics, and types of treatment programs, but a major contributor is also the lack of a consensus on what constitutes the concept of recovery.

### **OUTCOME**

Outcome can be defined as the long-term result of a pathological process (Gowers & Doherty, 2007, chap. 6); (Lask & Bryant-Waugh, 2007). In the course and outcome of Anorexia Nervosa there are four possible outcomes along the pathway of the disorder: treatment response, remission, recovery and death.

As long-term outcome of a disorder can be seen as the final destination of the pathological process, predicting course and outcome is an important aspect of describing a clinical syndrome (Pike, 1998). Since one of the prominent features of AN is its variable course and outcome such prognosis is especially challenging (Pike, 1998). Over the past 75 years, more than 150 outcome studies of Anorexia Nervosa have been published. These studies range enormously in terms of sample characteristics and size, diagnostic criteria, assessment methods, length of follow-up and follow-up procedures. As a result of this variability it is extremely difficult to generalize across studies (Pike, 1998). A range of criteria are defined in describing the overall outcome of the disorder. What is frequently evaluated in outcome studies are behavioral symptoms, biological symptoms, and most often also cognitive symptoms of AN. On the other hand, psychosocial functioning and personality symptoms are rarely evaluated (Rø, 2006). Most studies though, implement the global outcome criteria set up by Morgan and Russell, which include three basic

outcome groups: Good, intermediate, and poor. Other studies include definitions of the outcome variables remission and recovery. Steinhausen (2002) conducted a meta analysis of 119 outcome studies and found that approximately 50% of the patients had a good outcome or recovered, 30% had an intermediate outcome and still showed some symptoms, and about 20% had a poor outcome and were reported to be chronically symptomatic after 4-10 years. Recent outcome studies confirm this trend, with good outcome between 49% and 75.8%, intermediate outcome between 10.5% and 41%, and poor outcome between 8% and 14%, after follow-up of 10 or more years (Strober, Freeman, & Morrel, 1997; Saccomani, Savoini, Cirrincione, & Ravera, 1998; Herpertz-Dahlmann, Müller, Herpertz, & Heussen, 2001; Råstam, Gillberg, & Wentz, 2003). One of the limitations of discussing overall outcome is the lack of specificity regarding continuing symptoms affecting the patients' overall functioning even after classified as "good outcome", in "remission" or "recovered"; and the lacking consensus on defining these terms.

### TREATMENT RESPONSE

Treatment response is an outcome variable implying a direct relationship to treatment. It is indicated by either a clinically significant change from baseline values, or a change of a certain magnitude (i.e. 50% reduction in scores) from baseline (Couturier & Lock, 2006a). This outcome variable will not be discussed any further as it is less commonly described in outcome studies and has not been the focus of the controversial discussion regarding the development in the field of outcome research of Anorexia Nervosa.

## **REMISSION**

Remission can be defined as a categorical assessment conducted at a single point in time indicating that symptoms are, for at least a brief period in time, substantially no longer present (Couturier & Lock, 2006b). Remission is not dependent on treatment, nor does it require that baseline scores are available for comparison, and it can in fact be spontaneous. Continuation of remission for a significantly longer period of time is one way to define recovery (Couturier & Lock, 2006a)

The use of the term remission has varied extensively in studies of Anorexia Nervosa and there is currently little agreement on what constitutes remission in AN (Couturier & Lock, 2006b). According to Pike (1998) it is generally agreed that the state of remission from AN can be defined as the partial or whole abatement of symptoms for a period of time in which the individual does not meet criteria for the disorder. However, during a period of remission, the range of residual symptoms that remain varies greatly, and establishing the threshold of these symptoms for defining remission is difficult (Pike, 1998).

This lack of agreement on a definition of remission leads to problems in defining response to treatment, as well as recovery, and creates difficulty in clearly describing outcomes within studies, and in comparing outcomes across studies (Couturier & Lock, 2006b). Couturier and Lock (2006b) conducted a study with 86 adolescents suffering from AN, testing different definitions of remission. They used the Morgan-Russell criteria (good outcome), criteria set by Pike (weight ≥90% IBW, RCI ≥1.96 on psychological measures (EDE within 2 SD of normal), return of menstrual functioning, absence of compensatory behaviors), criteria set by Kordy et al. (weight ≥88% IBW or BMI >19, absence of extreme fear of weight gain (EDE 2SD of normal), no bingeing or purging, the DSM-IV criteria (weight ≥85% IBW, psychological symptoms within normal weight (EDE within 2SD of normal), absence of amenorrhea), different weight thresholds (85% IBW, 90% IBW, 95% IBW), psychological symptoms measured by the Eating Disorder Examination (EDE) (all 4 subscales within 1 or 2 SD of normal), and a combination of criteria

for remission. The authors found that the number of patients in remission varied between 3% - 96% depending on the criteria and methods used. By combining the percentage of normal body weight and EDE scores, the variability in numbers of patients in remission was reduced. The authors concluded that this combination seemed like the best way to go about the issue of defining remission.

### RECOVERY

Currently there seems to be great confusion and little agreement on what constitutes recovery in Anorexia Nervosa. There is also a lacking consensus on what is considered a successful outcome at the end of treatment (Couturier & Lock, 2006b). This lack of agreement makes it extremely difficult to define response to treatment as well as defining the ultimate goal, recovery, and thus hardships arises in clearly describing outcomes within and between studies. In his review of 119 outcome studies, Steinhausen (2002) found that recovery rates varied between 0% and 92%. This range of recovery rates likely has many origins, including time to follow-up, sample characteristics, and types of treatment programs, but a major contributor is also the lack of a consensus on what constitutes recovery among the various papers examined.

A suggested definition was given by Pike (1998), in describing recovery from AN as the point at which an individual who had previously been diagnosed with the disorder, currently has no symptoms and is at comparable risk for the recurrence of these symptoms as a matched control in the population at large. Strober et al. (1997) defined patients as "fully recovered" when they showed to be free of all symptoms of AN for 8 consecutive weeks.

Some authors suggest that absolute and wide-ranging symptom abatement is needed in order to categorize someone with AN as recovered, while others suggest recovery should be specific to AN (Couturier & Lock, 2006a). Jarman and Walsh (1999) propose that physical, psychological, and psychosocial adjustments are aspects that should be included in a definition of recovery. These broad definitions of recovery have the advantage of providing a more comprehensive

evaluation of patient functioning; however, there are also substantial disadvantages. Systematic evaluation of general psychological and social functioning is difficult and the requirement set for comprehensive recovery may be unreasonable. By setting the bar for recovery at a complete and comprehensive overall recovery, factors unrelated or not specific to AN may falsely decrease recovery rates and negatively affect the outcome (Couturier & Lock, 2006a). In contrast to comprehensive approaches to defining recovery, it could be defined more specifically, for example, as no longer meeting diagnostic criteria for AN for a specified period of time. Such specific and narrow definitions of recovery are often more practical as it is easier to assess and subjects can be more accurately categorized (Couturier & Lock, 2006a). Despite the variety and range of definitions, recovery is the most frequently reported outcome in studies of AN (Couturier & Lock, 2006a).

### **METHOD**

### LITERATURE REVIEW

This review is based on papers that address the concepts of recovery, remission and outcome in Anorexia Nervosa. Relevant literature included in this review was identified by searching the electronic databases Cochrane library, PubMed, Medline, Embase, and Psychinfo. Searches were made on literature published between the years 1996-2007, to provide and overview of the field from the past decade. The terms used in the search criteria were "anorexia nervosa", "anorexia", "outcome", "treatment outcome", "outcome assessment", "outcome study", "outcome and process assessment", "psychotherapeutic outcome", "recovery", "recovery of function", "recovery(disorders)", "remission", "spontaneous remission", "remission(disorders)", "symptom remission", "longitudinal studies", "treatment effectiveness evaluation", "follow up", and "follow up studies". Reasons for the vast inclusion of search terms were to make sure that the literature search was thoroughly conducted, including both controlled vocabulary and text words found in title or abstract. Various combinations of the terms were undertaken, duplicates removed, and limits set to Norwegian, Swedish, Danish, and English languages. The total numbers of articles found were 227. Of these, 42 articles were found to fit the specific aims of this dissertation and were included as the material for this review. Due to time constraint, eight of these articles were not readily available for utilization; hence a choice was made to not include these in the final evaluation of the research material reviewed in this dissertation. Consequently, the final number of articles reviewed in this dissertation was 34. As the field of research on outcome in Anorexia Nervosa is vast, a decision was made to rely heavily upon previous and recent reviews of this area of research. On the other hand, the field of research on Anorexia Nervosa has quite recently begun to turn its focus towards the issue of recovery, and papers written on this topic is quite scarce. As such, there is reason to believe that the search done for this dissertation includes all the papers published on the topic of recovery in Anorexia Nervosa.

## **FINDINGS**

Table 1. Description of terms reported in studies

Study	Follow-up period	Outcome	Remission	Recovery
Crisp et al. (2006)	22 yrs	Death, recovery, residual eating disorder ("still severe"-"mild")	NR	Strict criteria (the reader is directed to see video, Crisp, 1995a)
Bachner-Melman et al. (2006)	N/A	NR	NR	Fully behaviourally recovered: BMI of 19 or more, regular menstruation for at least 3 months, absence of bingeing and purging symptoms for at least 8 consecutive weeks. Fully behaviourally and cognitively recovered: same as above plus an absence of both fear of weight gain and body image distortion.
Fichter et al. (2006)	12 yrs	Morgan-Russell criteria, SIAB-EX criteria, BMI (good: 19-26, intermediate: 17.5-19, poor:<17.5), and PSR for overall outcome.	NR	SIAB-EX: No eating disorder diagnosis
Couturier & Lock (2006a)	(see "discussion" section p. 26)			
Couturier & Lock (2006b)	(see "remission " section p. 10)			
Lock et al. (2006)	2.3-6 yrs	Whether in any treatment, change in family structure, psychosocial functioning, weight (IBW and BMI), menses in past 6 months, global EDE	NR	NR
Treat et al. (2005)	N/A	ED diagnosis, axis 1 diagnosis, axis 3 problems, medications, duration of ED, BMI, 5IBW, EDI score, EDE-Q score, BDI score	NR	Partial: medically stabilized, refeeding initiated. Full: Not defined
Halvorsen et al. (2004)	3.5-14.5 yrs	DSM-IV diagnosis and eating attitudes (based on EDE and body weight), Morgan-Russell general outcome classification  Axis I and II disorders	NR	Not meeting DSM-IV criteria for AN, BN or EDNOS according to information from EDE and body weight
		(measured by SCID-I and II), OCD (measured by Y-		Recovery according to the person with AN: measured by interview

Råstam et al. (2003)	10 yrs	(measured by ASDI), general outcome classification **(modified Morgan-Russell scales), GAF, psychiatric	NR	interview. Full ED symptomatology recovery: free of all criterion symptoms of AN or BN for 8 consecutive
		treatment, neuropsychiatric examination, physical examination, neuropsychological assessment (WAIS-R), self-report questionnaires (TAS-20, EAT, BDI)		weeks. It requires sustained absence of weight deviation, compensatory behaviours, and deviant attitudes regarding weight and shape, including weight phobia. Also, a relaxed attitude towards eating in general (no tension at mealtime and the ability to enjoy eating with other people) for not less than 6 months. (this is the same as Wentz et al 2001)
Steinhausen et al. (2003)	6.4 yrs	No eating disorder, good or fair psychosocial outcome, no other psychiatric disorder, no eating disorder or other psychiatric disorder, no eating disorder or other psychiatric disorder and good or fair psychosocial outcome	NR	NR
Sutandar-Pinnock et al (2003)	6-24 months	Good: no symptoms and normal weight Poor: any other situation	NR	NR
Ward et al. (2003)	N/A	Residual psychopathology on measures of eating attitudes(EDI,BITE, EDE) and personality traits(TPQ,BDI)	NR	BMI>18.5, return of menses at least 3 mnts and "reasonably normal" eating habits.
Patton et al. (2003)	6 yrs	ED diagnosis( measured by BET), BMI, depression and anxiety, substance use	NR	NR
Kordy et al. (2002)	2.5 yrs	NR	Partial: BMI > 17.5, no vomiting or laxative use, no binges for 1 month Full: BMI > 19, no extremes in fear of weight gain, no vomiting or laxative use, no binges for 3 months	BMI > 19, no extremes in fear of weight gain, no vomiting or laxative use, no binges for 12 months
Bergh et al. (2002)	3-60 months	NR	Normal body weight, a normal psychiatric profile, normal laboratory test values, normal eating behaviour and resumption of social activities.	Suggests that recovery may be 12 months of remission
		Recovery and relapse according to PSR scale		Full recovery: absence of symptomatology or presence of minimal

		1 - 1		
Eddy et al. (2002)	8-12 yrs	Relapse: return of full criteria symptomatology (PSR = 5 or 6) for at least 1 week following a period of full recovery	NR	symptomatology for at least 8 consecutive weeks (PSR = 1 or 2) Partial recovery: reduction of symptomatology to less than full criteria for at least 8 consecutive weeks (PSR = 3 or 4)
Herpertz-Dahlmann et al. (2001)	7-10 yrs	Morgan-Russell categories (modified '91), excluding patients with weight phobia and not meeting criteria for any ED past 6 months	NR	Good outcome at 7 and 10 yrs with no symptoms last 3 yrs
Löwe et al. (2001)	21yrs	BMI, psychosocial outcome, ED outcome Good outcome: full recovery (PSR =1) Intermediate outcome: partial recovery (PSR = 2,3 or 4) Poor outcome: (PSR = 5 or 6, death due to AN)	NR	No ED diagnosis (DSM-IV, PSR = 1,2 or 3)
Towell et al. (2001)	N/A	Extent of body image disturbance (1-5, not disturbed-extremely disturbed), disordered eating behaviour (1-5, not disordered-extremely disordered), success of treatment (1-5, great improvement-got worse)	NR	NR
Wentz et al. (2001)	10yrs	**Morgan-Russell general outcome classification, modified and GAF scores	NR	Full recovery from ED symptomatology: Free from disturbed behaviours and attitudes in respect of food and shape for at least 6 months.
Tanaka et al. (2001)	8yrs	**Morgan-Russell general outcome classification, modified	NR	NR
Ben-Tovim et al. (2001)	5yrs	***Morgan-Russell- Hayward outcome assessment and presence of diagnosable ED	NR	NR
Bizeul et al. (2001)	5-10yrs	EDI scores, follow-up questionnaire from own department, and ***Morgan-Russell outcome assessment schedule.  Poor outcome: 1) progressive or relapsing AN during last 4 yrs, i.e., persistence of food restriction and body preoccupation, 2) BMI < 18, 3) psychological, somatic and digestive symptoms in relation to	NR	Recovery: no relapse last 4 yrs, and 1) normal BW, no fear of eating and of being fat, no major food restriction for more than 2 yrs, 2) satisfaction with quality of personal, relational, emotional, sexual and professional life, 3) autonomy from the family, 4) good insight capacity

		eating, and 4) repercussion on a personal, relational, emotional, family or professional level.		
Bulik et al. (2000)	12yrs	NR	NR	Partial: Not having an ED diagnosis, but reported binging or purging or maintained a weight<85% IBW Full: No current ED diagnosis, weight>85% IBW, no current binging and purging
Zipfel et al. (2000)	21 yrs	Good: PSR 1 Intermediate: PSR 2-4 Poor: PSR 5 or 6	NR	Good outcome (PSR 1)
Steinhausen et al. (2000a)	5-11.5 yrs	BMI, eating disorder score(ICD-10), total outcome score(the two latter assessed by semi structured interview modified after Sturzenberger et al. (1977), ratings on a 4 point scale of 11 topics dealing with ED symptoms, sexuality and psychosocial outcome. The first 5 items comprised the ED score, and the sum of all 11 interview variables comprised the total outcome score)	NR	No eating disorder
Steinhausen et al. (2000b)	5yrs	Eating disorder outcome score (5 topics from Sturzenberger interview-dieting, vomiting, bulimic episodes, laxative abuse, menstruation).  Psychosocial outcome score (the remaining 6 topics from the interview-attitudes toward sexuality, active sexual behaviour, quality of relationships with family, quality of social relationships in general, educational or occupational status. Total outcome score (sum of all 11 items). A 4-point scale reflecting the intensity or frequency of the item (absent, mild, moderate, or severe). BMI	NR	Not meeting ED diagnosis (ICD-10)
Fichter and Quadflieg (1999)	2-6yrs	Categorical and global outcome assessed by the SIAB-P expert interview.  Good: score of 0 or 1 Intermediate: score of 2 Poor: score of 3 or 4 Global outcome supplemented with PSR to	NR	NR

		compensate for missing SIAB data.  Good: PSR 1 or 2 Intermediate: PSR 3 or 4 Poor: PSR 5 or 6 Diagnostic outcome: fulfilment of AN diagnosis according to DSM-IV criteria assessed with SIAB interview.		
Herzog et al. (1999)	7.5	Full recovery, partial recovery, relapse (measured by PSR) Relapse: return of full criteria symptoms (PSR 5 or 6) for at least 8 consecutive weeks following a state of full recovery (PSR 1 or 2)	NR	Partial: reduction of symptoms to less than full criteria for at least 8 consecutive weeks(PSR3-4) Full: absence of symptoms or the presence of only residual symptoms for at least 8 consecutive weeks (PSR 1 or 2)
Strober et al. (1999)	10-15 yrs	Recovery, relapse, binge eating	NR	Partial: "good outcome" according to Morgan-Russell, with additional criterion of maintenance for at least 8 weeks Full: Restoration of weight to within 85'5 of average, normal menstruation, full absence of any deviant psychological behaviours or attitudes relating to eating behaviour or body weight for no less than 8 weeks, as well as absence of compensatory behaviours of any sort
Saccomani et al. (1998)	N/A	Morgan-Russell categories modified by Jeammet, 10 items. Good: at least eight item scores 1 or 2. Intermediate: 4-7 item scores 1 or 2. Poor: Three or fewer items score 1 or 2.	NR	Good outcome as described in Morgan- Russell categories (but not explained specifically, I had to find out from searching the text)
Sullivan et al. (1998)	12 yrs	Diagnostic Interview for Genetic Studies (DSM-III- R AN diagnosis and mood, anxiety, and substance related disorders), GAF, BMI, EDI, Three-Factor Eating Questionnaire	NR	NR
Strober et al. (1997)	10-15yrs	Good, intermediate and poor according to Morgan-Russell criteria	NR	Partial: "good outcome" according to Morgan- Russell criteria for 8 consecutive weeks Full: Free of all AN symptoms for 8 consecutive weeks
Herzog et al. (1997)	12yrs	*Good, intermediate and poor according to Morgan- Russell criteria	NR	NR

#### Note:

\*\*\*Modified Morgan-Russell outcome assessment schedule (Morgan & Hayward, 1988): Semi structured interview, 17 items, 5 subscales, scores 0-12. **Good outcome** = mean score 8-12, **intermediate outcome** = mean score 4-<8, **poor outcome** = mean score 0-<4.

Structured inventory for anorexic and bulimic syndromes (expert-rating SIAB-EX): six factors rated from 0 (symptom not present) to 4 (symptom very severely present).

Structured inventory for anorexic and bulimic syndromes (SIAB-P expert interview): 10 outcome categories. Each item and each outcome category, as well as the global outcome, ranged from 0 (no symptoms) to 4 (very severe pathology). Only the menstruation item ranged from 0 (no symptoms) to 3 (very severe pathology)

NR = Not reported

BMI = Body mass index

PSR = Psychiatric status rating scale

N/A = Not applicable

ABW = Average body weight

ED = Eating disorder

GAF = Global assessment of functioning scale

EDI = Eating Disorder Inventory

ASDI = Asperger Syndrome Diagnostic Interview

Table 2. Number of patients in each category

Study	N	Outcome (%	<b>%</b> )	Remission (%)	Recovery (%)
Crisp et al. (2006)	105	Death: 4.8 Some degree of residual ED: 20.0 Missing data: 6.7		NR	68.6
Bachner-Melman et al. (2006)	212	NR		NR	100 recovered or in recovery, 34.9 recovered fully behaviourally, 15.1 recovered both behaviourally and cognitively
Fichter et al. (2006)	103	Original criteria Good: 27.5 Intermediate: 25.3 Poor: 39.6 BMI: Good: 44 Intermediate: 25 Poor: 31	Modified crit. Good: 24.2 Intermediate:20.9 Poor: 47.2	NR	30.5 recovered completely, received no ED diagnosis at any of the follow- ups

<sup>\*</sup>Morgan-Russell outcome criteria (1975): **Good**: (a score of "0"), both weight and menstruation has returned to normal (weight ± 15% of ABW). **Intermediate**: (scored "1") if either a pathological menstrual status or a deviation in body weight of > 15% was documented. **Poor**: (scored "2") amenorrhea and a reduction in body weight > 15%.

<sup>\*\*</sup>Modified Morgan-Russell outcome classification (Ratnasuriya et al., 1991): **Good**: Normal body weight (100 +/- 15% ABW) and normal menstruation. **Intermediate**: Normal or near normal body weight or normal menstruation, but not both. **Poor**: underweight and absent or scanty menstruation. The difference from the original criteria being that patients with overeating or vomiting (weekly or more) should be classified as having a poor outcome regardless of weight or menstrual status.

Couturier & Lock (2006a)	(see "discussion" section p. 16)			
Couturier & Lock (2006b)	(see "remission" section p. 10)			
Lock et al. (2006)	71	Good: average BMI and EDE in normal range- 89 >90% IBW, 74 within adult norms on all subscales on EDE, only 9.5 had amenorrhea, 5.6 <85% IBW	NR	NR
Treat et al. (2005)	61	Reported in table 2, Treat et al. (2006)	NR	100 in partial recovery
Halvorsen et al. (2004)	55	82 no ED diagnosis, 2 AN, 2 BN, 14 EDNOS. Substantial weight gain. 4 amenorrhea last 6 months, 73 regular menstruation, 15 irregular menstruation, 4 amenorrhea last 3 months. 49 normal attitudes towards eating and BW, 32 some strain with eating and BW, 19 pronounced problems in eating attitudes and behaviour. According to Morgan-Russell criteria 80 had good, 16 intermediate and 4 poor outcome.	NR	NR
Råstam et al. (2003)	51	General Morgan-Russell categories: Good: 49 Intermediate: 41 Poor: 10 Modified Morgan-Russell categories: Good: 43 Intermediate: 29 Poor: 27	NR	Patients' own opinion: 39 not recovered. Full recovery: 40
Steinhausen et al. (2003)	242	No eating disorder: 70 Good or fair psychosocial outcome: 71 No other psychiatric disorder: 76 No eating disorder or other psychiatric disorder: 7 No eating disorder or other psychiatric disorder and good or fair psychosocial outcome: 51	NR	70
Sutandar-Pinnock et al (2003)	23	Good: 56.5 Poor: any other situation: 43.5	NR	NR
Ward et al. (2003)	18	ANBP recovered individuals were significantly different than the ANR subtype group in eating attitudes and behavior, mood and personality. ANR are similar to controls.	NR	100
Patton et al. (2003)	982	8.8 received an ED diagnosis, all had BMI over 20, 47of ED group had high level of depression and anxiety.	NR	NR
Kordy et al. (2002)	524	NR	Partial: 55 Full: 7	6
Bergh et al. (2002)	168	NR	75	NR
Eddy et al. (2002)	136	Relapse: 57.4	NR	Full recovery: 37 Partial recovery: 86.8
Herpertz-Dahlmann et al. (2001)	39	7yrs Good: 58 Intermediate:21	NR	NR

		Poor: 21		
Herpertz-Dahlmann et al. (2001)	39	10yrs Good: 69 Intermediate: 23 Poor: 8	NR	69
Löwe et al. (2001)	84	Good: 50.6 Intermediate: 20.8 Poor: 26 Poor ED outcome was related to poor psychosocial outcome	NR	Partial: 20.8 Full: 50.6
Towell et al. (2001)	46	Compliance at admission associated with lower levels of body image disturbance, less disordered eating and higher ratings of treatment success.	NR	NR
Wentz et al. (2001)	51	General Morgan-Russell outcome criteria; Good: 49 Intermediate: 41 Poor: 10 Modified Morgan-Russell criteria; Good: 43 Intermediate: 29 Poor: 27 GAF mean score: 65.3	NR	Full recovery from ED symptomatology: 39
Tanaka et al. (2001)	61	Good: 51 Intermediate: 13 Poor: 25	NR	NR
Ben-Tovim et al. (2001)	95	Good: 34 Intermediate: 54 Poor: 13 No diagnosable ED: 56	NR	NR
Bizeul et al. (2001)	26	Poor: 50	NR	50
Bulik et al. (2000)	70	NR	NR	Partial: 30 Full: 48.6
Zipfel et al (2000)	84	Good: 50.6 Intermediate: 20.8 Poor: 26.0	NR	50.6
Steinhausen et al. (2000a)	60	2year follow-up: AN: 17 BN: 0 Atypical AN: 17 BMI: 19.3 Total outcome score: NR 6 year follow-up: AN: 4 BN: 2 Atypical AN: 10 BMI: 19.6 Total outcome score: NR	NR	2 year follow-up: 66 6 year follow- up: 83
Steinhausen et al. (2002b)	138	BMI: 19.1, cut off ≥ 17.5. Normalization rate was 79% for total sample. Psychosocial outcome score: reported only for each item, no total score Total outcome score: 55% have a positive score	NR	68

				1
Fichter and Quadflieg (1999)	103	2 year Good: 12.9 Intermediate: 19.8 Poor: 62.3 AN: 36.6 BN: 9.9	NR	NR
Fichter and Quadflieg (1999)	101	6 year Good: 34,7 Intermediate: 38,6 Poor: 20,8 AN: 26,8 BN: 9.9	NR	NR
Herzog et al. (1999)	136	Relapse: 40	NR	Partial: 83.7 Full: 33.7
Strober et al. (1999)	77	Recovery: 74 Relapse: 35.1 Binge eating: 29.9	NR	Partial: 81.8 at some point during follow up Full: 74
Saccomani et al. (1998)	87	Good: 53 Intermediate: 34 Poor: 14	NR	53
Sullivan et al. (1998)	70	15.7 met full criteria or subthreshold anorexia nervosa. 11.4 met full or subthreshold criteria for BN. Mean BMI 16.9 compared to BMI 20.4 for subjects with no AN.  EDI and TFEQ: AN group had higher drive for thinness, perfectionism, and cognitive restraint, and lower hunger than non AN comparison group.  DIGS: More common prevalence of depression, alcohol dependence, OCD, panic disorder, separation anxiety disorder, and overanxious disorder in AN group. GAF score worse (68.9) in AN group.  (Good: 69)	NR	NR Partial: 86.3
Strober et al. (1997)	95	NR	NR	Full: 75.8
Herzog et al. (1997)	84	Good: 47 Intermediate: 27 Poor: 14	NR	NR

Note: IBW = ideal body weight N/A = Not applicable BMI = Body mass index AN = Anorexia Nervosa

BN = Bulimia Nervosa

EDI = Eating Disorder Inventory
GAF = General Assessment of Functioning Scale
TFEQ = Three-Factor Eating Questionnaire
DIGS = Diagnostic Interview for Genetic Studies

As can be seen from table 1 there is large variation between studies in the way the authors define recovery. Note worthy is also the fact that some refrain from defining the concepts at all. Depending on the definitions used, one can see from table 2, that recovery rates varies from a low 6% to a high 83%, in the studies that did not only include already recovered subjects. As is the case for recovery, in a substantial number of the studies reviewed, outcome and remission is not clearly defined. The authors have merely described the enormous variation in variables used for measurements, without explaining which scores on these variables would be considered good, intermediate, poor or as a preferable outcome. Where outcome is defined, it is mostly done based on the different Morgan-Russell categories. Remission is rarely adhered to in the various studies, but when put in focus it has been quite clearly defined. As found in table 1, remission and recovery are sometimes described similarly across different studies, thus contributing to the confusion of defining these terms. In about 35% of the studies recovery has not been defined. If recovery is the desirable endpoint for a person suffering from AN, it can be argued that a clear definition of the concept is absolutely necessary in order to be able to discover if it has been achieved or not. It seems extremely difficult to measure recovery if one does not know what one is trying to measure. Possible contributing factors to the large variation in findings will be explored in the following discussion section.

## **DISCUSSION**

### Lack of consistent definitions

One partial explanation for these inconsistencies in findings may be the lack of consensus and use of criteria for recovery and outcome. These inconsistencies limit the comparability across studies. As found in this review, recovery rates varied between 6% and 83% depending on the definitions used. In the study where the lowest recovery rate was found (Kordy et al., 2002) recovery was defined as BMI > 19, no extremes in fear of weight gain, no vomiting or laxative use, no binges for 12 months. Whereas in the study with the highest recovery rate (Steinhausen et al., 2000a), a definition of recovery as simply no eating disorder present, as assessed by a semi-

structured interview modified after Sturzenberger et al. (1977, in Steinhausen 2000a), was used. Some authors suggest that absolute and wide-ranging symptom abatement is needed in order to categorize someone with AN as recovered, while others suggest recovery should be specific to AN (Couturier & Lock, 2006a). Jarman and Walsh (1999) state that physical, psychological, and psychosocial adjustment are important aspects that should be included when defining recovery in AN. Bachner-Melman et al. (2006) agrees that both physical and psychological aspects should be included when defining recovery. Definitions of recovery from anorexia nervosa vary to a large extent and rarely include the cognitive criteria of lack of body image distortion and fear of weight gain (Bachner-Melman et al., 2006). Bachner-Melman et al. (2006) found in their study that women who had, in addition to behavioral recovery, also made full cognitive recovery from the disorder were indistinguishable from female controls on self-report measures of body dissatisfaction, disordered eating, drive for thinness, general symptomatology, endorsement of the thin ideal, concern for appropriateness, drive for success, fear of failure, harm avoidance, obsessiveness, perfectionism, and self esteem. The authors suggest that recovery criteria need to be refined and standardized, and should include cognitive criteria such that it is not possible to distinguish those patients who recover from healthy controls in relation to their eating attitudes and personality profiles. The authors found the best outcome for AN patients to be the state of full behavioral and cognitive recovery which was defined as BMI of 19 or more, regular menstruation for at least 3 months, absence of bingeing and purging symptoms for at least 8 consecutive weeks, plus an absence of both fear of weight gain and body image distortion. In other studies social aspects of recovery were also recognized as important (Deter, Herzog, & Petzold 1992; Nordenboos, 1992; Petterson & Rosenvinge, 2002, in Bachner-Melman, 2006). It seems, therefore, that a clinically relevant definitions of recovery from an eating disorder need to encompass both physical, psychological and social dimensions of functioning.

It has been suggested that the most stringent definition of recovery, providing the greatest conceptual clarity, is the absence of all symptoms of AN (Löwe, Zipfel, Buchholz, Dupont, Reas, & Herzog, 2001; Strober et al., 1997). A lack of all symptoms requires not only the biological criteria of normal weight maintenance and regular menstruation and the behavioral criteria of sustained absence of bingeing or purging and normal regular eating. It requires in addition, the cognitive criteria of lack of body image distortion, a lack of fear of weight gain and the absence

of vigilance over eating for weight control purposes (Bachner-Melman et al., 2006). These broad definitions of recovery have the advantage of providing a more comprehensive evaluation of patient functioning; however, there are also substantial disadvantages. Systematic evaluation of general psychological and social functioning is difficult and the requirement set for comprehensive recovery may be unreasonable. By setting the bar for recovery at a complete and comprehensive overall recovery, factors unrelated or not specific to AN may falsely decrease recovery rates and negatively affect the outcome (Couturier & Lock, 2006a). In contrast to comprehensive approaches to defining recovery, it could be defined more specifically, for example, as no longer meeting diagnostic criteria for AN for a specified period of time. Strober et al. (1997) defined full recovery as a patient being free of all AN symptoms for 8 consecutive weeks. Such specific and narrow definitions of recovery are often more practical as it is easier to assess and subjects can be more accurately categorized (Couturier & Lock, 2006a). However, a problem with defining recovery in this way is that many of the patients who no longer meet the criteria for diagnosis often still have significant residual eating or weight related psychopathology (Couturier & Lock, 2006a). According to Strober et al., (1997) the frequently used outcome criteria decided by Morgan-Russell are too restrictive, because good outcome defined by these criteria may in fact represent just partial recovery. Strober et al. (1997) introduced the concept of "full recovery", which implies that the characteristics of anorexia and bulimia nervosa are absent for eight successive weeks, weight is normal, and the patient demonstrates no compensation behavior (vomiting, laxatives, diuretics, excessive movement), no negative attitudes towards weight and no weight phobia. In addition to this Steinhausen (2002), proposed that the reduction of comorbidity, for instance alcohol abuse, mood disorders, fear disorders, personality disorders, and schizophrenia is also important when categorizing someone as fully recovered.

At the same time some of these studies suggest that another source of variance in rates of recovery is the delineation between recovery of weight and recovery of eating related cognitions to a functional level. In general, weight recovery appears to occur both at a higher rate and more quickly than psychological recovery, in published studies (Steinhausen, 2002). Effect and outcome studies that take both physical and psychological criteria for recovery into account show different percentages of recovery. Saccomani et al. (1998) found that when only somatic criteria were considered 79% of anorectic patients had recovered, but when psychological criteria were taken into account the recovery rate fell to 49%. They also found that the physical aspects of

recovery were achieved much earlier than psychosomatic aspects of recovery. Comparable results were found by Strober et al. (1997) in 95 anorexia nervosa patients. These patients' weight, eating behavior, and menses were recovered after 4.7 years, but it took 6.6 years for psychosocial criteria for recovery to be realized. In patients dealing with severely disturbed family relations, the recovery process took even longer (Noordenbos & Seubring, 2006).

A study done by Couturier and Lock (2006a) draws attention to the enormous range of outcome criteria used in different studies and the consequent variation in findings. They used data from a randomized clinical trial for adolescent AN, and followed-up on these same subjects for one to six years. Various strategies for defining recovery were used on the same group of subjects to examine the stability of recovery rates over time. Recovery was defined using various weight thresholds: 85% IBW, 90% IBW, and 95% IBW; various psychological thresholds: EDE scores within 1 or 2 SDs of normal, and combinations of weight thresholds and EDE criteria. In addition, Kaplan-Meier survival curves were used to compare remission in weight with remission in EDE score over time. The authors found much variability in recovery rates when using various criteria both individually and in various combinations. The recovery rates found ranged from a low of 57.1% (20/35) for scores within 1 SD on all subscales of the EDE to a high of 94.4% (67/71) for 85% IBW. Menstrual return, irregular or regular menstrual functioning resulted in a recovery rate of 90.5%. All of the proposed models showed a similar trend in that there was little substantive change in results from the 12-month point to long-term follow-up. It was found noteworthy that the recovery threshold of 85% IBW was achieved by 90% of subjects by 6 months. All together, it seemed like all of the proposed criteria were relatively stable, and that rates of recovery covered a wide range. The results of this study suggest that rates of recovery vary widely depending on the specific criteria used. It also showed that once remission was achieved, it was maintained, regardless of the specific criteria used. The main source of difference in recovery rates came from including both physical and psychological variables, and from using differing cut points for weight recovery. When the cut point of diagnostic criteria for weight (85% IBW) was used, long-term recovery was achieved by 94%; however, if recovery was based on a combination of weight and EDE scores, this rate dropped to 74%. The survival analysis conducted also supported the authors' conclusion that most weight and psychological change occurs within the first 12 months of treatment, but it indicates in addition that weight

recovery occurs significantly before psychological recovery, which appears to take an additional year.

#### Lack of consistent measures

In addition to problems created by lack of consensus when defining recovery from an eating disorder, evaluation of recovery is also complicated by the variation in outcome measures used by different researchers in their studies. Many different scales are referred to in the context of evaluating "recovery" from eating disorders. These include, but are not limited to, the Anorexia Nervosa Symptom Score, the Anorectic Outcome scale, the Body Dissatisfaction scale, the Eating Attitudes Test, the Eating Disorder Examination, the Eating Disorder Inventory, the Eating Disorders Longitudinal Interval follow-up Evaluation, the Morgan-Russell assessment scale, and the Psychiatric Status Rating scale (Jarman & Walsh, 1999). Such diversity of measures makes comparisons between different studies difficult, as recovery is often differentially defined and measured according to the scale being used. Comparisons have to be limited to the measures that are consistently reported across studies, usually the physical and behavioral aspects of the eating disorder. Problems also arise in relation to researchers choosing different values of outcome to indicate recovery, on the same outcome measure. For example, one frequently used outcome for anorexia nervosa is the Morgan and Russell outcome assessment schedule (Couturier & Lock, 2006b). Although the scale is designed to measure outcome across five dimensions (food intake, menstrual state, mental state, psychosexual state and socioeconomic state), no indication is given as to what score on the scale would discriminate "recovery". This in turn leads to researchers selecting their own criteria, resulting in variability between different outcome studies. In addition, despite the potentially comprehensive assessment available form the use of the Morgan-Russell assessment schedule, reports of outcome have often focused on two of the scale scores, measures of body weight and menstruation (Jarman & Walsh, 1999), constraining outcome measurements to physical aspects of the clients development.

Another important issue to be aware of concerns the use of long established scales in relation to a disorder where understanding is continually evolving (Jarman & Walsh, 1999). This is highlighted by modifications made to the Morgan and Russell outcome assessment schedule by present day researchers. No doubt, these and other modifications will continue to be necessary, especially in light of the DSM-IV sub classification of anorexia nervosa into binge eating/purging type and restrictor type, and also the continuing discussion of what constitutes an eating disorder (Fairburn, 2007).

According to the restricted Morgan-Russell criteria a good outcome is defined as weight within 15 % of normal weight and regular menstruation. A moderate outcome is defined as weight within 15% of normal weight and irregular menses. A bad outcome is defined as weight lower than 85% of the normal weight and no menstruation, or the development of bulimia nervosa (Noordenbos & Seubring, 2006). Steinhausen (2002) analyzed 119 effect and outcome studies that used this outcome criterion and found that 45 % of Anorexia Nervosa patients showed a good recovery, 35% showed improvement and 20% were defined as chronic. It has been pointed out that these percentages may be overly optimistic because the restricted Morgan Russell criteria do not take psychological, emotional, and social factors into count. For these reason the Morgan Russell criteria are seen as an insufficient indicator of full recovery (Strober et al., 1997).

An important conceptual issue also arises in relation to evaluation of recovery through use of measures designed to assess presence of eating disorder symptomatology (Noordenbos & Seubring, 2006). For example, the Eating Disorder Examination is commonly referred to as the "gold standard" for the assessment of eating disorders, and has also been used in assessment of outcome (Fairburn, 2007). It involves a standardized semi-structured interview that examines eating disorder psychopathology, with a particular focus on attitudes to shape and weight, and it is found to discriminate well between individuals with eating disorders and restrained controls (Rosen, Vara, Wendt, and Leitenberg, 1990, in Noordenbos & Seubring, 2006). However, when using the EDE, and other similar measures, evaluation of recovery is restricted to the absence of eating disorder symptoms, instead of looking at percents of qualitative changes in the patient's psychological functioning, which go beyond reduced concerns about body weight and shape (Noordenbos & Seubring 2006). This may be a significant constraint, as the importance of such changes for the overall well-being of patients have been highlighted in other literature examining

recovery from the clients' perspective (de la Rie, Noordenbos, Donker, & van Furth, 2006 & 2007; Tozzi, Sulivan, Fear, McKenzie, & Bulik, 2003). There is a need to find ways of integrating assessments of change in broader psychological functioning and to encompass a more holistic perspective of recovery in order to capture the essence of the important aspects of a patient's well being.

#### Assessment

Studies have shown that recovery rates also vary according to the method of assessment employed (Couturier & Lock, 2006a). Standardized assessment of Anorexia Nervosa is essential in research and when applied to, can greatly enhance clinical practice as well. To define the disorder and to be able to describe its course and outcome, reliable and valid diagnostic and outcome assessment is needed/of essential importance.

For research purposes such standardized assessments seems obvious, and for clinical practice there are multiple advantages to incorporate such instruments as well. Standardized interviews and self-report instruments provide consistent and comprehensive diagnosis, facilitate reliable monitoring of course and outcome for an individual, provide norms for comparison of clinical status and severity, and are often looked upon as useful self-learning for the individual (Pike, 2005).

The assessment of anorexia nervosa is complicated by the combination of categorical and continuous data. The classification systems in use are categorical in nature whereas the patients' symptoms which converge into the disorder occur on a continuum. According to Pike (2005) in clinical practice as well as in research, a comprehensive assessment battery for AN should generate both descriptive, continuous data with clinical sensitivity enabling us to capture changes that occur throughout the multiple dimensions comprising AN, and generate the necessary information for categorical diagnosis. In addition to diagnostic categories, categorical data is also useful in capturing overall clinical status of an individual over time (Pike, 2005).

Data gathering in the eating disorder population, as for other psychiatric populations are done by either interviews, self-report instruments or both. In research it is agreed that clinical interviews provide the most accurate data (Pike, 2005). Utilization of such interviews facilitates assessment of complex constructs such as binge eating and excessive exercise in addition to constructs for which everyday usage often differ from diagnostic definitions, f.ex. dieting. It also provides the clinician with an opportunity to evaluate the accuracy and reliability of the patient's self report, in a situation where cognitive capacity of the patient is commonly comprised. On the other hand self report assessment may prove superior to clinical interviews under some circumstances. During the initial stages of assessment and treatment at new places patients may be reluctant to convey extensive information to the clinician, with the possibility that self report instruments may provide the clinical team with more accurate and vast information. Also, another disadvantage of interview assessment is the required time, cost and expertise for training, supervision and the interview administration. Even though practical limitations frequently require that self-report instruments comprise most of the assessment battery in research studies inclusion of structured clinical interviews are essential to both research and clinical treatment (Pike, 2005).

According to Pike (2005) there are three deficiencies in the assessment of AN that needs to be adhered to. First, a lack of developmentally sensitive standardized instruments complicates the assessment of children and adolescents. Some instruments have been adapted to the young population, but limited data are available and further research on assessment procedures is needed. Second, standardized instruments to gather behavioral and observational information from parents, guardians and significant others are scarce. This is especially important for assessment of the young AN population and for patients who have low insight and high denial of their illness. Finally, cross cultural issues regarding assessment needs attention and future development. Reliability and validity of the application of the current assessments to cultures world wide is needed. Pike (2005) points to the significant assumptions regarding the expression of symptoms and their meaning in the currently used instruments and how this hinder our capacity to capture the global cultural diversity of eating disorders.

## Global vs. specific measures

Outcome studies have traditionally relied on relatively general classification systems. The most common is the trichotomy between good, intermediate and poor outcome, as exemplified by the Morgan Russell criteria. In all these schemas, "recovery" or "good outcome" is a weak index of overall status, since patients with residual psychological, cognitive, and personality features of AN are included (Bachner-Melman et al., 2006). Recovered AN patients, according to these global measures, have generally been found to display residual behavioral and attitudinal disturbances characteristic of the disorder. There have been a lot of inconsistencies in findings in regards to residual AN symptoms in studies. One partial explanation for these inconsistencies is that the lack of consensus on criteria for recovery or outcome limits the comparability of findings. Some studies define recovery using largely biological criteria of normal weight and regular menstruation (Pollice et al, 1997 in Bachner-Melman et al., 2006), others extend them to include the behavioral criteria of lack of bingeing and purging symptoms (Bulik, Sullivan, Fear, & Pickering, 2000) and yet others add the absence of restrictive eating patterns (Brown et al., 2003, in Bachner-Melman, 2006).

More precise classification systems exist. Herzog et al. (1993) developed a Psychiatric Rating Scale (PRS) for AN based on DSM-IV criteria that implements a 6-point rating scale with 1 representing full recovery and 6 representing active and severe AN. This scale however is not uniformly implemented. Whereas some studies (Löwe et al., 2001) define good outcome as a PSR level of 1 (absence of all symptoms), others (Herzog et al. 1993; Herzog, Dorer, Keel, Selwyn, Ekeblad, Flores et. al., 1999) include level 2 (presence of residual symptoms), which again includes those with lingering symptoms in the good outcome category

## **Physical measures**

Popular criteria for defining recovery from Anorexia Nervosa for research purposes, especially in early studies, have been measures of body weight and menses. Researchers describe recovery in

to the body mass index, and experiencing the return or onset of menstruation. These quantifiable measures of "restoration of weight and menstruation" are clearly attractive to researchers seeking objective data from which useful comparison can be made between studies (Jarman & Walsh, 1999). However, research has indicated that individuals considered to be "recovered" in terms of physical and behavioral features of serious eating disorders often continue to show distorted attitudes to food, eating and weight (Pike, 1998). Thus utility and adequacy of these physical and behavioral aspects of change in implying recovery from anorexia nervosa appear limited.

This issue of defining recovery merely according to physical measures is further exemplified by a study conducted by Watson and Anderson (2003). The authors pointed out the different weight criteria DSM has set over time for a diagnosis of Anorexia Nervosa. DSM III used 25% weight loss as a criterion, whereas DSM-IV used the weight criterion of 15 % weight loss. According to the authors the focus researchers have had on the physical aspect of recovery over time is not justified. As shown in their study amenorrhea can be present before significant weight loss, and quite a number of girls with BMI under the clinical cut-off of 17.5 continue to have their menstruation. So weight is clearly not equal to ovarian function. The conclusion set out by Watson and Anderson was that one should ignore the weight and amenorrhea criteria for recovery of AN, and focus on the more important cognitive symptoms of the disorder.

## **Psychological measures**

Within the eating disorder literature clinicians have long recognized the importance of psychological dimensions of recovery from eating disorders. However, psychological aspects of recovery, such as reduction on fears about becoming fat, preoccupation with food, and appearance and disturbances in body image, have historically received much less attention in outcome evaluations.

Recent research examining recovery from anorexia nervosa and bulimia nervosa does, however, reflect increasing attempts to evaluate psychological as well as the physical components of

change. Researchers' definitions of recovery often refer to the absence of any disturbance in perception of body image in addition to either the restitution in body weight and menses, in the case of anorexia nervosa. In addition to these psychological components, a number of authors have stated that assessment of recovery needs to be extended to include the patients' "social" environment (e.g., de la Rie et al., 2007; Tozzi et al., 2003). Suggested areas for assessment have included social contacts, social adjustment, educational adjustment, and/or vocational adjustment (Pike 1998). However, the difficulty in evaluating many of these social dimensions means that these "psychosocial" criteria tend to be excluded from definitions of recovery that are used in the majority of outcome evaluations.

## Physical vs. psychological measures

Many studies can be found that illustrate the importance of particular definitions of recovery criteria in relation to reported recovery rates. For instance, several studies illustrate discrepancies in recovery rates when comparing physical and psychological definitions of recovery. Crisp et al.'s (1980, in Jarman & Walsh, 1999) follow-up study of anorexics revealed that 80% of participants had recovered physically with normal or near normal body weights at follow-up, and relatively normal menstruation recurring for 70%. However, when additional psychological measures were included, 66% showed a highly variable dietary pattern and 40% continued to have intense fears about becoming fat and displayed cognitive distortions about body weight and shape. A similar discrepancy was revealed in a study by Saccomani et al. (1989, in Jarman & Walsh, 1999), which found 79% of adolescents formerly suffering from Anorexia Nervosa to be completely recovered in terms of physical aspects, but only 48% recovered when psychological aspects were taken into account.

## Time required for symptom abstinence

Although many studies of long-term outcome in eating disorders research have been conducted, reflection on adequate longitudinal concepts is rare. A source of variation in recovery rates likely results from the wide range of time spans used in the definitions. A meaningful constructs of recovery needs to consider not only severity of symptoms, but also duration of improvement. Several authors that have incorporated a "duration of wellness" into the assessment process require the symptom-free remission period to be maintained for at least 8 weeks before subjects are categorized as recovered (Herzog et al, 1993; Strober et al., 1997; Pike, 1998). Although this definition may be useful for research purposes, enabling comparisons between studies to be made, it is still unclear whether these clients are truly recovered from their eating disorders after only 8 weeks of symptom abatement. Indeed, many authors argue that meaningful evaluations of recovery from eating disorders only can be made after long-term follow-up (Pike 1998). Kordy, Krämer, Palmer, Papezova, Pellet, Richard et al. (2002) for example, suggest that recovery for AN consist of symptom abatement for at least a 12-month period. Couturier and Lock (2006a) conducted a survival analysis completed in an adolescent population in a naturalistic fashion, which revealed that the median time to recover in terms of physical symptoms was 57 months, while time to recover including psychological symptoms was 79 months. The authors concluded that recovery rates based on 8 weeks are likely to differ from those based on several years. A similar study was done by Keel, Dorer, Eddy, Delinsky, Franko, Blais et al. (2002). They found that the number of patients in recovery was reduced from 47% to 38% when the criterion for the time period of symptom abstinence was raised from 2 to 12 months. According to Strober et al. (1997) the median time to full recovery from AN is over 7 years from onset, and he argues that recovery may not be seen until 10 years or more. Several long-term outcome studies of AN have been conducted after 7 and a half (Herzog et al., 1999), 10 (Strober et al., 1997) and even 20 years or more (Löwe et al., 2001). This discrepancy in time spans for follow-up and time at measurement highlights the need for clarification about the use of the term recovery in outcome research. It also indicates that more studies that assess change over time by a series of short follow-up intervals could make a valuable contribution to this field (Bachner-Melman et al., 2006).

## Self-report vs. interview

In addition to the above complications arising from the variation in measures employed in outcome research, several authors have discussed how the evaluation of recovery may be affected by differences in the method of assessments used. For example, Cooper et al. (1989, in Jarman & Walsh, 1999) propose that semi structured interviews, such as the EDE, are superior to self-report measures for extracting and defining many features of an eating disorders. Specifically, they argue that much more reliable information can be learned about episodes of binge eating using this interview method, compared to questionnaires which focus on the frequency of binge-eating behavior, and that concerns about body shape and weight can be explored in more detail. Pike (1998) similarly emphasize the value of clinical interviews for assessment of eating disorders, arguing that these methods have less potential for bias and inaccuracies. Differences between reliability of self-report and interview methods are therefore important to consider in relation to varied measures used to evaluate recovery from eating disorders. Many of these are self-report questionnaires (EDI,EAT,BDA), and although easier to administer compared to standardized interviews, the information they provide may be less reliable compared to that obtained via standardized interview methods (Jarman & Walsh, 1999).

## Face to face vs. telephone interviews

Another divergence in method of assessment that may impact on the evaluation of recovery relates to whether follow-up interviews take place face to face or via the telephone. The relative ease of arranging telephone interviews makes the former assessment method an attractive option. However, research has indicated that agreement between telephone and face-to-face interviews varies according to the psychological problem that is being assessed (Jarman & Walsh, 1999). For example, a study comparing telephone and face-to- face interviews for the assessment of axis 1 and 2 disorders (Rohde et al., 1997, in Jarman & Walsh, 1999), found that agreement was excellent for anxiety disorders, very good for major depressive disorder and alcohol and substance abuse, but was problematic for adjustment disorder with depressed mood. Such variability indicates that judgments about the validity of these two methods for the assessment of

eating disorders need to be based on research specifically focused on the client group in question. A current lack of studies comparing these two methods suggest that more research comparing face-to-face versus telephone interviews in the follow-up of this client group, needs to be conducted (Jarman & Walsh, 1999).

#### **Comorbidity**

The findings from the previously mentioned review by Steinhausen (2002), show that at followup a large proportion of anorectic patients suffered from additional psychiatric disorders. Less than a half of the patients (46%), fully recovered from anorexia nervosa, whereas a third improved showing only partial or residual features of the eating disorder, and 20% remained chronically ill over the long term. In relation to other psychiatric disorders, exactly 25% of the Anorexia Nervosa patients had anxiety disorders and 25% had affective disorders. Substance use disorders, OCD, and obsessive-compulsive personality disorder were also very common diagnoses at outcome. Furthermore, there was evidence that some of these comorbidities, like depression, anxiety disorder, phobias, and personality disorders—served as risk factors for achieving a less favorable outcome of Anorexia Nervosa (Steinhausen, 2002). The two parameters of global outcome and other psychiatric disorders in this review overlapped greatly, so that at follow-up, more than 50% of the patients suffering from Anorexia Nervosa showed either a complete or a partial eating disorder in combination with another psychiatric disorder or another psychiatric disorder without an eating disorder. In another study by Löwe et al. (2001) the percentages of mood disorders and substance related disorders differed significantly between the good, intermediate and poor outcome groups. A higher proportion of other psychiatric disorders were found in the poor and intermediate outcome groups, compared to the good outcome group. However, a lot is still not known about the comorbidity of these various psychiatric disorders among each other, their true coexistence with Anorexia Nervosa, and their patterns across time.

## Young vs. adult patients

Some thought has been given over the past years to the idea that adolescents have a better prognosis than adults, and that those with an earlier onset of anorexia will have a better outcome, perhaps warranting more aggressive treatment in the adolescent age group. It is not completely clear however whether this impression is true, and those who treat adolescents with eating disorders are still not able to provide definitive answers to families requesting information on prognosis (Fisher, 2003). However, some studies show promising results for the younger age group. In an outcome study on younger patients conducted by Steinhausen, Seidel, and Metzke (2000), there was a slight trend for better global outcome and an increased rate of normalization of core symptoms in patients with AN onset before the age of 18.

The literature appears to confirm that adolescents do somewhat better than adults (Fisher, 2003), but it is unclear how large a difference there is. It remains unclear, also, whether adolescent patients in pediatric and adolescent medical settings who do not get hospitalized, either on medical or psychiatric units, have a better prognosis than most of the patients (outpatients) who have been studied in the literature. Ultimately, it is up to the clinicians who treat adolescent patients with eating disorders to perform the studies that will answer this question

## .Characteristics of participants

A closer examination of the reviewed studies indicates that some of the variability in outcome rates can be attributed to factors such as differences in the characteristics of participants. For instance, some studies are reporting data for individuals who have been treated in outpatient contexts, whereas others are reporting finding for individuals who have received inpatient treatment, and whose eating disorders may be more intractable. Other sources of variability in findings may be the age and gender of participants. Also, the patients' motivation for change should be a factor to look at in future outcome studies. It is a reasonable possibility that studies

which include patients highly motivated to change will have better outcome data and higher recovery rates than studies which include the most rigid patients who are unwilling to change.

Comprehensive evaluations of recovery, incorporating physical, psychological, social, and temporal dimensions of change are shown to be uncommon and inhibited by researchers' varied definitions of recovery, and choice of outcome assessment instruments. In addition to this lack of consensus, two other important shortcomings in the outcome literature, in relation to the clinical utility of research on recovery, are identified in the last section of this dissertation. First, patients' perspective on their recovery are almost always absent from the outcome evaluations; second, research has not so far been able to capture the interpersonal and organizational meanings of recovery which are negotiated between patients, clinicians and caretakers during the process of treatment

# Patients' perspectives

Very few studies take the patient's view of recovery into account. However, when patients themselves do not feel recovered, there is a high risk of relapse (de la Rie et al., 2006). Noordenbos and Seubring (2006) conducted a study on patients' perspectives on recovery asking these questions: Which criteria for recovery are important to ex-patients and therapists, and which criteria for recovery are actually realized by ex-patients? A list of 52 possible criteria for recovery was compiled from the literature on eating disorders, representing the domains of eating behavior, body experience, physical and psychological well-being, and emotional and social functioning. Ex-patients and therapists were asked to select criteria from this list that they viewed as important for recovery from eating disorders. Ex-patients were asked which criteria they had realized by the end of their most recent therapy or treatment and in the period thereafter. Most of the criteria for recovery were agreed on by the ex-patients and their therapists. At the end of their therapy, more than 50% of the ex-patients had realized 44 of the criteria for recovery, and thereafter they improved on 38 criteria.

The eating-disordered ex-patients and therapists in this study showed much agreement on criteria they evaluated as important for recovery from an eating disorder. Not only eating behavior and

weight seem to be important, but also the psychological, emotional, and social functioning of the former patients. The least important criteria (considered important by <50%) were regular menstruation, healthy teeth and intimate relationships. Although the criterion of no constipation was evaluated as important by only 44% of the ex-patients, the authors view it as important because constipation can be a risk factor for eating less or using laxatives (Noordenbos & Seubring, 2006). Only 38% of the therapists evaluated normal sleep as an important criterion for recovery, but for 83% of the ex-patients this was considered to be an important criterion. Anorectic patients can suffer from lack of sleep because of feelings of hunger, and bulimic patients often have binges during the night. For this reason it was viewed as important to maintain this criterion.

At the time of research, no criterion had been realized by 100% of the patients, and only six criteria had been realized by 90-97% of the patients(no binges, does not take laxatives, does not vomit after a meal, does not use diuretics, does not exercise excessively and has some friends). The question remains whether eating disorder patients can fully recover or, alternatively, whether we have to accept that they will never reach the point where the risk factors for eating disorders completely disappear. In the authors' opinion this conclusion can only be accepted when eating disorder patients have received the best possible treatment and follow-up care.

A point for discussion is which criteria for recovery deserve priority. Most of the therapists and ex-patients in the referred study expressed the opinion that recovery of eating behavior is an important condition for physical recovery. According to therapists, recovery of weight is an important condition for psychological, emotional, and psychosocial aspects of recovery alike. Several studies have shown that eating disorder patients who do not realize a healthy weight have a higher risk of relapse (Commerford et al, 1997, in Noordenbos & Seubring, 2006). However, there is no consensus on the question of which weight should be reached as basis for further recovery. Therapists have expressed different opinions, varying from a BMI of 18.5 to 19.5 or even 20. This can mean differences in weight of one or several kilos, depending on the individual patient. It is important to take the patient's gender, age and height into account, as well as bone structure, physical constitution, and ethnicity (Noordenbos & Seubring, 2006). The later you mature- the bigger chance you have of becoming taller and slimmer (lower BMI), and menstruate at a lower weight. The percentage of BMI at which the endocrine function is restored

is variable in individuals, and should be taken into consideration when conducting outcome research (Jacobi, 2007). Research on the BMI of 14,500 boys and girls in the Netherlands reported by Fredriks et al. (2000, in Noordenbos & Seubring 2006) found that BMI of 18.5 is normal for girls of 13 years, while for women who are 20 years old a BMI of 21.8 is normal. For therapists treating patients with eating disorders it is very important to develop more unambiguous criteria for weight recovery. Other studies of recovery have reported that retrospectively, recovered anorexics feel that factors such as self confidence, personality strength, being motivated to change, being understood, feeling that life has meaning, and a connection within oneself and connection with others (Garrett, 1997) were important ingredients of recovery.

This research shows that more agreement about criteria for recovery between patients and therapists is not only necessary but also possible. Recovery of physical aspects and eating behavior is important for an individual suffering from AN, but so is psychological, emotional and social functioning. To realize full recovery and to prevent relapse, it is important to consider not only eating behavior and weight, but also psychological, emotional, and social criteria. And the patients themselves should be brought in to share their views in this important discussion on outcome and recovery from AN. It seems that qualitative research, examining recovery from the client's perspective, can provide important insights for clinicians seeking information about the recovery process. A closer look at recovery in narrative terms and attempts to build bridges between qualitative and quantitative approaches may contribute to a better understanding of the recovery process and its predictors, promoters and catalysts (Bachner-Melman et al., 2006).

## The therapeutic negotiation of the recovery process

The second shortcoming in outcome research on recovery, especially for clinicians working in this area, concerns its detachment from the negotiation of the meaning of recovery, which takes place between patients and clinicians during the treatment process. The importance of the meanings of recovery play in relation to interactions between clients and clinicians and the organizational context of treatment seems obvious (Jarman & Walsh, 1999). With the wide range of theoretical models of eating disorders now available, clients and clinicians are likely to differ

in their understandings of eating disorders. These different understandings are brought in to the treatment context and this may, in turn, lead to the clients' and clinicians' different views on what it means to be recovered. Therefore it seems important for clinicians to explore their clients', and reflect on their own, understanding of what it means to be recovered from an eating disorder, during therapy, and in doing so, establish clear goals for the therapeutic process (Jarman & Walsh, 1999). In addition, the increasing emphasis on multifaceted treatment approaches for Anorexia Nervosa means that it is now common for a number of different health-care professionals to be involved in the treatment of any one client. Hence, consideration should be given to the possibility that each of these professionals bring with them a variety of perspectives on recovery, which will then be influencing decisions regarding the client's treatment. In addition, definitions of recovery may vary accordingly to the context in which treatment takes place. Thus, clinicians involved in different stages of clients' treatment need to be aware of both their own, and also other health-care professional's, specific contribution to the overall recovery process. It remains to be seen if this perspective will be included in the field of research in the future.

# **International eating disorders conference**

At the International Eating Disorders conference held in London March 2007, Kathleen M. Pike And James Lock gathered researchers and clinicians from all over the world in a themed symposium called "Outcome assessment for eating disorders", where the attempt was to further the debate on how to describe and measure outcome to move the field forward.

At this themed symposium Corinna Jacobi presented a lecture on methodological issues when dealing with outcome. She pointed out methodological obstacles it is important to address when conducting r reviewing outcome studies. Some of the ones being mentioned were predictor assessment, selected samples (boys, girls, age, length of disease, culture, motivation to change etc.), diagnostic systems/criteria (DSM or ICD), and length of follow up. In Jacobi's studies she found outcome rates varying between 27.5-69%, 13-38.6%, and 10-50% for good, intermediate, and poor outcome respectively. It was found that the outcome was better for adolescents

compared to adults, and better outcome was also found with increasing duration of follow-up (Jacobi, 2007).

At the same symposium Chris Fairburn (2007) held a lecture on functional impairment in ED and relation to outcome. He asked the questions: Why are we interested in outcome? What is our goal in treatment? He proposed an answer to the latter question by suggesting that the goal in treatment is to reduce the level of ED features to an extent so there is little or no secondary distress or impairment. He stated further that AN has two indices of impairment. First, the Morgan-Russell outcome classification has no developed norms, therefore it is not possible to decide when patients move in and out of categories. The categories are not standardized. The second indice of impairment in AN according to Fairburn is weight and BMI. As it is today, a person can show improvement in weight, but still have AN symptoms. We call it good outcome, but the person is still eating disordered. Fairburn went on to state that there is currently too much focus on weight. Patients aren't doing well even if we say they have had a good outcome. Clinicians and researchers alike wish that the AN patients have no functional impairments. The goal of treatment, according to Fairburn, should be to move a person out of the ED circle, not form one ED to the other. In order to do this it is absolutely necessary to define what an eating disorder is. When dealing with outcome Fairburn identified three main problems. First, some outcome criteria are arbitrary. The clinical cut-off for BMI is often set at 17.5, but this cut-off is not empirically based. There is not reason why the cut-off couldn't be 17.0 or 18.0. On the same note, outcome categories haven't been validated. Second, some outcome indices are too narrow. As it is today it is possible for a patient to have a "good outcome", yet still have an ED of clinical severity. Finally, no operational definition of what an ED is exists, especially for the EDNOS category. Fairburn suggests that a future research strategy should be to derive at an operational definition of an ED. Until this is done, one should not use terms such as remission and recovery because we don't know what they really are and we have no way of knowing when a patient have reached it (Fairburn, 2007).

Dasha Nicholls (2007) did her presentation on developmental aspects of outcome assessment. She started off by asking the question of what outcomes we are interested in as researchers and clinicians. An answer was provided in that response to treatment, remission, and recovery are the terms most researchers and clinicians are interested in when it comes to outcomes of ED.

Nicholls pointed out that there is something final about the word outcome. It doesn't hold a developmental aspect. When talking about recovery, we are talking about going back to something, but as individuals we are always moving forward- we are always developing. This aspect is especially important for children recovering from an ED. They are not going back to something that once was, they are moving forward and hopefully climbing back on the developmental ladder. This is one way to look at outcome, and definitions can be made such that a good outcome refers to a patient returning to normal or pervious developmental course, an intermediate outcome can be seen as a patient that has suffered too much damage, such that they cannot really get back on course, but have to continue at a lower level, and a poor outcome can be defines as a patient who continues to have an ED illness with associated functional impairment or death.

When should we measure outcome? The longer you wait, the bigger chance you have for patients to be better. One needs to be specific with the time of measurement. About 30% of the child onset EDs continues in to adolescence. About 11-27% of adolescent onset ED continues into adulthood. The continuity of ED is unclear. So, a big proportion of patients do not go on to have a chronic course or have it all through adulthood. It is also important to think about progression in that presentation of symptoms looks different at different ages.

In terms of biological recovery Nicholls feels that target weights are unhelpful. It is hard to know what is healthy, and it is therefore very difficult to set specific limits as to where to draw the "recovery-line". And example of this is that the later you mature, the bigger the chance for you to be taller and slimmer, and menstruate at a lower weight. The percentage BMI at which this occurs is variable and individual- depending on various things. Another example provided was of a girl from Eritrea who got pregnant at BMI 14. So, when setting weight limits according to age you can easily run in to problems. A proposal for a good biological outcome is an aim of restoration of endocrine functioning. As for psychological recovery and the aims of treatment it was suggested that recovering from an ED involves enabling a young person to be able to eat enough to grow and develop normally. This is done by finding a way of addressing her/his emotional needs.

So the question arises- how do we measure this? How can we use the outcome studies? We know for a fact that we cannot compare them due to the vast variety of outcome definitions and measures utilized. So, is it useful to conduct these studies? It would be useful for all parties involved to find what kind of treatment works. We want to measure outcome, but we just don't know how (Nicholls, 2007).

James Lock talked about categorical outcomes at the same symposium. He said that when using categories one is setting up boundaries. We do need them to some extent, but at the same time we are giving ourselves limits when using them. The limits are fairly arbitrary, but they have been drawn. In order to define the categories we need data, and we also need a process to assess categories in order to achieve agreement on the limits. When measuring outcome you can do it at any time, but it doesn't necessarily tell us about change. To be able to report on change a previous state is needed in order to look at outcomes compared to that previous state. WE have to keep in mind who we are talking about when dealing with outcome. Related to age there are developmental concerns, and males are not similar to girls when looking at differences between the sexes. So, who you are talking about makes a difference when measuring outcome. How you draw the boundaries also matter a great deal. Outcomes should relate directly to the disorder in question, but may relate to more general health concerns the way it is being measured today. Then there is the question of "why?". Outcome may relate to theory of illness. The weight you put on categorical outcome elements may vary as a result of such values. You measure what you think is important- and as such you will get different recovery rates. When you measure also matters. The later in the process the outcome measure is being conducted, the better outcome. So, what is recovery and how are we supposed to measure it? We rarely talk about emotional issues and this may present a problem when talking about recovery. Is a person recovered if they no longer have ED symptoms, but do still have anxiety, depression, OCD, family problems, refuses to go to school etc.? If recovery is to be functioning "normally", how do we define that? If a person with and eating disorder is still purging from time to time, but is functioning "normally", can they be considered as recovered? What if they are "recovered", but not functioning "normally", are they then considered recovered? (Lock, 2007).

As a closing remark to the themed symposium Øyvind Rø (2007) held a lecture on quality of life (QOL) and the patients' perspective. He asked the question why do we so seldom ask about the

patient's perspective? We run into problems when conducting follow- up studies because there are no clear outcome criteria. A big discrepancy has been seen between when the patient thinks they are recovered and when researcher and clinician think the patient is recovered. A way to measure recovery from ED is to use different Quality Of Life instruments. They are meant to measure subjective well being and satisfaction with different life aspects, as well as objective functioning. The problem with doing this is that there exists no consensus on which Quality Of Life assessments to use. We currently don't agree on what picture we want to capture and this is a big problem that has to be dealt with. Should we ask the patients about their view of recovery and QOL? The definite answer seems to be- yes, but there is much work still to be done. A consensus is needed of which QOL measures to be used. This has proven very difficult in the scientific world. We also need longitudinal studies to look at relation of ED symptoms in patients and changes in QOL. There is a pressing need for operational definitions of QOL, and we need baseline data and follow up data to look for changes over time (Rø, 2007).

# SUGGESTIONS FOR FUTURE RESEARCH

The final section of this dissertation considers ways of addressing the limitations of the current literature on recovery, and offers several suggestions for developing the research in a way it can most effectively be utilized by clinicians and their patients.

The first suggested development for the evaluation of recovery from eating disorders is to adopt a comprehensive model of recovery, encompassing physical, psychological, and social dimensions of change, by researchers and clinicians alike. The need for such a model has been indicated by a number of factor analytic studies of Anorexia Nervosa and Bulimia Nervosa (Jarman & Walsh, 1999). These studies have highlighted the multifaceted nature of these eating disorders, and identified a number of different dimensions to these problems. Some of which includes fasting and restrictive dieting, bingeing and purging, and fear of fatness/body image disturbance (Gleaves & Eberenz, 1993, in Jarman & Walsh, 1999). However, these studies have also highlighted factors relating to more general psychological and emotional functioning, including

emotional instability and low self-esteem, depression, anxiety and negative self-image. Therefore, in addition to the need for change in areas specific to "typical" eating disorder symptomatology (e.g., concerns about body shape and weight), it seems important that a model of recovery considers the need for change in more general areas of psychological well-being. Such a model would go beyond conceptualization of recovery as merely the absence of eating disorder symptomatology, and rather develop into a broader, multidimensional, model of recovery (Jarman & Walsh, 1999).

Complementary to the development of a multidimensional model of recovery from eating disorders a multidimensional assessment of outcome is needed. Such broad outcome assessment will enable change to be examined in a variety of areas, which are all important for the full recovery of the eating disordered patient. Therefore, the second suggestion for developing the clinical utility of outcome research would be to integrate the use of qualitative and quantitative research methods when evaluating recovery. Although quantitative methods and measures have tended to dominate in the eating disorder outcome literature, researchers have demonstrated that qualitative methodology can provide insightful information about client's perspectives on the recovery process. (Noordenbos & Seubring, 2006). The clinical utility of qualitative research methods is increasingly recognized by researchers working in health and clinical psychology. (de la Rie et al., 2006; Tozzi et al., 2003).

While qualitative approaches tend to be more time consuming, compared to standardized questionnaires, in terms of data collection and analysis, the detailed information they provide about peoples' experiences of recovery could be used to complement and enrich data derived from the more traditional, empiricist methods. Qualitative research could also be used to develop standardized assessment tools for exploring clients' personal definitions of recovery.

Although the description of specific definitions and methodological guidelines on how best to evaluate recovery form eating disorders would be beneficial to researchers and clinicians, if not absolutely necessary, this is not the aim of this dissertation of the evaluation of recovery.

Instead, this dissertation serves a converse function, illustrating how the conceptual and methodological confusion surrounding the evaluation of recovery makes such recommendations difficult to determine (Pike, 1998). More research, examining the utility of different definitions

and measures of recovery, needs to be conducted before such recommendations can be offered with sufficient confidence. The question still remains though, if such studies will provide clearer evidence for which definitions and measures of recovery should be used, or if a decision needs to be made in the nearest future on what constitutes recovery, in order to bring the field forward. Therefore, rather than providing a clear definition on recovery and detailed methodological guidelines, one of the points made in this dissertation is that researchers and clinicians need to critically reflect on how recovery from eating disorders is evaluated, consider the value of a multimethod, and develop an awareness of the particular advantages and limitations of different evaluative approaches.

Another suggested development need in the evaluation of recovery from eating disorders involves finding ways of integrating insights gained from research on the process of recovery, with more wide-ranging models of psychotherapeutic change and stages of change. It will also be important to include the patient's perspective on recovery and the process of change they feel they are in. Integration of stages and process of change can serve as a useful guide for clinicians, because awareness of the stage of change in which the patients find themselves in will allow the clinicians to know which process to apply in order to help the patient's progress to the next stage of change (Jarman & Walsh, 1999).

At the International Eating Disorder Conference held in London March 2007 researchers dealing with the issues of outcome and recovery on a daily basis discussed ways of bringing the field forward. Suggestions for the next steps to take were to make a common database that everyone could use and apply different measures to. It was further suggested that one has to develop a consensus on criteria for recovery and which assessments to use before applying it to this database. Researchers in Norway, Sweden UK and USA have begun the process of storing outcome data to such a database, and ideas are currently being shared on how to make it universal. Finally, it was agreed that a working party needs to be set up, which should include both patients, clinicians, and researchers, and that this group should have continuous meetings, the first being at the next eating disorder conference held in USA fall 2007.

#### **CONCLUSION**

When should a patient with Anorexia Nervosa be considered as recovered, as partially or fully remitting, or as having a good outcome? Although treatment response, remission, and recovery are distinct concepts, they are also highly related ones. In a very real sense, recovery is the ultimate judge of both remission and treatment response by defining the end points toward which treatment effects and intermediate outcome points are aimed. At the present state there is no global consensus about such definitions. Without a target definition for recovery, it is difficult to accurately compare outcomes in studies whether they are naturalistic, observational, or experimental. This dissertation illustrates the need for a consensus definition of recovery. It underscores the need for a refined concept of recovery and for internationally standardized criteria. Adequate definitions of the terms would allow for the comparison of estimates of recovery rates across outcome studies. Also, the use of widely accepted and applied definitions and criteria would enhance comparability between studies and promote a fuller understanding of the relationship between AN symptomatology, recovery form the disorder, and underlying personality characteristics. As shown, outcome studies range enormously in terms of diagnostic criteria, sample characteristics and size, procedures for assessment and follow-up, and in length of follow- up. The results of these studies show a large variation in number of patients belonging to the various outcome categories. As a result, it is extremely difficult to generalize across studies, hence the methodological procedures of each study must be considered in interpreting findings.

In summary, this dissertation reveals that the eating disorder outcome literature provides great confusion and little clear guidance to clinicians seeking information on how best to evaluate recovery from anorexia nervosa. The dissertation illustrates that long-term outcome studies utilize a diverse range of definitions and measures to evaluate recovery, complicating the interpretation of findings across and between studies. To be able to measure something, in this case recovery, one has to know and be clear on what one is trying to measure before actually going about doing it. In addition, this dissertation indicates that the client's perspective on recovery in seldom emphasized and incorporated into assessments of outcome, and that long-term

outcome studies offer little information about the process of recovery that takes place over time. Although suggestions have been made for developments in terms of defining recovery from AN, it is likely necessary that leaders in the field come together to agree on a working definition of recovery while further data are awaited.

At the 8<sup>th</sup> International Eating Disorder Conference held in London March 2007, experts in the field met for two concurrent sessions to discuss outcome assessment and how to move the field forward.

As found in this dissertation leaders in the clinical and research field of eating disorders stated the great confusion in this area. There exist a number of methodological issues when it comes to measuring outcome, not to mention the difficulties leaders in this field have with deciding on categorical definitions of outcome and operationalizations of terms such as remission, recovery and good and poor outcome.

However, despite the roaring confusion and strong disagreement there are active attempts and hopes for collaboration such that this very important matter will soon see, at least minimal, agreement. A working group is on the rise and thoughts and opinions are exchanged within e-mail groups. Discussion sessions on this topic will be arranged during the next international eating disorder conference, which will be held in the US later this year.

The importance of reaching a minimal consensus on outcome definitions seems clear- to be able to know what recovery is and when to expect it, to predict prognosis and to know what treatments will likely lead to what outcomes is of high value for patients, caregivers, clinicians and researchers alike. Continued dialogue and research is necessary to bring the field forward, and active attempts to reach a consensus are on the rise.

#### REFERENCES

- 1. American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4<sup>th</sup> ed.), text revision. Washington, DC: American Psychiatric Association.
- 2. Bachner-Melman, R., Zohar, A. H., & Ebstein, R. P. (2006). An examination of cognitive versus behavioral components of recovery from Anorexia Nervosa. *The Journal of Nervous and Mental Disease*, 194 (9), 697-703.
- 3. Ben-Tovim, D. I., Walker, K., Gilchrist, P., Freeman, R., Kalucy, R, & Esterman, A. (2001). Outcome in patients with eating disorders: A 5-year study. *The Lancet*, *357*, 1254-1257.
- 4. Bergh, C., Brodin, U., Lindberg, G., & Södersten, P. (2002). Randomized controlled trial of a treatment for Anorexia and Bulimia Nervosa. *PNAS*, *99* (14), 9486-9491.
- 5. Bizeul, C., Sadowsky, N., & Rigaud, D. (2001). The prognostic value of initial EDI scores in Anorexia Nervosa patients: a prospective follow-up study of 5-10 years. *Journal of European Psychiatry*, *16*, 232-238.
- 6. Bulik, C. M., Sullivan, P. F., Fear., J. L., & Pickering, A. (2000). Outcome of Anorexia Nervosa: Eating attitudes, personality, and parental bonding. *International Journal of Eating Disorders*, 28, 139-147.
- 7. Couturier, J., & Lock, J. (2006a). What is recovery in adolescent anorexia nervosa? *International Journal of Eating Disorders*, *39*, 1-6.
- 8. Couturier, J., & Lock, J. (2006b). What is remission in adolescent anorexia nervosa? A review of various conceptualizations and quantitative analysis. *International Journal of Eating Disorders*, 39, 175-183.
- 9. Crisp, A., et al.. (2006). Death, survival and recovery in Anorexia Nervosa: A thirty five year study. *European Eating Disorders Review*, *14*, 168-175.
- 10. de la Rie, S., Noordenbos, G., Donker, M., & van Furth, E. (2006). Evaluating the treatment of eating disorders from the patient's perspective. *International Journal of Eating Disorders*, 39, 667-676.

- 11. de la Rie, S., Noordenbos, G., Donker, M., & van Furth, E. (2007). The patient's view on quality of life and eating disorders. *International Journal of Eating Disorders*, 40, 13-20.
- 12. Eddy, K. T., Keel, P. K., Dorer, D. J., Delinsky, S. S., Franko, D. L., & Herzog, D. B. (2002). Longitudinal comparison of Anorexia Nervosa subtypes. *International Journal of Eating Disorders*, *31*, 191-201.
- 13. Fairburn, C. (2007, March). Functional impairment in ED and relation to outcome. Presentation at the themed symposium: Outcome assessment for eating disorders. International Eating Disorders Conference, London.
- 14. Fichter, M. M., & Quadflieg, N. (1999). Six-year course and outcome of Anorexia Nervosa. *International Journal of Eating Disorders*, 26, 359-385.
- Fichter, M. M., Quadflieg, N., & Hedlund, S. (2006). Twelwe-year course and outcome predictors of Anorexia Nervosa. *International Journal of Eating Disorders*, 39 (2), 87-100.
- 16. Fisher, M. (2003). The course and outcome of eating disorders in adults and in adolescents: A review. *Journal of Adolescent Medicine*, *14* (1), 149-159.
- 17. Garret, C. J. (1997). Recovery from anorexia nervosa: A sociological perspective. *International Journal of Eating Disorders*, *21*, 261-272.
- 18. Gowers, S. & Doherty, F. (2007). Outcome and prognosis. In Lask & Bryant-Waugh (Eds.). *Eating disorders in childhood and adolescence* (3<sup>rd</sup> ed., pp. 75-95). East Sussex: Routledge.
- 19. Halvorsen, I., Andersen, A., & Heyerdahl, S. (2004). Good outcome of adolescent onset Anorexia Nervosa after systematic treatment. Intermediate to long-term follow-up of a representative county-sample. *Journal of European Child and Adolescent Psychiatry*, 13, 295-306.
- 20. Herpertz-Dahlmann, B., Müller, B, Herpertz, S, & Heussen, N. (2001). Prospective 10-year follow-up in adolescent Anorexia Nervosa- course, outcome psychiatric comorbidity, and psychosocial adaptation. *Journal of Child Psychology and Psychiatry*, 42 (5), 603-612.
- 21. Herzog, D. B., Sacks, N. R., Keller, M. B., Lavori, P. W., von Ranson, K. B., & Gray, H. M. (1993). Patterns and predictors of recovery in Anorexia Nervosa and Bulimia Nervosa. *Journal of American Academy of Child and Adolescent Psychiatry*, 32 (4), 835-842.

- 22. Herzog, W., Deter, H.-C., Fiehn, W., & Petzold, E. (1997). Medical findings and predictors of long-term physical outcome in Anorexia Nervosa: A prospective, 12-year follow-up study. *Journal of Psychological Medicine*, 27, 269-279.
- 23. Herzog, D. B., Dorer, D. J., Keel, P. K., Selwyn, S. E., Ekeblad, E.R., Flores, A. T, et. al. (1999). Recovery and relapse in Anorexia and Bulimia Nervosa: A 7.5-year follow-up study. *Journal of American Academic Child and Adolescent Psychiatry*, *38*, 829-837.
- 24. Jacobi, C. (2007, March). *Methodological issues when dealing with outcome*. Presentation at the themed symposium: Outcome assessment for eating disorders. International Eating Disorders Conference, London.
- 25. Jarman, M., & Walsh, S. (1999). Evaluating recovery from Anorexia Nervosa and Bulimia Nervosa: Integrating lessons learned from research and clinical practice. *Clinical Psychology Review*, *19* (7), 773-788.
- 26. Keel, P. K., Mitchell, J. E., Davis, T. L., & Crow, S. J. (2002) Long-term impact of treatment in women diagnosed with bulimia nervosa. *International Journal of Eating Disorders*, 31(2), 151-158.
- 27. Kordy, H., Krämer, B., Palmer, R. L., Papezova, H., Pellet, J., Richard, M. et. al. (2002). Remission, recovery, relapse and recurrence in eating disorders: Conceptualization and illustration of a validation strategy. *Journal of Clinical Psychology*, *58* (7), 833-846.
- 28. Lask, B., & Bryant-Waugh, R. (2007). *Eating disorders in childhood and adolescence* (3<sup>rd</sup> ed.). East Sussex: Routledge.
- 29. Lock, J., Couturier, J., & Agras, S. (2006). Comparison of long-term outcomes in adolescent Anorexia Nervosa treated with family therapy. *Journal of American Academy of Child and Adolescent Psychiatry*, 45, 666–672.
- 30. Lock, J. (2007, March). *Articulation of categorical criteria of recovery*. Presentation at the themed symposium: Outcome assessment for eating disorders. International Eating Disorders Conference, London.
- 31. Löwe, B., Zipfel, S., Buchholz, C., Dupont, Y., Reas, D. L., & Herzog, W. (2001). Long-term outcome of Anorexia Nervosa in a prospective 21-year follow-up study. *Journal of Psychological Medicine*, *31*, 881-890.

- 32. McMaster, R., Beale, B., Hillege, S., & Nagy, S. (2004). The parent experience of eating disorders: Interactions with health professionals. *International Journal of Mental Health Nursing*, *13*, 67-73.
- 33. Morgan H. G. and Hayward A. E. (1988). Clinical assessment of anorexia nervosa. The Morgan-Russel outcome assessment schedule. British Journal of Psychiatry, 152, 367-371.
- 34. Nicholls, D. (2007, March). *Developmental considerations in outcome assessment*. Presentation at the themed symposium: Outcome assessment for eating disorders. International Eating Disorders Conference, London.
- 35. Noordenbos, G., & Seubring, A. (2006). Criteria for recovery from eating disorders according to patients and therapists. *Eating disorders: The journal of treatment and prevention*, 14 (1), 41-54.
- 36. Patton, G. C., Coffey, C., & Sawyer, S. M. (2003). The outcome of adolescent eating disorders: findings from the Victorian Adolescent Health Cohort Study. *Journal of European Child and Adolescent Psychiatry*, 12, 25-29.
- 37. Pike, K. M. (1998). Long-term course of Anorexia Nervosa: Response, relapse, remission and recovery. *Clinical Psychology Review*, *18*, 447-475.
- 38. Pike, K. M. (2005). Assessment of Anorexia Nervosa. *International Journal of Eating Disorders*, *37*, 22-25.
- 39. Rø, Ø. (2006). Presentation at the Norwegian research symposium for Eating Disorders. Gardermoen, Norway
- 40. Rø, Ø. (2007, March). *Quality of life and patient perspective as a part of outcome assessment*. Presentation at the themed symposium: Outcome assessment for eating disorders. International Eating Disorders Conference, London.
- 41. Råstam, M., Gillberg, C., & Wentz, E. (2003). Outcome of teenage-onset Anorexia Nervosa in a Swedish community-based sample. *Journal of European Child and Adolescent Psychiatry*, 12, 78-90.
- 42. Saccomani, L., Savoini, M., Cirrincione, M., & Ravera, G. (1998). Long-term outcome of children and adolescents with Anorexia Nervosa: Study of comorbidity. *Journal of Psychosomatic Research*, 44, 565–571.

- 43. Sokol, M. S., Steinberg, D., & Zerbe, K. J. (1998). Childhood eating disorders. *Current Opinion in Pediatrics*, 10, 369-377.
- 44. Steinhausen, H.-C., Boyadjieva, S., Griogoroiu-Serbanescu, M., Seidel, R., & Metzke, C. W. (2000). A transcultural outcome study of adolescent eating disorders. *Acta Psychiatrica Scandinavia*, 101, 60-66.
- 45. Steinhausen, H.-C., M., Seidel, R., & Metzke, C. W. (2000). Evaluation of treatment and intermediate and long-term outcome of adolescent eating disorders. *Psychological Medicine*, *30*, 1089-1098.
- 46. Steinhausen, H.-C. (2002). The outcome of Anorexia Nervosa in the 20th century. *American Journal of Psychiatry*, *159* (8), 1284-1293.
- 47. Steinhausen, H.-C., Boyadjieva, S., Griogoroiu-Serbanescu, M., & Neumärker, K.-J. (2003). The outcome of adolescent eating disorders. Findings from an international collaborative study. *Journal of European Child and Adolescent Psychiatry*, 12, 91-98.
- 48. Strober, M., Freeman, R., & Morrel, W. (1997). The long-term course of severe Anorexia Nervosa in adolescents: survival analysis of recovery, relapse and outcome predictors over 10-15 years in a prospective study. *International Journal of Eating Disorders*, 22, 339-360.
- 49. Strober, M., Freeman, R., & Morrel, W. (1999). Atypical Anorexia Nervosa: Separation from typical cases in course and outcome in a long-term prospective study. *International Journal of Eating Disorders*, 25, 135-142.
- 50. Sullivan, P. F., Bulik, C. M., Fear, J. L., & Pickering, B. A. (1998). Outcome of Anorexia Nervosa: A case-control study. *American Journal of Psychiatry*, *155* (7), 939-946.
- 51. Sutandar-Pinnock, K., Woodside, B., Carter, J. C., Olmsted, M. P., & Kaplan, A. S. (2003). Perfectionism in Anorexia Nervosa: A 6-24-month follow-up study. *International Journal of Eating Disorders*, *33*, 225-229.
- 52. Tanaka, H., Kiriike, N., Nagata, T., & Riku, K. (2001). Outcome of severe Anorexia Nervosa patients receiving inpatient treatment in Japan: An 8-year follow-up study. *Journal of Psychiatry and Clinical Neuroscience*, *55*, 389-396.
- 53. Towell, D. B., Woodford, S., Reid, S., Rooney, B., & Towell, A. (2001). Compliance and outcome in treatment-resistant Anorexia and Bulimia: A retrospective study. *British Journal of Clinical Psychology*, 40, 189-195.

- 54. Tozzi, F., Sullivan, P. F., Fear, J. L., McKenzie, J., & Bulik, C. M. (2003). Causes and recovery in Anorexia Nervosa: The patient's perspective. *International Journal of Eating Disorders*, *33*, 143-154.
- 55. Treat, T. A., Gaskill, J. A., McCabe, E. B., Ghinassi, F. A., Luczak, A. D., & Marcus, M. D. (2005). Short-term outcome of psychiatric inpatients with Anorexia Nervosa in the current care environment. *International Journal of Eating Disorders*, *38*, 123-133.
- 56. Ward, A., Campbell, I., Brown, N., & Treasure, J. (2003). Anorexia Nervosa: Differences in subtypes. *Journal of Nervous and Mental Disorders*, 191 (3), 197-201.
- 57. Watson, T. L., & Andersen, A. E. (2003). A critical examination of the amenorrhea and weight criteria for diagnosing Anorexia Nervosa. *Acta Psychiatrica Scandinavia*, 108, 175-187.
- 58. Wentz, E., Gillberg, C., Gillberg I. C., & Råstam, M. (2001). Ten-year follow-up of adolescent-onset Anorexia Nervosa: Psychiatric disorders and overall functioning scales. *Journal of Child Psychology and Psychiatry*, 42, 613-622.
- 59. Zipfel, S., Löwe. B., Reas, D. L., Deter, H.-C., & Herzog, W. (2000). Long-term prognosis in Anorexia Nervosa: lessons from a 21-year follow-up study. *The Lancet*, *355*, 721-722.