

# Literature Review:

## Outcome of Adolescents with Anorexia Nervosa

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### Introduction

Anorexia Nervosa most frequently affects young girls. According to the APA (1994), the prevalence in adolescents is estimated at 0.5 to 1%. These findings could be even higher in certain sub-populations. In 1979, Dally and Gomez estimated that 10% of brilliant young girls of upper socio-economic backgrounds would present a moderate episode of anorexia. Many questions arise on the possible recent increase in prevalence of this illness. We may want to question whether the increase is really due to an increase of incidence in the population or to a better understanding and screening of the illness.

For the last several years, the comprehension models of Anorexia have been modified to concentrate more on adolescent issues. During this period, developmental factors are a key issue. Anorexia confronts each characteristic of adolescence. Anorexia nervosa outcome studies are important for gathering scientific data as well as developing comprehension models. Furthermore, prognostic factors and treatment can only be improved if we truly understand adolescents with eating disorders and their evolution.

### Methodological problems of outcome studies

Since the early 80's, the number of publications on outcome of anorexic patients have multiplied. Today, there are approximately one hundred articles on the subject. However, the disparity of methods makes the results difficult to compare. In 1988, HSU suggests the following criteria for a good anorexia outcome study:

Use of precise diagnostic criteria and exclusion of atypical cases.

More than 25 subjects.

Minimum of 4 year follow-up following the beginning of the illness.

Less than 10% subjects lost to follow-up

Direct contact with at least half of the subjects

Use of several well defined standardized instruments.

In 1996, in the event of a review of several articles on anorexia beginning at adolescence, HSU still notes methodological problems, which we review here.

### Instruments

Certain scales have been specially developed to study the outcome of anorexic patients. In 1975, Morgan and Russell used a general outcome score pertaining to weight and menstruation during follow-up. General outcome is defined as:

Good outcome: if weight is maintained at 15% of ideal body weight and menstruations is regular.

Intermediary: if weight has reached 15% of ideal body weight (but not consistently) or abnormal menstruation.

Poor evolution: if weight is inferior to 15% of ideal body weight and has never been reached and amenorrhoea persists.

The “ Global Clinical Score –GCS ” validated by Garfinkel in 1977 allows us to categorize anorexic patients’ outcome based on other criteria defined by Morgan and Russell in 1975. GCS will be used in most studies. It takes in account the evolution of :

Weight compared to the ideal body weight (depending on age, height and sex)  
Menstruation  
Eating habits  
Social adjustment  
Education or employment

From these items will result a global score allowing to categorize the outcome of patients who have an eating disorder. The global score is the sum of these 5 items, from 0 to 23 (A score inferior to 8 will be considered a “ good evolution ”).

### **Types of studies**

Retrospective. For practical reasons, many studies are in part retrospective, with baseline characteristics collected from medical files. Among related methodological problems: missing data in files, diagnostic criteria not evaluated by the same person.

**The patient’s age at the beginning of the illness may also be a confusing data. For some studies, the beginning date can be either the beginning of amenorrhoea, the beginning of treatment, or hospitalization. One might ask if this was a deliberate choice of the authors or if it depended on reliable data that they were able to obtain.**

Prospective. The Herpertz-Dahlmann study in 1993 on associated depression is characteristic of a prospective study where patients are evaluated with the same instruments during the entire follow-up process. The Göteborg team (Rostam-Gillbers) published several articles on a cohort.

### **Population studied**

Each study only looks at its recruited population and extrapolation is sometimes difficult. As an example, a specialized center who cares for patients whose previous treatment failed, will treat the most difficult cases and is barely comparable to a primary care center.

### Diagnostic criteria

It is necessary to have standardized criteria for clinical studies. However, classification always reveals imperfections that force modification as in the DSM. As a result, DSM criteria have evolved and this evolution, over the last few years, has complicated the comparison of recruited groups in different studies. The DSM-III-R would introduce the notion of 25% difference of expected weight for height and age, and then the DSM-IV would bring it down to 15%.

Criteria A of the DSM-IV related to weight loss could be used as an example to show the difficulty of an objective and uniform measure from one study to another. “Impossibility to maintain their weight at 85% of the expected weight.” The expected weight varies with age and height. The expected weight calculation methods are not always specified in studies. As criteria, Steinhausen 1991 used weight, which was 20% above standard weight for an age group. Thus, he does not consider their height. By this method, he

must obtain an overestimation of anorexia diagnostic for the weight criteria among taller girls and an underestimation among shorter girls.

### Subjects lost to follow-up

In all studies that needed to relocate former patients, the difficulty to find all of their population is an important problem. Steinhausen notes in his literature review of 1991 that lost cases in studies go from 0 to 27% with an average of 24%. Groups of patients, both found and lost must be compared to eliminate significant differences in the intake data. Therefore, the data remains exploitable even though it might not be entirely satisfying.

### Other bias

The methodological problems of these types of researches can be resolved while others appear. Therefore, Kreipe 96 raises the problem of an increase of oral contraceptive prescriptions to limit the risk of osteoporosis; the rate of regular menstrual cycles will differ in future studies. This criteria is usually cited as an evaluation aspect of outcome and is even included in certain scores as the “Clinical Global Score”.

### **General Results**

The first studies and a number of those who followed were mostly published by teams of psychiatrists and the subjects were adolescents and young adults. In the 1990's, research related to adolescents was published either by psychiatric teams or by adolescent medicine teams.

In 1988, HSU chose 5 studies from a literature review; (Morgan and Russell 1975, Hsu 1979, Morgan 1983, Hall 1987, Burns and Crisp 1984) all of which could satisfy the rigorous methodological criteria that he defined. In these studies, the global outcome, according to Morgan and Russell's criteria went as follows:

Good outcome: 36% to 58%  
Intermediate: 19% to 36%  
Poor outcome: 20% to 34%

In 1991, Steinhausen published a literature review that analyzed 22 articles published from 1981 to 1989. According to the Global Clinical Score, he found the following outcomes:

- Good outcome: 25% to 75%  
(avg. of 50%)
- Intermediate: 1% to 47%  
(avg. of 30%)
- Poor outcome: 5% to 30%  
(avg. of 20%)

### **Results of adolescent psychiatric teams**

In 1996, HSU reviewed 6 methodologically rigorous studies that looked at populations in which anorexia began in adolescence.

**Table 1. Results From Six Pedopsychiatric Teams.**

<b>Authors</b>	<b>Bryant-Waught</b>	<b>Bryant-Waught</b>	<b>Higgs</b>	<b>Gillberg</b>	<b>Smith</b>	<b>Steinhausen</b>
<b>Year</b>	1988	1996	1989	1994	1993	1993
<b>Subjects Found</b>	30/4468,1%	18/2281,8%	23/2785,1%	51/5298%	23/3467,6%	26/26100%
<b>Boys/Girls in %</b>	23%	27%	30%	16%	0	0
<b>Age at Onset</b>	11,7	12,1	8 to 16	14,3	15,5 at diagnosis	?
<b>Time of Follow-up from Onset (years)</b>	8,9	5,5	7,3	6,7	6,6 from diagnosis	4 to 8 from diagnosis
<b>Death</b>	(2) 6%	0	0	0	0	0
<b>Good Outcome</b>	58%	56%	30%	47%		
<b>Intermediary</b>	6%	28%	30%	39%		
<b>Poor Outcome</b>	29%	17%	39%	14%	43% had an eating disorder	35% had an eating disorder

**Table 2. Results of Follow-up Studies of Psychiatric Teams**

Authors	Hamley 85	Jenkins 87	Walford 91	Jeammet 91	Herpertz 95	Gillberg 96
Country	England	UK	Ireland	France	Germany	Sweden
Number of Subjects	21	21	15	129	39	51
Number at Follow-up	18 / 85%		15	113 / 88%	34 / 88%	0
Mean age at intake	11,5 y 7,2 to 13,5	15 y	12,3 y 9,3 to 13,9	16 y	16,2 y	16 y
Age at onset AN	11,5 y 7,2 to 13,5	14,1 y 11,7 to 17,1	11,9 y 8,3 to 13,9			
Time of Follow-up	8,7 y 8,5 to 15,3	4 y or +	5,6 y	11,7 y	8 y 7 y	5 y
Good Outcome GCS	50%	50%	46,6%	54%	44% 58%	41%
Intermediary	33%	19%	26,6%		33% 21%	35%
Poor Outcome	17%	19%	26,6%		23% 21%	24%

### Studies on Follow-ups by Adolescent Medicine Teams

In 1985, Nussbaum published the first study on anorexic patients follow-up treated by adolescent medicine teams. In this specialty, the treatment modality requires the implementation of a multi

disciplinary team: physicians, pediatricians specialized in adolescents, nurses, dietitians, and psychologists or psychiatrists. Until now, 4 studies have been published, which are the following (see table 3).

Kreipe 1996 notes that the results of the first three studies were better than the researches related to adolescents and young adults treated in psychiatry. The hypotheses evoked by Kreipe are: 1) age difference; 2) the smallest interval of time between the onset of the illness and the beginning of treatment; the access to care was not stigmatized by mental illness; 3) the type of treatment.

**Table 3. Results from Adolescent Medicine Teams**

	Nussbaum 1985	Kreipe 1989	Steiner 1990	Kreipe 1996
<b>Number of patients</b>	63	49		38
<b>Response Rate</b>		89%		92%
<b>Time of Follow-up</b>	27 months	80 months	32 months	69 months
<b>Mean age at follow-up</b>		22,7 years		22,5 years
<b>Weight at onset in % of ideal weight</b>	41,8%	72,1%	80%	81%
<b>Weight at follow-up in % of ideal weight</b>	92%	96,1%	93%	97,9%
<b>Return of menses</b>	84%	80%		94%
<b>Good evaluation GCS</b>	72%	86%	71%	88%

## **Results by themes**

### **Eating habits**

In 1977, Garfinkel found 7% of obesity. Jeammet did not find any evolution towards obesity.

#### Restrictive

Jeammet found a 10 to 15% transition to chronicity. In 1993, Steinhausen, on a short and mid-term study described 4 types of possible evolution with regards to anorexia:

#### Acute:

short duration of the illness, a few months, then continuous remission (36%)

#### Simple chronicity :

remission after a few years (20%)

#### Chronic with exacerbation :

relapses (34%)

### Persistent chronicity : (10%)

After 20 years of evolution, Ratnasuriya 1991 noted that among those who had evolved well, half testified to having a restrictive diet regularly and one third testified to eating irregularly.

### Bulimia

The cross over between anorexia and bulimia after four years of evolution is 8% according to Van der Ham in 1994, 9% according to Steinhausen in 1993, 8% at three years and 11,7% at 7 years for Herpertz-Dahlman in 1995, and after 20 years of evolution, Ratnasuriya 1991 found that 15% were bulimic. In 1997, Steinhausen noted that the frequency of bulimia during the evolution is less important for younger ones. According to studies, the occurrence of bulimia varies from 0 to 45% (more or less complete clinical picture).

### **Mortality**

According to certain studies, mortality at mid-term, from 4 to 14 years is at 0 to 6 % (Crisp 1992). On a more extensive follow-up (20 to 35 years), the raw data is 17 to 20%. In 1988, Patton was the first to bring this raw data to a standardized mortality ratio, therefore taking into account the expected mortality rate for a given age category. The rate he found was 3.3%, which compared to a standardized mortality rate shows a 6-time increase in mortality rate among anorexic patients. In 1991, Steinhausen noted a decrease in the raw mortality rate compared to the previous review of literature that he had published in 1983. (1991, an average of 4.4 %; 1983, an average of 10%). Jeammet 91 noted that the causes of death are essentially a direct consequence of malnutrition or suicide, and that the lethal risk is primarily with chronic forms. Many studies find mortality rates nil with follow-ups from 3 to 6 years.

### **Menses**

The return of a regular menstrual cycle is directly evaluated in the Global Outcome Score. Many studies report rates over 65% of return of menstruation at 3 years.

### **Psychosocial Adaptation**

Hamley 1985, for a young group, finds that 62% have a good professional or academic integration, and 43% have sexual relationship difficulties. The study of Jeammet is representative: 55% of women are satisfied regarding their personnel life (sexual, family, and relationships). At a professional level, the outcome is satisfying in 74% of cases. However, in view of the usual exceptional academic performances of these girls during anorexia, we could expect a greater professional accomplishment.

### **Psychiatric comorbidity**

The psychiatric comorbidity varies from 36% to 62% according to 4 studies. In Jeammet's study, 20% are considered by the clinician as having a normal mental state, 5% have a good or fair mental functioning, but 45% still have psychiatric symptoms. The most frequently found

diagnosis is anxiety and affect disorders. Herpertz –Dahlman 1993, quoted several studies that found depression rates ranging from 20 to 40 % among patients affected by poor eating habits, and often, depression is linked with poor prognosis. In his sample, 9% were diagnosed with major depression associated with anorexia. In 1993, Smith found that 60 % of female patients still had poor eating habits, anxiety symptoms or associated depression. Concerning addictive behaviors, Ratnasuriya 91 noted that 7% had abused of alcohol. Jeammet 91 noted that 8% of patients considered themselves dependent on alcohol or drugs.

## **Psychic Functioning**

### Alexithymia

Jeammet (1991), as well as other clinicians, noted in a prospective study that insight was diminished; only 24 % of patients followed-up presented a good insight. Other authors attempted to demonstrate a correlation between anorexia and alexithymia. Alexithymia is defined as a incapability to assess one's emotions. Bourke et al (1992) studied a population consisting of 48 anorexic women at different stage of their illness and compared the T.A.S. scores (Toronto Alexithymia Scale) within those of a control group. They found 77% of Alexithymic individuals among the anorexic and 6,7% among the control group. Rastam and Gilberg (1997) published a study about young adults (average age of 22), having been treated for anorexia nervosa during their adolescence. They did not bring forth any significant differences between the anorexic and the control group on the T.S.A scores. However, among the highest scores they found more anorexics.

## **Prognostic Factors**

### Age at the onset of anorexia

There have been contradictory results with respect to prognosis in terms of age at illness' onset. According to studies, an early onset beginning means adolescence compared to adulthood, or simply an onset before the age of 11. In his sample, Morgan 1983 did not find any correlation with regards to age at the beginning. In 1988, Bryant-Waugh found a less favorable prognosis if the illness started before age 11, while studying a group of 30 children with a follow-up at 7 years. But in 1996, the same team, with a group of 18 children with a follow-up at 3 years did not confirm these findings. Walford 91, with a small sample and an average age of 12 years observed a worse outcome among the youngest, having started their anorexia before the age of 11. In 1995, Herpertz did not find any correlation with the age at the onset of anorexia. Steinhausen 1997, in his literature review writes that five studies did not find any influence of age at the onset and one describes a less favorable prognosis if anorexia begins before the age of 11. While studying a population of various ages, Ratnasuriya (1991) noted a less favorable prognosis associated with a later beginning, onset over 18, when compared to the 11-15 year olds. This variable is a predictive factor, still important after 20 years of evolution.



### Family structure and dynamic

Morgan 1983 found that difficult family relationships and hostility on the family's part towards the patient are more often correlated with a less favorable prognosis. In 1988, Bryant–Waugh showed a negative influence on the prognosis in situations of disruptive family life, single parent household, remarriage. These results were not confirmed however by the same authors in 1996. In 1991, Ratnasuriya noted that disruptive family relationships are more often associated with a less favorable prognosis after a twenty-year follow-up. In 1996, Herpertz did not find any correlation with regards to divorced parents.

### Weight

Among the factors that seemed to correlate with prognosis in many studies, we must mention weight. The minimum weight reached during the illness (Jeammet 92, Herpertz 95) or low BMI (body mass index) at admission (Herpertz 95, Steinhausen 93, 97) would be indicators of a less favorable prognosis. Comparing the subjects with eating disorders at 7 year follow-up, with those no longer ill, Herpertz 95 came with some significant results: Minimum lower weight: (32 Vs 41); Low BMI at admission (13.7 Vs 15).

Hebebrand 1997 studied the influence of the BMI on the prognosis at 5 years of 272 women whose average age was of 16,7. He found that patients with a low BMI at the onset of anorexia have a lower BMI at the time of the follow-up. The cut-off was a BMI of 13. The correlation between the BMI at the onset and at the time of the follow-up was significant, even when ignoring the deceased patients.

For the:

BMI < 13	the mortality rate is 11%
BMI > 13	the mortality rate is 0.6%

A BMI inferior to 13 means a poor prognosis. The authors concluded that even for a BMI < 15, the risk of death increased. A BMI superior to 13 would be related to an increased duration of the illness; long duration of the illness before the onset of treatment is also a factor for a less favorable prognosis.

### Hospitalization

According to certain studies, the duration and the number of hospitalizations are associated with an unsatisfying outcome. (Jeammet 92, Steinhausen 83, 87). Herpertz-Dahlmann 93 did not confirm these findings.

### Personality Problems and Depression

Ratnasuriya 91 noted a less favorable prognosis if personality disturbances already existed, in a follow-up study at 20 years. Steinhausen 1997 found a less favorable prognosis if depression was present. Smith 1993 noted a less favorable prognosis if there was evidence of depression at the time of diagnosis.

## Vomiting

For several authors, vomiting would be a sign of a poor prognosis (Jeammet 91, Garfinkel 77). Kreipe 96 found a persistence in auto vomiting for 18% of the study group and 2/3 of those patients had a CGS > 8, the outcome score ranking them in the intermediate or poor outcome. These results were significantly different from the rest of the group studied. Morgan 1983 did not find any correlation between vomiting and prognosis. Steinhausen 1997 did not find a significant difference between the restrictive and purgative sub-types; for younger subjects, 3 studies show correlation between bulimia or purge and a poor prognosis.

## Mid-term evolution

In 1992, Ratnasuriya published an outcome study with a 20 years follow-up of a population he had already studied after a five-year delay. He noted that a good outcome score at five years is a good predictor of a good outcome score after twenty years.

## **The Outcome of Bulimic Patients**

Few studies have been published on the outcome of Bulimia Nervosa, and even fewer for long term outcome.

In 1994, Van der Ham published a prospective study that included 25 anorexics and 25 bulimics. At 4 years, the outcome according to Morgan Russell score was good in 59% of Bulimic and 36% of anorexics. It was poor in 8% and 12 % respectively. These results do not show a significant statistical difference. In 1986, Toner and Garfinkel compared the outcome of a group of anorexics and bulimics to a control group. They did not find any difference in their general outcome. However, there is a higher rate of alcohol and drug abuse as well as smokers among bulimics. Bulimics as well as anorexics had a higher percentage of anxiety disorders than the control group. Here are the results for 17 studies with follow-ups ranging from 6 months to 6 years. (Kell 1997)

The estimated mortality rate for all the studies was 0.3 % even though this number cannot be considered absolutely exact considering the amount of subjects lost to follow-up; it would seem that this rate is lower than for anorexics. Crossover rates towards anorexia are between 0 and 7%. Relapse rates are between 26 to 43% for studies, which had follow-ups, ranging from 6 months to 6 years. Among the many studies, an obvious prognostic factor could not be found.

		BN at Follow-up	BN partial at Follow-up	Remission
Follow-up < of 1 y	6 studies N=7 to 75	6 studies 36% to 86%	1 study 28%	4 studies 28% to 33%
Follow-up 2 to 6 y	12 studies N=5 to 19	9 studies 20% to 60%	5 studies 9% to 29%	10 studies 13% to 69%
Follow-up at 10 y	1 study N=44	9%	89%	52%

