Original articles

Long term follow up of patients with early onset anorexia nervosa

R BRYANT-WAUGH, J KNIBBS, A FOSSON, Z KAMINSKI, AND B LASK

Department of Psychological Medicine, Hospital for Sick Children, Great Ormond Street, London

SUMMARY A long term follow up (mean 7.2 years) of 30 children with anorexia nervosa (mean age at onset 11.7 years) was carried out. The outcome was good in only 18 (60%), 10 children remaining moderately to severely impaired and two died. Poor prognostic factors included early age at onset (<11 years), depression during the illness, disturbed family life and one parent families, and those in which one or both parents had been married before.

We have previously described 48 children up to 14 years of age who met the diagnostic criteria of anorexia nervosa.¹ The group (which included 15 boys) had a mean age at onset of 11.7 years (range 7.7 to 13.2). Half the children were prepubertal at the time of referral. The most common clinical features after refusal of food, which was present in all the children, were physical wasting in 40 (83%), depression in 27 (56%), fear of fat in 24 (56%), distorted body image — that is perceiving self as fat although physically wasted—in half, and self induced vomiting in 19 (40%). Other features occurring less often included excessive exercising, obsessions or compulsions, binge eating and laxative abuse. The most common reasons for refusing to eat were the fear of becoming fat and various physical symptoms such as abdominal pain, nausea, or a feeling of fullness. Disturbed family life was common, and over half the families had several adverse characteristics. The correct diagnosis had often been missed or delayed.

This study aimed to investigate the long term outcome of early onset anorexia nervosa and identify prognostic indicators.

Patients and methods

We tried to follow up all the children who had been described in the earlier study and whose treatment had been completed more than two years before (n=44), as information obtained from a follow up of less than two years is not considered to be adequate in patients with anorexia nervosa.² Information is

required on weight and growth, menstrual state, eating behaviour, mental state, and psychosocial and psychosexual adjustment³; we obtained it in four ways.

INTERVIEW WITH PATIENT

After a physical examination a semistructured interview adapted for this younger age group was completed by a visiting consultant who was experienced and not managing the patients and their treatment.²

POSTAL QUESTIONNAIRE

Six patients were reluctant to be interviewed but agreed to complete a postal questionnaire based on the interview. This information was supplemented by medical reports.

GENERAL PRACTITIONER'S QUESTIONNAIRE

A short questionnaire devised for this study was circulated to each patient's general practitioner. Information requested included current weight and height, and details of menstrual functioning and general state of health.

OTHER QUESTIONNAIRES

Corroborative data were obtained using firstly, three self report questionnaires:—the general health questionnaire⁴; the eating attitudes test⁵; and the Great Ormond Street depression scale A: (unpublished). Secondly, parents or 'significant others' were asked to complete questionnaires: the Great Ormond Street depression scale B: (unpublished),

6 Bryant-Waugh, Knibbs, Fosson, Kaminski, and Lask

and the Rutter scale A.⁶ Thirdly, for children under the age of 16 at the time of follow up, the school teacher was asked to complete a questionnaire.⁷

When sufficient information obtained from the interview and the questionnaires became available it was used to rate outcome on five different scales and three scores.² These measures, designed to assess outcome as comprehensively as possible, and widely accepted in research into anorexia nervosa, are given below.

Nutritional state (scale A) included ratings of current food intake, worries about body size, and measurements of body weight and height.^{8,9}

Menstrual function (scale B) recorded whether menstruation was absent, occasional and irregular, intermittently cyclical, or regularly cyclical, using a four point scale.

Mental state (scale C) rated the degree of psychiatric disturbance at the time of follow up using a four point scale.

Psychosexual state (scale D) rated the subject's attitude towards sexual matters, the aims in sexual relationships, the amount of active sexual behaviour, and attitude towards menstruation.

Psychosocial adjustment (scale E) rated the quality of relationships with other members of the family, the amount of independence from the family appropriate for the subject's age, social contacts outside the home, and occupational record or school attendance.

We used three outcome scores: the average outcome score was calculated using the scores of all five scales (A to E), the physical outcome score was calculated using scores based on menstrual state (scale B) and weight, and the specific outcome score was calculated using scores obtained from scales A and B.

Ordinal data were generated from outcome scores and several correlations were analysed in an attempt to identify specific prognostic indicators. Because of the small sample size, the Statistical Package for the Social Sciences was used to calculate Kendall's rank correlation coefficient (τ).

Results

We obtained adequate information about 23 female and seven male subjects. The mean (range) follow up was 7.2 (2-17) years and mean age was 20.8 (14-30) years. Of the original sample of 48 children, six subjects could not be traced, four refused to participate, in four insufficient information was available, and it was too early to follow up four children. Two had died; the first was a boy aged 14 who had an apparently unrelated acute asthmatic attack, and the second was a girl of 12, who had

prolonged and persistent vomiting which ultimately led to rupture of the oesophagus. Despite surgical repair it ruptured again and she bled to death.

Weight is the most commonly used measure of outcome, but a more useful measurement is that given by the Tanner-Whitehouse standards^{8,9} in which weight for height, adjusted for age, is expressed as a percentage, 100% being normal and less than 80% indicating wasting. In the original sample 42 children (87%) scored less than 80% and at follow up only three subjects (11%) were wasted (table 1). The remaining 25 scored between 82% and 122%, mean 92%. Six patients scored over 100% weight for height.

SCALES AND OUTCOME SCORES

The results are summarised in tables 2 and 3. The totals for each score of scale and outcome differ because information was sometimes not available for one or more of the scales. The two children who died are included in the 'poor outcome' group. On each measure of scale and outcome a good score was obtained by between half and three quarters of the sample. We believe that the four subjects who refused to participate all had a poor outcome, and

Table 1a Weight for height adjusted for age (expressed as %) at time of first refusal

Weight/height (%)	No of patients	% Of total series
40-59	1	2
50-59	0	0
60-69	19	40
70-79	17	35
80-89	9	19
90-99	2	4
Total	44	100

Table 1b Weight for height adjusted for age (expressed as %) at time of follow up

Weight/height (%)	No of patients	% Of series followed up
60-69	1	3
70-79	1	3
80-89	5	17
90-99	10	33
100-109	5	17
110-119	0	0
120-129	1	3
Information not available	5	17
Died	2	7
Total	30	100

Follow up of patients with anorexia nervosa 7

Table 2 Grading within scales at follow up

Scale	Good No (%)	Intermediate No (%)	Poor No (%)	Total No
Eating difficulties (A)	17 (65)	5 (19)	4 (16)	26
Menstruation (B)	12 (55)	3 (14)	7 (31)	22
Mental state (C)	13 (62)	4 (19)	4 (19)	21
Psychosexual adjustment (D)	10 (50)	7 (35)	3 (15)	20
Psychosocial adjustment (E)	16 (59)	6 (22)	5 (19)	27

Table 3 Grading of scores of outcome

Score	Good No (%)	Intermediate No (%)	Poor No (%)	Total No
Physical outcome (scale B + weight)	18 (67)	2 (7)	7 (26)	27
Specific outcome score (scales A and B)	19 (70)	1 (4)	7 (26)	27
Average outcome score (all scales, A-E)	15 (75)	3 (15)	2 (10)	20

we have included these in adjusted outcome scores (table 4) which we consider more accurately reflects the prognosis—that is, a good outcome in only about 60% of the sample.

When they were asked to rate their own progress in general terms, 19 subjects (66%) claimed to have recovered, six (21%) thought they had improved, one thought she had remained the same, and one claimed to be worse. At the time of follow up, eight subjects (27%), seven girls and one boy, had required further inpatient treatment since their discharge from hospital. Of the 22 subjects who were aged 18 or more at follow up, only two were married, both women with children; for one it was her second marriage. None of the others had been married, although at least four were cohabiting.

Table 4 Adjusted scores of outcome

Score	Good No (%)	Intermediate No (%)	Poor No (%)	Total No
Physical outcome score (scale B + weight)	18 (58)	2 (6)	11 (36)	31
Specific outcome score (scale A + B)	19 (61)	1 (3)	11 (36)	31
Average outcome score (all scales A-E)	15 (62)	3 (13)	6 (25)	24

PROGNOSTIC INDICATORS

The data indicated that certain variables were associated with a poor outcome.

Age at referral

Young age at referral had a poor prognosis according to three different measures of outcome: low weight at follow up ($p < 0.001$, τ 0.43), low specific outcome score ($p < 0.05$, τ 0.35), and low physical outcome score ($p < 0.05$, τ 0.39). Furthermore, young age at the onset of eating difficulties was also positively correlated with low weight at follow up ($p < 0.05$, τ 0.35).

Hospital admission

The longer the hospital admission, the more likely it was that there would be a low specific outcome score ($p < 0.01$, τ 0.41); a low average outcome score ($p < 0.05$, τ 0.35); a high score on the Great Ormond Street depression scale—self rated ($p < 0.01$, τ 0.33); and a high score on the Great Ormond Street depression scale rated by 'significant others' ($p < 0.005$, τ 0.44).

More than one hospital admission had a poor prognosis in terms of low weight at follow up ($p < 0.05$, τ -0.31) and both forms of the Great Ormond Street depression scale ($p < 0.05$, τ 0.25 and 0.31).

Depressive features

Depressive features during the initial illness had a poor prognosis according to three measures of outcome: high scores on both forms of the Great Ormond Street depression scale ($p < 0.01$, τ 0.26+0.27), low physical outcome score ($p < 0.05$, τ 0.37), and low average outcome score ($p < 0.05$, τ 0.38).

Family structure

Children from one parent families, families in which one or both parents had been married before, and families in which several generations lived together had a poor prognosis according to four measures of outcome: low physical outcome ($p < 0.01$, τ 0.35), low specific outcome score ($p < 0.01$, τ 0.35), low score on scale C ($p < 0.05$, τ 0.44), and low score on scale D ($p < 0.05$, τ 0.36).

Other variables

None of the following factors seemed to be of any prognostic importance: social class, gender, weight at referral, length of illness at referral, history of excessive exercising, distorted body image, or fear of fatness.

CLINICAL FINDINGS

During the follow up interviews several important

issues were identified by patients. These, many of which overlap, form an essential part of the total picture of anorexia nervosa and illustrate a subjective view of the disorder.

Battles

Many spoke of the battles they had had, particularly with their parents, and often with their mothers with whom they felt they had a close bond. Later these battles were transferred to the hospital indicating that inner conflicts were first expressed within the family and then included difficult relationships with hospital staff.

Control

Control was considered to be important by several subjects. Many felt that they had been forced to accept admission to hospital despite their protests. Some felt that they had accepted that matters had got out of control, yet others remembered struggling for what they felt to be their freedom. This freedom was equated with their own emotional survival. Many had an overwhelming sense of being controlled, which in some cases was replaced by a more positive attitude: "I realised that I could do things for myself and I had control, and I could also see that others didn't have this control" . . . "I felt good about myself, that I could control myself, whereas before, I felt I had no control and was very frightened".

Growing up

Some subjects said that they had been frightened of growing up as this meant insecurity. Some also mentioned that they got much more attention from their parents when they acted as if they were younger, and many stated that they noticed how much more attention they got than their brothers and sisters.

Overinvolvement

Some identified feelings of being "tied", or "stuck", or "unable to move", in their relationships with their mother. One mother who was interviewed said "I wanted to be at one with my daughter" and spoke of the distress to both when this could not be achieved. Many recalled that they had desperately wanted to get home to their families. Some considered this to be the major influence in regaining weight—for example, "I had to get out, as I became so depressed being away from my family, and this pushed me to gain weight and get home".

Dependence and independence

Many spoke about their attempts to achieve autonomy and independence. The final insult was often

the admission to hospital against the subject's will. Some recognised their dependence and the conflicts that arose from this; on the one hand, they were tied to their parents and wanted this, but on the other hand they wanted independence and freedom. One person said: "I was tied to my parents and felt very dependent on them—I even broke off my engagement".

School difficulties

A few patients felt that their relationship with their parents had not been difficult, but that they had experienced considerable difficulties with their peer group, particularly at school. Some felt isolated and others said they suffered from rivalry among their friends. This made them feel sensitive and vulnerable to attacks from others.

Loneliness

Almost all said that they had felt alone and isolated, both before and during the illness. They felt that no one really understood what they were experiencing. They lost their self respect, decisions were made for them, and they were not accepted as independent people. They often felt a sense of worthlessness, which led to depression and anxiety.

Discussion

Anorexia nervosa is a difficult illness about which to obtain accurate information over a long period. Many patients do not wish to be reminded of their earlier problems; others cannot be traced. Follow up studies are only adequate if well defined diagnostic criteria are used in well defined samples. The follow up should not be less than two years, and the sample must be as complete as possible. Parents should be interviewed, and corroborating information obtained from close relatives, the general practitioner, or other doctors. The complexity of the illness necessitates evaluation of a number of factors, body weight alone being insufficient. These should include nutrition, menstruation, eating behaviour, mental state, and psychosocial and psychosexual adjustment.

A number of adequately controlled studies of anorexia nervosa of later onset (age 15 or more) have been carried out,¹⁰ but there are few studies in younger children.³ In general, with both types of the illness the outcome is unsatisfactory. Persisting psychiatric problems are common (in 50–70%) especially depression, obsessional behaviour, and social phobia. Psychosis is, however, rare. Psychosocial adjustment is variable, but psychosexual adjustment is often poor. Eating difficulties persist in over half the patients, but nutritional and men-

Follow up of patients with anorexia nervosa 9

strual condition improves in between half and two thirds of patients. The mortality among adult patients averages 7%, and in childhood studies 3%.

Our results are comparable with those of earlier childhood onset studies and are of additional importance because of the long mean period of follow up, and the relatively large sample. The children were all seriously ill at the time of referral and several, though they undoubtedly had anorexia nervosa, were much younger than is usually expected in this illness.

A number of worries arise as a result of this study. As previously mentioned¹ the diagnosis is often missed; because early age of onset has a poor prognosis, it is important to recognise such children quickly and treat them effectively. Menstruation remained impaired in nearly half the girls, raising doubts about their ability to have children.

The unsatisfactory prognosis indicates the need for more effective treatment. The clinical information gained at follow up is very helpful in highlighting a number of issues that patients were unable to discuss during their illnesses. Both psychological and social problems are commonplace, and point to the need for treatment of both the individual child and the family.

In conclusion, the long term outcome for patients with early onset anorexia nervosa is unsatisfactory; between a third and a half of a sample of 30 children remaining impaired in at least one (and usually in several) aspects of physical and psychological function. Over a quarter had required further admission to hospital with psychiatric disorders. Issues of control, growing up, independence v dependence, overinvolvement with parents, and loneliness were common problems for these children. The severity and complexity of the illness demands early, skilled, and comprehensive treatment, full details of which have been published elsewhere.¹¹

We thank the patients and their parents for cooperating in the follow up, the Society for the Advancement of Research in Anorexia and the Psychosomatic Research Trust for financial support, the academic department of child psychiatry at the Institute of Child Health for advice, and Jenny Ashford for secretarial help.

References

- ¹ Fosson A, Knibbs J, Bryant-Waugh R, Lask B. Early onset anorexia nervosa. *Arch Dis Child* 1987;**62**:114-8.
- ² Morgan H, Russell G. Value of family background and clinical features as predictors of long-term outcome in anorexia nervosa: 4 year follow-up study of 41 patients. *Psychol Med* 1975;**5**: 355-71.
- ³ Swift W. The long-term outcome of early onset anorexia nervosa—a critical review. *J Am Acad Child Psychiatry* 1982;**21**: 38-58.
- ⁴ Goldberg D, Miller V. A scaled version of the general health questionnaire. *Psychol Med* 1979;**9**:139-45.
- ⁵ Garner D, Olmstead M, Bohr Y, Garfinkel P. The eating attitudes test: psychometric features and chronic features. *Psychol Med* 1982;**12**:871-8.
- ⁶ Rutter M. A children's behaviour questionnaire for completion by teachers: preliminary findings. *J Child Psychol Psychiatry*; **8**: 1-11.
- ⁷ Rutter M, Tizard J, Whitmore K, eds. *Education, health, behaviour*. New York: Kriger, Huntington 1981.
- ⁸ Tanner J, Whitehouse R, Takaishi M. Standards from birth to maturity for height, weight, height velocity and weight velocity: British children 1965, part 1. *Arch Dis Child* 1966;**41**:454-71.
- ⁹ Tanner J, Whitehouse R, Takaishi M. Standards from birth to maturity for height, weight, height velocity and weight velocity: British children 1965, part 2. *Arch Dis Child* 1966;**41**:613-35.
- ¹⁰ Hsu L. Outcome of anorexia nervosa. *Arch Gen Psychiatry* 1980;**37**:1041-6.
- ¹¹ Lask B, Bryant-Waugh R. Childhood onset anorexia nervosa. In: Meadow R, ed. *Recent advances in paediatrics*. Edinburgh: Churchill Livingstone 1986:21-31.

Correspondence to Dr R Bryant-Waugh, Department of Psychological Medicine, Hospital for Sick Children, Great Ormond Street, London WC1N 3JH.

Received 28 July 1987