Original articles

Long term follow up of patients with early onset anorexia nervosa

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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). Secondy, parents or ‘significant others’ were asked to complete questionnaires: the Great Ormond Street depression scale B: (unpublished),
and the Rutter scale A. Thirdly, for children under the age of 16 at the time of follow up, the school teacher was asked to complete a questionnaire.

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. 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.

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 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 scale of score 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>
<thead>
<tr>
<th>Table 1a</th>
<th>Weight for height adjusted for age (expressed as %) at time of first refusal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight/height (%)</td>
<td>No of patients</td>
</tr>
<tr>
<td>40-59</td>
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<td>50-59</td>
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<tr>
<td>60-69</td>
<td>19</td>
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<td>70-79</td>
<td>17</td>
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<td>80-89</td>
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<tr>
<td>90-99</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
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<table>
<thead>
<tr>
<th>Table 1b</th>
<th>Weight for height adjusted for age (expressed as %) at time of follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight/height (%)</td>
<td>No of patients</td>
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<td>60-69</td>
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<tr>
<td>110-119</td>
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</tr>
<tr>
<td>120-129</td>
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<tr>
<td>Information not available</td>
<td>5</td>
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<tr>
<td>Died</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
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</table>
Follow up of patients with anorexia nervosa

Table 2 Grading within scales at follow up

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

Table 3 Grading of scores of outcome

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

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

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

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<0.01, 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 0.35), 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 sub-
jective 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 con-
trolled, 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 con-
sidered 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 auto-
nomy 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 engage-
ment”.

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 vulner-
able 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 ob-
tained from close relatives, the general practitio-
er, 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, 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. Psycho-
social adjustment is variable, but psychosexual
adjustment is often poor. Eating difficulties persist
in over half the patients, but nutritional and men-
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 mentioned 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

Follow up of patients with anorexia nervosa

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


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