

# Psychosocial functioning of young adults with cystic fibrosis and their families

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## Abstract

**Background** – The psychosocial functioning of adolescents and young adults with cystic fibrosis still living in the parental home was investigated. With its proven genetic aetiology cystic fibrosis is an ideal model with which to assess the impact of a chronic and life threatening disorder on family and individual psychological and social functioning.

**Methods** – Twenty nine patients with cystic fibrosis and their families were compared with those of 27 patients with anorexia nervosa and 31 well controls. Assessments were made using self reporting, interview, and observational methods.

**Results** – Most patients with cystic fibrosis were in robust psychological health and only differed from their healthy peers in that they were much less likely to be in employment. Mothers of patients with cystic fibrosis or anorexia nervosa were more likely than the mothers of the well group to be emotionally distressed, although this was not so for fathers. Young people in both illness groups were more likely to have parents with high levels of expressed emotion. Most families of patients with cystic fibrosis had good problem solving abilities.

**Conclusions** – In spite of the burden of illness in cystic fibrosis psychological functioning in many respects matches that of well young people.

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It is estimated that there are at least 2000 patients with cystic fibrosis over the age of 15 in the UK and that the prevalence is increasing at a rate of 100 cases a year.<sup>1</sup> Survival needs to be matched by reasonable levels of psychosocial adjustment and quality of life. Epidemiological studies indicate a high prevalence of psychiatric disorder and distress in people with chronic physical illness.<sup>2</sup> The early anecdotal accounts of young adults with cystic fibrosis<sup>3,4</sup> painted a grim picture of high levels of distress in both patient and parents, although more recent reports have been more optimistic.<sup>5-11</sup> Such research has suffered from certain limitations – for example, an absence of control groups either of well subjects or of families coping with other illnesses, and overreliance on self reporting questionnaires without the counterbalance of clinical assessment. In addition, the way that families or patients describe themselves may differ from the way that clinicians see them and their views need to be determined.

This study aimed to compare the psychological health and family functioning of young adults with cystic fibrosis with that of well controls and patients with anorexia nervosa and their families. Anorexia nervosa was chosen for comparison because it is a serious illness with a mortality of 20% over a 20 year follow up.<sup>12</sup> In common with anorexia nervosa, many patients with cystic fibrosis will be of low weight and have nutritional complications. Potentially important differences are that anorexia nervosa is thought to have a psychogenic aetiology and onset does not usually begin before adolescence.

## Methods

### SUBJECTS

Patients with cystic fibrosis were recruited consecutively from three regional cystic fibrosis centres serving the central belt of Scotland. Of the patients with anorexia nervosa 75% were recruited from the case register of a regional health authority with a specialist service for eating disorders. The remaining 25% came from a private clinic, again with a specialist service. They had all met the DSM-III-R<sup>13</sup> diagnostic criteria for anorexia nervosa within the previous year. A well family was defined as one in which no member of the household had a chronic illness or had attended a specialist within the previous two years. The well controls were either nominated by the ill group families, which gave a good social class match, or – where geographical distance was a problem – were obtained from an alphabetical search of the lists of two general practices. Inclusion criteria were that the cystic fibrosis, anorexia nervosa, or well proband had to be aged between 14 and 24 years, still living in the parental home, and that parents or step-parents in the household agreed to be interviewed. Single parent households were not excluded.

A power analysis was used to determine sample size. Assuming a significance level of 0.05 and a power of 0.90, 22 subjects in each group would enable a difference between groups of about 10 points on the Family Assessment Measure (see below) to be detected. A total of 105 families were approached (35 in each group). There were 6/35, 8/35, and 4/35 refusals from the cystic fibrosis, anorexia nervosa, and well families respectively. Reasons for refusal were established in all but three cases; family problems were sometimes the main reason for refusal and this applied equally to anorexia nervosa and cystic fibrosis families. Parents and the proband were equally likely to be the refuser.

Informed consent was obtained from both the proband and parent(s) and the project was approved by the local ethics committee.

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#### PROCEDURE

In the two illness groups an initial session was carried out in the clinic by an independent assessor blind to the aims of the study. She evaluated the psychosocial functioning and health status of the patient and collected demographic data. The second session was carried out by one of the authors (CB), usually in the family home. At this meeting the family assessments took place. For the well families all the assessments were carried out by CB in one meeting at the family home.

#### MEASURES

- (1) A structured clinical interview able to identify DSM-III-R diagnoses for major depressive disorder was carried out with the proband.
- (2) The General Health Questionnaire (GHQ-30),<sup>14</sup> a self reporting screening tool for emotional disturbance, was given to proband and parent(s).
- (3) The Morgan and Russell Scales<sup>15</sup> for anorexia nervosa. This is a guided interview during which detailed clinical information is obtained from both the patient and an informant (here the parents). It evaluates mental state, sexual and socioeconomic functioning, as well as eating behaviour.
- (4) The Impact-on-Family scale,<sup>16</sup> a self-reporting questionnaire which measures the financial, social and personal strains, and coping skills of families living with an ill child, was completed by both parents.
- (5) The Family Assessment Measure (FAM),<sup>17</sup> a self reporting questionnaire, was given to all members of the household aged 13 and over.
- (6) The Camberwell Family Interview<sup>18</sup> took place with the parent(s) alone. This was audiotaped and rated (by CB) for expressed emotion,<sup>18</sup> a well established technique that seeks to take the "emotional temperature" of a household by evaluating a relative's negative effect or intrusive overconcern. A household is defined as having high expressed emotion if either parent makes a large number of "critical comments" about their child or shows high levels of "emotional overinvolvement". A high level of expressed emotion is a predictor of poor outcome and relapse in several psychiatric disorders. As a check against bias in the rater the tapes of 15 families (29 parents) were scored by an independent assessor. Inter-rater reliability was good. The number of critical comments made ranged from 0 to 10 and the mean difference between raters was 0.17 critical comments with the 95% limits of agreement ranging from -1.2 to +1.3 critical comments. As emotional overinvolvement is scored categorically the appropriate coefficient of agreement is weighted  $\kappa$  and this was 0.84.<sup>19</sup>
- (7) Problem solving task. The parents and the index child were asked to discuss together for up to 10 minutes each two problems salient to their household. These vignettes were audiotaped and rated for good, medium, or poor problem solving skills using a scoring manual developed in pilot work. A sample of 20 problem solving tapes was rated blind by an inde-

pendent assessor and the weighted  $\kappa$  score was 0.84.

The health status of patients with cystic fibrosis was rated by their respiratory physician using the Cooperman scale.<sup>20</sup> Lung function was measured by forced vital capacity (FVC) and forced expiratory volume in one second (FEV<sub>1</sub>).

#### Results

Demographic features of the families are presented in table 1. While the anorexia nervosa and well families were well matched on social class, the cystic fibrosis families were more representative of Scotland as a whole. There were more boys in the cystic fibrosis group. Survival rates are better for boys with cystic fibrosis than girls, and girls were less likely than boys to be living with parents. Because of this bias all statistics were analysed for confounding effects of sex and class but none were found for the measures presented.

Health status of the probands is shown in table 2. Lung function of the patients with cystic fibrosis was comparable with that of a large British series.<sup>21</sup> Eleven of the patients with cystic fibrosis had been treated with intravenous antibiotics during the three months before the interview. Five patients were on a transplantation waiting list. A third of the anorexia nervosa sample had made a partial recovery and no longer met the DSM-III-R weight criterion although the other core features of the illness remained. The patients with cystic fibrosis were typically in good psychological health. Only four of the group had had a previous encounter with a GP or hospital for mental health problems. Only one patient had received treatment at some time for a depressive illness compared with 12 in the anorexia nervosa group. None of the well probands had a mental health history. Using a cut-off score of >5 for "caseness" on the GHQ, five cystic fibrosis probands were "emotionally distressed" compared with six of the well group and 16 of the anorexia nervosa group ( $\chi^2=12.3$ ; df 2;  $p<0.001$ ). With increased age emotional distress in the cystic fibrosis proband was likely to be higher (although still low) (Spearman's  $r=0.38$ ;  $n=29$ ;  $p<0.05$ ) – an effect not found in the anorexia nervosa and well samples. As age could be confounded by the severity of illness a composite variable termed "cystic fibrosis severity" was derived by calculating the mean of weight, FVC, and FEV<sub>1</sub>, all three variables being expressed as a percentage of expected score for age and height. However, the relation of high emotional disturbance and severity of cystic fibrosis failed to reach statistical significance (Spearman's  $r=-0.35$ ;  $n=29$ ;  $p>0.05$ ). Patients with cystic fibrosis who had received intravenous antibiotics in the previous three months were compared with those who had not, again with no differences between groups. Of the sicker group 3/11 were emotionally distressed compared with 2/18 in the fitter group ( $\chi^2=0.37$ ,  $p>0.05$ ). In the group of patients on the transplantation list only 1/5 fell into the distressed range. While personality was

Table 1 Demographic characteristics of families

	Anorexia nervosa (n = 27)	Cystic fibrosis (n = 29)	Well (n = 31)
Mean (SD) age (years)	18.7 (3.2)	19.2 (2.7)	18.2 (2.6)
Male:female	2:25	20:9	8:23
Work status			
Student	66%	35%	67%
Employed	15%	24%	32%
Unemployed	19%	41%	0%
Family structure			
Two parent households	85%	86%	94%
No. of children	2.4 (1.3)	2.3 (0.7)	2.2 (0.6)
Social class <sup>1</sup>			
I and II	63%	38%	64%
III	37%	52%	29%
IV and V	0%	13%	6%

<sup>1</sup> Head of household: proportions expected for Scotland, 26% 48%, 25% (General Register Office for Scotland, 1981).

Table 2 Health status of proband

	Anorexia nervosa (n = 27)	Cystic fibrosis (n = 29)	Well (n = 31)	
% weight <sup>1</sup>	78.7 (15.1)	84.5 (12.0)	94.7 (9.2)	
Cooperman mean (SD)	—	5.3 (2.8)	—	
FVC mean (SD)	—	70.8 (6.0)	—	
FEV <sub>1</sub> mean (SD)	—	58.6 (6.0)	—	
Morgan and Russell median scores				H <sup>2</sup>
Food intake	4	10	12	31.4
Menstrual	0	12	12	28.2
Socioeconomic	8	10	12	23.8
Psychosexual	7.5	10	10	15.2
Mental state	8	12	12	41.3
Average outcome	6.4	10.4	11	43.9

FVC = forced vital capacity; FEV<sub>1</sub> = forced expiratory volume in one second.

<sup>1</sup> Percentage of expected for weight and height.

<sup>2</sup> Kruskal-Wallis ANOVA by ranks. All p values < 0.001.

not formally measured, the clinical impression was that the young people with cystic fibrosis were indistinguishable from the well sample and quite distinct from the more troubled subjects with anorexia nervosa.

Each subscale on the Morgan and Russell has a maximum score of 12 denoting good functioning and a minimum score of 0 denoting poor functioning. Main effects for all the subscales were significant (table 2). The patients with cystic fibrosis had test profiles closer to the well group than the anorexia nervosa group. While this was only to be expected on the food intake and menstrual subscales, it is of note that both the mental state and psychosexual functioning scores for patients with cystic fibrosis matched the well controls. The socioeconomic subscale measures social relationships, social activities, educational, and economic performance. Here patients with cystic fibrosis functioned less satisfactorily than the well group, but in every case this was due to economic incapacity rather than social difficulty. Of the patients with cystic fibrosis 12 were unemployed compared with five of the anorexia nervosa and none of the well group (table 1).

On the GHQ 10/29 cystic fibrosis mothers reached the criterion for caseness compared with 13/27 anorexia nervosa mothers and 5/30 well mothers ( $\chi^2 = 6.5$ ;  $p < 0.05$ ). Numbers for fathers were 5/25, 7/23, and 7/26 respectively ( $\chi^2 = 1.4$ ;  $p > 0.05$ ).

The results of the Impact-on-Family scale are presented in table 3. Parents of patients with anorexia nervosa or cystic fibrosis experienced equivalent personal and social strain. Mothers of patients with cystic fibrosis felt under more financial strain than anorexia nervosa associated mothers, but this could be accounted for by the social class difference between groups. Both mothers and fathers of patients with cystic fibrosis had higher mastery scores, indicating that they felt more able to cope with the illness than parents of anorexia nervosa patients.

No differences between groups emerged when families were asked to describe themselves on the Family Assessment Measure ( $F = 0.95$ ;  $df 2,84$ ;  $p > 0.05$ ) and all scores were close to the population norms for this questionnaire. However patients with cystic fibrosis (10) and anorexia nervosa (11) were more likely to be living in high expressed emotion households as measured from the Camberwell Family Interview than the well families (1) ( $\chi^2 = 13.7$ ;  $p < 0.001$ ). This was due to overinvolved rather than critical behaviour. Typical examples of overinvolved behaviour would be a mother who had given up all interests outside the home to be available for her daughter even though the child was well enough to cope with a full time job or a mother who persisted in infantilising her teenage son. Fourteen families of cystic fibrosis patients were categorised as good problem solvers compared with nine well families and three anorexia nervosa families ( $\chi^2 = 8.07$ ;  $p < 0.02$ ).

## Discussion

While it had been anticipated that patients with cystic fibrosis would be less emotionally disturbed than patients with anorexia nervosa, the most striking finding in the cystic fibrosis associated families was the robust psychological health of the patients who were indistinguishable from their healthy peers. This confirmed previous reports that depended on self reporting methods alone.<sup>5-7,11</sup> It signifies a change from the dismal picture of psychological functioning in patients with cystic fibrosis in the early uncontrolled studies.<sup>3,4</sup> Even in the most severely affected group of patients – those awaiting heart-lung transplantation – levels of psychopathology were low. Of interest was the age appropriate social functioning of these young people many of whom, in spite of the physical limitations imposed by the disease, the social awkwardness of the symptoms, and shackles of the treatment regime, managed to relate appropriately to their peer group and to have close relationships with members of the opposite sex. Other studies have suggested that, where puberty is delayed and stature short, psychosexual functioning is likely to be compromised for healthy subjects and patients with cystic fibrosis alike.<sup>22,23</sup> Unemployment was a problem for the cystic fibrosis group. The proportion of patients with cystic fibrosis who were not either in paid employment or students was very similar to that found in a recent large British survey of adults with cystic fibrosis.<sup>24</sup> Employment was particularly difficult for

Table 3 Mean (SD) results of Impact-on-Family scale

	Anorexia nervosa	Cystic fibrosis	t	p
Fathers	n=22	n=25		
Financial	10.0 (3.1)	11.1 (2.1)	1.50	0.13
Social	15.9 (2.7)	16.8 (2.6)	1.30	0.22
Personal strain	15.2 (2.7)	15.8 (1.8)	0.95	0.36
Mastery	8.7 (1.3)	7.6 (1.6)	-2.76	0.008
Mothers	n=26	n=29		
Financial	9.8 (2.4)	11.5 (3.2)	2.16	0.04
Social	16.3 (2.9)	17.5 (3.9)	1.20	0.22
Personal strain	16.3 (2.0)	17.3 (2.2)	1.70	0.09
Mastery	8.8 (1.9)	7.7 (1.8)	-2.30	0.03

patients with cystic fibrosis from working class backgrounds, many of whom could have coped with flexible part-time employment had it been available.

It is well established that mothers of young children with cystic fibrosis suffer raised levels of emotional distress,<sup>25,26</sup> which is the case in many chronic illnesses.<sup>27</sup> We found that mothers of both cystic fibrosis and anorexia nervosa patients had raised levels of emotional distress compared with the well group. This confirms the finding of two uncontrolled studies<sup>4,8</sup> in patients with cystic fibrosis in the older age group. It should be noted, however, that the proportion of mothers with a mental health history (18%) was the same in each group, and that mothers of the well group appeared to be "superwell" compared with a large community survey using the GHQ.<sup>28</sup> Support for a minority of mothers may need to be continued well after the patient has reached the age of majority. The finding that the mental health status of fathers is indistinguishable from the well group has also been found in younger populations of patients with cystic fibrosis.<sup>8,25,29</sup>

Parents of both the anorexia nervosa and cystic fibrosis groups were more likely to be overinvolved with their child than parents of the well group, and this was more likely where illness was severe. However, the families of patients with cystic fibrosis as a whole functioned at a healthy adaptive level. They showed low levels of criticism, good problem solving skills, with clear communication, an ability to compromise, and were not afraid to tackle difficult issues. These family profiles had more in common with the well families than with the anorexia nervosa families.

Are there alternative explanations for these optimistic findings? It seems unlikely that sampling bias led to an exceptionally healthy group of cystic fibrosis patients being included in the study. More severely affected patients stood a greater chance of recruitment to the project because they attended the clinics more often. Young people living away from home and therefore excluded from the project tend to be a healthier group.<sup>30</sup> Only two of the seven patients who refused to enter the study were known by the clinic to have family problems. Moreover, the well families were if anything "superwell" by virtue of being nominated as healthy by the "illness" families or by being chosen from GP lists. Of families on GP lists 30% did not meet the good health criterion for entry to the project.

No systematic positive bias could be detected in the reporting of their difficulties by the families. Where problems did exist patients and families appeared open and willing to describe their distress.

In all three groups a greater proportion of families were classified as middle class than in the population of Scotland as a whole. Over-representation of the middle classes in anorexia nervosa treatment centres is well known and explains the absence of patients in classes IV and V, and the 25% drawn from a private clinic. The middle classes are also over-represented in regional cystic fibrosis centres for adolescents and adults,<sup>21</sup> and social class has a strong independent effect on age at death.<sup>31</sup> Our samples were therefore representative of clinic populations. There were two reasons for the high proportion of middle class families in the well group. Families tended to nominate acquaintances who were either in the same or in a higher social class. On GP lists working class families were more likely to have a sick family member and were thus excluded from the sample. The main point of social class interest in the study was that, in spite of there being nearly twice as many working class families in the cystic fibrosis group as in the well group, the patients with cystic fibrosis and their families were functioning just as satisfactorily as their well peers. Levels of psychiatric disturbance are greater in lower social groups,<sup>32</sup> so this finding was not anticipated.

Now that genetic screening for cystic fibrosis can identify over 85% of carrier couples, there is an implicit assumption that termination of an affected pregnancy or a decision to remain childless is preferable to having a child with cystic fibrosis.<sup>33</sup> In the absence of mental retardation there is generally a reluctance to termination<sup>34</sup> and postal surveys suggest that over half the parents of children with cystic fibrosis would not terminate an affected pregnancy.<sup>35,36</sup> The views of adults with cystic fibrosis and their parents are unknown, but this study suggests that in many respects quality of life for patients with cystic fibrosis and their families can equal that of well families. Consequently, where screening programmes are introduced, counselling should emphasise both the positive and negative aspects of cystic fibrosis and its effect on family life so that couples can make a fully informed choice on their reproductive future.

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