Developing a measure of eating attitudes and behaviours in cystic fibrosis

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Abstract

Background: Eating disorders or disturbed eating attitudes and behaviours (EABs) may contribute to poor nutritional status in Cystic Fibrosis (CF). Existing measures of disturbed EABs can have different meanings in this population and do not assess CF-related EABs. A self-report measure of EABs in CF was developed to highlight areas of eating disturbance.

Methods: The content validity of a draft measure was evaluated via expert evaluation and literature review and an amended measure piloted with 8 CF patients using cognitive interviewing. A further amended measure was administered to 155 CF patients (11–62 years) attending CF clinics.

Results: Principal components analyses revealed a three-factor structure (‘Desire for thinness and weight loss’, ‘Disturbed EABs’, and ‘Appetite’) with good internal consistencies for subscales and the 21-item whole measure.

Conclusions: The measure looks promising as a tool to highlight EAB disturbance in CF. Further work will establish its construct validity and clarify interpretation of subscales.

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Keywords: Eating; Cystic fibrosis; Eating disorder

1. Introduction

Eating disorders (EDs) or disturbed eating attitudes or behaviours (EABs) have been reported in young people [1–3] and adults [4–6] with Cystic Fibrosis (CF) and may contribute to poor nutritional status, which is associated with poor growth and delayed puberty [7], reduced lung function [8] and decreased survival [9]. It will be valuable to assess disturbances in EABs in the CF population; however, existing self-report measures of disturbed EABs (i.e. [10–12]) are not wholly appropriate for this population. For example, some questions can reflect consequences of CF or treatment guidelines rather than eating psychopathology, such as eating a high calorie diet and showing preoccupation with food/calories due to dietary recommendations. Existing measures also do not assess EABs related to the CF disease process or treatment regimen likely to be associated with poor nutritional status, such as feeling full easily or not taking enzymes or insulin for weight control. Some adaptations to an existing eating disorders measure [10] have been made based on a different factor structure being observed in an adult CF sample [4]; however, this does not allow for the assessment of CF-related EABs, as above.

A draft version of a self-report measure of EABs in CF was developed by Bryon [13]; this is subsequently referred to in this article as the draft CFEAB measure. This had 29 items and was aimed at patients aged 11 and over given the peak incidence of EDs in adolescence [14] and that eating problems in CF tend to decline from the teenage years onwards [15]. This measure assessed EABs associated with anorexic and bulimic psychopathology along with CF-related EABs that may impact on eating or weight. Although body image can impact on EABs, it was felt an assessment of body image was beyond the scope of this brief measure [13], particularly as body image in CF can be complicated by non eating-related issues (e.g. clubbing). Items were developed based on previous research findings [1], EDs diagnostic criteria [16] and clinical experience with patients with CF. Items assessing self-esteem were included since self-esteem has been highly correlated with disturbed EABs [17] although these

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items would not be scored since they were not part of the CFEAB construct. A 5-point Likert scale (Never–Always) was used.

The current study aimed to further develop and evaluate this draft measure in accordance with standard scale development recommendations [18]. The content validity of items was first evaluated via consultation with experts in the field and a literature review of target constructs. An amended CFEAB measure was then piloted with eight participants with CF using cognitive interviewing as an assessment of the measure’s practical acceptability and ease of understanding [19]. Finally, a further amended CFEAB measure was administered to a large sample of participants with CF (n = 155) to assess its factor structure and internal consistency.

2. Methods

2.1. Setting

Participants were recruited from three hospital CF clinics (two paediatric, one adult) at two Specialist CF Centres in central London. Ethical approval was obtained from relevant NHS and university bodies.

2.2. Review of the draft CFEAB measure’s content validity

2.2.1. Expert review

An evaluation form was designed that assessed each of the items’ relevance in the measure and their comprehensibility on a 5-point Likert scale (1 = ‘Not at all relevant/understandable’, 5 = ‘Very relevant/understandable’) and included space for qualitative comments and to identify EABs in CF that had been omitted from the measure. 25 health-care professionals (5 from the adult team, 20 from paediatric teams) were invited along with a service-user representative from the CF Trust (a national CF charity and service monitoring organisation). The final sample included 8 health-care professionals (3 paediatric consultants, 1 paediatric specialist nurse, 2 psychologists (1 adult, 1 paediatric) and 2 dieticians (1 adult, 1 paediatric)) and 1 service-user.

2.2.2. Literature review

A current literature review of the measurement of disturbed EABs and the presence of disturbed EABs in CF was completed. Keyword searches (‘disturbed EABs’, ‘EDs’, ‘subclinical EDs’, ‘partial syndrome EDs’, ‘disordered eating’, ‘eating’, ‘eating problems’ and ‘measure/s’, ‘measurement’, ‘questionnaire’, ‘assessment’ or ‘cystic fibrosis’) were carried out on empirical databases including PubMed, PsychInfo, Science Direct, JSTOR and Google Scholar.

The research team (Trainee Clinical Psychologist, two Clinical Psychologists) then met to review the findings of the expert evaluation and literature review and implications for amendments to the draft CFEAB measure; following amendments, this was termed ‘amended CFEAB measure #1’.

2.3. Cognitive interviewing study: piloting of amended CFEAB measure #1

During a cognitive interview, participants are asked to ‘think aloud’ whilst completing a questionnaire, describing their thought processes during comprehension and the response process, whilst interviewers ask relevant follow-up or planned probe questions to further evaluate this. Data from these interviews can help researchers to formulate or amend questions so they better or more clearly access targeted constructs. In the current study, interviews lasted a maximum of 45 min. Written informed consent/assent was obtained from all participants. Following guidelines in Willis [19], digital recordings of the cognitive interviews were reviewed and notes made regarding any difficulties participants experienced with comprehension or the response process. A written report summarising these was reviewed by the research team and amendments made to the amended CFEAB measure #1, which was then termed ‘amended CFEAB measure #2’.

2.3.1. Measures

The amended CFEAB measure #1 comprised of 22 statements relating to EABs in CF. For each statement, participants were asked to choose which word best applies to them from a 5 point Likert-scale (Never, Rarely, Sometimes, Often, and Always) or to mark ‘Never’ if an item did not apply.

2.3.2. Participants

In line with recommendations by Willis [19], a sample of 8 participants who were nominally representative of the target wider UK CF population above 11 years was targeted. A 50–50 split between adolescents (11–16 years) and adults (17 years and above) and males and females was targeted matching current demographics of the UK CF population [20]. Inclusion criteria were that participants were: aged 11–65 years and seen in a specialist CF clinic with an established diagnosis of CF made by a medical professional. Exclusion criteria were that participants: were not able to speak or read English or displayed clear evidence of a learning disability (i.e. in contact with learning disability services) or had received a lung transplant since patients post-transplant are not consistently managed by CF clinics.

Eligible participants were identified from clinic lists by a member of the clinical team. In total, 14 adults and 20 adolescents were invited. One eligible adult was identified by the team member as unsuitable to invite although reasons for this were not specified to maintain confidentiality. The sample obtained included 8 participants: 4 adolescents (2 females (11 and 14 years) and 2 males (11 and 16 years)) and 4 adults (2 females and 2 males, 24–34 years).

2.4. Psychometric study: administration of amended CFEAB measure #2 to large sample

Participants completed the amended CFEAB measure #2 during their CF clinic visit, at a time convenient to them. Written
informed consent/assent was obtained and all participants allocated a code number to maintain confidentiality.

2.4.1. Measures

The amended CFEAB measure #2 comprised of 24 statements relating to EABs in CF. Response options remained the same. Each item was scored from 0 to 4, with higher scores indicating more disturbed EABs. Clinical and demographic data were collected via a brief questionnaire completed by accessing medical notes.

2.4.2. Participants

A ratio of at least 5 participants per item has been recommended when using factor analytic methods to develop a psychometric measure, with a 10:1 ratio thought to represent a more ‘ideal’ scenario [21]. A sample of 150 that was representative of the target UK CF population above 11 years in terms of age and gender, as above, was targeted. Inclusion and exclusion criteria were the same as above.

Eligible participants were identified from clinic lists by a member of the clinical team. In total, 124 patients from the adult service and 119 patients from paediatric services were invited. Five adults were ineligible for the study (2 post-transplant, 2 learning disability, 1 not confirmed CF) and eleven identified as unsuitable to invite although reasons for this were not specified. Three adolescents were ineligible due to learning disabilities and nine deemed unsuitable to invite for unspecified reasons. The final sample included 155 participants indicating a response rate of 64% (62%; adolescents, 65%; adults); if only participants who attended their clinic visit were included an 80% recruitment rate was achieved. A diagrammatic representation of recruitment for the psychometric study can be found in Fig. 1. Clinical and demographic characteristics of the sample are displayed in Table 1. The sample was representative of the wider UK CF population above 11 years described on the UK CF Trust Registry [20] in terms of age, gender, ethnicity, weight, lung function, pancreatic sufficiency and use of supplementary feeding.

3. Results

3.1. Review of the draft CFEAB measure's content validity

3.1.1. Expert review

Using Lyn’s [22] criteria for the number of experts who need to agree for an item to be considered content valid (a rating of either 3, 4, or 5 on the ‘Relevance’ question of the evaluation form), there were 3 items on the draft CFEAB measure that did not achieve content validity and were removed from the measure. A number of other amendments were made based on experts’ qualitative comments. Full details of these are beyond the scope of this paper. However, in summary, another 6 items were deleted (including all self-esteem items) and small wording changes made to 11 items; for example, ‘I avoid eating because my CF makes me sick or vomit’ was changed to ‘I avoid eating because my CF makes me feel sick’ and ‘I feel full even when my stomach is empty’ was changed to ‘I feel full even after eating a small

![Diagram](image-url)
amount. An additional treatment (gastrostomy feeds) was added to an item assessing non-adherence to enzymes and insulin for weight control purposes.

3.1.2. Literature review

Two items were added to the measure (‘I pretend to others that I have eaten’, ‘I feel guilty after eating’) based on the literature review. These were concepts assessed in existing measures of disturbed EABs that the research team felt would be valuable to assess in CF. No additional relevant CF-related EABs were identified.

3.2. Cognitive interviewing study: piloting of amended CFEAB measure #1

Following the cognitive interviews, small wording changes were made to 5 items. For example, ‘When others pressure me to eat, I don’t feel like eating’ was changed to ‘I don’t feel like eating when others tell me to eat’ and ‘I only feel happy with myself when I am thin’ was changed to ‘I feel I need to be thin to be happy with myself’. The item assessing non-adherence to enzymes, insulin or gastrostomy feeds for weight control was made into 3 separate items assessing ‘enzymes’, ‘insulin’, and ‘extra feeds or supplements’.

3.3. Psychometric study: administration of amended CFEAB measure #2 to a large sample

3.3.1. Psychometric properties

Less than 5% of data was missing on each variable and its distribution appeared random. Therefore, mean substitution for missing data was used for normally distributed variables and median substitution for non-normal distributions [23]. Data met all requirements for factor analysis suggested by Tabachnick and Fidell [24] and Field [23]. Principal components analysis (PCA) was used over exploratory factor analysis since this is more appropriate for a novel measure with no existing empirical theory regarding the structure of relationships between items [25].

The PCAs were carried out in rounds, with the analysis re-run if any item was deleted. Three factors were extracted based on the scree plot (Fig. 2); although four eigenvalues were above 1 throughout the PCAs, the fourth was always only a little above 1 (1.06–1.22 depending on the round) and accounted for a maximum of 5% of variance in the data. Oblique rotations were used throughout since these best approximated simple structure and at least one of the correlations between factors

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Table 1

Clinical and demographic characteristics of the sample (N=155).

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>95% White British</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age distribution</td>
<td>Adolescents n=74 Median: 13 years (11–15 years)</td>
</tr>
<tr>
<td>Gender distribution</td>
<td>Total sample 47.7% male</td>
</tr>
<tr>
<td>Weight</td>
<td>Adolescents: % WFH (Range) 100.7 (78.1–138.8)</td>
</tr>
<tr>
<td>Mean FEV1 (Range)</td>
<td>71 (18–134)</td>
</tr>
<tr>
<td>% pancreatic insufficient</td>
<td>94</td>
</tr>
<tr>
<td>% CF-related liver disease</td>
<td>6.5</td>
</tr>
<tr>
<td>% prescribed tube feeding</td>
<td>5</td>
</tr>
<tr>
<td>% prescribed food supplements</td>
<td>27</td>
</tr>
<tr>
<td>% prescribed steroids</td>
<td>11</td>
</tr>
<tr>
<td>% food allergies</td>
<td>5</td>
</tr>
</tbody>
</table>

Abbreviations:
FEV1: forced expired volume in 1 s percent predicted.
BMI: body mass index.
% WFH: percentage weight for height.
was above $r=0.15$. In the first PCA, Item 4 was a complex variable, loading onto Factors 1 and 3 with loadings greater than 0.4 (an appropriate cut-off given existing recommendations and the current sample size [23,24,26]). Complex variables make interpretation of factors more ambiguous [24] and this item was deleted from the measure. All other items then loaded onto one factor each.

Prior to interpretation of this structure, Cronbach’s alpha analyses were carried out to examine the reliability of subscales suggested by the factors and the total measure. Standardised alpha was used when means and/or variances of items being assessed appeared substantially different. ‘Alpha if item deleted’ values were examined to identify candidate items for exclusion. Alpha values for Factors 1 and 2 could not be improved by deleting any items. One item was deleted from Factor 3 since its deletion raised alpha from 0.77 to 0.80 and the item appeared to access a slightly different construct to other items on the subscale (see Table 2). Following this, alpha for Factor 3 was further improved (0.80 to 0.83) by the deletion of another item also appearing to access a different construct. Final alpha values for subscales were 0.92, 0.84 and 0.83, respectively, and 0.90 for the whole measure. Items retained in the final measure and their factor loadings along with factor eigenvalues and amount of variance in the data accounted for are displayed in Table 2. All other items then loaded onto one factor each.

4. Discussion

The expert evaluation and cognitive interview components of the study identified a number of amendments to the CFEAB measure, including the deletion of nine items, to enhance its content validity, acceptability and ease of completion for different distributions compared to other items on this factor, with a median and mean (Item 15 was non-normally distributed and Item 21 normally distributed) of 4 and 2.2 respectively, compared to all other items with medians of 0 (see Table 3). This appears to be related to characteristics of the current sample, where many participants were not underweight (see Table 1), and thus may not indicate that they ‘spend time wishing they weighed more’ (Item 15) or ‘feel happy when they gained weight’ (Item 21) on these negatively skewed items.

Factor 2 seemed to access a mix of CF-specific EABs (Items 10–12 and 20) and EABs that may be related to eating-disordered psychopathology (Items 16 and 24) or perhaps to CF-related phenomenology (Items 8 and 23). All of these items were also extremely positively skewed with more than 75% of the sample responding ‘Never’ and any score greater than 0 classed as an outlier [27]; only one other item (Item 22) displayed such a skewed distribution although most items were positively skewed (see Table 3). This factor was provisionally named ‘Disturbed EABs’ to reflect the more ‘extreme’ and ‘disturbed’ nature of attitudes and behaviours on this factor, which were also very uncommon in the study population.

It seemed clear that the three items on Factor 3 (I enjoy eating, I feel full quickly, I have a good appetite for food) were assessing concepts around appetite for food and this was named ‘Appetite’.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Items</th>
<th>Factor loading</th>
<th>Eigenvalue</th>
<th>Variance accounted for (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2. I want to be thinner</td>
<td>.917</td>
<td>7.75</td>
<td>36.90</td>
</tr>
<tr>
<td>3</td>
<td>1. I enjoy eating a</td>
<td>.871</td>
<td>1.85</td>
<td>8.80</td>
</tr>
<tr>
<td></td>
<td>9. I feel full quickly</td>
<td>.774</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13. I have a good appetite for food a</td>
<td>.840</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Deleted items (reason): 4. I find it hard to gain weight (complex variable), 5. I don’t feel like eating when others tell me to eat (deletion improved subscale alpha), 7. Even if I feel unwell, I try to eat something** (deletion improved subscale alpha).

a Negatively scored items.
Table 3

Descriptive statistics for individual items on the final CFEAB measure.

<table>
<thead>
<tr>
<th>Item</th>
<th>Median</th>
<th>Percentiles</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>25'</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>1.46*</td>
<td>1.06 b</td>
</tr>
<tr>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>14</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>15</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>16</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>17</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>18</td>
<td>0</td>
<td>0</td>
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<tr>
<td>19</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>21</td>
<td>2.2*</td>
<td>1.47 b</td>
</tr>
<tr>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>23</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>24</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

* Mean.

b Standard deviation.

respondents. Following the addition of 2 items from the literature review, the CFEAB measure’s target constructs (EABs related to EDs and to CF) appeared to be adequately sampled. After administering the amended CFEAB measure to a large sample of people with CF attending routine clinics, a three-factor solution explaining an adequate 64% of variance in the data was found [28]; this was interpreted as ‘Desire for thinness and weight loss’ (10 items), ‘Disturbed EABs’ (8 items) and ‘Appetite’ (3 items). Three items were deleted due to complex factor loadings or because their deletion improved subscale alpha. Internal consistencies of all CFEAB subscales and the overall measure were above the recommended cut-off of 0.70, with values for the whole measure and Factors 1 and 2 classified as ‘Very Good’ [18].

A clear CF-related EABs factor did not emerge. Five EABs related to disruptions in normal appetite reported in CF or pressure from others to eat loaded onto Factor 3 (‘Appetite’), although two of these were deleted following internal consistency analyses. Four remaining EABs that directly referenced CF or its treatments (Items 10, 11, 12 and 20) loaded onto the second factor, although were accompanied by other EABs more indicative of EDs. Factor 2 was named ‘Disturbed EABs’ in an attempt to summarise this range of constructs that also displayed a floor effect in the study population; however, it will be helpful to further investigate the nature of this factor in future construct validity analyses, described below.

Distributions of the vast majority of items (19 out of 24) on the CFEAB measure were positively skewed, particularly those on Factor 2, with many outlying observations identified. Although some authors [29,30] suggest outlying scores can have an undue influence on the factor solution, a satisfactory solution was attained. However, it is possible this is unstable and replication of the factor structure needs to be investigated in other CF samples, particularly those where greater variability in scores may be observed (i.e. patients with identified problems with eating). The fact that CFEAB items have not demonstrated ‘desirable’ psychometric properties of a relatively high variance and mean close to the centre of the range of possible scores [18] does not detract from the potential clinical utility of the measure. That is, the measure will be helpful in identifying any disturbance in EABs associated with weight loss or low weight maintenance in people with CF, given the negative health implications of this. The low prevalence of disturbed EABs found within this community CF sample is also consistent with the lower prevalence of EDs [1] and disturbed EABs [2,4,5] found in CF compared to control samples.

It is possible that the lack of control over when the measure was completed during clinic visits may have introduced bias, for example, a minimising of disturbances in EABs if completed after seeing a dietician where problems with nutritional status were discussed or an increased desire for thinness after being weighed. More generally, as described in the general population [31], some participants may have been reluctant to disclose disturbed EABs due to a lack of complete response anonymity (there was face-to-face contact with researchers to promote recruitment rates).

The next stage in the development of the CFEAB measure will be to examine its construct validity and that of the subscales. This will involve comparing the CFEAB measure with existing measures of DEABs related to EDs [i.e. 10–12] including diagnostic interviews for EDs [32], weight/BMI, health indicators and other related psychological variables (i.e. mood, self-esteem, quality-of-life). Group comparisons using participants with EDs, CF and EDs or CF and ‘eating problems’ identified by the clinical team may be useful along with the comparison of scores and CFEAB factor structure between males and females and adolescents and adults. The use of cut-offs for total or subscale CFEAB scores to identify likely disturbances in EABs and qualitative descriptions of CFEAB scores based on normative values in the CF population could also be investigated.

4.1. Implications for practice

The CFEAB measure has demonstrated good psychometric properties and, once validated, may be used to identify disturbances in EABs in patients with CF in need of further assessment. Further guidance regarding interpretation of CFEAB scores, particularly concerning indicators for treatment (i.e. referral to specialist ED team, management by in-house CF team), can be given following validation. This will help ensure the CFEAB measure can be administered by any member of the CF team, not just psychosocial professionals. The nature of EDs and CF-related EABs in CF and the efficacy of interventions for these also need to be further investigated before the CFEAB measure can be used to reliably inform evidence-based treatments.

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