



THE CF SUPPLEMENT

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ARE EATING DISORDERS PRESENT IN CYSTIC FIBROSIS?



Since optimal weight is essential for the overall wellbeing and longevity of persons who have CF, food intake and weight are important foci of care. With the lifelong emphasis on these indicators by healthcare professionals, it might seem reasonable to expect that persons who have CF may be at risk for eating disorders. This newsletter reviews available research regarding CF and eating disorders (EDs) and disordered eating behaviors (DEBs).

FEATURED PAPERS

Eating disorders and disturbance in children and adolescents with cystic fibrosis. Bryon M, et al. *Children's Health Care*. 2008;37:67-77. **Objective:** To determine the prevalence of eating disorders/disturbances in adolescents who have CF. **Methods:** Cross-sectional study. Child Eating Disorder Examination questionnaire administered by trained interviewer at end of routine outpatient appointment. **Subjects:** 55 subjects (19 female) from 2 CF Centers; mean age: 14.2 yrs (11-17 yrs). **Results:** No participant met full criteria for diagnosis of anorexia nervosa (AN) or bulimia nervosa (BN). Importance of shape was reported by 8% of females (9% for males); importance of weight was reported by 10% of females (13% of males). Scores indicating disturbed eating attitudes were obtained by 53%; scores indicating disturbed eating behaviors were obtained by 16%; there was no gender difference in either category. **Conclusions:** Eating disturbances were present in this study population. These findings warrant the development of a screening measure for frequent use by health professionals in a CF Center.

Nutritional status, perceived body image and eating behaviors in adults with cystic fibrosis. Abbott J, et al. *Clin Nutr*. 2007;26:91-99. **Objective:** To provide a psychosocial profile and compare 3 groups of CF patients (1. Enteral tube-feeding (NG vs. PEG); 2. Oral supplements; 3. Diet alone); with a group of nonCF healthy controls. **Methods:** A cross-sectional questionnaire design with measures of: eating attitudes, perceived and desired body shape, body image, self-esteem and quality of life (QoL). Some measures were CF-validated. **Subjects:** Adults from 2 CF Centers: 219 CF patients (102 male) and 148 nonCF healthy controls (74 male). **Results:** A minority of CF patients reported disordered eating behaviors; those receiving interventions engaged in less dieting behaviors; all CF groups received more pressure to eat. For CF females, intervention groups desired to be heavier while the nonCF females desired to be slimmer; CF males desired to be heavier and nonCF males were happy with their body. CF

patients receiving tube-feedings were less satisfied with their body image, reported lower self-esteem, and poorer quality of life (QoL). **Conclusions:** Body image and eating behaviors are important considerations of nutritional interventions for maintaining QoL.

Eating disorders in patients with cystic fibrosis. Raymond NC, et al. *J Adolesc*. 2000;23:359-363. **Objective:** To examine the rates of eating disorders and psychopathology in patients with CF. **Methods:** Structured or semi-structured psychiatric interviews and rating scales, including the Diagnostic Interview Schedule (DIS) and Diagnostic Interview Schedule for Children (DISC). All CF patients were interviewed by a clinician at an outpatient visit; 79% of controls were interviewed over the phone. **Subjects:** Adolescents and young adults from one CF Center; 58 CF patients (22 female); ages 13 to 20 yrs; and 43 age-matched controls (21 female). Mean age of both groups = 16 yrs. **Results:** No CF subjects but 2 control subjects met the criteria for EDs. 11 CF subjects were diagnosed with one or more psychiatric disorders including: anxiety disorders, major depression, disruptive behavior disorders, and alcohol and /or nicotine dependence. **Conclusions:** These data indicate no evidence for elevated rates of EDs in the CF group. Rates for other psychiatric disorders in the CF group were not greater than the prevalence in the general population.

SPECIAL POINTS OF INTEREST:

- *True eating disorders are psychiatric disorders defined by specific diagnostic criteria.*
- *Disturbed eating behaviors, but rarely eating disorders, are seen in persons who have CF.*
- *Screening for and identifying disturbed eating behaviors may help in designing nutrition care plans.*

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REVIEW

As early as the 1800s, eating disorders (EDs) were reported in the medical literature, with a definition of AN provided by Marce in 1859.¹ In 1994, the American Psychiatric Association established the definition and classification standards for AN, BN, and eating disorders not otherwise specified (EDNOS).² These conditions continue to be diagnosed as mental disorders.³ The reader is referred to those references, along with the paper by Sigel,⁴ for excellent narrative summaries and tables of the diagnostic definitions and criteria of EDs.^{4,5}

In general, physical and psychological criteria for EDs include refusal to maintain normal body weight, abnormal body image, bingeing, purging, and excessive exercise. To be diagnosed with AN or BN, the patient must meet all of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR) criteria of the specific condition.³ If the patient does not, the term EDNOS is applied. EDs often co-occur with other psychiatric disorders and disturbances, including depression, anxiety, obsessiveness, substance abuse disorders, and marked impairments in social functioning.⁶ The diagnosis of AN, BN, or EDNOS is made by a mental health professional specializing in eating disorders.

Some healthcare professionals inappropriately may use the phrase "eating disorder" even when the patient does not meet all the diagnostic criteria. Such patients may exhibit disturbed eating behaviors (DEBs) or eating disturbances, terms which can be used interchangeably. These terms apply to persons who do not have an EDs, but who exhibit obsessive behavior related to food, calories, body size, weight, body image, nutrition beliefs, and/or exercise. This newsletter uses the term DEBs. An example is the patient who restricts specific food categories, such as carbohydrate-containing foods, in an attempt to control weight. The RD can screen for and address concerning behaviors. It is important to note that even if patients do not meet the diagnostic criteria for EDs, they may still be at nutritional risk and require professional intervention. A table describing the continuum of normal eating behaviors and body image including DEBs to EDs is provided in reference seven.⁷

In the USA, 1-2% of teenagers develop AN and 2-4% develop BN.⁴ Although prevalence in adolescent females is thought to be higher than other groups, current work indicates that younger children, boys, adult women, and adult males experience EDs at a higher rate than previously thought with EDs reported regardless of gender, age, race, ethnicity, or social class.^{4, Bryon, Featured paper} Some research indicates that EDs may be based in genetics, neurotransmitter and endocrine aberrations, and possibly intrauterine hormonal milieu.⁸ Family dysfunction and negative family food-related experiences can contribute to the relationship between family dysfunction and disordered eating.⁹ The prevalence of DEBs is much higher than AN or BN. In the 2007 Youth Risk Behavior Survey of teens in the USA, 60% of girls and 30% of boys reported having attempted to lose weight in the previous 30 days; 12% had fasted for more than 24 hours; 5.9% had used diet pills or liquids; 8.6% self-induced vomiting; and 76% had had at least one episode of binge eating during their lifetime.^{10, Bryon, Featured paper} These signs may be concerning if one considers the developmental continuum from eating disturbances to EDs.¹¹ The reader is referred to two references for overviews of EDs.^{12, 13}

In CF, there is very little work assessing the prevalence of DEBs and even less for EDs. Research is hampered by a paucity of satisfactory screening or diagnostic instruments specific for populations with diseases, including CF.¹⁴ CF researchers used a variety of techniques to define and screen for behaviors that

may place a person at risk for EDs. Some findings were based on self-reported surveys which may not provide optimal information.^{Abbott, Featured paper, 15} Several of the tools, including the Eating Attitudes Test (EAT-26) a standardized screening questionnaire that measures concerning behaviors characteristic of EDs, are designed for healthcare professionals to screen for EDs and are not specific to CF due to some types of questions they contain.^{16, 17} To address this concern Abbott¹⁴ adapted the EAT-26 questionnaire to study adults who have CF. Setnick provided a list of screening tools for EDs, again not specific to CF, that can be used by healthcare professionals.¹⁸ Importantly, it is necessary to keep in mind that the diagnosis of EDs is made by mental health professionals using instruments validated for that task. They include measures of depression, body image, body satisfaction, quality of life, self-esteem, and anxiety, none are specific to CF.^{19,20}

Usual CF care places a constant emphasis on the importance of weight and food intake. Thus, when compared to the general public, some clinicians and researchers consider the possibility of a higher incidence and prevalence of EDs. Available research does not indicate increased EDs, although increased DEBs have been reported.^{Bryon, Featured paper, 21} Reasons remain unclear regarding the decreased prevalence of EDs. It has been postulated that the notable lack of EDs may reflect the positive regular interactions of the patient with the CF care team in preventing EDs.^{Raymond, Featured paper}

Using the diagnostic criteria for EDs, Steiner, et al.²² identified CF patients with less than 75% ideal body weight. None met the criteria for AN or BN. Using a variety of diagnostic tools including the DISC, Raymond evaluated EDs and psychopathology in patients with CF.^{Raymond, Featured paper} Although some patients were diagnosed with psychiatric disorders, none were diagnosed with EDs. Scales administered to assess eating disordered thinking and behavior did not reveal abnormalities in the CF group greater than the nonCF group. The CF group had lower scores (indicating no EDs) for: drive for thinness; perfectionism; and body dissatisfaction. Bryon^{Featured paper} hypothesized that if, "when correctly measured EDs will occur at a higher rate in the CF population." Using the Child Eating Disorder Examination, no participant met full criteria for the diagnosis of AN or BN. The majority of subjects had weight just within the desirable BMI, yet a number were engaging in behaviors to lose weight or avoid weight gain. On self-evaluation, 8-13% reported the importance of shape and weight and denied low weight. One male was diagnosed with EDNOS; he met all of the criteria for AN with the exception of weight. In a reanalysis of the same population, Shearer²⁰ noted 5% of the subjects used compensatory behaviors such as exercising or misusing pancreatic enzyme replacement therapy (PERT) to facilitate weight loss. Six participants (11%) (none of whom were overweight) felt fat with one female reporting binge-eating.

Investigating body image, Truby, et al.¹⁷ used a structured interview with CF patients and controls (7-12 years of age), and found: subjects with CF were more satisfied with body image than controls; no differences in body dissatisfaction between girls and boys with CF; of girls with CF at or below 50th BMI percentile, 54% wanted to stay the same weight or be thinner; for girls with CF, body dissatisfaction was a significant predictor for BMI; for boys with CF, body dissatisfaction and body esteem were significant predictors of BMI. Using a mailed questionnaire to adults who had CF, Walters¹⁵ explored attitudes towards weight and diet. Women who had CF and were underweight perceived their weight as being greater and more likely used fewer enzymes than prescribed and less frequently used oral

REVIEW (CONT.)

calorie supplements. Men who had CF and who perceived their thin weight as normal demonstrated similar behaviors. Conversely, patients who correctly perceived themselves as underweight were more likely to use the correct dose of enzymes and oral supplements. Abbott¹⁴ compared actual, perceived, and desired shape/body mass and body satisfaction, eating behaviors and attitudes and self-esteem in a group of adults who had CF and a group of nonCF controls. The men with CF perceived their BMI as greater and desired to be heavier; conversely, females with CF perceived their BMI as less than it actually was but were happy with their perceived shape/weight. The control groups, especially females, were more preoccupied with food, and reported binge eating and vomiting. The CF group reported greater pressure on them by others to eat. Lower scores about body satisfaction and self-esteem were associated with increased issues with food and eating behavior. Abbott^{Featured paper} continued her work with adults and assessed the impact of nutritional interventions on patients' perceptions and behaviors concerning body image and eating. Patients who had feeding tubes were less satisfied with their body image and had lower self-esteem and quality of life.

CLINICAL APPLICATIONS

The RD holds a unique position on the CF team in identifying patients at risk for EDs. From the initial visit, the RD can highlight positive food and mealtime behaviors for the entire family and patient. At each subsequent visit, anticipatory guidance and advice can be offered. A trusting relationship, without prejudice, between the CF team members and the family and patient is imperative. This kind of mutual openness may encourage the patient and family to be comfortable in honestly discussing issues about food, eating, weight, and body image.

Although either EDs or DEBs may be considered, weight loss, inadequate weight gain, and/or loss of appetite need to be assessed in the context of the CF disease process itself, with the differential diagnosis including, but not limited to: CF-related diabetes, pulmonary exacerbation, hyperthyroidism, inflammatory bowel disease, neoplastic disorders, or celiac disease.^{21, 23} Additionally, patient behavior may reflect overzealous implementation of CF medical advice. For example, exercise may be advised as physical therapy. The patient, however, inadvertently may overdo the exercise prescription resulting in unintended weight loss.²¹ CF patients with suboptimal BMIs may be perceived by peers as having EDs or other illness.²⁴ Disclosure of CF may curtail negative peer perception.²⁴

In CF, EDs can occur. Gilchrist, et al. reported a 15 year old female who developed classic AN.²⁵ CF patients may not meet all of the criteria for EDs, but researchers did find patients who exhibited DEBs, such as limiting food intake or PERT use to control weight.^{Bryon, Featured paper, 21} Parents or friends may voice their concerns to the CF care team about changes in eating and/or exercise.²³ If DEBs are identified, members of the CF healthcare team can provide support in modifying behaviors and beliefs regarding eating, weight, and/or body image. When AN or BN is suspected the patient requires referral to and care by professionals skilled in the treatment of EDs. At that time, nutritional and medical management intertwines CF and ED care.

Patients may have abnormal body image.¹⁷ By learning more about a patient's perception of weight and body image, the RD may be able to respond proactively in preventing DEBs and in

designing realistic care plans. Adolescent girls who have CF are not excluded from the media driven ideal to be thin which makes discussions of health and healthy weight important.¹⁷ For adolescent boys who have CF, focusing on height and growth may foster greater adherence to nutrition recommendations.¹⁷ Patients who perceive their weight as being greater than they desire may attempt to control it by not using PERT as prescribed.²¹ Patients who have a realistic perception of body weight are more likely to follow PERT and oral caloric supplement recommendations.¹⁵ Increased pressure to eat is likely to be counterproductive if used alone. Greater pressure to eat is associated with lower self-esteem and body physique satisfaction. Placing a feeding tube in a patient who does not have a realistic perception of his/her weight may result in adherence challenges.^{Abbott, Featured paper}

Considering the continuum of DEBs to EDs, some authors have recommended screening for DEBs as a routine part of the annual CF nutrition assessment.^{Bryon, Featured paper; Abbott, Featured paper} An assessment of individual attitudes towards eating, weight, and shape might be an initial step in identifying those who may be at risk of DEBs.^{Raymond, Featured paper, 21} To provide optimal screening, a relationship built on trust between the CF team members and the patient is important, so that the patient feels comfortable in providing information and discussing issues surrounding weight and food in an open and honest manner.¹² At an appropriate age, seeing the patient without the parent may provide the opportunity for the patient to be more at ease in discussing eating and body image concerns. Although using a screening tool specific to CF is imperative, none is available. Consequently, the use of open-end questions in the context of motivational interviewing may provide sufficient information on which to base further conversations. Examples of questions include, but are not limited to: Are there any foods that you used to eat, but you don't eat anymore? Why did you change? Tell me how you feel about eating fatty foods. Do you ever stop eating before you are full? More examples of questions are provided by Setnick, but the RD must be cognizant of questions inappropriate for the patient who has CF.^{18, Abbott, Featured paper} Attention to parental comments about their own diet, weight, and exercise plus family eating behavior and patterns may help identify patients who could be at risk for DEBs or EDs.^{9, 26} If concerns are identified the RD and CF care team can address them in a nonjudgmental manner. This entails unbiased interaction about eating, weight, body image, and exercise. The focus is on helping the patient and family develop normal attitudes and behaviors towards weight, food, and exercise commensurate with increasing self-esteem through a focus on health and growth.¹⁴

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