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Review

Enteral tube feeding for individuals with cystic fibrosis: Cystic Fibrosis Foundation evidence-informed guidelines

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Abstract

Nutrition is integral to the care of individuals with cystic fibrosis (CF). Better nutritional status is associated with improved pulmonary function. In some individuals with CF, enteral tube feeding can be useful in achieving optimal nutritional status. Current nutrition guidelines do not include detailed recommendations for enteral tube feeding. The Cystic Fibrosis Foundation convened an expert panel to develop enteral tube feeding recommendations based on a systematic review of the evidence and expert opinion. These guidelines address when to consider enteral tube feeding, assessment of confounding causes of poor nutrition in CF, preparation of the patient for placement of the enteral feeding tube, management of the tube after placement and education about enteral feeding. These recommendations are intended to guide the CF care team, individuals with CF, and their families through the enteral tube feeding process.

Keywords: Cystic fibrosis; Enteral nutrition; Gastrostomy; Nasojejunal tube; Feeding tube

Abbreviations: CF, Cystic Fibrosis; COPD, Chronic obstructive pulmonary disease; CFRD, Cystic Fibrosis Related Diabetes; FEV, Forced Expiratory Volume; GER, Gastroesophageal Reflux; GERD, Gastroesophageal Reflux Disease; GT, Gastrostomy; NG, Nasogastric; NJ, Nasojejunal; PEG, Percutaneous Endoscopic Gastrostomy.

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Contents

1. Introduction

Optimal growth in children and weight status in adults are important in maintaining best possible lung function in CF [1–3]. Parents are taught the importance of good nutrition soon after diagnosis, and best practices dictate frequent reassessment of growth and weight through childhood and adulthood [4,5]. Many factors impede achievement of nutritional goals in people with CF [6]. When nutritional progress sufficient to ensure optimal lung function cannot be achieved, the CF Team, patient and family may consider enteral tube feeding to provide adequate nutrition for growth and weight maintenance. Although this strategy has been used and reported since the early 1980's, there are no large-scale clinical trials of enteral tube feeding in individuals with CF. Nonetheless, small single center retrospective studies have demonstrated improved weight gain and some suggest improved pulmonary function [7–19].

The purpose of this guideline is to provide the CF Team with information critical to the use of enteral feeding tubes, including criteria for recommending enteral tube feeding, assessment of confounding causes of poor nutrition, preparation for placement of the enteral feeding tube, and management of the tube after placement. Education of patients and family caregivers on enteral feeding tubes is important throughout the lifespan, to ensure that they are active participants in this important choice.

Finally, the term "enteral feeding tube" may include gastrostomies (GT) (surgical, percutaneous endoscopic gastrostomy (PEG), radiographic insertion), gastrojejunal tubes, nasoenteral tubes (nasogastric (NG), nasojejunal (NJ)), or surgically-placed jejunal tubes for administration of feeding. Where the literature refers to a specific form of enteral feeding tube, that term is used.

2. Methods

The CF Foundation (CFF) invited a multidisciplinary team, including pediatric and adult dietitians, gastroenterologists, pulmonologists, a clinical psychologist, social worker, nurse, parent of a child with CF, and an individual with CF to participate in the development of these consensus guidelines. The committee met on March 24, 2015 at the CFF National Office in Bethesda, Maryland to determine the PICO (Population Intervention Control Outcome) questions, structured clinical questions that are used to guide a literature search. The committee was divided into three workgroups: shared decision making, enteral feeding tube management, and management after placement. These workgroups established the PICO questions for their topics. The committee discussed and, when needed, revised the questions prior to accepting the PICO questions.

The workgroups determined MeSH (Medical Subject Headings) and key terms for the PICO questions. These terms were used to search Medline using the OVID database at Dartmouth.

The literature search resulted in 1080 unique citations, and committee members found an additional 77 titles. After de-duplication, the workgroups reviewed the 1138 unique titles and selected articles relevant to the PICO questions; 421 abstracts were selected for further review; 238 full articles were reviewed. An additional 3 articles were added after the public comment period. The workgroups developed draft recommendation statements to address the PICO questions.

The committee reconvened in September 2015 to revise and adopt the draft recommendation statements presented by the workgroup. The committee established an a priori voting threshold of 80% agreement. All statements reached 100% agreement.

In January 2016, the draft manuscript was distributed for a two week public comment period. The committee reviewed and responded to the public feedback and revised the manuscript as appropriate. One statement was revisited after public comment, and the committee re-voted on the revised statement.

3. Discussion of consensus statements

1. The CF Foundation recommends enteral tube feeding as a means to improve age-dependent anthropometrics in individuals with CF that are unable to consume adequate calories and protein to meet growth/weight maintenance goals, despite appropriate evaluation and intervention by a multidisciplinary team.

There are no randomized clinical trials to inform decisions regarding enteral tube feeding and CF, however, multiple retrospective studies suggest that its use can improve age-dependent anthropometrics [7–18,20]. Age-dependent anthropometrics include weight/age percentile, length/age percentile and weight-for-length percentile for 0–2 years; weight/age percentile, stature/age percentile and body mass index (BMI) percentile for 2–20 years; and BMI value for adults [21–23]. Enteral tube feeding can be offered as a means of meeting calorie goals to achieve optimal weight gain when other strategies are not sustainable or successful but should be presented when there is a chance of success; enteral tube feeding is generally not successful at end of life.