Appetite 123 (2018) 1–6

Contents lists available at ScienceDirect

Appetite

journal homepage: www.elsevier.com/locate/appet

Characteristics of feeding tube dependency with respect to food aversive behaviour and growth

Markus Wilken [a,*], Peter Bartmann [b], Terence M. Dovey [c], Soyhan Bagci [b]

[a] *Institute for Pediatric Feeding Tube Management and Weaning, Siegburg, Germany*
[b] *Department of Neonatology, University of Bonn, Bonn, Germany*
[c] *Division of Psychology, Department of Life Sciences, Marie Jahoda Building, Brunel University London, Uxbridge, UB8 3PH, United Kingdom*

A R T I C L E I N F O

Article history:
Received 22 February 2017
Received in revised form
17 November 2017
Accepted 27 November 2017
Available online 2 December 2017

Keywords:
Tube feeding
Enteral nutrition
Feeding and eating disorders of childhood
Growth faltering
Gastrostomy

A B S T R A C T

The use of feeding tubes in pediatric medical procedures and management has dramatically increased over the last three decades. With this increase, the prevalence of Feeding Tube Dependency (FTD) – a reliance on enteral feeding following medical recovery due to lack of oral intake of nutrition, despite being able to eat– has increased too. It has been suggested, that cases with FTD show avoidant feeding behaviours such as food refusal, gagging or swallowing resistance, but evidence for this hypothesis is scarce. In a German population of 146 cases requesting feeding tube dependency treatment between 2005 and 2008 the frequency of occurrence of avoidant behaviour in FTD cases has been evaluated and was correlated to growth. The study includes children under 50 months of age being tube fed for at least three months. Parents received the Anamnestic Questionnaire for Feeding Disorder and Tube Weaning (AFT), which evaluates nutritional supply, tube feeding, feeding disorder symptoms, medical diagnosis, growth and psychosocial variables. The study group was comprised of 101 children (50 male, 51 female), with a median age of 15 months (IQR: 10–26.5) and a median tube feeding duration of 13 months (IQR: 8–27). The most prevalent medical diagnoses were congenital malformations ($n = 51$) and prematurity ($n = 27$). Parents reported daily symptoms of food aversion through all age groups, like food refusal 2 (IQR: 1–3), gagging 1 (IQR: 0–3), vomiting 1 (0.1–2) and total symptoms 6 (5–11). Vomiting was negatively correlated with weight and length percentile and head circumference. Cases with FTD show frequent and persistent food avoidant behaviors, which may be explain the need for specific psychological treatment during transitioning from tube dependency to oral eating.

1. Introduction

When infants are unable to meet their nutritional requirements orally, a feeding tube is a safe procedure for nutrition and fluid supplementation (Gottrand & Sullivan, 2010; Avitsland et al., 2006). Despite the need for placing the tube, transferring onto, or back to, oral feeding is not necessarily automatic (Dunitz-Scheer et al., 2009; Kindermann et al., 2008; Wilken, Cremer, Berry, & Bartmann, 2013; Wright et al., 2011). Khalil et al. (2016) reported, that only 33% of infants which were discharged with a feeding tubes after NICU treatment, were full orally fed at age 6 months. Even when children are considered to be ready to transfer to oral feeding, they often remain dependent on the feeding tube for months or even years (Pediatric Society New Zealand, 2013). Feeding Tube Dependency (FTD) has been defined, as the reliance on a feeding tube to provide nutrition support to ensure growth and/or sustenance to aid recovery and/or maintain developmental trajectory despite being able to eat orally (Dovey, Wilken, Martin, & Meyer, 2017; Dunitz-Scheer et al., 2009). FTD has been included as a psychological disorder under the diagnostic criteria of avoidant/restrictive food intake disorder (ARFID) in the Diagnostic and Statistical Manual version 5 (2013).

Due to the relative novelty and recent addition to diagnostic manuals, limited evidence on the presence of food avoidance in children with FTD is available within the scientific literature (Dunitz-Scheer et al., 2009). Early data from this emerging field of

Abbreviation: AFT, Anamnestic Questionnaire for Feeding Disorder and Tube Weaning; ARFID, Avoidant/Restrictive Food Intake Disorder; FAS, Feeding Adversity Scale; FTD, Feeding Tube Dependency; PEG, Percutaneous endoscopic gastrostomy; NG, Nasogastric; OMS, Oral Motor Scale; SD, Standard Deviation; SES, Socioeconomic Status.

* Corresponding author.
E-mail address: mail@markus-wilken.de (M. Wilken).

https://doi.org/10.1016/j.appet.2017.11.107
0195-6663/

study suggests that there is no hunger-motivated drive to eat within FTD children, due to enteral feeding via tube (Kindermann et al., 2008). Furthermore, some FTD treatment studies have reported avoidant feeding behaviours that are maintaining the disorder (Wilken et al., 2013; Wilken & Bartmann, 2014; Silverman et al., 2013). With each specialist service located in a specific geographical region, published studies on children with tube dependency often contain small sample sizes and behavioural variables are rarely assessed, therefore data on this condition is limited (Sharp, Volkert, Scahill, McCracken, & McElhanon, 2017).

The primary goal of tube feeding is to maintain the growth trajectory (Avitsland et al., 2006; Gottrand & Sullivan, 2010) and/or mitigate excessive weight loss of the medically vulnerable child. It has been shown that the use of feeding tubes does not aid in the improving growth trajectories in the form of catch up gains (Di Maria et al., 2013). One possible explanation to the lack of catch-up growth is stress (Porges, 2001). Children with aversive feeding behaviour experience high levels of permanent stress (Wilken & Bartmann, 2014; Zangen et al., 2003). If children with FTD suffer from food aversion, without appropriate psychological intervention, it may result in a in inadvertent reinforcement of the aversive behaviour to food and increasing the risk of growth faltering (Nicolaides, Kyratzi, Lamprokostopoulou, Chrousos, & Charmandari, 2015). In summary, there is a need for more data exploring the behavioural characteristics of children with FTD and to examine a possible impact on the growth of the child.

The present study was set out to examine a large cohort of children referred to Feeding Tube Dependency treatment. The first aim was to assess if food avoidant behaviours were present in children with FTD and how often these were observed. A second hypothesis considered whether food avoidant symptoms were related to age or method of enteral feeding. The third hypothesis was whether the presence and severity of FTD would be negatively associated with growth and weight gain even in case of nutritional supply via tube.

2. Method

2.1. Participants & procedures

Parents or hospital services in Germany referred patients with FTD to the Institute for Pediatric Feeding Tube Management and Weaning. This is a specialist service designed to treat children with the FTD variant of ARFID. On admission to the program, the parents completed the Assessment Questionnaire for Feeding Disorder and Tube Weaning (AFT) (Wilken & Jotzo, 2004), as well as a parental informed consent form. Parents were also required to bring their child's full medical history to the first referral meeting. Between January 1, 2005 and June 1, 2008 146 children were recruited to take part in the study.

Inclusion criteria were as follows: Enteral feeding via tube for a minimum of 3 months.

Exclusion criteria included the following: The child was full oral feeding at referral, were receiving parenteral nutrition, did not have a tube fitted, aged over 50 months of age, parents were non-German or non-English native speakers, or either parent had or were currently suffering from a serious psychiatric condition.

The Research Ethics Board of Bonn University Hospital provided written approval of the protocol.

2.2. Measures

Medical Diagnoses: The medical diagnoses were taken from the medical records of the child delivered to the centre at referral. Only those medical diagnoses that met the ICD 10 international standards and were substantiated through standardized tests were included in the study.

The AFT-Questionnaire is a 145 item composite questionnaire designed by Wilken and Jotzo (2004) as a clinical assessment instrument for children with AFRID as well as with FTD. The revised version (Wilken & Jotzo, 2009) of the questionnaire have been used as outcome measurement for tube weaning service (Wilken et al., 2013). To obtain as much relevant data to assess readiness for wean, it had been design in six separate sections: 1. Feeding tube data, 2. Growth and nutrition, 3. Oral motor scale, 4. Feeding adversity scale, 5. Frequency of food aversive behaviour and 6. Parent socioeconomic status. In the following sections, each of the sections will be discussed.

Tube feeding data were gathered regarding the patients' tube feeding characteristics for inclusion in the analysis. The section contained 22 items measured by open ended short answer questions. This category included: questions concerning the placement of the feeding tube; date of tube placement; daily nutritional and fluid supply. Parent were asked to report the ratio of tube to oral feeding were regard to nutrition and fluids. This approach was undertaken to show if any of the children were consuming at least part of their nutrition orally. The higher the percentage of nutrition and fluids fed via tube the lower the percentage of oral intake. Therefore, the percentage of the calories consumed orally vs. Supplemented via tube would be taken as one indicator for the level of FTD the child exhibited at referral.

Growth and Nutritional data related to birth weight and gestational age were retrieved from the medical reports. Body length and weight were taken by the referring physician. Body length, weight and age-appropriate BMI were matched with standardized national percentiles (Kromeyer-Hauschild et al., 2001).

Oral Motor Scale (OMS) contained 22 items and was completed using a four point Likert-scale. Parents providing answers to questions regarding swallowing ability and safety as well as motor and oral-motor competencies of their child sufficient for oral feeding. The OMS was specifically designed to provide insight to oral motor competence independent from actual performance. Mean values of 1.0–1.9 would indicate no, 2.0–2.9 moderate, and 3.0–4.0 severe lack of oral motor and swallowing competencies.

Feeding Adversity Scale (FAS) contained 14 items asking parents to provide details on their child's feeding behaviour. Originally designed to assess food aversive behaviors of premature infants (Wilken, 2008), it has shown to be a reliable and valid instrument for children with FTD (Wilken et al., 2013). Answers were provided on a 4-point Likert-scale. Mean values of 1.0–1.9 would indicate no food aversion, 2.0–2.9 moderate, and 3.0–4.0 sever food aversion.

Frequency of occurrence of food aversion behaviours. Parents were asked to report the frequency of food refusal, vomiting, gagging, force-feeding, bizarre eating habits, and swallowing resistance per day, months or week. Parents were asked how many mealtimes they offered orally and how long a mealtime takes on average. If the symptoms occurred weekly or monthly, the total sum of the symptoms was converted to a daily occurrence. The total of avoidant behaviours was calculated as the mean sum of avoidant behaviours per day.

Parental socioeconomic data considered the Parents' age, education, occupation, employment status, and family household income, as well as the family structure. The socioeconomic data were used to compute the Hollingshead Four Factor Index for each family (Hollingshead, 1975).

2.3. Data analysis

Data were analysed using SPSS for Windows, version 22.0 (IBMSPSS, Chicago, IL). We tested normal distribution with the