Prevalence and side effects of pediatric home tube feeding

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SUMMARY

Background & aims: Tube feeding ensures growth, but can have negative effects on health and psychosocial functioning, resulting in health related costs. The aims of this study were to determine the prevalence of pediatric home tube feeding in the Netherlands and to assess the clinical characteristics of tube fed children and side effects of tube feeding.

Methods: The prevalence of pediatric home tube feeding was calculated using data (2010–2014) of both the Medicines and Devices Information Project of the National Health Care Institute, and Statistics Netherlands. Subsequently, a cross-sectional parental online questionnaire was used to obtain data regarding clinical characteristics of tube fed children and side effects of tube feeding. Children aged ≤17 years receiving tube feeding ≥2 weeks were included.

Results: The prevalence of pediatric home tube feeding was 83–92:100,000 children/year. Parents of 279 children (53% boys) completed the questionnaire. Most children (88%) had ≥1 medical diagnosis, of which congenital abnormalities (42%), perinatal problems (38%) and neurologic diseases (16%) were most common. They had gastrostomy (60%), nasogastric (33%), or other tube types (7%). Parents of most children (74%) mentioned ≥1 side effect due to tube feeding. Vomiting (37%), lack of appetite (29%), and gagging (29%) were reported most frequently. Nasogastric tube placement resolved in negative experiences (94%).

Conclusions: The prevalence of pediatric home tube feeding varies between 83 and 92:100,000 children/year in the Netherlands. These children are characterized by various underlying medical diagnoses. Side effects of tube feeding are frequently reported by parents. Further studies should focus on methods reducing side effects.

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1. Introduction

Tube feeding, also called enteral feeding, sustains life and ensures growth in children who are malnourished, or unable to eat and drink, by providing the nutritional requirements by a feeding tube [1]. Since various groups of children are at risk for malnutrition, the indications for tube feeding include a wide range of conditions, such as prematurity, neurological disorders, and cardiorespiratory disorders [2–4]. Besides the beneficial effects, tube feeding formula, or the tube itself, can contribute to negative effects. These may include health (complications or side effects such as aspiration, gagging, vomiting, infections, a difficult transition to oral feeding), psychosocial (for example parental distress, impaired interaction between parents and child), and economy-related effects (for the tubes, formula, tube care, and complications) [4–11].

When tube feeding is required for longer periods (months to years), home tube feeding can be beneficial for patients and families [12]. The prevalence of home tube feeding increased in most developed countries since it was first practiced, due to improved tubes, gastrosomy procedures, and organization of home care [12–14]. In addition, home tube feeding also became more available worldwide, which is thought to be the result of increased
community based care. Prevalence and incidence rates seem to be related to the gross domestic product and health care budgets, and therefore differ widely between countries [15].

To our knowledge, epidemiological data regarding pediatric home tube feeding in the Netherlands have not been published. Therefore the primary aim of this study was to determine the prevalence rates of home tube feeding in the pediatric population in the Netherlands. Secondary aims were to assess the clinical characteristics of these home tube fed children and possible side effects of tube feeding.

2. Materials and methods

2.1. Participants and procedure

The study consisted of two parts. Firstly, we used the Medicines and Devices Information Project databank (“Genees- en hulpmiddelen Informatie Project”; GIP databank) of the National Health Care Institute (“Zorginstituut Nederland”) to obtain data of tube fed children in the Netherlands [16]. In the Netherlands, all citizens (including children) are obliged to have a health insurance. The Health Insurances supply data to the National Health Care Institute, which checks, corrects, and registers these in the GIP databank [16]. The amount of children receiving tube feeding formula at home amongst various age and gender categories were extracted from the GIP databank for the years 2010–2014. We calculated the prevalence rates of pediatric home tube feeding in the Netherlands by combining these data with population related data per age category of the Statistics Netherlands (“Centraal Bureau voor de Statistiek”), which is an independent administrative body, performing governmental tasks, financed by the State Budget [17].

Secondly, in a cross-sectional survey we collected data of children receiving home tube feeding nationwide, aiming to determine the clinical characteristics of these children and the side effects of tube feeding. We recruited parents with tube fed children by using an advertisement in several patient associations newsletters, medical nurseries and online communities for parents of tube fed children. The advertisement contained a digital link to both a letter, medical nurseries and online communities for parents of tube fed children. The advertisement contained a digital link to both a letter, which outlined the purpose and procedure of the study, and a self-designed web based questionnaire containing 27 items. All Dutch children between 0 and 17 years of age, receiving feeding by a tube for ≥2 weeks were included. Parental informed consent of all patients was obtained.

2.2. Measures

The questionnaire (see Supplementary 1), completed by the parents of tube fed children, provided data on sex, age category, gestational age, birth weight, medical conditions, primary indication for tube feeding, age of onset of tube feeding, total duration of tube feeding, type of tube (gastrostomy, nasogastric, duodenal or other tube), type of feeding via tube (infant formula, tube feeding, blended diet), the amount of tube feeding per day (in milliliters), timing of tube feeding, route of administration, side effects, percentage of oral intake (both eating and drinking), medication administered by tube, involved healthcare professionals, tube dependency, and if applicable attempted weaning methods. In case children had a nasogastric tube, the questionnaire included questions regarding who replaces the tube (parents, home care, emergency room/hospital), and how the child experiences this procedure.

2.3. Definitions

We used the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10 Version: 2016) to categorize medical conditions. The categorizations of the ESPGHAN Committee on Nutrition were used to describe the primary indication for tube feeding, such as treatment for Crohn’s disease, disorders of digestion and absorption, disorders of gastrointestinal motility, increased nutritional requirements and losses, metabolic diseases, growth related (wasting, stunting, chronic malnutrition, growth failure), and insufficient/inadequate oral intake [4]. We added the category ‘delivery of medications’.

We categorized the reported experiences considering nasogastric tube replacement in four categories: traumatic (including Dutch terms for dramatic, awful, traumatic, very annoying, terrible, crying, arching, sad, resistance, passing out, panicking, fearful), unpleasant (including Dutch terms bothersome, annoying, tolerable, unpleasant, shortly distressing, angry), no problems, or alternating experiences (from unpleasant and traumatic to not problematic).

Prematurity was defined as gestational age <37 weeks. Small for gestational age was defined as birth weight ≤ p10, according to The Netherlands Perinatal Registry (“Stichting Perinatale Registratie Nederland”) [18].

Tube dependency was defined as receiving tube feeding even though the primary indication for the tube feeding did no longer exist.

2.4. Statistical analysis

Normality was tested using both eye balling and the Shapiro–Wilk Test. Non normal distributed data were described as median and interquartile ranges (IQR). The Fischer’s exact test was used to compare binary data of ≥2 groups. Bootstrapped confidence intervals (Bca CI 95%) were generated based on 1000 samples to enable comparing results with other studies. All statistical analyses were carried out using SPSS 23 (IBM SPSS Statistics 23).

2.5. Medical ethics

The Medical Ethics committee of the Academic Medical Center in Amsterdam, the Netherlands, confirmed that the Medical Research Involving Human Subjects Act does not apply to the present study.

3. Results

3.1. Prevalence

The prevalence of children receiving home tube feeding in the Netherlands was 84-92-91-84-83 per 100,000 children per year during the period 2010–2014 respectively. As depicted in Fig. 1, the peak prevalence of tube feeding was at one year of age. Thereafter, the prevalence decreased with increasing age.

3.2. Characteristics of tube fed children

Parents of 347 tube fed children completed the questionnaire of whom 279 were included in this study. A total of 68 patients were excluded, because they did not fulfill the inclusion criteria; currently no tube feeding ≥2 weeks (n = 64), age ≥18 years (n = 1), citizen of another country (n = 1), lack of informed consent (n = 2).

Demographics and characteristics of tube fed children are shown in Table 1. Most children were amongst age categories 0–3 years (50.9%). Despite requiring a tube, 11.1% of the children had no medical diagnosis. The ICD-10 categories of the children whose parents reported medical diagnoses (n = 244 [87.5%]; missing data n = 4) are depicted in Table 2. The children were treated by several healthcare professionals (see Table 3).
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