



## Original article

## 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  $\leq 17$  years receiving tube feeding  $\geq 2$  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  $\geq 1$  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  $\geq 1$  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, gastrostomy 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

**Abbreviations:** GIP databank, Medicines and Devices Information Project databank (“Genees- en hulpmiddelen Informatie Project”); IQR, interquartile range; PEG, percutaneous endoscopic gastrostomy.

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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 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, 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  $\geq 2$  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 health care 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 gastro-intestinal 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  $\leq p10$ , 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  $\geq 2$  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  $\geq 2$  weeks ( $n = 64$ ), age  $\geq 18$  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](#)).

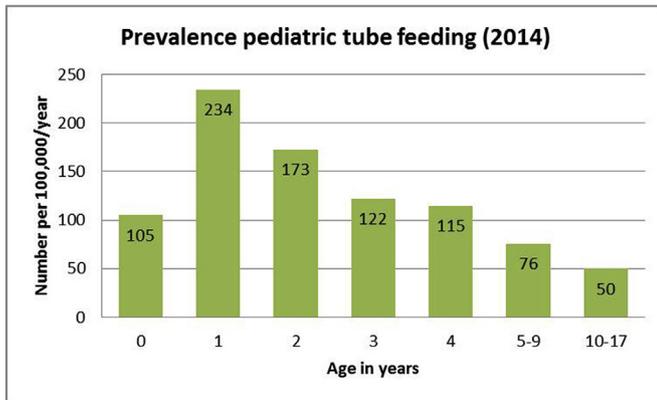


Fig. 1. Prevalence of pediatric tube feeding per age category.

Table 1  
Demographics and characteristics.

Demographics and characteristics of tube fed children	
	n (%)
Male	148 (53)
≥1 medical diagnosis <sup>a</sup>	244 (87.5)
Age category in years	
0	24 (8,6)
1	44 (15,8)
2	41 (14,7)
3	33 (11,8)
4	29 (10,4)
5–9	62 (22,2)
10–17	46 (16,5)
	Median (IQR)
Gestational age <sup>b</sup> , weeks	38.57 (36.57–39.86)
Birth weight <sup>c</sup> , grams	3000 (2305–3500)

<sup>a</sup> Missing data n = 4.

<sup>b</sup> Missing data n = 6.

<sup>c</sup> Missing data n = 10.

### 3.3. Tube and tube feeding characteristics

Parents considered the following primary indications for tube feeding (missing data n = 1): inadequate oral intake (n = 163; 58.4%), growth failure or chronic malnutrition (n = 66; 23.7%), increased nutritional requirements and losses (n = 24; 8.6%), metabolic diseases (n = 9; 3.2%), disorders of gastrointestinal motility (n = 8; 2.9%), medication (n = 5; 1.8%), or disorders of digestion and absorption (n = 3; 1.1%). The feeding tube was used for the delivery of medications in 79.9% (primary indication n = 5; additionally n = 218; missing data n = 1) of the children.

Onset of tube feeding was more frequently at young ages (see Fig. 2 and Table 4), including 86 children (31.5%) with tube feeding since birth. Characteristics of the tube and tube feeding are shown in Table 4.

### 3.4. Side effects of tube feeding and experiences of tube replacement

Parents of most children (73.5%) considered ≥1 side effects as result of tube feeding (see Table 5).

Most of the children were able to drink (n = 174; 62.4%) or eat (n = 168; 60.2%) themselves. A total of 199 of parents (73.7%; missing data n = 9) reported that their child is eating ≤25% of the total daily nutritional intake themselves.

Table 2  
Medical diagnoses.

Categories ICD-10 Version: 2016 classification	n (%) <sup>a</sup>	Bca 95%CI
Congenital malformations, deformations and chromosomal abnormalities	118 (42.3)	37.3–48.3
Certain conditions originating in the perinatal period	107 (38.4)	33.3–43.0
Prematurity <sup>b</sup>	73 (26.4)	22.1–31.5
Small for gestational age <sup>c</sup>	55 (19.7)	15.8–24
Diseases of the nervous system	45 (16.1)	12.2–20.8
Diseases of the digestive system	40 (14.3)	10.8–18.3
Endocrine, nutritional and metabolic diseases	33 (11.8)	8.6–15.1
Mental and behavioral disorders	22 (7.9)	5.4–10.4
Symptoms, signs and abnormal clinical and laboratory findings <sup>d</sup>	13 (4.7)	2.5–7.2
Diseases of the respiratory system	12 (4.3)	2.5–6.5
Diseases of the eye and adnexa	9 (3.2)	1.4–5
Diseases of the musculoskeletal system and connective tissue	8 (2.9)	1.4–4.7
Diseases of the genitourinary system	8 (2.9)	1.4–4.4
Diseases of the ear and mastoid process	7 (2.5)	1.1–3.9
Diseases of the circulatory system	7 (2.5)	0.7–4.3
Factors influencing health status and contact with health services <sup>e</sup>	7 (2.5)	1.1–3.9
Neoplasms/malignancy	5 (1.8)	0.4–3.6
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	5 (1.8)	0.4–3.6
Infectious and parasitic diseases	2 (0.7)	0–2.1

<sup>a</sup> Percentages are described as percentage of total patients (n = 279). As parents were able to report several medical diagnoses, the total does not equal 100%.

<sup>b</sup> Prematurity was defined as gestational age <37 weeks.

<sup>c</sup> Small for gestational age was defined as birth weight ≤ p10.

<sup>d</sup> Including higher energy needs (n = 1), ataxia (n = 2), disturbed gastrointestinal passage (n = 1), disturbed swallowing (n = 3), hypotonia (n = 2), enuresis not otherwise specified (n = 1), hyperventilation (n = 1), food refusal (n = 1), bi-lateral spasm without diagnosis (n = 1).

<sup>e</sup> Including a personal history of allergy to drugs, medicaments and biological substances (n = 6) and shaken baby syndrome (n = 1).

We found no statistical difference between receiving a blended diet alone or combined with other tube feeding versus other types of tube feeding considering the proportion of children with gagging (p = 0.435) or vomiting (p = 0.627). Neither was there a statistical difference between children with a nasogastric tube and other types of tubes regarding the proportion of children with gagging (p = 0.092) or vomiting (p = 0.191). When children had a nasogastric tube (n = 93), replacement was performed by home care (n = 74; 81.3%), in the hospital (n = 32; 35.2%), by parents (n = 20; 22%), the child itself (n = 2; 2.2%) and/or at the medical nursery (n = 1; 1.1%), or unknown (n = 2). Parents of children having a nasogastric tube (n = 93; missing data n = 3) described tube replacement as traumatic (n = 51; 56.7%), unpleasant (n = 28; 31.1%), not problematic (n = 7; 7.8%), or alternating experiences by tube replacements (from traumatic or unpleasant to not problematic) (n = 4; 4.4%).

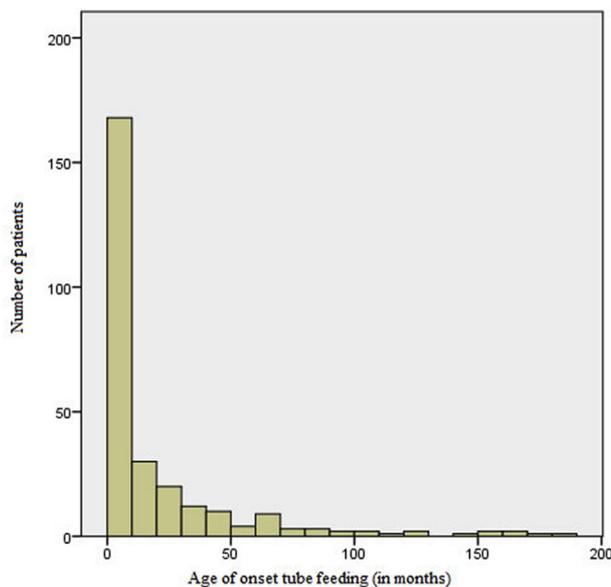
We assessed differences between timing of tube feeding (including at night, daytime, both and else) and schedule (including one bolus, multiple boluses, continuously, combination and else) with the following general side effects: nausea (p = 0.207 and p = 0.675 respectively), gagging (p = 0.089 and p = 0.528 respectively), vomiting (p = 0.034 and p = 0.861 respectively), lack of appetite (p = 0.144 and p = 0.418 respectively), and oral intake (p = 0.000 and p = 0.657 respectively). Only the differences between the timing of tube feeding with vomiting (p = 0.034) and oral intake (p = 0.000) were statistically significant.

By assessing differences for the subdivisions timing of tube feeding only at night compared to not only at night (including daytime, both and else), and only at daytime compared to not only at daytime (including at night, both and else) with regard to both

**Table 3**  
Health care workers.

Health care worker	n (%)
<i>Medical</i>	
Pediatrician	265 (95.0)
Rehabilitation physician	121 (43.4)
General practitioner	76 (27.2)
Neurologist	37 (13.3)
Cardiologist	22 (7.9)
Gastroenterologist	18 (6.5)
Orthopedic surgeon	14 (5.0)
Ear nose throat specialist	10 (3.6)
Ophthalmologist	10 (3.6)
Surgeon	8 (2.9)
Nephrologist	8 (2.9)
Metabolic specialist	7 (2.5)
Pulmonologist	7 (2.5)
Urologist	7 (2.5)
Oncologist	4 (1.4)
Other medical specialists	19 (6.8)
<i>Paramedical</i>	
Dietician	212 (76.0)
Physiotherapist	178 (63.8)
Speech therapist	173 (62.0)
Occupational therapy	100 (35.8)
Child's life specialist	58 (20.8)
Psychologist	36 (12.9)
<i>Alternative medicine</i>	
Osteopath	12 (4.3)
Complementary medicine	10 (3.6)
Other	11 (3.9)
<b>Total</b>	<b>279 (100)</b>

vomiting as oral intake, we found that vomiting occurred in 20% (8/40) of the children who were only tube fed at night, while it occurred in 39% (94/239) of the children not only fed at night, which is statistically significant ( $p = 0.021$ ). Furthermore, there was a statistically significant difference between oral intake and feeding only at daytime versus not only at daytime ( $p = 0.033$ ), as well as between only at night versus not only at night ( $p = 0.000$ ). Children tube fed only at daytime had oral intake themselves in 55% (64/117), children not only tube fed in daytime had oral intake

**Fig. 2.** Onset of tube feeding.  
\*missing data n = 6.**Table 4**  
Tube and tube feeding characteristics.

	n (%)
<i>Type of tube</i>	
Gastrostomy tube	164 (58.8)
Nasogastric tube	93 (33.3)
Duodenal tube	6 (2.2)
Jejunostomy tube	3 (1.1)
Jejunal tube	2 (0.7)
Other	11 (3.9)
<i>Type of tube feeding</i>	
Tube feeding formula	191 (68.5)
Infant formula/breast feeding	60 (21.5)
Blended diet	14 (5.0)
Combination of above	6 (2.2)
Only water	4 (1.4)
Other	6 (2.2)
<i>Tube feeding schedule<sup>a</sup></i>	
Bolus feeding	198 (71)
Continuously	60 (21.5)
Both bolus feeding and continuously	18 (6.5)
One bolus	2 (0.7)
<i>Tube feeding delivered at</i>	
Daytime	117 (41.9)
Evening/night	40 (14.3)
Both	121 (43.4)
Other	1 (0.4)
	<b>Median (IQR)</b>
Age at onset of tube feeding, months <sup>b</sup>	4 (0–23.5)
Duration of tube feeding, months <sup>c</sup>	24 (12–48)

<sup>a</sup> Missing data n = 1.<sup>b</sup> Missing data n = 6.<sup>c</sup> Missing data n = 35.

themselves in 68% (110/162). Children tube fed only at night had oral intake themselves in 98% (39/40), children not only tube fed at night had oral intake themselves in 56% (135/239).

Hundred parents (35.8%) thought their child was tube dependent (see methods for definition). Of these patients, 47% were treated for tube dependency in the past or present to facilitate the transition from tube to oral feeding by several methods, including appetite inducing methods as well as behavioral methods.

#### 4. Discussion

This study shows prevalence rates of home tube feeding in the Netherlands between 83 and 92 per 100,000 children/year (2010–2014). These children are characterized by various underlying medical conditions, treated by many different health care professionals. Side effects of tube feeding and negative experiences due to tube replacements are frequently reported by parents.

**Table 5**

Side effects.

General side effects; n = 279	n (%) <sup>a</sup>
Vomiting	102 (36.6)
Lack of appetite	80 (28.7)
Gagging	80 (28.7)
Nausea	73 (26.2)
Coughing	51 (18.3)
Arching	18 (6.5)
Stomy related side effects; n = 177	n (%)
Skin irritation	61 (34.5)
Fibroma	56 (31.6)
Infection	23 (13.0)

<sup>a</sup> Considering several side effects co-occurring the total does not equal 100%.

To our knowledge, this is the first study assessing the prevalence of pediatric home tube feeding in the Netherlands. Epidemiological data amongst other European countries are limited. The Polish Society for Clinical Nutrition of Children sent retrospective questionnaires to all Polish regional centers ( $n = 14$ ) providing pediatric home tube feeding. Each center responded and 433 children received tube feeding on January 1st and 525 on December 31st in 2010, representing prevalence rates of 1.134 and 1.375 per 100,000 inhabitants (both children and adults) respectively [19]. The British Artificial Nutrition Survey, a committee of the British Association for Parenteral and Enteral Nutrition, found 1336 children up to 16 years receiving home tube feeding in the United Kingdom in 2010. The prevalence was not described as total of the population. They relied on reporting centers, and described a decreasing number of reporting centers. Therefore, data were incomplete, and under registration of home tube fed children seems likely [20]. In Spain, 529 pediatric patients were registered between 2003 and 2007 in the online Register of Pediatric Outpatient and Home Enteral Nutrition kept by the Spanish Society for Gastroenterology, Hepatology and Pediatric Nutrition. They described the prevalence of pediatric home tube feeding to remain unknown, because data were biased due to a small number of centers including patients [21]. A study from the Italian Society for Parenteral and Enteral Nutrition, in which regional coordinators recorded all ongoing cases of home tube feeding in April 2005 by a structured questionnaire, a prevalence of 0.84 children ( $\leq 18$  years) per 100,000 inhabitants was found [22]. The prevalence rates of the former described studies are difficult to compare with ours, because different methods were used to report the amount of children receiving tube feeding. Only one study, from Italy, described the prevalence rate comparable to ours. Data of patients entering a home tube feeding program were analyzed retrospectively. Using national data from the Institute of Statistics, they assessed a prevalence rate of 3.47 per 100,000 children ( $\leq 18$  years) in 2009 [23], which is far lower than our prevalence rate.

It is unclear why the prevalence of pediatric home tube feeding varies substantially amongst European countries. In accordance with earlier explanations we hypothesize that differences are explained by underestimations of home tube feeding in other countries due to the retrospective designs of studies or the need for active registration [20,21]. Unfortunately, only patients receiving tube feeding formula were included in the GIP database (children receiving infant formula/breast milk, blended diet or water by the tube were not). Therefore, it is likely that we missed patients, especially amongst the youngest age category (0 years), which would explain the relatively low prevalence amongst this age-group. This seems reasonable in the light of a study from the United Kingdom where infants and young children were a substantial group of home tube fed children (69% of the 448 home tube fed children up to 16 years were  $< 2$  years of age) [20], and our own survey (24.4% of 279 tube fed children were  $< 2$  years of age). Therefore, we hypothesize that the real prevalence of home tube feeding in the Netherlands is even higher than the reported 83–92 per 100,000 children/year. Another difference amongst European countries is the reimbursement for tube feeding. In contrast to some other countries, tube feeding formula is completely reimbursed by the health insurances, while regular infant feeding has to be paid by the parents. Therefore, a pursuit of tube feeding may be caused for financial benefits. This, however, may be very difficult to determine and reveal.

Some interesting results were found analyzing our questionnaires completed by parents of tube fed children. Firstly, we found most of the children to be diagnosed with congenital malformations, perinatal diseases and neurologic conditions. According to a French study, the most common indications extracted from medical

charts for children up to 18 years receiving home tube feeding, were digestive disorders (35%) and neurological/muscular disorders (35%) [2,12]. In Poland, tube feeding was indicated for neurological disorders (64.2%) most frequently [19]. Those differences between patient characteristics can be due to different populations, but might also indicate an over- or underrepresentation of certain groups of children in our or other studies [21]. Differences might as well be explained by different methods of collecting data (by health care professionals or parents).

Three quarter of parents reported side effects of the tube feeding. The study of Pahsini et al. analyzing the parental perspective of side effects due to tube feeding, found that 87.3% of the 425 tube fed children entering a tube weaning program experienced side effects [24]. Although parents might misinterpreted the causality of these complaints, these high numbers emphasize the need for specialized care for tube fed children, and further research to reduce side effects. Neither a nasogastric tube nor a blended diet correlated significantly with demonstrating gagging or vomiting in our study. However, considering the small amount of children receiving blended diet, these findings should be interpreted with caution. Furthermore, we did not study the severity of gagging and vomiting (instead of only the presence yes or no), which could be influenced by the type of tube or diet. Interestingly, we found that children who were only tube fed at night had a better oral intake themselves. These children receiving tube feeding only at night did not show more side effects such as vomiting, compared to children who were not only tube fed at night. However, considering the cross-sectional design of this study, we cannot draw any conclusions with regard to the causality of these findings.

In the literature the term tube dependency is often reserved for children remaining on tube feeding when the primary indication for the tube feeding has resolved [5,6]. A third of the parents in our survey thought this was the case for their child. More than half of these children, however, did not receive any treatment for this situation, while several methods, such as appetite stimulating weaning methods, have shown great successes [25,26]. This finding might implicate that these children could benefit from tube weaning methods.

The strength of our study is that we used very reliable data from the national GIP databank, in which almost all children from the Netherlands are registered. Therefore, under registration is less likely compared to the other mentioned studies regarding the prevalence of pediatric home tube feeding. However, a major limitation of this study is that children receiving infant formula, breast feeding, or a blended diet through their tube were not included in this databank. Future prospective studies should collect data considering tube supplies and combine these with tube feeding formula data to minimize under registration of pediatric home tube feeding. The GIP databank did not show when the tube feeding was delivered for the first time. Consequently, unfortunately, we were not able to calculate the incidence, which would have been interesting.

Another strength of this study is the high number of web-based questionnaires completed by parents. We found the parents considering tube feeding very important and interesting. However, considering medical data this method of data collection was a limitation, especially with respect to side effects and complications. To achieve this large sample size, we used advertisements in online communities. If this method of achievement might have led to selection bias is discussable. Concerning the fact that we used passive (instead of active) recruitment only, we can't really talk about a response rate, since we don't know how many people saw the advertisements. Based on the prevalence rate, we calculated that our sample responding to the questionnaire comprised of almost 10% of all children receiving tube feeding in the Netherlands.

#### 4.1. Conclusion

The prevalence rate of pediatric home tube feeding in the Netherlands is 83–92 per 100,000 children per year. Parents do often report side effects and negative experiences caused by the tube or tube feeding, suggesting a high impact of tube feeding for both patients and families. During consultations, health care professionals should pay attention to these side effects and negative experiences. Both the causality and the severity of these side effects, however, should be confirmed in prospective research not only relying on parental perspective, but also including data from health care practitioners. Further studies should focus on methods reducing the side effects of tube feeding. The prevalence rate of pediatric home tube feeding in the Netherlands can be used to perform a cost-analysis to examine the burden for society.

#### Statement of authorship

Hilde Krom, Suzanne M.C. van Zundert, Marie-Anne G.M. Otten, Liesbeth van der Sluijs Veer, and Angelika Kindermann contributed to conception/design of the research; Hilde Krom, Marc A. Benninga, and Angelika Kindermann contributed to acquisition, analysis, or interpretation of the data; Hilde Krom drafted the manuscript; Suzanne M.C. van Zundert, Marie-Anne G.M. Otten, Liesbeth van der Sluijs Veer, Marc A. Benninga, and Angelika Kindermann critically revised the manuscript; and Hilde Krom, Suzanne M.C. van Zundert, Marie-Anne G.M. Otten, Liesbeth van der Sluijs Veer, Marc A. Benninga, and Angelika Kindermann agree to be fully accountable for ensuring the integrity and accuracy of the work. All authors read and approved the final manuscript.

#### Conflict of interest

None conflicts of interest are declared.

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#### Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.clnu.2018.01.027>.

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