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Characterisation of information Hospitals Provide Parents on Tube Feeding, Including Tube Weaning

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ABSTRACT

Purpose: The purpose of this study was to characterise the content of hospital parent guides related to pediatric tube feeding.
Design and Methods: A naturalistic search strategy was used to retrieve parent guides produced by hospitals using Google. Guides were analysed and content identified as being associated with codes which were derived from previous research into the education of parents on tube feeding and the prevention and treatment of tube feeding dependency and tube weaning.
Results: Of the 17 collected guides from Australia, New Zealand, the United Kingdom, the United States of America, and Canada, most (64.7%) were published between 2009 and 2016. The guides provided comprehensive information regarding the reasons for and types of tube feeding, details of multidisciplinary teams and the practical management of tube feeding. All guides covered common medical problems and trouble-shooting solutions. Yet there was infrequent coverage of goal setting, risks and prevention of oral aversion and tube feeding dependency, social and emotional management of tube feeding and tube exit planning including tube weaning.
Conclusions: A gap exists in the education of families regarding psychosocial implications of tube feeding, oral aversion and tube feeding dependency and prevention, and tube exit planning.
Practice Implications: Improvements need to be implemented in the development of education materials for families of children who require tube feeding. Families need information on all aspects of tube feeding including practical, social, and emotional management as well as advice on tube exit planning including tube weaning.

Introduction

Tube feeding is a common method of providing adequate nutrition for growth and development to a child who is unable to achieve adequate nutrition via conventional oral feeding. Some children will require long term permanent feeding tubes (e.g., children with significant dysphagia or aspiration, or severe metabolic conditions) as they are unlikely to ever be able to meet their nutritional requirements via full oral feeding (Gottrand & Sullivan, 2010). Others will be able to be weaned and transitioned from tube feeding to eating and drinking orally (Gottrand & Sullivan, 2010). The experiences of families with children who are tube fed vary significantly (Hunt, 2007; Martinez-Costa et al., 2011; Tawfik, Dickson, Clarke, & Thomas, 1997). Tube feeding can be a welcome intervention for some (Brotherson, Oakland, Secrist-Mertz, Litchfield, & Larson, 1995) whereas others find that it adds to family stress (Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003). The mixed feelings experienced by families can be related to a lack of information provision before and after proceeding to tube feeding (Craig, Scambler, & Spitz, 2003; Townsley & Robinson, 1999). Providing guidance to parents and carers has the potential to improve knowledge of pediatric tube feeding and health outcomes by better preparing and supporting families (Brotherton & Abbott, 2009; Hunt, 2007; National Health Service Quality Improvement Scotland, 2007).

The National Health Service (NHS) Quality Improvement Scotland conducted a study in 2007 that looked at the information and advice families of children who were tube fed were receiving. Guidance was provided in various forms, with visual information such as demonstration videos being identified as particularly helpful (NHS Quality Improvement Scotland, 2007). Families indicated that there was the need for simply worded, understandable written information, preferably a detailed guide that was consistent across service providers (i.e., hospitals, community health centres, etc.) (NHS Quality Improvement Scotland, 2007). Many researchers have also recommended that the information provided to parents cover the practical,

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social, and emotional aspects related to maintaining tube feeding (Braegger et al., 2010; Craig, 2013; Fereday, Thomas, Forrest, & Darbyshire, 2009; Gunton-Bunn & McNee, 2009). Families of children who require long term or permanent tube feeding may be less stressed by the presence of the tube if they better understand the reasons for the tube and the overall management of tube feeding (Craig, 2013).

Provision of tube exit planning information is also essential for the prevention of tube feeding dependency in children with the potential for oral feeding. Preventable tube feeding dependency has been described as the need to remain tube fed after the period of indicated use of enteral feeding (Dunitz-Scheer et al., 2009; Hannah & John, 2013). It is the inability, active refusal, or lack of will to learn to start eating and drinking (Dunitz-Scheer et al., 2009; Ishizaki, Hironaka, Tatsuno, & Mukai, 2013). Although families of children with tube feeding dependency are thankful for their child's survival or weight gain, many are eager for their children to transition to more normalized eating and drinking patterns (Forbes & Grover, 2015). Yet, families can often be unsuccessful at reintroducing oral feeding on their own because of a lack of professional guidance (Blackman & Nelson, 1985). Development and supply of a detailed guide which outlines and addresses all aspects of tube-feeding, including tube weaning has the potential to improve outcomes for children who are tube fed. Little research has, however, been directed towards critically evaluating current educational support materials for families with children with feeding tubes. This study, therefore, aimed to characterise the content of existing online parent guides on pediatric tube feeding produced by hospitals.

Methods

This study was developed after a poor response rate (3%; n = 6) to a letter to 200 feeding services worldwide in October 2016 requesting copies of any policies, procedures, or guidelines pertaining to tube feeding management in pediatric patients, including tube weaning. The study team, consisting of a dietitian, occupational therapist, and speech pathologist, decided to change focus and methodology and search the internet for parent guides on tube feeding.

The first guide was collected from the authors' hospital's website. The search terms were derived from a review of the terminology used in this guide and based on the key findings of the NHS Quality Improvement Scotland (2007) investigation into information and advice provision for parents and carers of nasogastric and gastrostomy tube fed children. A search was undertaken using Google, which had been identified to have the best performance in retrieving health information for consumers (Lopes & Riberio, 2011), to locate other hospitals' parent guides. A primarily naturalistic search strategy was used to reflect the way families would search for information on tube feeding. Therefore, the features of the search engine were largely accepted. The following keywords were used: parent and nasogastric or "NGT" or gastrostomy or "g-tube" or "PEG" or enteral or "tube feeding" or "tube weaning" and guide or handout or brochure or factsheet. No limits were placed on which hospitals or countries were eligible. However, documents located were only included if (1) they were produced by a hospital, (2) formatted as a printable handout or PDF and were able to be downloaded, (3) specific to the general management of one or more types of pediatric tube feeding, (4) available in English, and (5) written directly for parents/families. Documents were excluded if they were (1) written by non-hospital services (i.e., charitable foundations or private feeding therapy centres), and (2) only related to one specific phase of tube feeding (i.e., surgery) or (3) a specialist population (i.e., neonates). As a largely naturalistic search strategy was employed, it was decided to assess the top 50 search results as research has shown that on average internet searchers rarely look beyond the first 20–25 results (Eysenbach & Köhler, 2002; Wang et al., 2012).

All collected guides were initially read by one of the investigators. Identifying information was firstly recorded (i.e., website, country, length of guide, type of feeding tubes covered by guide, year of publication) and entered in an Excel spreadsheet, Microsoft Office 2010. The content of each guide was then broken down into units of interrelated information and coded. The codes related to topic areas that families of children that were tube fed should receive appropriate training and information in from health professionals, as identified in the literature (Braegger et al., 2010; Townsley & Robinson, 1999). Additional codes were derived based on recommendations in the literature relating to the prevention and treatment of tube feeding dependency and tube weaning (Blackman & Nelson, 1985; Dunitz-Scheer et al., 2009; Forbes & Grover, 2015; Ishizaki et al., 2013). The study team then validated all codes.

Content was identified as being associated with one of six primary codes, including background information, practical management, social management, emotional management, facilitating tube weaning and criteria for tube weaning. Content was recorded as being present or absent for each of these six major codes. Information under the six major codes was then further unitized under a total of 42 sub-codes. One subcode of common problems and trouble-shooting under the primary code practical management was further delineated into a further 19 sub-codes. All codes are shown in Table 1.

A reliability audit of the coding was performed by another investigator who independently coded eight randomly selected guides. Agreements and disagreements in the coding were identified according to category membership. An acceptable inter-rater agreement between the two investigators of 80.3% was achieved. Once reliability was determined, discrepancies were adjusted. Discrepancies were all related to one or the other investigator missing content and marking categories as absent from guides. These discrepancies were, therefore, easily resolved. Results were collated and analysed using basic descriptive statistics in Excel, including frequencies and percentages.

Results

As shown in Table 2, 17 guides were collected from 14 different hospital' websites from five countries including Australia, New Zealand, the United Kingdom (UK), the United States of America (USA), and Canada. Six other parent guides were located but were excluded as two were not produced by a hospital service, and four only related to helping children that were tube fed transition to oral feeding. The documents varied in length from 6 to 62 pages in length. The median was 27 pages. More than half of the documents (n = 11; 64.7%) were published between 2009 and 2016.

All parent guides included a background section. All guides in this section contained information on what tube feeding involved, why children may need to be tube fed and the different types of tube feeding. It was documented in most of the guides (n = 15; 88.2%) that the tube feeding process should involve multiple disciplines, but the identified team composition varied and typically involved a medical practitioner and one other health professional (i.e., nurse, dietitian, speech pathologist). All guides listed contact details for various health personnel and services. Goal setting was referred to in general terms in five of the guides (i.e., "*GT tubes may be used for a short time or for a long time*"). In these guides, it was recommended that parents talk to their child's doctors regarding setting goals around their child's tube feeding. Four of the guides provided space for recording weights as well as a space for recording a goal weight for when the tube could be removed.

All 17 guides contained information relating to the practical management of tube feeding. Table 3 shows the different areas of practical management covered by the guides and the frequency with which these areas were covered. As can be seen from Table 3, information on common problems and trouble shooting was included in all the guides. Frequency of inclusion of different types of common problems and their management in the 17 guides was as follows: feeding tube falling out (n = 15; 88.2%); tube blockages (n = 15; 88.2%); skin infections/irritations (n = 14; 82.4%); vomiting/reflux/regurgitation (n = 13; 76.5%); leaking and burns (n = 11; 64.7%); diarrhea (n = 11; 64.7%); stomach

Table 1
Coding of parent guides.

Primary codes	Sub-codes	
Background information	• What tube feeding involved	• Multidisciplinary team information provided
	• Reasons for tube feeding provided	• Contact details provided
	• Types of tube feeding explained	• Goal setting
Practical management	• Insertion of tube	Expanded sub-codes for common problems and trouble-shooting
	• Checking placement	• Aspiration • Damaged equipment
	• Removal of tube	• Blocked feeding tube • Leakage and burn
	• Oral hygiene cares	• Constipation • Reflux/regurgitation
	• Care of tube and skin	• Dehydration • Vomiting
	• Feeding schedules	• Diarrhea • Venting
	• Formula	• Feeding tube falls out • Bathing
	• Infection control	• Stomach fullness • Clothing
	• Equipment	• Granulation • Oral aversion
	• Giving tube feeds	• Skin infections/irritation • Tube feeding dependence
	• Giving oral feeds	• Breathing difficulties
	• Giving medications	
	• Positioning	
	• Venting the tube	
	• Common problems and trouble-shooting	
Social management	• Physical activities (i.e., swimming, physiotherapy, tummy time	• Child/school care
	• Feeding in public	• Travel/holidays
Emotional management	• Description of emotions of child, siblings, and/or friends	• Identified could request contact with other families with a feeding tube
	• Description of emotions of parent	• Quotes provided from other families regarding experiences
Facilitating tube weaning	• Nutritional advice	• Self-feeding advice
	• Oral motor activities	• Mealtime dynamics
	• Sensory activities	• Language for mealtimes
Criteria for tube weaning	• Timing	• Nutritionally ready/weight stable
	• Resolution of medical condition	• Caregiver readiness
	• Safe swallow	• Hunger
		• Adequate oral skills

fullness/bloating (n = 10; 58.8%); granulation (n = 9; 52.9%); constipation (n = 9; 52.9%); aspiration (n = 3; 17.7%); breathing difficulties (n = 3; 17.7%); and damaged equipment (n = 3; 17.7%). Oral aversion or the development of tube feeding dependency was not documented in any of the 17 guides.

Ten of the 17 guides (58.8%) contained information relating to the social management of tube feeding. All ten guides included advice on how to handle the physical activities of a tube fed child such as physiotherapy, swimming, and tummy time. Five of the guides provided a discussion on how to prepare for travelling and holidays and two guides contained information on how to prepare and educate childcare or school personnel on how to feed children with feeding tubes. For example, one guide included the statement, "*ask that the other kids don't touch the tube and have a plan ready for what the school should do if the tube comes out.*" One guide provided a description of how to feed children in public (i.e., "*any area that serves food is appropriate to use. Consider the parents room in shopping centres or at the table in cafes/food courts. Don't use a bathroom to do the feed.*").

Only one Canadian hospital included information relating to emotional management in their guide for parents of children with gastrostomy feeding tubes. This guide outlined how parents might feel about gastrostomy tube feeding as well as how the child, other family members and friends might feel about tube feeding. Quotes from families regarding their experiences with tube feeding were included and it was identified that families could request contact with other families of children with feeding tubes if they so desired.

Ten of the seventeen guides (58.8%) contained information relating to facilitating tube weaning. Areas mentioned as important for preparing children for tube weaning are shown in Table 4.

Five of the guides also identified criteria for tube weaning. Frequency of the reported criteria in the five guides was as follows: resolution of the original medical condition (n = 3; 60%); presence of a safe swallow (n = 4; 80%); the child being nutritionally ready or having a stable

Table 2
Characteristics of guides for families on tube feeding.

Number	Code	Type of feeding tube	Year published
1	CAN-1	NGT only	2003
2	CAN-1	Mixed	2003
3	CAN-2	NGT only	2015
4	CAN-2	GT only	2006
5	CAN-3	GT only	Unknown
6	CAN-4	Mixed	2005
7	USA-1	GT only	2015
8	USA-2	Mixed	Unknown
9	USA-3	Mixed	2015
10	USA-4	Mixed	2015
11	UK-1	GT only	2010
12	UK-2	GT only	2014
13	UK-3	GT only	2016
14	AUS-1	Mixed	2016
15	AUS-2	GT only	2012
16	AUS-2	NGT only	2012
17	NZ-1	GT only	2016

Note. NGT = nasogastric tube; Mixed = different types of tube feeding covered; GT = gastrostomy tube.

Table 3
Aspects of practical management covered in guides.

Aspect	Percentage of inclusion in all guides (n = 17)
Insertion of tube	64.7% (n = 11)
Checking tube placement	76.5% (n = 13)
Removal of tube	52.9% (n = 9)
Oral hygiene cares	82.4% (n = 14)
Care of tube and skin	94.1% (n = 16)
Feeding schedules	100.00% (n = 17)
Formula	100.00% (n = 17)
Infection control	100.00% (n = 17)
Equipment	100.00% (n = 17)
Giving tube feeds	100.00% (n = 17)
Giving oral feeds	35.3% (n = 6)
Giving medications	94.1% (n = 16)
Positioning	35.3% (n = 6)
Venting the tube	64.7% (n = 11)
Common problems and trouble shooting	100% (n = 17)

Table 4
Information included related to transitioning from tube to oral feeding.

Area	Percentage of inclusion in guides that had information on weaning (n = 10)
Inclusion of tube-fed child at family mealtimes	60% (n = 6)
Nutritional management (i.e., use of continuous overnight feeds, use of bolus feeds during the day)	20% (n = 2)
Engagement in oral motor stimulation/developmental activities	90% (n = 9)
Participation in sensory activities	30% (n = 3)
Opportunities for self-feeding	20% (n = 2)
Use of positive language during mealtimes	10% (n = 1)

weight (n = 3; 60%); the caregiver being ready for tube weaning (n = 3; 60%); and the child displaying hunger (n = 1; 20%).

Discussion

Some parents find tube feeding adds to family stress (Craig, 2013; Gunton-Bunn & McNee, 2009; Rouse, Herrington, Assey, Baker, & Golden, 2002) and that it increases the visibility of their child's disability, causing a source of unwanted public attention (Craig et al., 2003; Fereday et al., 2009; Gunton-Bunn & McNee, 2009). Other families, however, have reported tube feeding as having a positive impact on their lives through a reduction in parental stress and their child receiving nutritional benefits including improved growth weight (Avitsland et al., 2012). It has been identified that parents' experiences with tube feeding can be positively influenced through the provision of adequate information and advice (Craig et al., 2003; Hunt, 2007; NHS Quality Improvement Scotland, 2007; Rouse et al., 2002; Townsley & Robinson, 1999). Detailed written material has been recognised as a valuable way to educate and support families (NHS Quality Improvement Scotland, 2007).

As part of this study, 17 written parent guides relating to tube feeding were sourced from hospital service websites. All guides provided background information on tube feeding including reasons for tube feeding and what was involved, as has been recommended by the European Society for Pediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) Committee on Nutrition (Braegger et al., 2010). The majority also indicated that families would be supported by a multidisciplinary team and provided contact details. The exact composition of the teams listed varied but usually included a medical practitioner and one other health professional (i.e., nurse, dietitian, speech pathologist). A multidisciplinary approach has been identified as crucial for developing parents' understanding of the issues around tube feeding and for ensuring the provision of the most appropriate support (Braegger et al., 2010; Brotherton & Abbott, 2009; Craig, 2013; Dunitz-Scheer et al., 2009; Rouse et al., 2002).

Such support involves providing families with appropriate and attainable goals specific to their child (Brotherton & Abbott, 2009). Despite knowledge that goal setting is vital to shared decision making and improved communication (Craig, 2013; Novak, Wilson, & Ausderau, 2009), none of the guides emphasised its importance. Goal setting was either briefly mentioned in general terms (i.e., talk to your doctor regarding goal setting), or a space was simply provided to record weight targets. This is of concern as if used in isolation and without proper education, weight targets could be interpreted wrongly by families and result in undue stress or ultimately place children in jeopardy. Researchers have identified that goal setting should be highly individualised and encompass not only specific anthropometric goals, but the time, method and duration of tube feeding, the team for tube maintenance and weaning, and inclusion and exclusion criteria for tube weaning (Davis et al., 2016; Dunitz-Scheer et al., 2009; Krom, de Winter, & Kindermann, 2017; Wilken, Cremer, Berry, & Bartmann, 2013; Wright, 2013).

A set date for tube weaning is often difficult to determine as it can often be uncertain how long treatment or recovery will take. However, setting a date for review is essential, as it ensures that tube fed children with the potential to eat are helped to do so as soon as possible (Dunitz-Scheer et al., 2009; Trabi, Dunitz-Scheer, Kratky, Beckenbach, & Scheer, 2010). It also provides early intervention for families whose children have no possibility of ever weaning off tube feeds. Regular monitoring will further prevent families from desperately undertaking tube weaning themselves.

All the guides provided information on the practical management of tube feeding. The guides covered a range of topics such as insertion methods and preparation, feed types and formulation, feeding equipment, feeding schedules, giving tube feeds and medications, and health and safety aspects of care. Medical complications of tube feeding and how to prevent or treat them was a major focus of all the guides. Tube feeding can be associated with several medical complications, such as tube blockages and tube dislodgement (Avitsland et al., 2012; Evans, Holden, & McDonald, 2006; Lee & Spratling, 2014; Pahsini, Marinschek, Dunitz-Scheer, & Scheer, 2016). Adequate provision of information to parents regarding trouble-shooting should result in timely and proper intervention and prevent long-term difficulties (Braegger et al., 2010).

None of the guides, however, outlined the risks of oral aversion or tube feeding dependency. Oral aversion can develop because of repeated aversive oral experiences such as frequent vomiting, ventilation, suctioning, and nasogastric tube placement (Hawdon, Beauregard, Slattery, & Kennedy, 2000). Some children with tube feeding may also develop oral aversion because of extended periods of not eating and missing the opportunity to learn how to eat by mouth (Hawdon et al., 2000). Children with oral aversion often learn that food refusal behaviours such as crying, tantrums, food expulsion, food storing and/or clamping their mouths leads to avoidance of aversive feeding situations (de Moor, Didden, & Korzilis, 2007). Consequently, the longer the tube feeding the more likely children are to develop oral aversion, and to then take longer to wean.

Tube feeding dependency occurs when children continue to rely on their feeding tubes despite their health status having improved (Braegger et al., 2010; Dunitz-Scheer et al., 2009; Hannah & John, 2013). Development and maintenance of positive mealtime experiences and oral skills, largely through continuing oral feeds wherever possible, has been identified as crucial for tube weaning, and the prevention of tube feeding dependency (Craig, 2013; Dunitz-Scheer et al., 2009; Guerriere et al., 2003; Hannah & John, 2013; Hunt, 2007; Tawfik et al., 1997; Townsley & Robinson, 1999). Yet only six of the guides provided information on the practical management of oral feeding whilst also giving tube feeds and only nine of the guides outlined oral motor stimulation and development activities. This is consistent with the results of a study by Sleigh in 2005. Sleigh (2005) identified that parents perceived that health professionals had inadequate knowledge about the promotion of oral feeding.

Common problems with tube feeding have been identified by parents to be more socioemotional as opposed to medical (Craig & Scambler, 2006; Michaelis, Warzak, Stanek, & Van Riper, 1992). Yet, results of the study indicate that social management of tube feeding was only included in 58.8% of the guides and information on emotional management was only included in one guide. Families of children with feeding tubes have been found to experience a range of psychosocial problems, such as increased levels of stress, anxiety, and depression

(Avitsland et al., 2012; Craig & Scambler, 2006; Martinez-Costa et al., 2011; Pahsini et al., 2016; Pedrón-Giner, Calderón, Martinez-Costa, Gracia, & Gómez-López, 2013; Rouse et al., 2002). Tube feeding can also result in families feeling that they have failed to care for their child adequately (Craig & Scambler, 2006; Rouse et al., 2002). Parents of children that are tube fed have reported reduced sleep, difficulties participating in recreational activities, childcare problems, and coping with negative attitudes of others (Craig & Scambler, 2006; Evans et al., 2006; Fereday et al., 2009). Families have reported spending extended time with children who are tube fed places strain on marriages and pressure on relationships with other family members, particularly siblings (Lee & Spratling, 2014; Rouse et al., 2002). Parents need to be provided with advice on restoring as much normalcy to family life as possible, and to enhance their quality of life (Hannah & John, 2013; Novak et al., 2009).

Researchers have also identified that families of children that are tube fed with the potential to eat and drink orally should be provided with information on exit planning, including tube weaning as early as possible (Davis et al., 2016; Dunitz-Scheer et al., 2009; Krom et al., 2017; Wilken et al., 2013; Wright, 2013). Providing information early on tube weaning should minimise later problems and help to assist in preventing tube feeding dependency Dunitz-Scheer et al., 2009; Hannah & John, 2013). Only ten guides included such information. Areas mentioned in these documents as important for preparing children for tube weaning were consistent with the available literature. These areas included inclusion of the child who is tube fed at family mealtimes, the stimulation of hunger through appropriate nutritional management (i.e., use of continuous overnight feeds, use of bolus feeds during the day, appropriate selection of food types and textures), participation in sensory activities (i.e., food play), provision of opportunities for self-feeding, and use of positive language during mealtimes (Davis et al., 2016; Krom et al., 2017; Nowak-Cooperman & Quinn-Shea, 2013; Schauster & Dwyer, 1996; Tarbell & Allaire, 2002).

Five of the guides identified criteria for tube weaning. Reported criteria were again consistent with the available literature and included the resolution of the original medical condition, presence of a safe swallow, the child being nutritionally ready or having a stable weight, the caregiver being ready for tube weaning and the child displaying hunger and appropriate oral motor skills (Craig & Scambler, 2006; Liley & Manthorpe, 2003; Pedrón-Giner et al., 2013; Sleigh, 2005).

Clinical Implications

Families of children who are tube fed have identified the need for jargon free, easy to understand, written information on pediatric tube feeding. This study identified that hospitals in Australia, New Zealand, the UK, the USA, and Canada are providing families with written handouts that provide comprehensive practical information, focusing on potential medical complications and trouble-shooting solutions.

Families, however, need information on all aspects of tube feeding including practical, social, and emotional management. There is a gap in the provision of written information and advice to families regarding the immense psychosocial implications of tube feeding. Health services are encouraged to ensure written information provided to parents covers common social and emotional problems, just as thoroughly as medical complications (Craig, 2013; Fereday et al., 2009; Townsley & Robinson, 1999). Researchers have identified that families crave information on the impact tube feeding will have on their child and family within the context of their everyday lives (Craig, 2013; Fereday et al., 2009). Families want to know how to tube feed in different social settings, how to explain tube feeding to siblings, how to handle feelings of guilt and social embarrassment, practical tips for travelling, and how to engage in physical and therapeutic activities (i.e., swimming, physiotherapy) (Craig, 2013; Craig & Scambler, 2006; Liley & Manthorpe, 2003; Townsley & Robinson, 1999). Families also want to hear about experiences of other families and if possible, meet other families face to face to receive emotional support (Craig, 2013; Craig et al., 2003; Fereday et al., 2009; Guerriere et al., 2003; Gunton-Bunn & McNee, 2009; Rouse et al., 2002). None of this is new information (Craig, 2013; Craig et al., 2003; Gunton-Bunn & McNee, 2009; Townsley & Robinson, 1999) but the results of this study show that it is rarely a formalised and documented practice.

There is also a lack of advice on exit planning, including tube weaning despite a growing recognition of the problems of oral aversion and tube feeding dependency (Davis et al., 2016; Dunitz-Scheer et al., 2009; Forbes & Grover, 2015; Ishizaki et al., 2013; Schauster & Dwyer, 1996; Tarbell & Allaire, 2002; Wilken et al., 2013; Wright, 2013). The plan for tube maintenance and weaning should be formally documented in the child's medical chart by a multidisciplinary team, and then copies distributed to all involved health professionals and the family (Craig, 2013; Dunitz-Scheer et al., 2009; Gardiner, Fuller, & Vuillermin, 2014). Inclusion of comprehensive information on the significance of goal setting in relation to tube feeding, and room for recording of specific, individualised goals, and a review schedule would improve outcomes for children and their families.

Limitations

This study was limited by the small number of parent guides collected for analysis. A larger sample may have provided more representative data. The guides sampled were, however, readily available to the public and were recent publications. The lack of key information in these guides indicates the need for further research into the material provided to families. Written guidelines are only one avenue of providing health education. The NHS Quality Improvement Scotland (2007) identified that demonstration videos on the management of tube feeding were preferred by families. Analysis of the content of hospital audiovisual guides in the future would provide useful information regarding any current gaps in parent training regarding tube feeding management in children.

This study also did not assess the readability of the guides. A previous study found families wanted parent guides that were easy to understand and written in plain English (NHS Quality Improvement Scotland, 2007). Future research should be directed towards assessment of the readability of parent education materials for tube fed children. Obtaining consumer feedback regarding the content and readability of parent guides should improve health literacy and enhance patient outcomes.

Conclusion

The current study demonstrates that the examined written parent guides on tube feeding provided useful information on the reasons for and types of tube feeding, details of multidisciplinary teams and the practical management of tube feeding. Common medical problems associated with tube feeding and trouble-shooting solutions were also well covered. Guides lacked information on goal setting, risks and prevention of oral aversion and tube feeding dependency, social and emotional management of tube feeding and tube weaning. These findings are clinically relevant for clinicians who are responsible for the development and education of caregivers of children who require tube feeding. Future research directed towards identifying best practices in parent education in tube feeding will result in optimal maintenance of children's tube feeding as well as facilitate tube weaning for those children with the potential to feed orally.

Policy Issues

All authors of this paper participated in this research and agree with the contents of the material.

Ethics Approval

As no animal or human subjects were involved in this study, it was deemed of negligible risk and was not required to undergo ethics review by the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee. The study involved audit of documents that were freely available to the public.

Conflicts of Interest

All authors report that there are no personal or financial conflicts of interest.

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CRediT authorship contribution statement

Maryanne Syrmis: Conceptualization, Methodology, Software, Formal analysis, Investigation, Resources, Writing - original draft, Writing - review & editing, Visualization, Supervision. **Nadine Frederiksen:** Conceptualization, Methodology, Validation, Writing - review & editing. **Claire Reilly:** Conceptualization, Methodology, Writing - review & editing.

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References

Avitsland, T. L., Faugli, A., Pripp, A. H., Malt, U. F., Bjørnland, K., & Emblem, R. (2012). Maternal psychological distress and parenting stress after gastrostomy placement in children. *Journal of Pediatric Gastroenterology and Nutrition*, *55*, 562–566 https://dx.doi.org/10.1186%2F1477-7525-11-158.

Blackman, J. A., & Nelson, C. L. A. (1985). Reinstituting oral feedings in children fed by gastrostomy tubes. *Clinical Pediatrics*, *24*, 434–438.

Braegger, C., Decsi, T., Dias, J. A., Hartman, C., Kolaček, S., Koletzko, B., ... Van Goudoever, J. (2010). Practical approach to pediatric enteral nutrition: A comment by the ESPGHAN Committee on Nutrition. *Journal of Pediatric Gastroenterology and Nutrition*, *51*, 110–122 https://doi.org/10.1097/MPG.0b013e3181d336d2.

Brotherson, M. J., Oakland, M. J., Secrist-Mertz, C., Litchfield, R., & Larson, K. (1995). Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities. *The Journal of the Association for Persons With Severe Handicaps*, *20*, 202–212 https://doi.org/10.1177%2F154079699502000305.

Brotherton, A., & Abbott, J. (2009). Clinical decision making and the provision of information in PEG feeding: An exploration of patients and their carers' perceptions. *Journal of Human Nutrition and Dietetics*, *22*, 302–309 https://doi.org/10.1111/j.1365-277X.2009.00966.x.

Craig, G. M. (2013). Psychosocial aspects of feeding children with neurodisability. *European Journal of Clinical Nutrition*, *67*, 17–20.

Craig, G. M., & Scambler, G. (2006). Negotiating mothering against the odds: Gastrostomy tube feeding, stigma, governmentality, and disabled children. *Social Science & Medicine*, *62*, 1115–1125 https://doi.org/10.1016/j.socscimed.2005.07.007.

Craig, G. M., Scambler, G., & Spitz, L. (2003). Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support. *Developmental Medicine and Child Neurology*, *45*, 183–188.

Davis, A. M., Dean, K., Mousa, H., Edwards, S., Cocjin, J., Almadhoun, O., ... Hyman, P. E. (2016). A randomized controlled trial of an outpatient protocol for transitioning children from tube to oral feeding: No need for amitriptyline. *Journal of Pediatrics*, *172*, 136–141 https://dx.doi.org/10.1016%2Fj.jpeds.2016.02.013.

Dunitz-Scheer, M., Levine, A., Roth, Y., Kratky, E., Beckenbach, H., Braegger, C., ... Scheer, P. (2009). Prevention and treatment of tube dependency in infancy and early childhood. *Infant Child Adolescent Nutrition*, *1*, 73–81 https://doi.org/10.1177%2F1941406409333988.

Evans, S., Holden, C., & McDonald, A. (2006). Home enteral feeding audit: 1 year post-initiation. *Journal of Human Nutrition and Dietetics*, *19*, 27–29 https://doi.org/10.1111/j.1365-277X.2006.00662.x.

Eysenbach, G., & Köhler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal*, *324*, 573–577.

Fereday, J., Thomas, C., Forrest, A., & Darbyshire, P. (2009). Food for thought: Investigating parents' perspectives of the impact of their child's home enteral nutrition (HEN). *Neonatal, Paediatric & Child Health Nursing*, *12*, 9–14.

Forbes, D., & Grover, Z. (2015). Tube feeding: Stopping more difficult than starting. *Journal of Paediatrics and Child Health*, *51*, 245–247.

Gardiner, A. Y., Fuller, D. G., & Vuillermin, P. J. (2014). Tube-weaning infants and children: A survey of Australian and international practice. *Journal of Paediatrics and Child Health*, *50*, 626–631.

Gottrand, F., & Sullivan, P. B. (2010). Gastrostomy tube feeding: When to start, what to feed and how to stop. *European Journal of Clinical Nutrition*, *64*, S17–S21 https://doi.org/10.1038/ejcn.2010.43.

Guerriere, D. N., McKeever, P., Llewellyn-Thomas, H., & Berall, G. (2003). Mothers' decisions about gastrostomy tube insertion in children: Factors contributing to uncertainty. *Developmental Medicine and Child Neurology*, *45*, 470–476 https://doi.org/10.1111/j.1469-8749.2003.tb00942.x.

Gunton-Bunn, C., & McNee, P. (2009). Psychosocial implications of gastrostomy placement. *Paediatric Nursing*, *21*, 28–31 https://doi.org/10.7748/paed2009.09.21.7.28.c7230.

Hannah, E., & John, R. M. (2013). Everything the nurse practitioner should know about pediatric feeding tubes. *Journal of the American Association of Nurse Practitioners*, *25*, 567–577 https://doi.org/10.1002/2327-6924.12075.

Hawdon, J. M., Beauregard, N., Slattery, J., & Kennedy, G. (2000). Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine and Child Neurology*, *42*, 235–239.

Hunt, F. (2007). Changing from oral to enteral feeding: Impact on families of children with disabilities. *Paediatric Nursing*, *19*, 30–32 https://doihttps://doi.org/10.7748/paed2007.09.19.7.30.c4455.

Ishizaki, A., Hironaka, S., Tatsuno, M., & Mukai, Y. (2013). Characteristics of and weaning strategies in tube-dependent children. *Pediatrics International*, *55*, 208–213 https://doi.org/10.1111/ped.12030.

Krom, H., de Winter, J. P., & Kindermann, A. (2017). Development, prevention, and treatment of feeding tube dependency. *European Journal of Pediatrics*, *176*, 683–688.

Lee, J., & Spratling, R. (2014). Care of gastrostomy feeding tube in children with developmental disabilities. *Rehabilitation Nursing*, *39*, 221–224.

Liley, A. J., & Manthorpe, J. (2003). The impact of home enteral tube feeding in everyday life: A qualitative study. *Health & Social Care in the Community*, *11*, 415–422.

Lopes, C. T., & Riberio, C. (2011). Comparative evaluation of web search engines in health information retrieval. *Online Information Review*, *35*, 869–892.

Martinez-Costa, C., Borraz, S., Benlloch, C., López-Sáiz, A., Sanchiz, V., & Brines, J. (2011). Early decision of gastrostomy tube insertion in children with severe developmental disability: A current dilemma. *Journal of Human Nutrition and Dietetics*, *24*, 115–121 https://doi.org/10.1111/j.1365-277X.2010.01146.x.

Michaelis, C., Warzak, W., Stanek, K., & Van Riper, C. (1992). Parental and professional perceptions of problems associated with long-term pediatric home tube feeding. *Journal of the American Dietetic Association*, *92*, 1235–1238.

de Moor, J., Didden, H., & Korzilis, H. (2007). Behavioural treatment of severe food refusal in five toddlers with developmental disabilities. *Child: Care, Health and Development*, *33*, 670–676 https://doi.org/10.1111/j.1365-2214.2007.00734.x.

NHS Quality Improvement Scotland (2007). *Information and advice provision for parents and carers of nasogastric and gastrostomy fed children.* Edinburgh: Progressive Partnership.

Novak, P., Wilson, K. E., & Ausderau, K. (2009). The use of blenderized tube feedings. *Infant Child Adolescent Nutrition*, *1*, 21–23.

Nowak-Cooperman, K., & Quinn-Shea, K. (2013). Finding the balance: Oral eating and tube feeding one pediatric hospital's experience with a hunger-based intensive feeding program. *Infant Child Adolescent Nutrition*, *5*, 283–297 https://doi.org/10.1177%2F1941406413503683.

Pahsini, K., Marinschek, S., Dunitz-Scheer, M., & Scheer, A. J. (2016). Unintended adverse effects of enteral nutrition support: Parental perspective. *Journal of Pediatric Gastroenterology and Nutrition*, *62*, 169–173.

Pedrón-Giner, C., Calderón, C., Martinez-Costa, S., Gracia, B., & Gómez-López, L. (2013). Factors predicting distress among parents/caregivers of children with neurological disease and home enteral nutrition. *Child: Care, Health and Development*, *40*, 389–397 https://doi.org/10.1111/cch.12038.

Rouse, L., Herrington, P., Assey, J., Baker, R., & Golden, S. (2002). Feeding problems, gastrostomy and families: A qualitative pilot study. *British Journal of Learning Disabilities*, *30*, 122–128 https://doi.org/10.1046/j.1468-3156.2002.00149.x.

Schauster, H., & Dwyer, J. (1996). Transition from tube feedings to feedings by mouth in children: Preventing eating dysfunction. *Journal of the American Dietetic Association*, *96*, 277–281 https://doi.org/10.1016/S0002-8223(96)00081-8.

Sleigh, G. (2005). Mothers' voice: A qualitative study on feeding children with cerebral palsy. *Child: Care, Health and Development*, *31*, 373–383 https://doi.org/10.1111/j.1365-2214.2005.00521.x.

Tarbell, M. A., & Allaire, J. H. (2002). Children with feeding tube dependency: Treating the whole child. *Infants & Young Children*, *15*, 29–41.

Tawfik, R., Dickson, A., Clarke, M., & Thomas, G. (1997). Caregivers' perceptions following gastrostomy in severely disabled children with feeding problems. *Developmental Medicine and Child Neurology*, *39*, 746–751 https://doi.org/10.1111/j.1469-8749.1997.tb07376.x.

Townsley, R., & Robinson, C. (1999). More than just a health issue: A review of current issues in the care of enterally-fed children living in the community. *Health & Social Care in the Community*, *7*, 216–224.

Trabi, T., Dunitz-Scheer, M., Kratky, E., Beckenbach, H., & Scheer, P. (2010). Inpatient tube weaning in children with long-term feeding tube dependency: A retrospective analysis. *Infant Mental Health Journal*, *31*, 664–681 https://doi.org/10.1002/imhj.20277.

Wang, L., Wang, J., Wang, M., Li, Y., Liang, Y., & Xu, D. (2012). Using Internet search engines to obtain medical information: A comparative study. *Journal of Medical Internet Research*, *14*, e74 https://doi.org/10.2196/jmir.1943.

Wilken, M., Cremer, V., Berry, J., & Bartmann, P. (2013). Rapid home-based weaning of small children with feeding tube dependency: Positive effects of feeding behaviour without deceleration of growth. *Archives of Disease in Childhood*, *98*, 856–861 https://doi.org/10.1136/archdischild-2012-303558.

Wright, C. (2013). Failure to wean? *Archives of Disease in Childhood*, *98*, 838–840.