



Educational needs for parents and caregivers caring for children with PEG tube

A literature Review

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Abstract

Neurologically impaired children often suffer immobility or muscular weakness that impair their ability to eat and swallow, which in the long run makes them susceptible to malnutrition. Enteral nutrition is suggested to avoid malnutrition and as preventive measurement for aspiration. Percutaneous endoscopic gastrostomy (PEG) in specific allows for long term nourishment and is more often being used for the nutritional management of neurological impaired children. The parents and caregivers of these children carry the responsibility to care for them taking into account the implications of the PEG tube.

The aim of this study is to determine what are the key areas of pediatric percutaneous endoscopic gastrostomy tube care that parents and care givers should be aware of.

A literature review was conducted where data was retrieved from Cinahl Plus and PubMed data bases. Six articles were reviewed and analyzed using an inductive content analysis approach.

Four educational themes were identified: Availability to professional support, Receiving practical training, Prevention of complications and Medication administration.

In conclusion the education of parents and caregivers is currently at a suboptimal level. Reinforcement of professional support available to these families is much needed as well as a deeper and fuller training and education process that includes feeding and nutrition assessment, correct hygienic practices for manipulating and cleaning the tube and stoma, and medication administration by parents and caregivers.

Keywords/tags (subjects)

Percutaneous endoscopic gastrostomy, PEG, Children, Education

Miscellaneous

For example, the confidentiality marking of the thesis appendix, see Project Reporting Instructions, section 4.1.2

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1 Introduction

Enteral feeding to achieve appropriate nutrition is needed by a considerable number of children and teenagers in homes, schools and hospitals (Guidelines And Audit Information Network (Northern Ireland, 2015). For every 100,000 children around 88 utilizes some form of home tube feeding (Krom et al., 2019). Enteral nutrition is the favored mode of nutrient delivery for chronically ill patients with a functional gastrointestinal system. Low cost and low complication rate of enteral nutrition makes it preferable over parenteral nutrition (Mehta et al., 2009). The need for enteral feeding comes down to a plethora of conditions and diagnosis. Approximately, congenital abnormalities represent 42% of the indications for tube feeding, followed by perinatal problems with 38% and lastly neurologic diseases with 16% (Krom et al., 2019).

Often families are faced with the significant impact that enteral feeding can have on their lives. Social, psychological, and practical issues come to light and have to be dealt on a daily basis. The healthcare system oversees the provision of multi-professional teams comprised of pediatricians, nurses, and nutritionists to aid in and educate parents and caregivers in the management of enteral feeding tube patients. All parents and caregivers attending to the needs of these children must require the correct knowledge and abilities to safely deliver effective care. (Guidelines And Audit Information Network (Northern Ireland, 2015). The aim of this literature review is to determine what are the key areas of pediatric percutaneous endoscopic gastrostomy tube care that parents and care givers should be aware of with the purpose of offering nurses evidence based current knowledge to support the education of parents and caregivers caring for these children with percutaneous endoscopic gastrostomy tube.

2 Percutaneous Endoscopic Gastronomy

2.1 Percutaneous endoscopic gastrostomy in children

Enteral feeding refers to the delivery of nourishment through a tube directly into the stomach or small intestine. Enteral feeding tubes can be inserted through different routes to reach the gastrointestinal (GI) tract; these include nasal (nasogastric), oral (orogastric), or through the skin of the abdomen (percutaneous) (Vudayagiri et al., 2021). Percutaneous endoscopic gastrostomy (PEG) refers to the insertion of an EFT through the abdominal wall into the stomach with the use of an endoscope (White et al., 2015). PEG is considered the best choice among insertion methods of percutaneous enteral feeding tubes by reason of being less invasive as well as preferable for long term patients with a functional GI tract (Rahnemai-Azar et al., 2014).

Neurologically impaired children often suffer immobility or muscular weakness as underline symptoms of their diseases, which in the long run makes them susceptible to malnutrition if it affects their feeding capability (Skalsky & Dalal, 2015). Gastroesophageal reflux and oropharyngeal dysfunction are mostly prevalent in children with neurological impairments which ultimately can lead to malnutrition and opens the possibility for aspiration to become a potential hazard due to the inability to properly swallow (Di Leo et al., 2019). In consequence to this, the immune system is impaired, bones are weakened, respiratory capacity is diminished, and brain function is reduced conclusively increasing morbidity and mortality rates. Eventually, to ensure healthy development specific nutritional management tailored individually is required to prevent or amend the deterioration of the children's nutritional status (Suh et al., 2020).

Enteral nutrition is suggested to avoid malnutrition and as preventive measurement for aspiration in children with a functioning GI tract (Di Leo et al., 2019). Swallow inability, neuromuscular disorders, injury, gastroesophageal reflux and oropharyngeal dysfunction are among the most prevailing indications for PEG in

children (Behrens et al., 1997; Khattak et al., 1998). Di Leo et al. (2019) points out in (Gauderer, 1991) that gastrostomy in specific allows for long term nourishment in children with chronic diseases. More often PEG is being used for the nutritional management of neurological impaired children, demonstrating an improvement in their nutritional intake as well as a reduction in the prevalence rate of illness produced by malnutrition. (Park et al., 2011)

Determining the nutritional needs of children with neurological impairment becomes a complicated endeavor that requires a multidisciplinary evaluation (Kuperminc et al., 2013). A large number of children with neurological impairment have a lower energy requirement compared to neurotypical children and it might differ from child to child depending on the level of their impairment (Vernon-Roberts et al., 2010).

Enteral nutrition can constitute pureed foods or commercial enteral formulas. Currently pureed food diets are in the rise in terms of popularity by reason of parents believing they are healthier and more natural (Escuro, 2014). However, Orel et al. (2017) found that commercial enteral formula is more effective when treating undernourished patients with neurological impairments compared to a pureed food diet, even when formulated by professionals.

Despite PEG being recommended to neurological impaired children suffering from malnutrition they are considered a high-risk group for complications associated with PEG, regardless of also being recognized as a group that can benefit the most from it (Campoli et al., 2009). Early complications (within 30 days of PEG insertion) can include pain in the abdomen area, pneumoperitoneum, small intestine or colon injury, liver/spleen injury; while late complications include buried bumper syndrome, infection or granulation of the skin in the PEG tube site, gastric ulcers and mechanical problems. (Fröhlich et al., 2010). Out of these complications mechanical problems like failed placement of the PEG tube, intraperitoneal leakage and dislodgement of the tube by accident are within the most common (Sandberg et al., 2018). Despite this, PEG is still considered a safe and

efficient option for neurologically impaired children as a long term treatment for nutritional support when performed by an experienced specialist and followed up by postoperative checks (Park et al., 2011; Macchini et al., 2018).

2.2 Nursing interventions

Friginal-Ruiz & Lucendo (2015) identified that in order to maintain appropriate long-term care of PEG tube that assures optimal nutrition and avoids PEG related complications these three approaches are to be considered: PEG tube care, stoma care and feeding care. PEG tube care refers to the maintenance of the mechanical components, this involves cleaning on a daily basis the caps and tube with clean gauze/swab, water, soap and letting it dry after rinsing (Thompson, 2019). The stoma should be cleaned every day; water, soft soap and clean gauze are recommended as well as cleaning in a “inside out” manner followed by a drying time. Scanning for redness, irritation, inflammation or leakage can be done during the cleaning process (Friginal-Ruiz & Lucendo, 2015).

For nutritional care nurses can provide education to caregivers and parents improving their knowledge and skills on how to prepare and deliver the enteral formula and observe the child’s response to feeding (Agustin, 2018). Gravity feeding, syringe and pump are the three feeding delivery methods available. Serena (2006) in Thompson (2019) noted that to lower the risk of aspiration an upright sitting position or inclinations of 30 to 40 degrees is recommended. Pumps are the most convenient as they provide nutrition automatically at a pre-set rate and volume; longer feeding sessions at slower rates are most appropriate as they increase absorption and decrease vomiting (Stenvers et al., 2012).

Drug administration via enteral tubes can increase the risk of nursing errors and technical errors such as blockage of the tube due to incorrect drug preparation, risk of cross contamination between different drugs as a result of inappropriate handling, along with hazardous exposure to the same (White et al., 2015). Some drug formats like chewables, buccal/sublingual tablets and cytotoxic mixtures

are not recommended for enteral administration, also enteric coated tablets and sustained release tablets should not be crushed in an attempted to be administered. Authorized drugs should be diluted in water individually with 5 to 30 milliliters of water in between each and not be mixed with nutritional formula (Friginal-Ruiz & Lucendo, 2015). To avoid blockage of the PEG tube drugs in liquid form are favorable over crushed and mixed ones (Blumenstein et al., 2014).

2.3 Parents/caregivers Experiences

Brotherton et al. (2007) identified several themes among parent's perspectives towards PEG feeding; Although positive themes like: "relieving pressure at mealtime" and "relieving pressure to give medication orally" were found, negative themes like: "a restricted ability to go out and take family holidays" and "impact on the family/Divisions in the family" helped to conclude that despite PEG being recommended it can spark issues among the family and caregivers. The life changing effects and acceptance of PEG among parents/caregivers has been studied considerably. A classic study done by Dickson et al. (1997) concluded that despite a great number of parents/caregivers being reluctant to PEG in the beginning, eventually they were pleased by the results of it.

It has been demonstrated that the decision has positive repercussions in the life and wellbeing of family, caregivers, and the children. Mealtime with children with limited feeding capability can result in frustration and stress for parents/caregivers and the children itself. Instead, PEG tube feeding allows for a more flexible and calmer experience for both parties, taking the strain away from those who feed and care for the children. One of the ways that this is achieved is by reducing the feeding time (Fröhlich et al., 2010; Brotherton et al., 2007).

Thompson (2019) points out how mothers were very satisfied after PEG feeding in contrast to previously when they felt a lot of time stressing during mealtime. On that same note Sullivan et al. (2004) noted how parents of neurologically impaired children described a shortening of the time when feeding as well as easier

medicine delivery after PEG insertion, which in turn eased their mind regarding the nutrition of the child. Caregiver also expressed feeling less mentally strain and having more energy.

In order to increase the approval of PEG it is essential to include parents in the decision making process (Fröhlich et al., 2010). To aid this initiative nursing care should be provided to parents, caregivers and family members instead of only focusing on the patient (Banhara et al., 2020). As previously explained, the care of a child with a PEG tube can give rise to issues that harm the overall health of parents/caregivers which in turn can also damage the health of the child, as it has been a reason for increased morbidity and mortality rate among children with feeding tubes. It has been found that family support helps lower the strain and stress of parents/caregivers (Banhara et al., 2020). Nurses (together with a multiprofessional team) can provide education regarding basic care of the feeding tube and avoidance of possible complications as part of the family support recommended, making nursing an immeasurable resource for parents (Thompson, 2019).

3 Study Aim, Purpose and Research Question

Aim: The aim of this literature review is to determine what are the key areas of pediatric percutaneous endoscopic gastrostomy tube care that parents and caregivers should be aware of.

Purpose: To offer nurses evidence based current knowledge to support education of parents and caregivers caring for children with percutaneous endoscopic gastrostomy tube.

Research question: What are the educational needs for parents/caregivers caring for children with percutaneous endoscopic gastrostomy tube?

4 Methodology

4.1 Literature review

A literature review is considered to be a research method that aims to summarize and synthesize in an objective and comprehensive manner the, at the time, available empirical or theoretical literature on a given topic, problem, phenomenon or healthcare issue as the subject of study (Cronin et al., 2008; Whitemore & Knafl, 2005). The objective of a literature review is to educate the reader on the contemporary and new knowledge of the topic in question (Cronin et al., 2008). In turn this helps improve and enlarge nursing science and nursing care by enabling theory development and up to date practice (Whitemore & Knafl, 2005). The authors of this study choose a literature review due to the availability of studies regarding pediatric PEG care, previous working experience and the necessity to analyze the aspects/components that constitute pediatric PEG care. This research uses a ten steps approach adapted from Rew (2011) (see Table 1).

Table 1. Steps in a Systematic Review of Literature (Rew, 2011)

Steps in a Systematic Review of Literature
1. Identify specific research question(s) to be answered.
2. State purpose of the review. What are its aims?
3. Identify inclusion and exclusion criteria.
4. Select search terms to use.
5. Identify appropriate databases to search.
6. Conduct the electronic search.
7. Review outcome of search and match with inclusion/exclusion criteria.
8. Data extraction. Systematically retrieve data from each paper included.
9. Interpret meaning of the evidence retrieved.
10. Acknowledge limitations and biases inherent in the process.

4.2 Literature search

The studies included in this review were extracted from two data bases, Cinahl Plus and PubMed. Boolean operators “AND” and “OR” were used along with the key words “percutaneous endoscopic gastrostomy”, “children”, “parents”, “caregivers”; acronyms and synonyms of these terms were also employed. The inclusion criteria consisted of having full text access to JAMK students, English language, published between 2010 and 2020, answers or is related to the research question. A preliminary search was done using PICOS as shown below in Table 2.

Table 2. PICOS Criteria

P (Problem or Patient or Population)	Children with PEG tubes OR Pediatric PEG AND Parents OR Caregivers
I (interest)	Care OR Management OR Practice
CO (Context)	Experience OR Perspective OR Education
S (Study design)	Full text access to JAMK students, English language, published between 2010 and 2020.

A step by step process was used by the author to select the studies included in the review. As seen in Figure 1. A total of 263 studies were identified in the PubMed and Cinhal Plus data bases after the use of the key words and Boolean operators. 1 study was found to be a duplicate, so it was removed. The 262 studies remaining were screened and filtered based on the title and abstract, considering the relevancy and relatedness with the main topic of the research, from which 21 studies were selected. The final 5 studies were chosen based on providing answers to the research question (Appendix 2.).

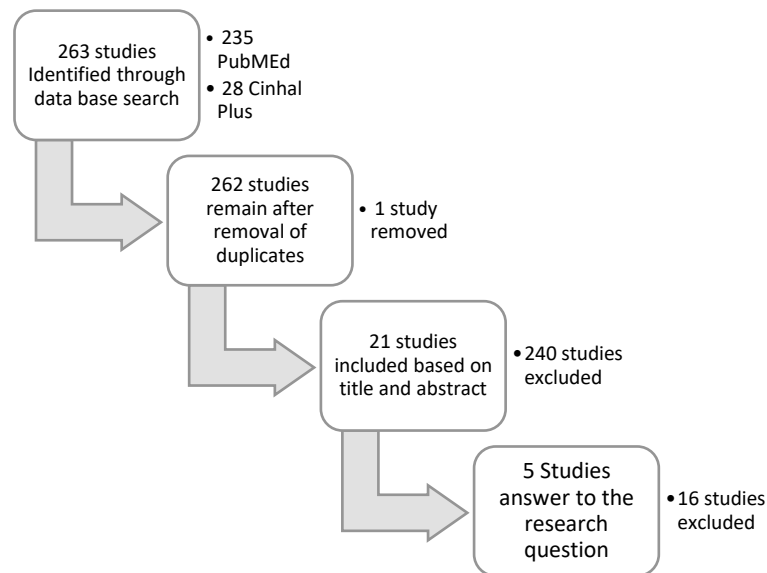


Figure 1. Studies selection process

4.3 Data analysis

Content analysis can be used as a research method to quantify and properly analyze the data in a systemic way, allowing researcher to better the understanding of it (Elo & Kyngäs, 2008). This method makes it possible to refine key words or sentences into related categories or themes within the content that is being analyze, which gives in return the crucial elements of the date while making it replicable and somewhat objective for practical application (Elo & Kyngäs, 2008). For this research the author opted to use inductive analysis (from specific to general) considering the lack of experience in relation to the topic.

An open coding process was followed to identify and categorize the findings after the data extraction in sentence form. A specific code was assigned to the extracted content from the studies reviewed. These codes were meant to describe the core point of the content. The codes were further merged into broader categories which were further merged into educational themes. An example of the process can be seen in Figure 2. below.

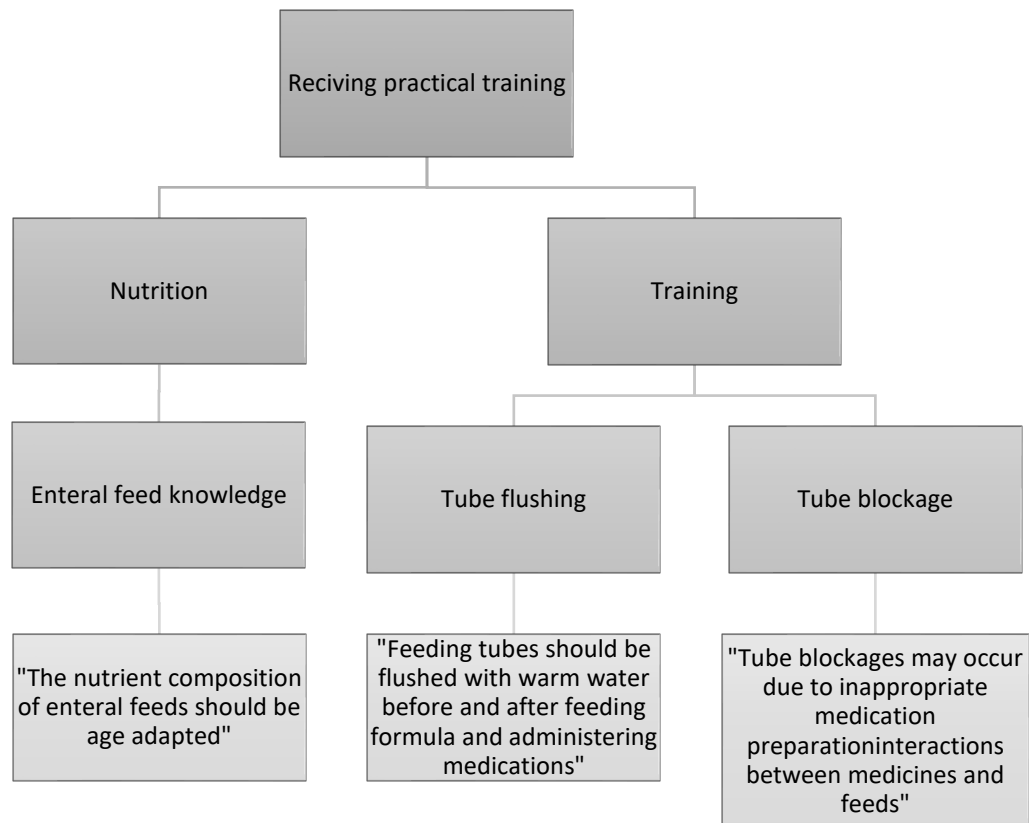


Figure 2. Data analysis process

5 Results

After the analysis four educational themes were identified. These are: Availability to professional support, Receiving practical training, Prevention of complications and Medication administration (see Table 3). The themes represent main areas of healthcare in relation to children with PEG tubes and their parents or caregivers.

Table 3. Educatinal themes and subcategories from data analysis

Availability to professional support	<ul style="list-style-type: none"> ▪ Professional support ▪ Communication with healthcare professionals ▪ Reliable information ▪ Care knowledge
Receiving practical training	<ul style="list-style-type: none"> ▪ Insufficient training ▪ Availability of training ▪ Mechanical knowledge of the tube ▪ Enteral feed knowledge ▪ Nutrition delivery method ▪ Nutrition knowledge
Prevention of complications	<ul style="list-style-type: none"> ▪ Stoma care ▪ Contamination of the tube ▪ Significant complication ▪ Hygiene
Medication administration	<ul style="list-style-type: none"> ▪ Medication delivery knowledge ▪ Suboptimal choice of medicine ▪ Misusage of medication

5.1 Availability to professional support

Availability to professional support was a recurrent theme among most of the studies included in the review. This theme envelops the need for parents/caregiver to have access to reliable information and support from healthcare professionals. Having a system that provides unrestrained continuous monitoring and support for children with PEG tubes and their families or caregivers is essential (McSweeney et al., 2013). Page et al. (2019) suggests that providing a sufficient amount of community services with experienced professionals is needed to support the families of the children. Braegger et al. (2010) then seconds this by adding that families in the PEG community should have at their disposal the support of a multidisciplinary team that includes nutritionists, specialist nurses, pediatrician, and pharmacists.

It would be crucial for parents/caregivers to maintain a close communication with a support team that covers nutritional needs, medication, equipment, and problem solving support (Braegger et al., 2010). For instance, caregivers should have a contact number for a support nurse that could aid with questions and

technical support regarding equipment like feeding pumps (Spratling et al., 2021). An example illustrated by Spratling et al. (2021) explains that to prevent PEG tube dislodgement or undesired removal the tube should be replaced routinely every 8 to 12 months and that caregivers should contact their nurse to confirm what is needed to replace the tube or have available a written documents with specific information about the size of the tube, type and date of the last change. The importance for the healthcare workers to push the communication factor is affirmed by Alsaeed et al. (2018) as they reported that often caregivers are not always well informed when it comes to their practices, which may affect therapeutic outcomes and safety of the procedure. Consistent care appointments involving parents/caregivers and nurses or pediatricians are important to ensure the healthy development of the children (Braegger et al., 2010).

5.2 Receiving practical training

Initially parents can be reluctant about PEG placement and the changes in lifestyle that it brings, but after the procedure is done and the family gets comfortable with the health care parents become satisfied with the outcome (Koca et al., 2015). Page et al. (2019) found that families and caregiver do not receive sufficient training or information reporting that inadequate training of caregivers was a frequent concern. Cases of defective or broken equipment were identified and partially attributed to misuse from parents and caregivers due to a lack of training (Page et al., 2019). Therefore training should include and prioritize the needs of the parents/caregivers taking into account their experience (Alsaeed et al., 2018). Training must be given by experienced healthcare workers. Page et al. (2019) suggests an online training platform available at a national level to parents and caregivers as part of a training curriculum, with the inclusion of videos and situational examples; they also added that experienced parents and a professional team should be involved in caregivers training.

Mechanical care and knowledge of the PEG tube is essential for the caring of the patients with PEG tube. Appropriate tube care and flushing technique must be

taught and trained as is it a crucial piece of knowledge to assure the wellbeing of the user of the tube, as blockage is a common problem among users (Alsaeed et al., 2018). To prevent blockage the tube should be flushed with warm water before and after feeding and medication administration. Saline solutions should be avoided to flush the tube, crystallization in the tube may occur and block it (Spratling et al., 2021). Other causes of blockage include the inappropriate use of medication and formula as these may interact with each other (Alsaeed et al., 2018). Another tube inconvenience is accidental removal, a replacement tube of the same size should be in hand and immediately placed in the stoma (Spratling et al., 2021).

Nutrition and feeding were found to be a major point for education and training. Page et al. (2019) recommends that nutritional support teams should take enough time training caregivers and health care professionals involved in PEG tube care to safeguard the everyday care complications and how to manage them. Blenderized food are not recommended for feeding by reason of being insufficient for optimal nutrition as well as being more likely to cause microbial contamination in the tube. Feeding formula supplies a balance mix of the essential nutrients for growth and psychological development. Formula should have an age appropriate composition, often found as Junior options. However, adult formulas can be used for children older than 8-10 years if there is no junior option available. Supplemental feeds can be given in addition to regular formula, these helps increase energy supply and contain additional nutrients. Formulas for specific diseases may be available and beneficial and should be considered. (Braegger et al., 2010)

The proper use of an enteral feeding pump is fundamental for the care children with PEG tubes as it is the piece of equipment that facilitates their nutrition. Braegger et al. (2010) indicates that intermittent feeding preferable over continuous feeding considering that it is more physiological, yet continuous feeding may be better if the goal is to provide more energy or increase weight. Caregivers should be given learning material in the form of a guide or video about set-

ting up feeding pumps as well as regular evaluations of nutritional objectives in within the health care plan (Braegger et al., 2010).

5.3 Prevention of complications

PEG related complications are considered as frequent problem among the PEG community. Complications can vary in severity degree and can escalate to more serious problems. Braegger et al. (2010) found that 73% of patients reported a stoma-related complication mostly taking place during the first 2 years after the procedure. McSweeney et al. (2013) later supported this as they reported that 10% of patients will have a major complication in the first 6 to 12 months after PEG placement, nonetheless serious complications may still surface many years after placement.

Children's PEG tubes are commonly contaminated with microbes at their homes and in hospitals (Braegger et al., 2010). While tube blockage is one of the most common complication with feeding tubes according to Alsaeed et al. (2018) the most frequent complication of PEG is wound infection (Koca et al., 2015; Braegger et al., 2010). Preparation of the feed, poor handwashing and not paying enough attention when handling the feeding equipment during feeding time are risk factors for tube contamination, feeding preparations should be done in a clean environment and practicing proper hygiene techniques (Braegger et al., 2010). It is recommended to maintain a strict hygiene protocol during feeding as it has been found to reduce contamination rates in homes and hospitals (Braegger et al., 2010).

To prevent gastrointestinal infection and stoma infection handwashing and keeping the equipment clean must be part of the basic care plan and held as a priority (Spratling et al., 2021). The stoma should be kept clean and dry, creams are to be avoided as they can keep the stoma moist (Spratling et al., 2021). Cleaning the stoma is very important part of the wound care process, this can be done with mild soap and water (Spratling et al., 2021). Extra attention must be given to the

PEG tube changing process due to being the time where complications are more likely to happen (McSweeney et al., 2013).

5.4 Medication administration

Alsaeed et al. (2018) expresses that proper medication administration information aimed at parents/caregivers is scarce as well as having a poor choice of medicines that are safer for enteral tube route. It was reported that 62% of caregivers receive guidance on how to safely administer medication, and only 8% receive written instructions/information on the matter. On top of this 87% of care givers reported no concerns about medication administration which indicates a lack of awareness on safe administration and manipulation of medicine. (Alsaeed et al., 2018)

Mixing medicine with formula or alternating them can cause complications (Alsaeed et al., 2018). Viscous formula and crushed tablets can cause tube blockage on their own, it is not recommended to mix them together (Spratling et al., 2021). Untrained and uninformed caregivers can potentially use or modify medicines in unsafe ways such as dissolving tablets in boiling water or preparing syringes with medication in advance of administration time (Alsaeed et al., 2018). Alsaeed et al. (2018) found that some caregivers can go to the extent of mixing different medicines together and delivering them at the same time which creates cross contamination risk and undesired drugs interactions. For safer administration liquid options are preferable, in the case of a medicine being only available as a tablet this must be properly crushed and mixed with water, enteric coated and slow-release tablets are not recommended (Braegger et al., 2010). Education regarding safe and adequate medicine administration must be taken more into consideration for unexperienced parents and caregivers caring for a child with PEG tube (Alsaeed et al., 2018).

6 Discussion

6.1 Discussion of the results

This literature review managed to identify four educational themes related to the care of children with PEG tubes, focusing on the parents or caregivers as the providers for the care. The themes were: Availability to professional support, Receiving practical training, Prevention of complications and Medication administration. Based on these results it appears as the education of parents/caregivers is lacking in several crucial areas of the care, and as seen before this lack can be detrimental to the health of the children (Banhara et al., 2020). Friginal-Ruiz & Lucendo (2015) also identified similar themes in their study, they found that to maintain appropriate long-term care of PEG tube these approaches are to be considered: PEG tube care, Stoma care, Care during feeding and Administration of medication through PEG tube. Their results are reassuring for the author of this review as it is possible to correlate “PEG tube care” and “Care during feeding” with “Receiving practical training”, “Stoma care” with “Prevention of complications” and “Administration of medication through PEG tube” with “Medication administration” meaning there is certain level of corroboration of results with other studies recently done.

It appears to be of great importance that parents/caregivers maintain a constant and healthy communications with health care professionals (Braegger et al., 2010), the inclusion of this topic in several of the studies included in the review confirms this. McSweeney et al. (2013), Page et al. (2019), Braegger et al. (2010) and Spratling et al. (2021) all mention the need so have some sort of support services available to the families of the children. Braegger et al. (2010) supports that a multidisciplinary team would be ideal for the betterment of the practices and knowledge of the parents/caregivers. Recently Thompson (2019) has also proposed that nurses along with a multidisciplinary team should provide healthcare education to the families of the children. In a similar vein nursing care should also be provided to the parents and family members who may interact

with the children instead of only focusing on them as patients; taking a more holistic approach to their life situation, as it has been shown that family support helps lower the strain and stress of parents (Banhara et al., 2020).

The results of this review helps homogenize and confirm certain practices as universal, such as stoma care. It is safe to consider that a PEG tube stoma must be cleaned on a daily basis with mild/soft soap and water and left to dry properly after (Thompson, 2019; Frigal-Ruiz & Lucendo, 2015; Spratling et al., 2021). Yet, other areas like the nutrition and feeding of the children needs to be taken more seriously. Regarding nutrition, it was evident that many studies take into consideration the technical approach of operation of the feeding pump and care of the equipment, even suggesting learning material in the form of videos for setting up the pump (Braegger et al., 2010). Nutrition education for parents and caregivers has been implied, with nurses, nutritionists, and nutritional support teams being mentioned (Agusdtin, 2018; Page et al. (2019). However, despite some studies being more specific about care and assessment of feeding and nutrition (Stenvers et al., 2012), it is the notion of the author that the nutrition element hasn't been mentioned enough from a more clinical view. More specifically how to assess aspects like absorption, feeding rate and duration, position, reaction of the child; further research that focuses on this is needed.

On another note, drug administration showed to be an area of care that needs much improvement. It was surprising to the author to find that a big percentage of parents/care giver have not received proper training for administrating medication (Alsaeed et al., 2018). Medication errors can cause cross contamination in between different drugs enabling their effect or causing undesirable ones (White et al., 2015) or block the tube if not well prepared or mixed with formula (White et al., 2015). This is not only attributed to lack of education but also to poor options of medication better suited for enteral tube rout such as liquid forms (Blumenstein et al., 2014; Alsaeed et al., 2018).

In conclusion the education of parents and caregivers is currently at a suboptimal level. The Negative implications of the lack of education is detrimental to the health and wellbeing of children with PEG tube as well as the families of the children. Reinforcement of professional support available to these families is much needed as well as a much deeper and fuller training and education process that includes feeding and nutrition assessment, correct hygienic practices for manipulating and cleaning the tube and stoma, medication administration by parents and caregivers.

6.2 Critical appraisal, Ethical considerations, Reliability and validity

The Hawker et al (2002) appraisal tool was used to assess the reliability and quality of the articles included in this literature review (Appendix 1.). The tool evaluates the following aspects of an article: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalizability, and implications and usefulness on a scale of 1 to 4 (1 being the lowest grade and 4 the highest) for a total score of 36. The minimum requirement for an article to be included this review was 30. It is worth noting that due to this selection rule the number of articles included was so limited (six articles). Several other articles were considered to be included, as they offered compelling information related to the research question and aim of this review. In an attempt to maintain an appropriate level of quality the author opted to exclude articles that didn't met the mark.

All articles used recognized the ethical considerations of their research and/or mentioned approval from various ethical committees. Articles that utilized personal information of patients or answers from questionnaires did so in an anonymous manner protecting the image and rights of the subjects. The author of this review acknowledges the ethical responsibility of presenting data retrieved from studies with personal information of patients, and considers that the same was used in a continuous, respectful manner. All the information displayed in this review was properly cited and referenced from the original sources giving full

credit to the authors in question using the latest parameters of The American Psychological Association (APA, 7th edition).

The author considers that the reliability and validity of the research is displayed in the meticulous documentation of the processed followed and that this could be followed and replicated. This research was limited to the use of articles in the English language available for free to JAMK students or public free access. Specific country of origin of the articles was not taken into consideration for the analysis, nonetheless an effort was made to include articles from countries considered to be developed (Several European countries and the United States).

Despite this effort the author considers that this may have limited the research and if replicated it would be benefited by a more demographic focused approach for more relatable/extrapolatable results.

References

- Agustin, D. A. (2018). THE ROLE OF NURSES IN PROVIDING HEALTH EDUCATION TO THE FAMILY ABOUT THE CHILDREN ENTERAL NUTRITION. *International Journal of Advancement in Life Sciences Research*, 1(2), 13–19.
<https://doi.org/10.31632/ijalsr.2018v01i02.003>
- Alsaeed, D., Furniss, D., Blandford, A., Smith, F., & Orlu, M. (2018). Carers' experiences of home enteral feeding: A survey exploring medicines administration challenges and strategies. *Journal of Clinical Pharmacy and Therapeutics*, 43(3), 359–365. <https://doi.org/10.1111/jcpt.12664>
- Banhara, F. L., Farinha, F. T., Bom, G. C., Razera, A. P. R., Tabaquim, M. de L. M., & Trettene, A. dos S. (2020). Parental care for infants with feeding tube: psychosocial repercussions. *Revista Brasileira de Enfermagem*, 73(2).
<https://doi.org/10.1590/0034-7167-2018-0360>
- Behrens, R., Lang, T., Muschweck, H., Richter, T., & Hofbeck, M. (1997). Percutaneous Endoscopic Gastrostomy in Children and Adolescents. *Journal of Pediatric Gastroenterology & Nutrition*, 25(5), 487–491.
<https://doi.org/10.1097/00005176-199711000-00001>
- Blumenstein, I., Shastri, Y. M., & Stein, J. (2014). Gastroenteric tube feeding: Techniques, problems and solutions. *World Journal of Gastroenterology*, 20(26), 8505. <https://doi.org/10.3748/wjg.v20.i26.8505>
- Braegger, C., Decsi, T., Dias, J. A., Hartman, C., Kolacek, S., Koletzko, B., Koletzko, S., Mihatsch, W., Moreno, L., Puntis, J., Shamir, R., Szajewska, H., Turck, D., van Goudoever, J., & ESPGHAN Committee on Nutrition: (2010). Practical approach to paediatric enteral nutrition: A comment by the ESPGHAN committee on nutrition. *Journal of Pediatric Gastroenterology and Nutrition*, 51(1), 110–122.
<https://doi.org/10.1097/MPG.0b013e3181d336d2>
- Brotherton, A. M., Abbott, J., & Aggett, P. J. (2007). The impact of percutaneous endoscopic gastrostomy feeding in children; the parental perspective. *Child: Care, Health and Development*, 33(5), 539–546.
<https://doi.org/10.1111/j.1365-2214.2007.00748.x>

- Campoli, P. M., Cardoso, D. M., Turchi, M. D., Ejima, F. H., & Mota, O. M. (2009). Assessment of safety and feasibility of a new technical variant of gastrostomy for percutaneous endoscopic gastrostomy: an experience with 435 cases. *BMC Gastroenterology*, *9*(1). <https://doi.org/10.1186/1471-230x-9-48>
- Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: A step-by-step approach. *British Journal of Nursing*, *17*(1), 38–43. <https://doi.org/10.12968/bjon.2008.17.1.28059>
- Di Leo, G., Pascolo, P., Hamadeh, K., Trombetta, A., Ghirardo, S., Schleef, J., Barbi, E., & Codrich, D. (2019). Gastrostomy Placement and Management in Children: A Single-Center Experience. *Nutrients*, *11*(7), 1555. <https://doi.org/10.3390/nu11071555>
- Dickson, A., Clarke, M., Tawfik, R., & Thomas, A. G. (1997). Caregivers' perceptions following gastrostomy in severely disabled children with feeding problems. *Developmental Medicine & Child Neurology*, *39*(11), 746–751. <https://doi.org/10.1111/j.1469-8749.1997.tb07376.x>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Escuro, A. A. (2014). *Blenderized Tube Feeding: Suggested Guidelines to Clinicians*. Google Scholar. <https://med.virginia.edu/ginutrition/wp-content/uploads/sites/199/2014/06/Parrish-Dec-14.pdf>
- Frigal-Ruiz, A. B., & Lucendo, A. J. (2015). Percutaneous Endoscopic Gastrostomy. *Gastroenterology Nursing*, *38*(5), 354–366. <https://doi.org/10.1097/sga.0000000000000150>
- FRÖHLICH, T., RICHTER, M., CARBON, R., BARTH, B., & KÖHLER, H. (2010). Review article: percutaneous endoscopic gastrostomy in infants and children. *Alimentary Pharmacology & Therapeutics*, *31*(8). <https://doi.org/10.1111/j.1365-2036.2010.04246.x>
- Gauderer, M. W. L. (1991). Percutaneous endoscopic gastrostomy: A 10-year experience with 220 children. *Journal of Pediatric Surgery*, *26*(3), 288–294. [https://doi.org/10.1016/0022-3468\(91\)90504-m](https://doi.org/10.1016/0022-3468(91)90504-m)

- Guidelines And Audit Information Network (Northern Ireland). (2015). *Guidelines for caring for an infant, child or young person who requires enteral feeding*. Gain.
- Khattak, I. U., Kimber, C., Kiely, E. M., & Spitz, L. (1998). Percutaneous endoscopic gastrostomy in paediatric practice: Complications and outcome. *Journal of Pediatric Surgery, 33*(1), 67–72. [https://doi.org/10.1016/s0022-3468\(98\)90364-5](https://doi.org/10.1016/s0022-3468(98)90364-5)
- Koca, T., Sivrice, A. C., Dereci, S., Duman, L., & Akcam, M. (2015). Percutaneous endoscopic gastrostomy in children: a single center experience. *Türk Pediatri Arşivi, 50*(4), 211–216. <https://doi.org/10.5152/turkpediatriars.2015.3157>
- Krom, H., van Zundert, S. M. C., Otten, M.-A. G. M., van der Sluijs Veer, L., Benninga, M. A., & Kindermann, A. (2019). Prevalence and side effects of pediatric home tube feeding. *Clinical Nutrition, 38*(1), 234–239. <https://doi.org/10.1016/j.clnu.2018.01.027>
- Kuperminc, M. N., Gottrand, F., Samson-Fang, L., Arvedson, J., Bell, K., Craig, G. M., & Sullivan, P. B. (2013). Nutritional management of children with cerebral palsy: a practical guide. *European Journal of Clinical Nutrition, 67*(S2), S21–S23. <https://doi.org/10.1038/ejcn.2013.227>
- Macchini, F., Zanini, A., Farris, G., Morandi, A., Brisighelli, G., Gentilino, V., Fava, G., & Leva, E. (2018). Infant Percutaneous Endoscopic Gastrostomy: Risks or Benefits? *Clinical Endoscopy, 51*(3), 260–265. <https://doi.org/10.5946/ce.2017.137>
- McSweeney, M. E., Jiang, H., Deutsch, A. J., Atmadja, M., & Lightdale, J. R. (2013). Long-term Outcomes of Infants and Children Undergoing Percutaneous Endoscopy Gastrostomy Tube Placement. *Journal of Pediatric Gastroenterology and Nutrition, 57*(5), 663–667. <https://doi.org/10.1097/mpg.0b013e3182a02624>
- Mehta, N. M., McAleer, D., Hamilton, S., Naples, E., Leavitt, K., Mitchell, P., & Duggan, C. (2009). Challenges to Optimal Enteral Nutrition in a Multidisciplinary Pediatric Intensive Care Unit. *Journal of Parenteral and Enteral Nutrition, 34*(1), 38–45. <https://doi.org/10.1177/0148607109348065>

- Orel, A., Homan, M., Blagus, R., Benedik, E., Orel, R., & Fidler Mis, N. (2017). Nutrition of patients with severe neurologic impairment. *Radiology and Oncology*, *52*(1), 83–89. <https://doi.org/10.1515/raon-2017-0060>
- Page, B., Nawaz, R., Haden, S., Vincent, C., & Lee, A. C. H. (2019). Paediatric enteral feeding at home: an analysis of patient safety incidents. *Archives of Disease in Childhood*, *104*(12), archdischild-2019-317090. <https://doi.org/10.1136/archdischild-2019-317090>
- Park, J. H., Rhie, S., & Jeong, S. J. (2011). Percutaneous endoscopic gastrostomy in children. *Korean Journal of Pediatrics*, *54*(1), 17. <https://doi.org/10.3345/kjp.2011.54.1.17>
- Rahnemai-Azar, A. A., Rahnemaiazar, A. A., Naghshizadian, R., Kurtz, A., & Farkas, D. T. (2014). Percutaneous endoscopic gastrostomy: Indications, technique, complications and management. *World Journal of Gastroenterology*, *20*(24), 7739. <https://doi.org/10.3748/wjg.v20.i24.7739>
- Rew, L. (2011). The systematic review of literature: Synthesizing evidence for practice. *Journal for Specialists in Pediatric Nursing*, *16*(1), 64–69. <https://doi.org/10.1111/j.1744-6155.2010.00270.x>
- Sandberg, F., Viktorsdóttir, M. B., Salö, M., Stenström, P., & Arnbjörnsson, E. (2018). Comparison of major complications in children after laparoscopy-assisted gastrostomy and percutaneous endoscopic gastrostomy placement: a meta-analysis. *Pediatric Surgery International*, *34*(12), 1321–1327. <https://doi.org/10.1007/s00383-018-4358-6>
- Skalsky, A. J., & Dalal, P. B. (2015). Common Complications of Pediatric Neuromuscular Disorders. *Physical Medicine and Rehabilitation Clinics*, *26*(1), 21–28. <https://doi.org/10.1016/j.pmr.2014.09.009>
- Spratling, R. (2021). Best Practices with Use of Feeding Tubes for Children at Home. *Pediatric Nursing*, *47*(1), 7–10.
- Stenvers, D. J., Jonkers, C. F., Fliers, E., Bisschop, P. H. L. T., & Kalsbeek, A. (2012, January 1). *Nutrition and the circadian timing system* (A. Kalsbeek, M. Merrow, T. Roenneberg, & R. G. Foster, Eds.). ScienceDirect; Elsevier. <https://www.sciencedirect.com/science/article/abs/pii/B9780444594273000204>

- Suh, C., Kim, W., Eun, B.-L., & Shim, J. O. (2020). Percutaneous Endoscopic Gastrostomy and Nutritional Interventions by the Pediatric Nutritional Support Team Improve the Nutritional Status of Neurologically Impaired Children. *Journal of Clinical Medicine*, *9*(10), 3295.
<https://doi.org/10.3390/jcm9103295>
- Sullivan, P. B., Juszczak, E., Bachlet, A. M., Thomas, A. G., Lambert, B., Vernon-Roberts, A., Grant, H. W., Eltumi, M., Alder, N., & Jenkinson, C. (2004). Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Developmental Medicine & Child Neurology*, *46*(12). <https://doi.org/10.1017/s0012162204001392>
- Thompson, N. M. (2019). Nursing Care and Management of Gastrostomy and Gastrojejunostomy Tubes in the Pediatric Population. *Journal of Pediatric Surgical Nursing*, *8*(4), 97–111.
<https://doi.org/10.1097/jps.0000000000000229>
- VERNON-ROBERTS, A., WELLS, J., GRANT, H., ALDER, N., VADAMALAYAN, B., ELTUMI, M., & SULLIVAN, P. B. (2010). Gastrostomy feeding in cerebral palsy: enough and no more. *Developmental Medicine & Child Neurology*, *52*(12), 1099–1105. <https://doi.org/10.1111/j.1469-8749.2010.03789.x>
- Vudayagiri, L., Hoilat, G. J., & Gemma, R. (2021). *Percutaneous Endoscopic Gastrostomy Tube*. PubMed; StatPearls Publishing.
<https://www.ncbi.nlm.nih.gov/books/NBK535371/#article-26928.s14>
- White, R., Bradnam, V., & British Pharmaceutical Nutrition Group. (2015). *Handbook of drug administration via enteral feeding tubes* (3rd ed., p. 7). Pharmaceutical Press.
<https://books.google.fi/books?id=yyikBwAAQBAJ&printsec=frontcover&dq=PEG+tube+definition&hl=en&sa=X&ved=2ahUKEwjMzaWMu-XzAhUOvYsKHTbfCW4Q6AF6BAgLEAI#v=onepage&q&f=false>
- Whittemore, R., & Knaf, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553.
<https://doi.org/10.1111/j.1365-2648.2005.03621.x>

Appendices

Appendix 1. Critical Appraisal of the articles (Hawker et al. 2002)

Author	Ab- stract/title	2 Introduc- tion and aims	3 Methods and data	4 Sam- pling	5 Data analysis	6 Ethics and bias	7 Results	8 Transferabil- ity/generalizability	9 Implications and usefulness	Total
Spratling et al. (2021)	3	4	4	4	2	1	4	4	4	30
Alsaeed et al. (2018)	4	4	4	3	3	4	4	3	4	33
Braegger et al. (2010)	4	4	4	4	2	1	4	3	4	30
McSweeney, et al. (2013)	4	4	4	4	3	3	4	4	4	34
Page et al. (2019)	4	4	4	4	4	4	4	4	4	36
Koca et al. (2015)	4	3	4	4	4	3	4	4	3	33

Appendix 2. Summary of reviewed articles

Author, year, and country	Aim of the study	Method and design	Main finding of the study	Critical Appraisal (Hawker et al. 2002)
Spratling, R. (2021). United States	The aim of this review is to identify best practices in the care of children with feeding tube	The literature search uses the electronic database of Georgia Library Learning Online (Galileo). Literature with titles directly related to search terms and those articles published in the past five years were included in the initial review. Key words used in the search included combinations of the following words: pediatric, children, feeding tube, guidelines, placement, verification, and replacement.	Evidence-based literature to support and guide best practices for use of feeding tubes in children is readily available; however, more research is needed to determine best practices in developmental aspects of care for children who have feeding tubes, specifically for those managed in the home setting.	30
Alsaeed, D., Furniss, D., Blandford, A., Smith, F., & Orlu, M. (2018). England	The aim of this study was to identify issues carers experience in medicines administration; the strategies they have developed to cope; and suggestions to better the medicines administration	National online survey. Descriptive statistical analysis was applied, as well as thematic analysis of open-ended responses.	Responses identified 5 medicines administration issues experienced by carers; 4 strategies they developed to cope; and 3 main areas of suggestions to improve medicines administration via enteral feeding at home.	33

	process.			
Braegger, C., Decsi, T., Dias, J. A., Hartman, C., Kolacek, S., Koletzko, B., Koletzko, S., Mihatsch, W., Moreno, L., Puntis, J., Shamir, R., Szajewska, H., Turck, D., van Goudoever, J., & ESPGHAN Committee on Nutrition: (2010). Eu- ropean Union (internation- al)	The aim of this study is to provide a clinical prac- tice guide to enteral nutrition support in pae- diatric patients	Relevant studies were identified by searching the MEDLINE database and the Cochrane Database of Systematic Reviews. We used the terms EN, tube, feeding, gastrostomy, jejunostomy, refeeding, indica- tions, and complications, and limited our search to the pediatric population using the additional search terms infants or children or adolescents.	Among the various gastrostomy techniques avail- able, percutaneous endoscopic gastrostomy is currently the first option. In general, both pa- tients and caregivers express satisfaction with this procedure, although it is associated with a number of well-recognized complications. We strongly recommend the development and appli- cation of procedural protocols that include scru- pulous attention to hygiene, as well as regular monitoring by a multidisciplinary nutrition sup- port team to minimize the risk of EN-associated complications.	30
McSweeney, M. E., Jiang, H., Deutsch, A. J., Atmadja, M., & Lightdale, J. R. (2013). United States	The aim of this study was to examine tube-related major complications in pediatric patients under- going PEG placement.	A retrospective chart review of patients undergoing PEG placement from April 1999 through December 2000 at Boston Children's Hospital was performed. Cumulative incident rates of major complications as well as time between PEG placement and major complications were evaluated using Kaplan-Meier survival analysis.	Children undergoing PEG placement have a long- term high risk of morbidity related to enteral tubes. Major complications can occur many years after PEG placement.	34

<p>Page, B., Nawaz, R., Haden, S., Vincent, C., & Lee, A. C. H. (2019). England and Wales</p>	<p>The aim of this study is to describe the causes of patient safety incidents relating to care at home for children with enteral feeding devices.</p>	<p>We analysed incident data relating to paediatric nasogastric, gastrostomy or jejunostomy feeding at home from England and Wales' National Reporting and Learning System between. Manual screening identified 274 incidents. Each report was descriptively analysed to identify the problems in the delivery of care, the contributory factors and the patient outcome.</p>	<p>The most common problems in care related to equipment and devices (28%), procedures and treatments (24%), information, training and support needs of families (15%), feeds (15%) and discharge from hospital (9%). Contributory factors included staff/service availability, communication between services and the circumstances of the family carer.</p>	<p>36</p>
<p>Koca, T., Sivrice, A. C., Dereci, S., Duman, L., & Akcam, M. (2015). Turkey</p>	<p>The aim of this study was to evaluate the demographic data and complication rates in children who had undergone percutaneous endoscopic gastrostomy in a three-year period and to interrogate parental satisfaction.</p>	<p>The demographic data, complications and follow-up findings of the patients who had undergone percutaneous endoscopic gastrostomy between March 2011 and March 2014 were examined retrospectively using medical files.</p>	<p>A significant increase in the mean weight Z score from -2.41 to -1,07 (p=0.000) and in the mean height Z score from -2.29 to -1.99 (p=0.000) was found one year after percutaneous endoscopic gastrostomy catheter was placed in these 24 patients. Patients with neurological and metabolic diseases constituted the majority (64.7% and 26.5% respectively). Peritoneal leakage of food was detected in one patient and local stoma infections were detected in three patients after the procedure.</p>	<p>33</p>