

Bridging the Gap in Pediatric Feeding Tube Education

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She has no known conflict of interest to disclose.

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Abstract

Background: Existing practice standards for discharge education are insufficient to support parents of children with new enteral feeding devices in the outpatient setting which has led to increased clinic and emergency department visits, hospital stays, and preventable complications. The purpose of this Doctor of Nursing Practice (DNP) project was to design and deliver a comprehensive evidence-based enteral feeding tube hospital-based discharge education intervention for parents after their child's gastrostomy tube placement surgery. Guided by Transition's theory, the project aims to bridge the gap in education by providing the parent with ongoing support and education about their child's gastrostomy tube. **Methods:** This project measured the impact of inpatient discharge education with ongoing support and outpatient education on parent knowledge and confidence. All English-speaking parents of pediatric patients ages 0-17 years with new gastrostomy tubes at a large, urban, freestanding pediatric hospital in the southwest United States were eligible for participation. Institutional Review Board approval was obtained. Informed consent was obtained from all participants. The education intervention was delivered at hospital discharge then reinforced at the first follow-up visit in the surgery clinic. Data analysis included demographic items, a Paired Samples T-Test, and a Two-tailed Wilcoxon Signed Rank Test analyses. **Results:** Results indicated a statistically significant difference in parent knowledge after the educational intervention. Results also indicated a clinically significant increase in parent confidence. **Conclusion:** Providing ongoing support and education positively impacts parent knowledge and confidence related to the care of their child's new gastrostomy tube. Future impacts of this educational intervention may demonstrate a decrease in clinic and emergency department (ED) visits, hospital expenditure, and preventable complications.

Keywords: pediatric, gastrostomy tube, feeding tube, enteral feeding, discharge education

Bridging the Gap in Pediatric Feeding Tube Education

Not all children can consume food orally and they require the assistance of a feeding device to prevent malnutrition, promote adequate growth, and sustain life (Hopwood et al., 2020; Krom et al., 2019; Mundi et al., 2017). An enteral feeding device can provide an alternative source of nutrition for these children through a tube that bypasses the oral cavity and terminates in the stomach. The incidence of children who receive nutrition in this way is increasing worldwide (Majka et al., 2013; Mundi et al., 2017). Having a child who is tube-fed can also negatively affect the child's parent or caregiver (Pahsini et al., 2016). Along with the psychological and emotional stress that may accompany their child's diagnosis, the parent must learn how to effectively feed their child through another route. Current hospital discharge education practices after gastrostomy tube (GT) placement may not be enough to give parents the confidence they need to provide management and care for their child's enteral feeding device.

Problem Statement

Even though there are current evidence-based standards of clinical practice for new feeding tube education, studies have shown that current hospital discharge education is not sufficient to support parents of children with new enteral feeding devices (Hopwood et al., 2020; Northington et al., 2017; Schweitzer et al., 2014; Szymis et al., 2018; Zamvar et al., 2014). Inconsistency in the type of hospital discharge education a patient or caregiver receives contributed to the lack of support and knowledge because hospital discharge feeding tube education practices vary among nurses, healthcare providers, and medical staff (Schweitzer et al., 2014). In one study, 96% of nurses said that they thought the education they received at orientation and through continuing education was inadequate to educate the parents of patients with new gastrostomy tubes prior to discharge (Schweitzer et al., 2014). Therefore, parents and

caregivers were not receiving the necessary education from nurses to successfully care for their child in the home environment. The lack of education given to patients and caregivers failed to prepare them adequately and led to extra outpatient clinic visits, ED visits, and preventable complications (Schweitzer et al., 2014).

Purpose and Rationale

Having a child who has a feeding tube device can pose a burden for the parent or caregiver and cause significant stressors, challenges, emotional distress and anxiety (Hopwood et al., 2020; Pahsini et al., 2016; Singhal et al., 2017; Syrmis et al., 2018; Zamvar et al., 2020).

Without adequate education, that burden may intensify and cause parents severe emotional and physiological stress, which may decrease parental confidence in caring for their child's feeding tube device. The purpose of this Doctor of Nursing Practice (DNP) project is to design and deliver a comprehensive evidence-based enteral feeding tube education for parents after their child's gastrostomy tube placement surgery and prior to the child's hospital discharge.

Comprehensive hospital discharge education along with ongoing outpatient education has the potential to increase parental confidence when caring for their child's new enteral feeding device.

Background and Significance

Malnutrition occurs when children cannot consume an adequate amount of food and calories orally to sustain life. Malnutrition can occur in conjunction with an acute, complex, or chronic health condition and may lead to a host of medical issues such as the increased risk of disease and death (Mundi et al., 2017). Malnutrition also causes failure to thrive. Failure to thrive is a medical condition where an infant or child does not gain weight quickly enough to support their normal growth and may lead to a need for another way to nourish the body (Feeding Tube

Awareness Foundation (FTAF), 2021). An enteral feeding tube provides an adequate source of nutrition through an alternate route (Hopwood et al., 2020; Mundi et al., 2017; Schweitzer et al., 2014). Children may develop the need for an enteral feeding tube as early as infancy and the parent or caregiver needs comprehensive education about how to manage and care for their child's new enteral feeding device (Schweitzer et al., 2014; Syrmiš et al., 2018). Because feeding a child enterally can be a sudden and often lifelong change, the parent may also need additional ongoing support and education after hospital discharge (Hopwood et al., 2020).

In recent years, enteral tube feeding is becoming more common, and the number of enteral feeding devices in the pediatric population continues to increase worldwide (Lyman et al., 2016; Majka et al., 2013; Mundi et al., 2017). According to a recent study in 2017, there were 189,036 pediatric patients with enteral feeding tubes (Mundi et al., 2017). One study conducted in the Netherlands found that 83 to 92 per 100,000 pediatric patients received home enteral feeding between 2010 and 2014 (Krom et al., 2019). In addition, the prevalence of tube feeding was highest at 12 months of age and the incidence of children with home enteral tube feeding decreased as the child grew older (Krom et al., 2019). In the United States, patients receiving home tube feeding have increased exponentially since 1992. Approximately 152,000 patients were receiving enteral nutrition (597 per million), but the incidence has increased to an estimated 436,874 in the year 2013 (1382 per million). Furthermore, approximately 189,036 pediatric patients currently have feeding tube devices. This is about 40% of the overall tube feeding population (Feeding Tube Awareness Foundation [FTAF], 2021; Mundi et al., 2017). In a study completed in 2010, gastrostomy tube (GT) complications were thought to be as high as 83% in the pediatric population (Naiditch et al., 2010). This high percentage of negative sequelae can negatively impact the healthcare system's financial situation. The additional use of healthcare

resources can be decreased, and complications can be resolved safely and effectively with proper parent education (Naiditch et al., 2010).

Parents of Patients with Pediatric Feeding Tubes

Parents of patients with pediatric feeding tubes refers to any person who is parenting a child with an enteral-feeding device. Parents of enterally-fed children often experience significant burdens and stressors due to the life-altering adjustment that enteral feeding involves (Pahsini et al., 2016; Singhal et al., 2017; Syrmis et al., 2018; Zamvar et al., 2014). They can experience a sense of loss and struggle to cope and help their child adapt to their new normal of everyday life with a feeding tube (Hopwood et al., 2020). These feelings can occur because the parent does not fully understand how to care for their child's new feeding device (Hopwood et al., 2020; Northington et al., 2016). They are merely surviving not thriving (Hopwood et al., 2020).

Outpatient Education

Increasing the quality and quantity of parental education is a promising option to resolving the issue of lack of support and education for parents of children with new enteral feeding tube devices (Hopwood et al., 2020; Schweitzer et al., 2014; Syrmis et al., 2018). This solution is beneficial because it increases parents' knowledge about caring for their child's enteral feeding device and helps troubleshoot common everyday issues (Hopwood et al., 2020; Schweitzer et al., 2014; Syrmis et al., 2018). Another positive outcome of improved discharge education is that it increases parental confidence in caring for their child's enteral feeding device (Schweitzer et al., 2014). Authors also suggest the use of support groups as an additional avenue to offer to families. They found that around the clock constant support and guidance during the initial period after discharge is especially valuable to parents and caregivers (Schweitzer et al.,

2014). Overall, providing additional parental support and ongoing education is vital during the initial transition period after their child receives a new enteral feeding tube device (Hopwood et al., 2020; Schweitzer et al., 2014; Syrmiš et al., 2018).

Current Education Practices

Current education that parents are receiving is in the hospital is not adequate to support them in the home environment (Northington et al., 2017; Schweitzer et al., 2014; Syrmiš et al., 2018). While in the hospital, parents receive minimal education regarding the use, management, and care of their child's feeding tube (Hopwood et al., 2014; Schweitzer et al., 2014; Syrmiš et al., 2018). An Australian study by Syrmiš et al. (2018) found that educational parent guides distributed by hospitals lacked critical social, emotional, and practical components necessary to educate caregivers of children who require tube feeding and information on the long-term psychosocial effects of tube feeding. Furthermore, caregivers noted that written easily understandable information, without medical jargon, was also lacking (Syrmiš et al., 2018).

Another study by Schweitzer et al. (2014) found that hospital education was inconsistent, varied between providers, and was not focused on the patient and caregiver's needs. There was little to no hands-on or teach-back instruction which led to poor patient and family satisfaction (Schweitzer et al., 2014). When the parent and child return to normal life, questions about handling everyday life situations with a feeding tube arise (Hopwood et al., 2014; Syrmiš et al., 2018). If they do not have adequate ongoing support and education on how to handle these situations, there can be a significant increase in ED visits, clinic visits, hospital readmissions, and preventable complications (Schweitzer et al., 2014).

Parental Confidence

Mediocre quality and inconsistency of initial education contribute to a lack of parental confidence in the care and management of their child's new feeding tube device (Hopwood et al., 2014; Schweitzer et al., 2014; Syrnis et al., 2018). Ongoing outpatient parental support and education about their child's new feeding tube can make a remarkable difference, help overcome barriers, and demonstrate positive outcomes (Hopwood et al., 2020). Incorporating outpatient education for parents of children with new enteral feeding tubes about how to overcome the challenges that arise in everyday life may be beneficial during a patient's initial transition period and may help to decrease clinic and ED visits, financial costs, and hospital readmissions, and enteral feeding tube complications (Hopwood et al., 2020; Syrnis et al., 2018).

Literature Synthesis

Overall, current studies have found a lack of ongoing support and education for parents of children with new enteral feeding tubes (Hopwood et al., 2014; Northington et al., 2017; Schweitzer et al., 2014; Syrnis et al., 2018). The current education is inconsistent and not comprehensive enough to prepare patients and families for life after hospital discharge (Hopwood et al., 2014; Schweitzer et al., 2014; Syrnis et al., 2018). Parents have noticed this especially during the initial transition period when they are unsure how to handle everyday life occurrences when their child has a feeding tube. This apprehensiveness leads to stress, anxiety, and a lack of confidence surrounding managing and caring for their child's new enteral feeding device. Increasing ongoing parental support and education may give them peace and eliminate stress, doubt, and anxiety (Hopwood et al., 2020).

Internal Evidence

An analysis of a non-profit organization designed to raise awareness for pediatric feeding tubes and provide ongoing support and outpatient education for their caregivers found that

parents did not receive sufficient education about their child's feeding tube upon hospital discharge. The leaders of this organization believed this contributed to preventable complications (B. Goodman, personal communication, January 21, 2021). The division chief of gastroenterology at the project site, a non-profit, urban pediatric hospital, agreed with the preliminary analyses and noted inconsistencies in current education which was attributing to increased clinic visits, ED visits, and hospital readmissions (A. Patel, personal communication, March 4, 2021). A nurse practitioner (NP) and physician assistant (PA) on the surgery team at the project site also agreed with the analysis. They related that the current education is completed by two nurses who only teach basics of how to care for the tube, clean the site, and what to do if the tube falls out. The brevity of the education was attributed to time constraints. The education was considered not sufficient enough education to make parents feel confident in caring for their child's tube at home. The NP and the PA report that the floor nurses are supposed to supplement this education with the hospital education booklet. However, the floor nurses are under the impression that the nurses on the surgery team are completing the entirety of the education. This leaves a gap in the education that the parents receive. The patient's first follow-up appointment with the surgical team where there is an opportunity for the parent to receive further education and ask questions does not occur until two weeks after surgery (T. Gonzalez, personal communication, October, 14, 2021; K. Gibson, personal communication, January 19, 2022). Prior studies from Hopwood et al. (2020), Schweitzer et al. (2014), and Syrmis et al. (2018) were consistent with these findings.

The current gastrostomy tube educational needs and goals of the surgery clinic and hospital organization were identified through discussion with the division chief of gastroenterology, the inpatient gastroenterology floor nurse manager, and the nurse practitioner

and physician assistant on the general surgery team. The educational intervention including parent education booklet and the pre and post-test survey questionnaires were then reviewed with the stakeholders to determine their applicability to this project, the patient population, and needs of the organization.

In looking for options to provide additional support and education for parents of children with a new feeding tube device following discharge, increased professional (i.e., nurses) education was an effective tool to increase parents' understanding of caring for their child's new feeding tube (Hopwood et al., 2020). This literature review and review of the internal evidence led to the development of the PICO question: "In parents of pediatric patients with new enteral feeding tubes does outpatient education, compared to current education practices, impact parental confidence in caring for their child's enteral feeding device?"

Search Strategy

A thorough and comprehensive literature search was conducted within the Cumulative Index of Nursing and Allied Health Literature (CINAHL), The Cochrane Library, ProQuest, and PubMed databases to answer the PICO question. These search databases were chosen because of their scientific contributions to healthcare, in particular, the nursing profession, and their endorsement and promotion of evidence-based practice. Aside from The Cochrane Library, which only yielded three non-relevant results, each of these databases gave a high yield of relevant studies. Further detail on how this search strategy was conducted is described in the following sections.

Literature Limitations and Literature Inclusion and Exclusion Criteria

Because of the nature of the subject matter, there were a limited number of quantitative studies available on the topic. Very few high-quality evidence studies were available. Further,

there were a decreased number of recent studies on parent perceptions on current feeding tube education practices and ongoing education. Some reviewed studies are older than five years. With these limitations, the search inclusion criteria included new enteral-feeding device education studies in the pediatric population, focusing on the parent or caregiver. The studies had to be written in the English language in peer-reviewed academic studies between 2014 and 2022. Exclusion criteria were non-peer-reviewed articles and those published in other languages, propositions for future studies, studies with inconclusive results or mixed findings, studies on parental education of other medical devices, and studies that did not focus on the pediatric population.

Keywords

An initial search was conducted using the following key words: *parent, caregiver, mother, father, infant, pediatric, child, adolescent, youth, teen, education, outpatient education, discharge education, discharge protocol, discharge process, discharge management, discharge teaching, confidence, feeding tubes, enteral feeding, enteral feeding tube, enteral nutrition, gastrostomy tubes, jejunostomy tubes, nasogastric tubes, g-tubes, j-tubes*. Combinations of these words yielded moderate results across the databases. Boolean phrases were also used in all search databases to include all potential keyword combinations.

Search Results

An initial search was conducted using the following keywords: *parent, pediatric, feeding tube, and education*, and similar Boolean phrases brought about 558 results in CINAHL, 19,805 results in ProQuest, and 58 results in the PubMed database. Inclusion criteria were then added, which narrowed the results to a final yield of 42 results in CINAHL, 780 results in ProQuest, 35 results in the PubMed database. The article titles and abstracts were then reviewed to determine

pertinence to the PICO question. Many studies were duplicates, outside of the timeline, or irrelevant to the PICO question, which further narrowed the applicable studies available for critical appraisal. The final yield included nine applicable studies published within seven years and one study published within 13 years. Grey literature and reference lists were also searched, but no relevant results were found aside from one or two duplicate studies. Critical appraisal of applicable studies was conducted before selecting articles for the literature review. The final ten studies that were included for an in-depth critical appraisal included three quasi-experimental studies, one descriptive quantitative study, two quantitative questionnaire studies, and four qualitative studies.

Critical Appraisal & Synthesis of Evidence

Studies related to the subject topic were assessed with rapid critical appraisal (RCA) tools and 10 were chosen according to strength and hierarchy. (Melnynk & Fineout-Overholt, 2019). While quantitative studies were more predominant, qualitative studies also were incorporated because the primary caregiver's attitudes and feelings about their confidence in caring for their child's feeding device were best captured through qualitative analysis. For this reason, quantitative (see Appendix A, Table A1) and qualitative studies (see Appendix A, Table A2) were incorporated into evaluation tables and then integrated into a synthesis table (see Appendix A, Table A3). This review process provided a thorough evaluation of the evidence regarding current feeding tube education protocols and its impact on parental confidence levels.

Similar demographics were present throughout all studies as the studies all assessed primary caregiver's knowledge, confidence, skill level, and attitudes towards their child's new feeding tube device. However, the studies took place in several different countries and the intervention length varied from several weeks to several months. Six of the 10 studies had less

than 100 participants (Boebel Toly et al., 2019; Cooper, 2008; Hopwood et al., 2020; Pars & Soyer, 2020; Schweitzer et al., 2014; Suluhan et al., 2021). Most studies took place in regional hospitals except one study took place in the patient's home (Cooper, (2008). One setting for the intervention was not disclosed (Hopwood et al., 2020). Measurement tools were heterogeneous and included interviews, surveys, focus groups, and various scales. The studies targeted the role of discharge education practices in affecting confidence and skill level or captured parental attitudes and feelings while transitioning to life with their child's new enteral feeding device.

There are a wide variety of discharge education practices in use for new enteral feeding tubes throughout hospitals worldwide. However, a recurring theme found in the current literature is the lack of standardized discharge education protocols. This gap, combined with lack of support following discharge leads to increased device complications, increased anxiety, burden, and stress, and lack of parental confidence in meeting their child's healthcare needs and caring for the enteral feeding device (Boebel Toly et al., 2019; Suluhan et al., 2021). Therefore, standardized discharge education interventions and additional outpatient support are necessary to meet the needs of these patients and their caregivers.

While there is limited research on successful standardized discharge enteral feeding tube education practices, several authors have demonstrated success in applicable literature (Schweitzer et al., 2014; Suluhan et al., 2021). Nurse delivered educational intervention were a strong component in these standardized education practices. For this reason, using a nursing theory and related conceptual framework to develop a discharge practice intervention to educate primary caregivers has the potential to decrease stress and increase parental knowledge, skills, and confidence.

In summary of the critically appraised literature, discharge education procedures play a vital role in parental confidence while caring for their child's enteral feeding device. Inadequate discharge procedures have heightened caregiver burden, stress, and anxiety exponentially, leading to increased complications with their child's care. Implementation of a comprehensive discharge education intervention with ongoing support and continued outpatient education provide the comprehensive plan of care that primary caregiver's need to care for their child's healthcare needs following discharge. Decreased caregiver stress, anxiety, and burden are all secondary outcomes of these educational interventions which have been shown to enhance overall quality of life and aid in the transition to their child's new lifestyle (Suluhan et. al., 2021)

Complications with enteral devices contribute to heightened parental anxiety and stress levels. Ongoing support and education from providers are paramount to these families' success following discharge. Evidence from the literature demonstrates the feasibility of standardized comprehensive discharge education procedures and to strengthen parental confidence and decrease anxiety and complications (Schweitzer et. al., 2014; Suluhan et. al., 2021). Ongoing support is also vital because complications may not occur immediately following discharge. As the family transitions back to their normal lifestyle and adapts to the changes of a child with a medical device, these concerns continue to arise. Implementation of a comprehensive discharge feeding tube education, including ongoing support, routine follow-up, and continued education should be considered by hospitals and outpatient clinics to provide a solid foundation of care the patients and families they serve.

Theory Application

As parents adjust to their child's newly acquired enteral feeding device, they enter a transition period. This transition brings about many life changes and forces them to adapt quickly

to their new way of life to find a new sense of normalcy. The literature shows that this life change can be a traumatic experience for parents as it causes a disruption in daily life. They often find support is lacking from friends, family, and caregivers (Boebel Toly et. al., 2019). The Transitions Theory (Meleis, 1985) is a middle-range theory that describes feelings of connectedness and interaction while also promoting confidence in oneself and the development of positive coping skills (see Appendix B, Figure B1). The model focuses on human life experiences, individual reactions, and how transition can positively or negatively influence experiences (Meleis, 2010). This theory's goal is to provide support for humans to adapt to new life transitions and cope with the associated stressors in a healthy manner. This includes becoming aware of one's thoughts, feelings and attitudes towards the life transition and mastering the behaviors and feelings that accompany their new role or identity (Meleis, 2010). The model demonstrates a clear representation of how families transition to their child's new healthcare needs and enteral feeding device. Furthermore, it offers a picture of the psychological aspects that influence the parent's behavior and adaptation during the change process. Through this model, nurses can provide enhanced support and education for primary care givers leading to mastery of the primary caregiver's new role and a healthy life transition for the patient and family. By understanding and adapting to their new role as the primary caregiver of a technology-dependent child, the parent will be able to feel supported and in turn, provide the best care for their child leading to positive health outcomes.

Implementation Framework

Although the Transitions Theory Model teaches parents to make healthy lifestyle transitions and cope with the behaviors associated with the change process, hospitals and health care practices must also be open to changing their procedures to further support patients and

parents' new lifestyle associated with technology dependence. Providers have the tools to ensure success with this transition process. The Rosswurm and Larrabee Model is a framework that is often used for quality improvement projects in large organizations to bring about process change. (see Appendix B, Figure 2). This model is appropriate for this DNP project because it can be modified to conform to the organization's specific needs. A six-step process works to bridge gaps in care and solve the issues within an organization. The six steps are as follows: assess, link, synthesize, design, implement and evaluate, and integrate and maintain. This model fits with the implementation of a quality improvement DNP project as the outlined steps parallel that of the essential steps in the doctoral nursing project timeline. With this model, each step moves the project forward towards the goal but it also allows flexibility to go back and forth if necessary. This model worked well for planning and implementing this DNP project in a large hospital organization. The model provides the steps necessary to develop comprehensive education for primary caregivers and reinforce or change of the education intervention as needed (Rosswurm and Larrabee, 1999).

Implications for Practice Change

Compelling findings in current literature and information from stakeholders demonstrate the need for an enteral feeding device discharge educational intervention as well as ongoing support for caregivers following hospital discharge. Findings also demonstrate the success of a comprehensive in-depth standardized discharge education procedure and outline its numerous benefits to patients and their families (Schweitzer et al., 2014; Suluhan et al., 2021). A comprehensive standardized educational tool that addresses common everyday problems and misconceptions associated with enteral feeding tube devices, in addition to instruction on how to use the feeding tube can impact this population. By providing the support that parents are

searching for, this educational intervention can enhance their knowledge, skills, and confidence related to their child's care. The success of prior studies supports the feasibility of an educational intervention for primary caregivers in the inpatient and outpatient setting and will offer ongoing support and education that parents need to give their child the care they deserve.

Stakeholders for this DNP project include a large, urban, pediatric freestanding hospital and level 1 trauma center in the southwest United States, the inpatient general surgery team, the staff and healthcare providers on the inpatient gastroenterology floor, and the staff and healthcare providers in the outpatient surgery clinic. Additional stakeholders included the participants in the study who were English-speaking parents of pediatric patients age 0-17 with newly placed gastrostomy tubes.

Methods

Setting

The inpatient floor is part of a large, urban, pediatric freestanding hospital and Level 1 trauma center in the southwest United States. The outpatient surgical clinic functions as their own entity but are a division of the large southwest pediatric Level I trauma center. The inpatient floor and the outpatient surgical clinic are the optimal settings for a comprehensive enteral feeding tube education intervention as they regularly provide post-surgical care for pediatric patients with gastroenterology related disorders who require enteral feeding tube devices. In addition, the outpatient surgical clinic provides ongoing support and education for pediatric patients and their families. Furthermore, this project site is the largest pediatric hospital in the state and treats the majority of children with gastroenterology, nutrition, and feeding related disorders. Assessing and modifying current feeding tube education practices to provide better patient outcomes and decrease complications also aligns with the mission, vision, and

values of the hospital organization. For these reasons, the inpatient gastroenterology floor and the outpatient surgery clinic of this larger pediatric hospital organization was selected as the project site.

Participants and Recruitment

Inclusion & Exclusion Criteria

All parents and/or primary caregivers of pediatric patients, ages 0 to 17 years of age with a new gastrostomy feeding tube who can read and understand the English language were eligible for participation. Parents and/or primary caregivers of patients over the age of 17 years were excluded as these patients will be transitioning to an adult provider and can often take care of their own device. At this time, participants who could read or understand the English language were excluded from the DNP project. There was no obligation to participate and participation was completely voluntary. If there were questions related to the DNP project, the DNP student or advanced practice provider answered them prior to initiating consent procedures.

Participants were recruited from the current parents and caregivers of patients after consulting the upcoming surgical schedule for patients scheduled for gastrostomy tube placement surgery during the implementation phase. The surgery PA notified the DNP student every Monday about the patients that were scheduled to receive gastrostomy tube placement surgery during the coming week.

Procedures. Prior to initiating the project, the Institutional Review Board (IRB) approval was obtained from the project site IRB and Arizona State University IRB (see Appendix D). Informed consent was obtained from all parent participants at the time of the post-surgical educational intervention on the inpatient hospital floor prior to administering the pre-test survey questionnaire. Written consent was obtained using the hospital approved informed consent form.

Confidentiality was maintained through anonymity and recruitment occurred through the use of the upcoming surgery schedule of patients with gastrostomy tube placement surgery. After obtaining participants consent, they completed an anonymous pre-test survey questionnaire to assess current knowledge, skills, and confidence, and skills related to the care of their child's feeding tube (see Appendix E). The education intervention was implemented over a 2-hour period to the parents and/or primary caregivers of pediatric patients with new gastrostomy tubes on the inpatient floor following their child's surgery. Content and components of the intervention program included the current discharge gastrostomy tube education booklet developed by the hospital library that addresses comprehensive care and everyday challenges that caregivers face when managing the care of their child's new gastrostomy feeding tube. A follow-up intervention with reinforcement of the same education took place approximately two weeks later in the outpatient surgery clinic over a 15-minute period during routine surgery follow-up appointments in the clinic. A post-test survey questionnaire was then administered to parents and/or primary caregivers at the follow-up appointment at the completion of the intervention to re-assess knowledge, skills, and confidence related to the care of their child's gastrostomy tube (See Appendix F). This education intervention was performed by the DNP student facilitator who is a registered nurse on the inpatient unit.

Data Collection, Outcomes Measurement, and Data Analysis

Demographics on the pre-test survey questionnaire included patient age, reason for gastrostomy tube placement, the patient's chronic health conditions, the patient's primary caregiver, and the patient's primary insurance. No personal information was requested. The parent or caregiver created a personal six-digit number. This identification number consisted of the first two digits of the parent's birth month and the last four digits of their phone number.

There was no document that linked the parent's identification number with their name. The de-identified data was organized and stored in an Excel spreadsheet and then uploaded into Intellectus® to calculate statistics. This de-identified information will be securely stored until five years after data analysis, reports, presentations, and publications have been completed per hospital request.

The pre-test survey questionnaire had 21 questions that included demographic items, items with a 5-item Likert scale, and yes and no questions. The survey assessed parent knowledge, skills, and confidence in caring for their child's gastrostomy tube. The post-test survey questionnaire had 20 questions that included items with a 5-item Likert scale and yes and no questions to assess parent knowledge, skills, and confidence in caring for their child's gastrostomy tube. Content validity on the pre-test and post-test surveys was established by Dr. Diana Jacobson, Kristina Gibson, PA, and Dr. Ashish Patel.

Knowledge and confidence were the measurable outcomes. These outcomes are related to the Transitions Theory because they represent ways of measuring how well a person is coping with stressors and adapting to a life change (Meleis, 2010). Further, this project was able to be successfully planned and implemented through the guiding steps in the Rosswurm and Larabee Model (Rosswurm and Larabee, 1999).

Intellectus® software was utilized for data analysis procedures. Descriptive statistics provided information on the participants and children. A paired samples t-test was used to calculate the statistical and clinical significance of the Likert scale items measuring knowledge and confidence. Finally, a two-tailed Wilcoxon signed rank test was used to individually analyze the yes and no knowledge questions.

Budget/Funding

A budget was created for this project. The budget included considerations for printing of surveys and educational intervention tools, poster board and materials for nurse education presentations, Intellectus® software purchase, increased time for surgery clinic appointments, and review of results by hospital financial advisors (See Appendix C). There were no direct costs associated with this project. Therefore, there was a direct potential revenue savings to the hospital when considering additional phone calls, surgery clinic visits, ED visits, and hospital readmissions. No funding was applied for or obtained for this DNP project.

Results

Demographics

Although five participants were recruited and enrolled in the project, one was lost to attrition (20% attrition). Four parents received the educational intervention and completed the pre and post-test surveys. The results of the demographic analysis showed that patients receiving gastrostomy tube placement ranged in age from 12 months to 60 months with a mean age of 25 months. All patients received their gastrostomy tube for medications or supplemental nutrition. One hundred percent of children received the gastrostomy tube for supplemental nutrition. In addition, forty percent of children received it for medications and fifty percent received tube placement for both medications and nutrition. Seventy-five percent of children had a wide range of underlying medical conditions including neurological and gastrointestinal disorders while 25% percent of parents reported no underlying medical conditions in their children. Seventy-five percent of participants reported the mother as the primary caregiver. Twenty-five percent of participants reported the grandmother as the primary caregiver and twenty-five percent of participants reported that both mother and father were the primary caregivers. Lastly, 50% of

participants reported that their child's health care costs were covered by public health insurance and 50% reported that it was covered by private health insurance.

Knowledge

As demonstrated in Table 1, a statistically significant difference in parent knowledge was noted after the intervention. In addition, Figure 1 demonstrates the mean difference between the pre-knowledge and post-knowledge sum scores. The results indicate that the education intervention was effective in increasing parent knowledge in relation to caring for the child's gastrostomy tube.

Table 1

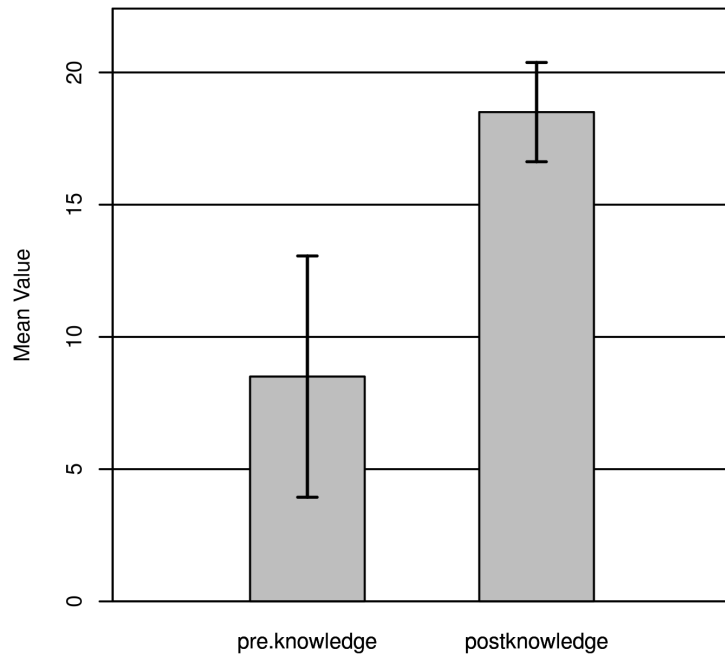
Two-Tailed Paired Samples t-Test for the Difference Between Pre-Knowledge and Post-Knowledge

Pre-Knowledge		Post Knowledge		<i>t</i> -test	<i>p</i> value.	Cohen's <i>d</i>
<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	<i>d</i>
8.50	4.65	18.50	1.91	-4.71	.018	2.36

Note. N = 4.

Figure 1

The Means of Pre- Knowledge and Post-Knowledge



Confidence

There was no statistically significant difference in parent confidence after the educational intervention (see Table 2). As can be seen in Figure 2, which demonstrates the mean difference between the pre-confidence and post-confidence sum scores increased. While there was no statistical significance, there was clinical significance in the confidence outcome variable. Although the results do not indicate statistical significance, the education intervention did demonstrate an increase in the mean scores of parent confidence. Non-significance could be attributed to small sample size or to the fact that one participant received the same confidence score on both the pre and post-test survey.

Table 2

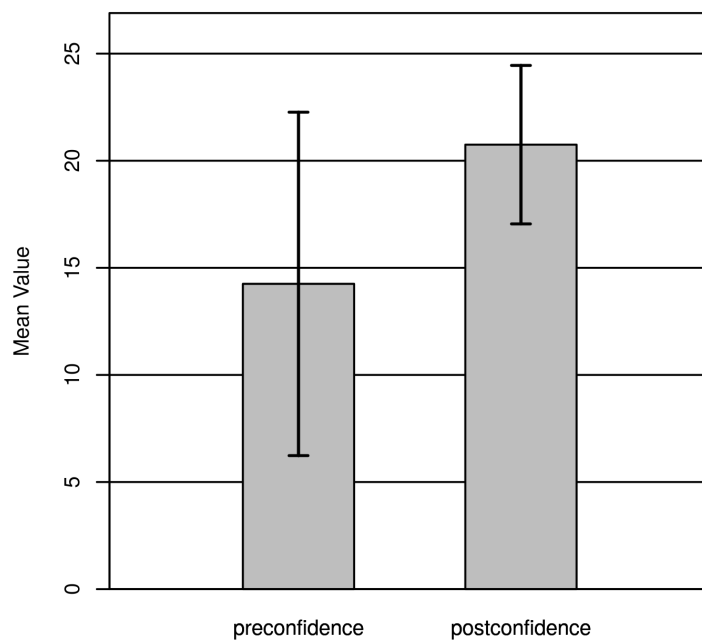
Two-Tailed Paired Samples t-Test for the Difference Between Pre-confidence and Post-Confidence

Pre-Confidence		Post-Confidence		<i>t</i> -test	<i>p</i> value.	Cohen's <i>d</i>
<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	<i>d</i>
14.25	8.18	20.75	3.77	-2.29	.106	1.14

Note. N = 4

Figure 2

The means of Pre-Confidence and Post-Confidence



Knowledge/Skills

Based on the Wilcoxon test with an alpha coefficient of .05, two yes and no questions were not able to be analyzed based on their duplicate variables. The first question demonstrates a 100% change from the pre-test survey questionnaire to the post-test survey questionnaire when

the parent was asked if they could demonstrate how to inflate or deflate the balloon of their child's gastrostomy tube. The second question demonstrated 0% change as the answers were yes on both the pre-test survey questionnaire and the post-test survey questionnaire when the parent was asked if they could demonstrate how to give their child medicine through their gastrostomy tube. The other three dichotomous questions focused on describing how to bathe a child with a gastrostomy tube, how the child can safely sleep with a gastrostomy tube, and what to do if the child starts vomiting. All of these were found to have no change from pre to post-test survey.

Qualitative Analysis

Qualitative analysis of the evaluation questions from the post-test survey demonstrated that parents had satisfaction with the intervention and 100% of participants did not think any topics were absent from the education. Fifty percent of participants thought the demonstration and hands-on teaching was most helpful and 25% of participants thought having an education packet to take home to other family and caregivers was most helpful. Lastly, one participant thought everything was helpful and loved the intervention. All participants thought every part of the education was helpful and necessary and did not find anything "least helpful."

The qualitative question asking participants, "What advice would you give to another parent or caregiver whose child is going to receive a feeding tube?" included finding a support group (25%), asking questions (25%), and utilizing handouts, notes, and the email for future questions (25%). One participant (25%) stated that she was "very satisfied and loved it" in this section.

Discussion

Project Aim

The goal of this DNP project was to bridge the gap between current discharge education and outpatient education by providing the parent with comprehensive discharge education and ongoing outpatient support and education related to the management and care of their child's gastrostomy tube. The immediate goals of this education intervention were to empower parents with knowledge and confidence to successfully implement comprehensive care for their child's gastrostomy feeding tube in the home setting. The long-term future goal of this education intervention is to decrease enteral feeding tube complications, ED visits, and hospital admissions leading to an overall decrease in resources and optimal patient outcomes.

Project Impact

This educational intervention will positively impact the patient because it has the potential to improve their health outcomes in relation to their gastrostomy tube and overall nutrition status. Further, this intervention will have a significant impact on the parent/primary caregiver by increasing their knowledge and confidence in relation to the care of their child's gastrostomy tube. Parents expressed satisfaction with the education. They also reported how much they loved it and how it every aspect was necessary and helpful. Further, they reported that nothing was missing or absent from the education. The DNP project may impact healthcare providers because the educational intervention demonstrated the need for comprehensive patient and parent discharge education with ongoing support, reinforcement, and routine follow-up of education to improve patient outcomes. The DNP project may also impact the entire hospital organization because it demonstrates the need for a clinical staff member to focus solely on the role of educator to have the time to provide comprehensive education with ongoing support and follow-up for these patients and their families. Finally, this DNP project demonstrates that nurses

need time dedicated specifically to patient and family education to ensure safe patient care and optimal patient outcomes which demonstrates the critical need for safe staffing ratios.

Sustainability

An educational ticket will be submitted to the hospital with these findings for the purpose of recommending this comprehensive discharge education intervention with ongoing support, reinforcement, and follow-up education for all future pediatric patients with gastrostomy tube placement surgeries. Floor nurse time constraints may negatively impact sustainability of the intervention in the future. With high staffing ratios, nurses are often too busy to give patients and parents the one-to-one attention that they need for sufficient education. This could be solved by hiring a nurse educator whose specific role is to provide comprehensive discharge education and ongoing support and education to these families.

Strengths/Facilitators

One strength of this project was that it took place at a well-known and reputable pediatric study site. The general public trusts the project site so it was less challenging to find parents that were willing to participate. Another strength is that the educational intervention was cost-effective and was a minimal risk intervention. Furthermore, because the hospital education booklet was not tailored specifically to each patient or participant, it was generalizable to all patients with a gastrostomy feeding tube regardless of their underlying medical diagnosis. Lastly, the evidence-based intervention booklet was already in use at the project site. Using this booklet created by the hospital made this intervention more feasible because it was readily available to order from the hospital library when needed for patient education.

Limitations

Limitations that may affect the outcomes of this DNP project included a small sample size and a limited time frame of only 6 weeks for recruitment and implementation of the intervention. If this project were to be implemented again, it would be beneficial to have more participants to strengthen the quality of the data. With the surgery schedule being spread out for new gastrostomy tube placements, there was only an average of one or two potential participants each week that met the project criteria. Therefore, it was difficult to recruit and enroll a large number of participants in a short time frame.

Related Findings to Current Literature

The literature demonstrates that comprehensive discharge education with ongoing support and education for parents of children with new feeding tubes will improve knowledge and confidence in caring for their child's new feeding tube and decrease anxiety, stress, and preventable complications (Hopwood et al., 2020; Schweitzer et al., 2014; Syrnis et al., 2018). Similarly, this project confirms some existing findings by demonstrating that comprehensive discharge education with ongoing support and education for parents of children with new gastrostomy tubes will increase their knowledge and improve their confidence in caring for their child's new gastrostomy tube.

Future Recommendations

It would be beneficial to include a larger sample size to anticipate attrition. This could be accomplished by increasing the project implementation time frame. Including father figures would also be another potential for further study to see if the intervention affects them differently. Another recommendation would be to train the inpatient nurse staff to implement the intervention on the inpatient floor. Hiring or training a nurse into an educator role with the task of implementing the intervention on the inpatient floor and at the outpatient clinic follow-up

appointments with every patient would allow for continuity of care and ensure comprehensiveness and continuity of the intervention. This education intervention could also be recommended to be used as a guide to teach parents about other types of feeding tubes and medical devices in hospitals and outpatient clinics worldwide.

Analyzing the number or percentage of parents who called the clinic with questions, brought their child in to the ED or clinic or were admitted to the hospital with gastrostomy tube complications would give the necessary data to further examine this educational intervention. This additional information would determine if comprehensive ongoing education with the addition of outpatient education effectively meets the educational needs of parents and caregivers following discharge.

Conclusion

While the evidence is still evolving in the realm of gastrostomy tube education, there have been several previously mentioned landmark studies within the last decade that demonstrate successful comprehensive gastrostomy tube discharge education programs. A common theme in the literature is that the authors describe interventions that consist of inpatient education which is closely followed up with ongoing support and outpatient reinforcement of education. The implementation and resultant findings of this DNP project reflect the theme of current literature. A comprehensive discharge education with ongoing outpatient support and education can have a significant impact on parent knowledge and confidence in relation to the management and care of their child's new gastrostomy tube. In the future, there is hope that more pediatric hospitals will adopt this type of comprehensive education intervention for parents of pediatric patients with feeding tubes and other medical devices.

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Appendix A

Evaluation and Synthesis Tables

Table A1
Quantitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Worth of Study to Practice
<p>Chang et al. (2015). The effects of systematic educational interventions about NGT on CG’s knowledge and skills and the incidence of feeding complications.</p> <p>Country: Taiwan Funding: None – potentially the hospital Bias: Selection Bias</p>	<p>None specifically listed.</p> <p>HBM or CBT or SLT inferred</p>	<p>Design: Quasi-Experimental</p> <p>Method: pretest/post-test</p> <p>Purpose: Compare the influence of a systematic nursing intervention on PCG’s knowledge and skills about NGT feeding and number of NGT related complications with that of routine nursing instructions</p>	<p>N=233 C= 127 IG= 106</p> <p>Demographics: No SIG differences in PCG’s age, G, education, patient relationships and having NGT feeding experience or in patients’ G, history of NGT feeding, in-hospital stay, and discharge status between the E and C groups. Mean age of patients was SIG different between groups.</p> <p>Sample: Inpatients receiving continuous NGT tube feeding from</p>	<p>IV1: Systematic Nursing Intervention DV1: PCG Knowledge DV2: PCG Skills Definitions: PCG: Persons taking frontline care of patients during on a routine basis. Systematic Nursing Intervention: Instructional video, educational pamphlet, nurse’s demonstrations, nurses answering questions PCG Knowledge: The knowledge that the PCG has about NGT.</p>	<p>Questionnaire Incidence of Complications Validity/Reliability: The individual content validity index of each question on the questionnaire reached 80%--satisfactory validity. Cronbach’s α of 0.967 for knowledge scale and 0.926 for skill scale indicated satisfactory reliability of questionnaire. Complication rate considered a significant indicator of patient outcome and used to evaluate effectiveness of a</p>	<p>Nonparametric Mann–Whitney <i>U</i> test -The independent two samples <i>t</i>-test -Fisher’s exact test -The Wilcoxon signed-rank test -Simple and multiple linear regression -Multiple linear regression model</p>	<p>IG: Posttest Scores: Knowledge: 11.0 Skill: 9.5 <i>p</i> value: <0.001 CI: 95% C: Posttest Scores: Knowledge: 10.0 Skill: 7.0 <i>p</i> value: <0.001 DV1 Knowledge: 1.66 CI: 95% (1.27–2.05) <i>p</i> value: < 0.001 DV2 Skill: 2.38 (1.97–2.80)</p>	<p>LOE: III Strengths: Quasi-Experimental Low Risk Non-Invasive Low attrition rate Weaknesses: Time sequence –potential selection bias. Unknown if presentation or video or combination was more influential Skills and teaching abilities of nurses could have improved before instruction of second group Type of feed, feeding</p>

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			<p>internal medicine and surgical wards from May–December 2004</p> <p>Setting: Regional hospital in Central Taiwan</p> <p>Inclusion Criteria: -received NGT feeding during hospital stay -needed NGT feeding after discharge -lived within the range of home visits provided by the hospital -had post discharge primary caregivers able to speak Chinese, Taiwanese or English</p> <p>Exclusion Criteria: Anyone who did not meet inclusion criteria</p> <p>Attrition: 23 patients did not complete the three-month follow up data due to death (n=2) or imminent death (n=21)</p>	<p>PCG Skills: The skills that the PCG has to care for an NGT</p>	<p>systematic nursing intervention.</p>		<p>CI: 95%</p> <p>p value: <0.001</p> <p>Complications Constipation 12.3% vs. 23.6%</p> <p>p value: 0.028</p> <p>Diarrhea 9.4% vs. 22.0%</p> <p>p value: 0.012</p> <p>Abdominal Distention 1.9% vs. 10.2%</p> <p>p value: 0.013</p>	<p>regimen, allergies, co-morbid conditions, previous abdominal surgery, medications, clinical presentation and disease process not controlled. Did not evaluate the persistence of knowledge and skills over time</p> <p>Important to clearly justify the possible causal relationship between incidence of complications and the educational intervention.</p> <p>Conclusion: Systematic nursing intervention including comprehensive educational pamphlets and video education improved</p>
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								knowledge and skills relative to NGT feeding by PCG's as compared to routine education. Feasibility: Recommend use as guide or reference for assessing future healthcare profession's discharge protocols and knowledge and skill of CG's to facilitate improvement of nursing interventions related to NGT's and the care of patients who are fed by NGT
Northington et al. (2017). Current practices in home management of nasogastric tube placement in pediatric	None specifically listed. SCT inferred.	Design: Descriptive Method: Two voluntary surveys Purpose: -Collect data in the pediatric population to better describe the state of use, placement, and management of displacement of NGT in	N=210 CG=PG (144 PG) CG= HG (66 HG) No intervention group -No predetermined sample size due to the nature of the study and	Tube Replacement Tube Placement Verification Misplaced NG tubes Definitions: NGT placement: Placing an NGT	Survey Monkey platform to house the web-based questionnaire Tools: Two separate survey tools composed of 13 items: one directed at parents and one	Descriptive Statistics	Results: PG -144 responses from parents with children who had a child with an NGT -Largest percentage of children	LOE: VI Strengths: Geographically diverse population -Identify variation in practices -Exposure to experience of parents and HHC providers

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<p>patients: A survey of parents and homecare providers Country: United States Funding: None Bias: None</p>		<p>pediatric homecare patients -Primary aim is to address data gap that exists related to placement, misplacement/complications of NGT's and describe methods for placement and verification in the home when x-ray is not an option. -Introduce questions to guide further research on NGT placement verification methods and establish best practices for homecare settings.</p>	<p>solicitation of participants -Researchers only able to determine number of participants based on the final count in survey tall Sample: -Parents and HHC providers caring for children at home with NGT's -Convenience sample contacted by email and voluntarily complete online survey -Some referred by nurses with knowledge of and participated in the primary NOVEL study. -Others from organizations associated with members of NOVEL project, and companies with hospital affiliations or exceptional working relationships.</p>	<p>into a patient's stomach Tube Placement Verification: Verifying that an NGT is in the stomach or gastric cavity</p>	<p>at health care providers Validity/Reliability: Content validity was established for each instrument. Reliability was not tested prior to using either of the survey tools.</p>		<p>(28%) were between 4-7 months of age. -Second largest group (17%) were between 8-12 months of age -Children with an NGT in place (96%) -Most common size—6fr (51%) -23% did not know the size -47 (33%) children had an NGT for 0-3 months 47 (33%) children had an NGT for 4-6 months -102 respondents (71%) stated that the PCG replaced the dislodged tube. 20 (14%) took child to</p>	<p>and identify variations in practice -Address a gap in practice and literature -Serves as mandate for all health care providers to provide consistent evidence-based practice for children who require NG tubes at home Weaknesses: -Poor study design -Weak quantitative analysis of findings -Low level evidence -Convenience sample -Reliability not established. -No ability to determine a response rate -No ability to determine how many people were contacted. -No phone calls or email</p>
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			<p>-A webmail request of participating organizations in which members of the NOVEL project are affiliated were contacted for participation</p> <p>Setting: Online</p> <p>Inclusion Criteria:</p> <ul style="list-style-type: none"> -Parents with children <18 years of age with NGT at time of survey completion -HHC companies that employed home health nursing and supplied NGT's to pediatric patients <p>Exclusion Criteria:</p> <ul style="list-style-type: none"> -Children with surgically inserted feeding tubes such as a gastrostomy tube <p>Attrition:</p> <ul style="list-style-type: none"> -None 				<p>healthcare agency</p> <ul style="list-style-type: none"> -17 (12%) said health care provider replaced NGT -81% used NEMU method to replace NGT -44% used auscultation to verify NGT placement -25% used pH to verify NGT placement -18% inspected return of stomach contents in the syringe -67 (48%) stated that NGT is replaced monthly -35 (25%) replaced NGT weekly -15 (11%) changed the tube every 2 weeks 	<p>follow-up for potential participants</p> <ul style="list-style-type: none"> -No demographic data collected in those who completed home care survey -Responses may vary on depending on professional responsibilities of individuals -Surveys not designed to link a child to a homecare provider or agency -No data collected on type of pH testing or on value -Participants represent a small sample of population of interest -No generalizable results <p>Conclusion: Knowledge deficit regarding NGT</p>
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							<p>-48 (33%) replaced a tube that was removed accidentally at least monthly</p> <p>-33 (23%) said this occurred 2-4x per week</p> <p>-22 (15%) said it occurred every week and the same number said it occurred every 2 weeks</p> <p>-106 (74%) stated no known placement complications</p> <p>-36 (25%) reported complications</p> <p>-Of the 36, 12 (33%) with complications had additional symptoms</p> <p>HG</p> <p>-In homecare, 66 respondents</p> <p>-63 (95%) had patients at</p>	<p>management in homecare patients and with challenges surrounding replacement of NGT's and methods to verify replacement.</p>
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							home with NGT feedings -Respondents from 21 states -42 (64%) served mostly pediatrics -Low number of patients seen with NGT's in homecare -11 (17%) replaced tube monthly and 15 (23%) replaced tube weekly -49 (33%) used auscultation and 32 (25%) used inspection of gastric contents to verify placement -pH was used by 35 (28%) to verify placement Findings: Inconsistencies in practice surrounding care of pediatric patients with
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							<p>NGT's in the home especially with methods used to verify NGT placement. -Need for standardization of best practice guidelines and widespread education of nurses, parents, and homecare providers regarding methods to verify NGT placement -Need for evidence-based procedure for verification of NGT placement</p>	
<p>Pahsini et al., (2016). Unintended Adverse Effects of Enteral Nutrition Support</p>	<p>None specifically listed. Transitions theory inferred</p>	<p>Design: Quantitative analysis of standardized questionnaire Purpose: To highlight occurrence of unintended adverse effects of enteral nutrition in infancy and</p>	<p>N=425 C=No adverse effects IG=Adverse Effects Demographics: 44.2%-NG tubes 55.8% PEG tubes</p>	<p>Vomiting NG/PEG tube adverse effects Distribution of Adverse Effects as reported by parents Definitions:</p>	<p>Online Standardized Questionnaire</p>	<p>Reaction to food SIG more often had a negative reaction in children who retched or gagged often (p<0.05)</p>	<p>SIG distribution of vomiting by age/sex Each child showed 2 adverse effects on average.</p>	<p>LOE: IV Strengths: Large sample size Keen quantitative evaluation of adverse effects: each child</p>

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<p>Country: Austria Funding: Potentially the Medical University of Graz Bias: None listed. Possible bias if researchers are hospital employees No bias of nonverbal consent or disapproval</p>		<p>childhood from a parental perspective</p>	<p>Almost all with TF since birth. Patients: 193 (45.4%)-male; 232 (54.4%) -female. -32 different countries. 16.9%-Germany 16%-United States 13.9%-Australia 13.7%-Austria 9.2%-UK 4.9%-France Age: 0.26-10.68 years Median Range of boys: 1.79 years Median Range of girls: 1.51 years Girls were SIG younger than boys. Sample: Parents of TF children enrolled for assessing a tube-weaning program Setting: Medical University/Hospital in Austria Inclusion Criteria: Children fed by</p>	<p>Enteral Nutrition Support (ENS): When patients are unable to meet nutritional needs orally, ENS ensures nutritional supply by the use of intranasal (NGT) or percutaneous feeding tube (PEG).</p>		<p>Duration of TF to adverse effects not SIG ($p>0.05$) Children with vomiting were SIG younger than those who were not ($p<0.05$) No correlation with any other adverse effects ($p>0.05$)</p>	<p>Distribution of adverse effects as reported by parents The duration of TF had no influence on the reported adverse effects ($p>0.05$) Children who experienced vomiting were SIG younger than those who did not. All other adverse effects had no SIG correlation with age. No SIG correlations between adverse effects, sex, diagnoses, feeding schedule, duration of TF, and parent's attitude</p>	<p>developed > or = 2 side effects Weaknesses: Missing key points of information. Only included TF patients although they would typically be allowed to consume food PO. Online questionnaires —no face-to-face contact Questionnaires only distributed among parents seeking help for TF weaning. Conclusions: To optimize FT management, important to acknowledge complications that occur every day in the clinical setting. Duration of TF had no SIG influence on other adverse effects.</p>
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			<p>NG or PEG tubes, age 0-18 years, found to be suitable to transition to PO foods by the medical team</p> <p>Exclusion Criteria: Children fed by jejunal enteral feeding, age >18 years, and children unable to eat orally because of severe dysphagia or underlying consuming disease</p> <p>Attrition: None 8 of the 433 recruits (1.8%) eligible for the weaning program did not meet study criteria</p>				<p>related to child's feeding situation</p>	<p>Children who experienced vomiting were SIG younger than those who did not. Parents report burden imposed on them and their children if their child is fed through a FT. They need 2x as much care. This offers a new perspective for healthcare professionals.</p> <p>Feasibility: Not specifically recommended for repeat use. Further research is recommended on parent and professional's perspectives on adverse effects of long-term EF and physical and psychosocial aspects related to it.</p>
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<p>Pars et al., (2020). Home gastrostomy feeding education program: Effects on the caregiving burden, knowledge, and anxiety level of mothers Country: Turkey Funding: None—potentially the hospital Bias: None listed</p>	<p>Transitions Theory inferred</p>	<p>Design: Quasi-Experimental Methods: Interviews Pre-test/Post-test Evaluation Purpose: -Investigate the effects of a standardized evidence-based discharge education program prepared for children with GT’s on the CG’s knowledge, anxiety levels, and caregiver burden -Describe the effectiveness of the discharge education program for children with GT’s on CG burden, knowledge, and anxiety level of mothers</p>	<p>N=30 IG= 30 -study group CG= 30 no discharge training -historical comparison group Sample: -30 PCG’s (mothers) who voluntarily agreed to participate -Fully dependent children -60% of children with cerebral palsy -Historical comparison group included children who had GT placement between 2016-2017 and did not receive discharge training—GT’s inserted and</p>	<p>IV: Standardized, Evidence-Based Discharge Education Program -study group DV1: Knowledge DV2: Anxiety Level DV3: Caregiver Burden Definitions: GT: a tube that feeds a patient directly into the gastric cavity when a patient cannot receive nutrition by mouth PCG: Persons taking frontline care of patients on a routine basis</p>	<p>-Evidence-based training guide -Pre-test/Post-test questionnaires -Zarit Caregiver Burden Scale -State-Trait Anxiety Inventory Validity/Reliability: -Training guide reviewed by 20 experts- doctors, nurses, and faculty experienced in enteral nutrition Opinions tested with Predictive Analytics software 18. -Content validity was stat. SIG according to Kendall coefficient of correlation test (p<.001). Expert opinions were compatible with</p>	<p>-Kendall’s coefficient of concordance test -Descriptive Statistics -Cochran Q -Post hoc Dunn tests -ANOVA -Bonferri adjustment -IBM SPSS -SIG fixed at value .05</p>	<p>DV1 Knowledge: Increased DV2 Anxiety Level: Decreased DV3 Caregiver Burden: Decreased The study revealed that the knowledge level of mothers increased in the first week and third month after training and caregiver burden and state trait anxiety levels SIG decreased.</p>	<p>LOE: III Strengths: Single Service Training by a specialist for the families Questionnaires carried out by another researcher who had no information about the study Repeatable in a clinic (where no multidisciplinary discharge training is planned) by including control group cases Weaknesses: -Small sample size</p>

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			<p>monitored by the same service</p> <p>Setting: Pediatric surgery service of a university hospital in Ankara, Turkey</p> <p>Inclusion Criteria: -PCG of <1 – 18 yea old children with newly placed GT -Single Service -Children who had just opened a GT</p> <p>Exclusion Criteria: -No GT insertion by the surgery service at the university hospital in Ankara, Turkey</p> <p>Attrition: None</p>		<p>each other and scope of material was accepted as valid.</p> <p>-All instruments are valid and reliable.</p>		<p>A stat. SIG difference was found between the group that received the standardized education and the group that received no training.</p> <p>p value: <.005</p> <p>A stat. SIG positive correlation was found between the ZCBS and STAI scores</p> <p>p value: .000</p>	<p>-Only conducted in one country</p> <p>-Only completed with surgery service</p> <p>-No other limitations listed</p> <p>Conclusion: Standardized, evidence-based discharge training and a multi-disciplinary team approach increases the knowledge level of mothers while decreasing the care burden, anxiety level, and complications in home care Informing the family during the process of GT feeding SIG affects treatment adaptation and disease course and ensures</p>
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								<p>active participation of families in treatment</p> <p>When mother is involved in treatment, knowledge of care increases; she knows what to expect during illness course; and stress and care burden are decreased as control improves.</p> <p>-Discharge education is vital in the process.</p> <p>Feasibility: Recommended for use in a clinic (where no multidisciplinary discharge training is planned) by including control group cases</p>
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<p>Schweitzer et al., (2014). Evaluation of a discharge protocol for pediatric patients with gastrostomy tubes Country: United States Funding: None – potentially the medical center Bias: None listed</p>	<p>None specifically listed. HBM or CDT inferred</p>	<p>Design: preintervention-postintervention Purpose: -To evaluate a new evidence-based GT education protocol -To evaluate if a GT education protocol decreased complications within the first 3 months of GT placement procedure</p>	<p>N=49 CG=23 (24) IG=26 (18) Sample: Study group: 26 PCG/patient pairs -Patients with a GT recommended by their PCP -Not all PCG were biological parents -Half were 31-40 years old -89% were female -50% Caucasian, 39% African American 11% other nationalities HC group: 23 children who underwent GT placement from Jan. 2006-Jan. 2007 Setting: children’s hospital within a 924 bed Magnet tertiary medical center Inclusion Criteria:</p>	<p>IV: Interdisciplinary Education Protocol DV1: GT complications DV2: Confidence Level DV3: Anxiety DV4: Information Mastery DV5: Provider Satisfaction Definitions: Providers: -Participating staff including nurses caring for the patient population Gastrostomy tube: a tube that feeds a patient directly into the gastric cavity when a patient cannot receive nutrition by mouth Interdisciplinary: Involving multiple different specialties and avenues of care</p>	<p>-QDTS -MIQ Validity/Reliability: -Established by previous studies of adult and pediatric patients with a reported Cronbach’s alpha of 0.89. -Content validity determined by 3 pediatric providers at the institution identified as experts in GT care and placement</p>	<p>-Chi-Square -Wilcoxon signed rank test -Paired t-tests -Descriptive Summary Statistics</p>	<p>DV1 GT complication s: All patients in both groups: -42 complications for 27 patients (55%) -No complications for 22 patients (45%) -12 patients had more than one complication -5-study group (41.67%) and 7-HC group (58.33%) Location of Complication Study Group SIG higher. p value=<.05 Complication Outcome: Stat. SIG decrease in frequency of additional education -Increase in “other” (GT replacement, granulation tissue, fluid</p>	<p>LOE: IV Strengths: -Strong quantitative design -Low risk -Non-invasive intervention Weaknesses: -Small number of participants -Small Sample Size—attrition -Data Collection from EMR—phone calls may have been missed -No assessment of financial impact -Replication with larger sample size would increase confidence of findings Conclusions: -Increased PCG knowledge and confidence -Improved patient outcomes -Well accepted by health care providers Feasibility:</p>
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			<p>-Any child who needed a GT at least 3 months</p> <p>-PCG’s who spoke, read, and wrote in English and had no experience in GT care</p> <p>Exclusion Criteria:</p> <p>-Any child who could learn how to care for a GT without a PCG</p> <p>Attrition:</p> <p>-2 PCG lost to follow-up after discharge— unknown reason</p> <p>-Several patients withdrew due to complications which led to a new device (i.e. GJ tube) or disease progression</p>	<p>Patient Education:</p> <p>Teaching the patient or PCG information on how to manage a medical device or how to manage a disease process</p>			<p>replacement) category</p> <p>p value= <.01</p> <p>SIG increase in HC group for education outcomes (lack of education that led to complication)</p> <p>p value=<.01</p> <p>DV2 Confidence Level:</p> <p>Stat. SIG increase from PreP to PP</p> <p>p value=<.05 and PrePP to 3 months PP</p> <p>p value=<.05</p> <p>No difference between PP and 3 months PP</p> <p>DV3 Anxiety:</p> <p>No Stat. SIG difference between PP and 3 months PP</p> <p>DV4 Information Mastery:</p> <p>Stat. SIG increase in PCG knowledge</p>	<p>-Recommended for use in hospitals to decrease variation among providers, confusion among patients and PCG’s and increased patient safety and satisfaction</p>
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							scores from PreP to PP p value =<.001 and PreP to 3 months PP p value =<.001 SIG increase from PP to 3 months PP p value =.08 DV5 Provider Satisfaction: 12 providers completed surveys -5 physicians -4 RN's -2 NP's -1 RD -7 providers reported a change in patient calls (85.7% reported a decrease in number) -9 providers (75%) reported a positive change in PCG knowledge of GT care
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							-9 providers reported a decrease in PCG anxiety with GT care -11 providers (91.7%) reported that new protocol could be implemented as permanent protocol	
Suluhan et al., (2021). Effect of gastrostomy tube feeding education on parents of children with gastrostomy Country: Turkey Funding: None Bias: None	Transition Theory inferred	Design: Quasi-Experimental Method: Pre-test/Post-test Evaluation Purpose: Evaluate the effect of education on satisfaction with GT feeding, quality of life, caregiver burden, and anxiety	N =78 IG =78 --study group CG =None Sample: 78 mothers Setting: Pediatric intensive care units and pediatric surgery services in 3 pediatric hospitals in Turkey Inclusion Criteria: -CG's with a child to undergo an operation for GT feeding or who had a GT placement for <2 weeks	IV: Education DV1: Satisfaction with GT feeding DV2: Quality of Life DV3: Caregiver Burden DV4: Anxiety Definitions: Parent: Someone with parental responsibility, including mothers, fathers, and grandparents.	-Child/Parent Data Form -Zarit Caregiver Burden Scale -Satisfaction Questionnaire with Gastrostomy Feeding (SAGA-8) -State-Trait Anxiety Inventory (STAI) -36 Item Short Form Quality of Life Scale (SF-36) -Complication Control Form -Gastrostomy Care Skill Assessment Checklist All instruments are valid and reliable.	-SPSS Statistics Software 20.0 -Descriptive Statistics -Paired t-test -Level of SIG was p <.05	DV1 Satisfaction with GT feeding: Satisfaction was higher at the end of the 3 rd month than at the end of the 1 st month Stat. SIG p value: <0.01 At the end of 1 st month, most common complication was GT dislodgement DV2 Quality of Life: More positive than before GT placement	LOE: III Strengths: -Strong quantitative design -High level of evidence -Low attrition rate -Low risk, non-invasive intervention -Moderate number of participants Weaknesses: -Limited duration— follow-up only extended 3 months -No control group -No comparison of

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			<p>-CG's with no previous involvement in a discharge education program</p> <p>-CG's with a lack of communication disability</p> <p>-CG's with primary care of the child at home</p> <p>-CG's who volunteered to participate in the study</p> <p>Exclusion Criteria:</p> <p>-Parents of children who were not able to learn gastrostomy care</p> <p>-18 children cared for in hospital by the Child Protection Agency—not able to obtain research permission from the agency</p> <p>-4 parents in initial group did not consent</p> <p>Attrition:</p> <p>2 parents in the 1st month</p>		<p>1:1 education session with the same researcher who previously worked as a nurse in the pediatric surgery department</p>		<p>Mean score at 3 months was higher than before GT placement</p> <p>-Increasing GT care skills and self-confidence are related to improvements in physical and emotional quality of life through education</p> <p>DV3 Caregiver Burden:</p> <p>Decreased moderate care burden before education to light care burden after education</p> <p>DV4 Anxiety:</p> <p>Difference in mean scale scores of state anxiety levels was</p> <p>Stat. SIG -- decreased at 3 months</p> <p>p value:</p> <p><0.001</p> <p>-Home counseling via</p>	<p>training methods</p> <p>-Studies to evaluate different types of educational methods are most effective</p> <p>-Mothers' satisfaction with GT feeding evaluated on SAGA-8 scale but other outcomes were not evaluated with specific scales</p> <p>Conclusions:</p> <p>-Mothers of children with GT had positive outcomes with education and support—especially increased skills</p> <p>-Caregiver burden and anxiety levels decreased after education</p> <p>-Most anxious period is prior to GT placement</p> <p>-Follow-up after discharge</p>
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							phone and teaching GT care skills provided competency and decreased anxiety	and educational programs should be provided to CG's of children with GT's to overcome caregiving difficulty. -Practical training to gain competence in care, assess CG skills in GT care, and monitoring children and CG's after discharge is critical to increase positive outcomes and decrease minor complications. Feasibility: Not specifically recommended for repeat use. Further research is recommended with a follow-up period extending >3 months post-placement of GT device and
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									to compare outcomes of CG's with a control group or 1 group that receives 1 education session and a 2 nd group that receives > or =2 education sessions.
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Table A2
Qualitative Studies

Citation	Theoretical Conceptual Framework	Design/ Method/ Sampling	Sample/Setting	Major Variables/ Research Questions	Measurement/ Instrumentation	Data Analysis	Findings/ Themes	Level of Evidence; Application to practice/ Generalization
Boebel Toly et al., (2019). Mothers' voices related to caregiving:	Transition Theory	Design: Qualitative descriptive longitudinal Purpose: Explore how	N=19 Demographics: Sample: 19 mothers of life-saving TD infants Setting:	-Description of Mothers' Transition Experience -Tell me what it is like for you right now as you prepare to take your infant home on medical technology?	-Investigator developed demographic survey -Audio-recording -Transcribed verbatim	Descriptive Content Analysis with quantitative and qualitative components	Pre-transition: -Negative emotions -Post cognitive behavioral efforts -Preparation for life at home Post-transition:	LOE: VI Strengths: -Strong qualitative design -Demonstrates importance of

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<p>The transition of a TD infant from the NICU to home Country: United States Funding: None Bias: None listed</p>		<p>mothers perceive their transition experiences just prior to and during the first three months after initial NICU discharge</p>	<p>Large Midwest NICU at a children’s hospital Inclusion Criteria: -Mothers (female PCG’s) -Age > or = 18 years -Caring for a TD infant to be discharged within 2-3 weeks for the 1st time -Understand English— read/speak -Expected to require technology for >3 months after discharge Exclusion Criteria: -Mothers with cancer or terminal diagnosis due to potential grief reactions with these diagnoses Attrition: -10 from pre to post transition</p>	<p>-What would you like healthcare providers to know about your experience of bringing your infant home on medical technology? What were your needs for information and support? (3 months post discharge) Definitions: Technology-Dependent (TD) Child: A child who relies on technology to meet the basic human needs in everyday life</p>			<p>-Negative transition experiences -Positive transition experiences During transition: -Heightened anxiety, fear, and stress about life threatening situations</p>	<p>supporting mothers of TD children Weaknesses: -Small sample size -One geographic area of the United States -Over 50% of potential participants approached declined participation -Less than half of participants in pretransition participated after transition -Unclear about attrition rate due to inability to reach drop-out participants by telephone -No question about HHC pr financial issues of family after NICU discharge -Convenience sampling Conclusion/Applicatio n: -Highlighted mothers’ voices regarding their TD child’s discharge and transition experience from NICU to home -Imperative for health care provider to conduct standardized assessments of</p>
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								<p>discharge readiness and provide mental health and social support to increase parental confidence and decrease readmission rates for the TD infant</p> <ul style="list-style-type: none"> -Quality of discharge education is critical to helping parents to be competent and confident in daily care of their infant -Gradual is important to avoid overwhelming PCG's -Preparing PCG's by using shared decision making and assisting them in solving real-life issues based on their child's equipment is critical. -Provide mental health and support
<p>Boebel Toly et al., (2019). Mothers' caring for TD children at home: What is most helpful and least helpful?</p>	<p>None specifically listed.</p> <p>Transition Theory or Experiential Learning Theory-inferred</p>	<p>Design: Qualitative Descriptive</p> <p>Purpose: Explore what is most helpful and least helpful for mothers</p>	<p>N=103</p> <p>Demographics: Sample: Mothers (primary female caregivers) caring for TD children < or = to 16 years old. -Age: 21-66 years -Predominately Caucasian</p>	<p>-What is most helpful to you now? -What is least helpful to you now? -in regard to caring for the TD child at home</p> <p>Definitions: Technology-Dependent (TD) Child:</p>	<p>-Feetham Family Functioning Survey (FFFS) (25, 7-point Likert scale questions) -Two open ended questions -Face-to-Face Interviews</p>	<p>Independent readings of participant responses to FFFS open-ended questions and developing codes -Group cross-check</p>	<p>-Absence of support (family, health care providers, social network) -Disruption of daily life (scheduling conflicts, lack of normalcy, self-care deficit, negativity, mental health)</p>	<p>LOE: VI Strengths: -Strong qualitative design -View of parents' perspectives on how they handle life with a TD child -Identifies gaps to fill for support and</p>

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<p>Country: United States of America Funding: Alpha Mu Chapter of Sigma Theta Tau International, Frances Payne Bolton School of Nursing Alumni Association, Case Western Reserve University Research ShowCASE, and the Society of Pediatric Nurses Study supported by grant UL1RR024989, the Clinical and Translational Collaborativ</p>		<p>who care for their TD children at home</p>	<p>-Married -Income of 60,000 or less -TD children from 7 months to 16.8 years -Majority dependent on respiratory or nutritional technology -Most frequent technology—feeding tube -Approx. 50% of children required 2-4 types of technology Setting: Midwestern Children’s Hospital -Mothers identified by staff at pediatric specialty clinics (Gastroenterology, Pulmonology, Trach/Vent, pre-term infant follow-up) Inclusion Criteria: -Participants were > or = to 18 years of age and cared</p>	<p>A child who relies on technology to meet the basic human needs in everyday life</p>	<p>-Investigator-developed demographic survey</p>	<p>and discussion to identify themes - Quantitative Content Analysis—tallying frequencies for verbalization of subthemes to identify data patterns -Descriptive Analysis of demographic data—frequencies and examination of central tendency and score dispersion</p>	<p>Subthemes: -Absence of other family member’s support -Last minute cancellations of private duty shifts by home care nurses</p>	<p>education for these caregivers Weaknesses: -One geographic region-sample -Only female caregivers -Limited response space—fully expounded response—not possible</p>
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<p>e at Case Western Reserve University, Dahms Clinical Research Unit. Bias: None Listed</p>			<p>for a TD child at home -Children were based on 3 categories: group 1: mechanical ventilation Group 2: IV nutrition/medication Group 3: Respiratory or Nutritional Support Exclusion Criteria: Mothers of children with cancer or in terminal phase of illness Attrition: 10; only 93 answered at least one of the questions</p>					
<p>Cooper (2008). Family caregiver perspectives on management of long-term home enteral nutrition via a</p>	<p>None specifically listed. Transition Theory inferred</p>	<p>Design: Qualitative Purpose: -Identify information and resources that will assist the family CG in</p>	<p>N=9 Demographics: Setting: Patients' homes in Canberra, Australia Sample: -With CG's of pediatric patients with home enteral nutrition</p>	<p>4 domains of care: -Technical</p> <ul style="list-style-type: none"> • Formula and medication administration • Aspiration pneumonia • Pain management • Peristoma • Pump 	<p>Semi-structured interviews -35 minutes -in-home -with PCG -11 questions -1 additional open-ended question -Audio tape recorder</p>	<p>-Informed by domains of care—developed from the literature review and clinical experience -Points of interest classified</p>	<p>Technical: Leakage of gastric contents through stoma onto abdomen reported by 6 CG's -Hyper granulation of tissue reported by 5 CG's -Bacterial/Fungal infections reported by 5 CG's</p>	<p>LOE: VI Strengths: -Strong qualitative design -Identified information and resources to assist CG's in managing routine care, challenges, and complications with home ENS via GT Weaknesses: -Small sample size</p>

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<p>gastrostomy tube Country: Australia Funding: Primary Health Care Research Education Development (PHRED) Grants Program Bias: Possible if researchers are employees of the PHRED program</p>		<p>managing routine care and complications associated with home enteral nutrition via a GT -Explore and describe family CG's perspective on challenges and complications in managing long-term enteral nutrition via a GT</p>	<p>-9 patients between 2-24 years—5 females and 4 males -GT for 3 months to 9 years Inclusion Criteria: -Registered with home enteral nutrition scheme (HENS) -Living at home with family support -Age of 1 year or older -20% of these patient's CG's were approached and all agreed to be interviewed for the study Exclusion Criteria: -No GT use for nutrition source -Less than 1 year of age -Non-members of HENS -Not living at home -Without family support Attrition:</p>	<ul style="list-style-type: none"> • Tube -Nutrition <ul style="list-style-type: none"> • Formula • Hydration • Weight -Gastrointestinal <ul style="list-style-type: none"> • Abdominal distention • Constipation • Cramping • Diarrhea • Flatulence • Nausea • Vomiting -Family Caregiver <ul style="list-style-type: none"> • Preparation • Quality of life • Satisfaction • Support <p>Definitions: Enteral Nutrition: A type of nutrition that is received directly into the gastrointestinal system through a feeding tube that goes straight into the stomach (gastrointestinal cavity) T: a tube that feeds a patient directly into the stomach (gastrointestinal cavity) when a patient</p>	<p>-Transcribed verbatim -Transcriptions</p>	<p>according to major or minor significance and occurring early or late under the domains of care</p>	<p>-Moist stoma reported by 3 CG's -Pain management not an issue for most patients except 1 -Accidental tube dislodgement reported by 7 CG's -Tube malfunction reported by 5 CG's -Disconnection accidentally/blocked tube/buried bumper syndrome -Aspiration pneumonia reported by 3 CG's Nutrition: -not an issue -2 reports of unnecessary weight gain GI function -Constipation reported by 3 CG's -Diarrhea reported by 2 CG's -Vomiting reported by 2 CG's Family CG -8 of 9 CG's looked at the tube as a source of convenience -Some CG's found it difficult to get a spare balloon GT from the hospital</p>	<p>-One geographic region -Convenience sample Conclusion/Application: Insufficient evidence to guide practice in management of patients with GT's in the community CG's benefit from preparation for routine care and complications in tube management including resources and contacts Additional GT support for challenges and complications is necessary</p>
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			None	cannot receive nutrition by mouth			but others found it easy -Several expressed concerns about lack of availability of replacement GT's for emergencies and procedures -Positive responses by outpatient services at local hospital, nutrition department, multidisciplinary clinics, and continuing care program, pre-op and post-op education provided by dietician and nurses -CG's did not feel prepared for complications. Contact lists and expert advice at review clinics, not just other parent supports groups, were necessary.	
Hopwood et al. (2020). Parenting children who are	CHT	Design: Cultural Historical Approach Purpose:	N=20 Demographics: Sample: 20 Parents:	-What matters to parents of children who are enterally fed in their everyday practices?	Two-two-hour focus groups followed by	-MAXQDA software -2 rounds of coding: one for each	Themes: -Maintaining participation in everyday activities	LOE: VI Strengths: -Strong qualitative design -Little is previously known about parental

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<p>enterally fed: How families go from surviving to thriving Country: Australia Funding: Relevant Health and University Human Research Ethics Committee Bias: None listed</p>		<p>Investigate strategies families, develop and use to adjust and adapt to enteral feeding to not just survive but thrive as a family</p>	<p>Parents of enterally fed children Two were husband/wife -One with more than one enterally fed child 20 children: Age: Several months to 7 years old 6 weaned from NG to PO feeding 2 transitioned from NG to PEG tube 4 still using an NGT, 7 changed from NG to PEG that was still in use and one passed away while feeding from a PEG tube -17 received an NGT within days of birth, the rest at 9 weeks, 35 weeks, and 14 months -8 transitioned off TF between 4 months to 2 years -Children with PEG tube had it inserted between</p>	<p>-How do parents resolve challenges associated with enteral feeding in everyday life? Definitions: EF: Receiving nutrition directly into the gastrointestinal system</p>	<p>10 1:1-hour long interviews 6-12 months later -Phone interviews -Video recordings -In -person interviews -Specific tools of capturing data not listed. (recordings, notes, etc.)</p>	<p>research question</p>	<p>-Responses to the use of tubes for feeding -Doing what feels right for the child -Memory aids and readiness tools -Metaphors and narratives -Repurposed everyday objects -Personalized routines and materialities</p>	<p>knowledge as they learn and adapt to EF Weakness: -Relatively small N -Convenience Sample -Low level evidence -Demographic Homogeneity (low generalizability) -Tools to collect data not listed -No mention of bias -Does not study all types of pediatric feeding tubes</p>
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			<p>12-18 months of age.</p> <p>Reasons for TF:</p> <ul style="list-style-type: none"> -Premature Birth -Cleft lip/palate -DD -Down's Syndrome -Noonan's Syndrome -Oral aversion linked to ASD -Aspiration -Rare genetic disorders <p>Setting:</p> <p>Two two-hour in-person focus groups followed by 10 interviews. Exact in-person setting not listed. Per parent preference, in person, phone, or online video call – 6 phone or online interviews</p> <p>Inclusion Criteria:</p> <p>Parents of a child with an NGT or PEG tube enteral feeding device</p> <p>Exclusion Criteria:</p>					
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			Parents of children with no past history of an NGT or PEG tube Attrition: None					
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Key: **ASD**=autism spectrum disorder **C**=control **CG**=caregiver **CI**=confidence interval **CBT**=Cognitive Behavioral Theory **CHT**=Cultural Historical Theory **CDT**=Cognitive Dissonance Theory **D**=descriptive **DV1**=dependent variable 1 **DV2**=dependent variable 2 **DD**=developmental delay **E**=experimental **ELT**=experiential learning theory **EF**=enteral feeding **ENS**=enteral nutrition support **FT**=feeding tubes **G**=gender **GJ**=gastrojejunostomy tube **GT**=gastrostomy tube **HBM**=Health Belief Model **HC**=historical comparison group **HG**=home care group **HHC**=home health care **IOC**=incidence of complications **IG**=intervention group **IV1**=independent variable 1 **LOE**=level of evidence **Q**=qualitative **QD**=qualitative descriptive **QI**=quasi-experimental **M**=mean **N**=participants **NGT**=nasogastric tube **NICU**=neonatal intensive care unit **NL**=not listed **P value**=level of significance **PO**=by mouth **PCG**=primary caregiver **PCP**=primary care provider **PEG**=percutaneous endoscopic gastrostomy tube **PG**=parent group **PreP**=pre-procedure **PP**=post-procedure **RH**=regional hospital; **SIG**=significant **SCT**=Social Cognitive Theory **SLT**=Social Learning Theory **T**=target audience **TD**=technology dependent **TF**=tube feeding **TT**=transition theory

Table A3 Synthesis Table

Study	Boebel Toly et al.	Boebel Toly et al.	Chang et al.	Cooper	Hopwood et al.	Northington et al.	Pahsini et al.	Pars et al.	Schweitzer et al.	Suluhan et al.
Year	2019	2019	2020	2008	2020	2017	2016	2020	2014	2020
Study Characteristics										
Design	QD	QD	QI	Q	CH	D	QA of SQ	QI	Pre-INT/Post INT	QI
LOE	VI	VI	III	VI		VI	IV		IV	III
Framework	TT or ELT IF	TT	HBM/CBT/SLT IF	TT IF	CHT	SCT IF	TT IF	TT IF	HBM or CDT IF	TT IF
Sample										
N	103	19	233	9	20	210	425	30	49	78
C	N/A	N/A	127	N/A	N/A	PG-144 HG-66	N/A	30-HC	23	N/A
IG	N/A	N/A	106	N/A	N/A	N/A	N/A	30	26	78
Attrition	10	10	23	N/A	N/A	N/A	N/A	N/A	2	2
Target	PCG	PCG	PCG	PCG's	PCG's	PCG/HC	PCG's	PCG's	PCG's	PCG's
Age-parent	> or =18	21-66 yrs	NL	NL	NL	NL	NL	NL	50% 31-40 yrs	NL
Age-child	< or =16 yrs	< or =16 yrs	NL	2-24 years	Few months-7 yrs	<18 years	3m-10.5 years	<1-18 years	0-17 yrs	NL
Setting										
Homes				X						
Office-IF					X					
Hospital	RH	NICU at RH	RH				RH	RH	RH	RH
Online					X	X				

Key: ASD=autism spectrum disorder C=control CG=caregiver CI=confidence interval CBT=Cognitive Behavioral Theory CHT=Cultural Historical Theory CDT=Cognitive Dissonance Theory DV1=dependent variable 1 DV2=dependent variable 2 DD=developmental delay E=experimental EB=evidence-based EF=enteral feeding ELT=experiential learning theory ENS=enteral nutrition support FT=feeding tubes G=gender GJ=gastrojejunostomy tube GT=gastrostomy tube HBM=Health Belief Model HC=historical comparison group HG=home care group HHC=home health care IF=inferred IG=intervention group INT=intervention IOC=incidence of complications IV1=independent variable 1 LOE=level of evidence Q=qualitative QA=quantitative analysis QD=qualitative descriptive QI=quasi-experimental M=mean N=participants NGT=nasogastric tube NICU=neonatal intensive care unit NL=not listed P value=level of significance PO=by mouth PCG=primary caregiver PCP=primary care provider PEG=percutaneous endoscopic gastrostomy tube PG=parent group PreP=pre-procedure PP=post-procedure RH=regional hospital; SIG=significant SCT=Social Learning Theory SLT=Social Learning Theory SNI=systematic nursing intervention SOC=standardization of care SQ=standardized questionnaire T=target population TD=technology dependent TF=tube feeding TT=transition theory

Phone					X			X		
Country	USA	USA	Taiwan	Australia	Australia	United States	Australia	Turkey	USA	Turkey
Interventions										
SNI			X							
Standardized EB D/C Education								X	X	
Video			X							
Pamphlets			X							
Nurse Education			X					X		X
Interviews				X	X			X		X
Measurement Tools	Feetham Family Functioning Survey Two open ended questions	Audio Recording Transcribed Verbatim Survey	Questionnaire Incidence of Complications	Semi-structured interviews Audio Recordings Transcribed Verbatim Transcriptions	2-2-hour focus groups 10 1:1-hour long interviews Phone Interviews Video Recordings In person interviews	Web-based Questionnaire Two separate survey tools: one for parents and one for HHC workers	Online Standardized Questionnaire	Pre-test/Post-test survey Zarit Caregiver Burden Scale State Trait Anxiety Inventory	Pre-test/Post-test QDTS MIQ questionnaire	Child/Parent Data Form Zarit Caregiver Burden Scale SAGA-8 STAI SF-36 complication control form, and the gastrostomy care skill assessment checklist
Outcomes										
PCG Knowledge			↑					↑	↑	
PCG Confidence									↑	
PCG Skills			↑							↑

Key: ASD=autism spectrum disorder C=control CG=caregiver CI=confidence interval CBT=Cognitive Behavioral Theory CHT=Cultural Historical Theory CDT=Cognitive Dissonance Theory DV1=dependent variable 1 DV2=dependent variable 2 DD=developmental delay E=experimental EB=evidence-based EF=enteral feeding ELT=experiential learning theory ENS=enteral nutrition support FT=feeding tubes G=gender GJ=gastrojejunostomy tube GT=gastrostomy tube HBM=Health Belief Model HC=historical comparison group HG=home care group HHC=home health care IF=inferred IG=intervention group INT=intervention IOC=incidence of complications IV1=independent variable 1 LOE=level of evidence Q=qualitative QA=quantitative analysis QD=qualitative descriptive QI=quasi-experimental M=mean N=participants NGT=nasogastric tube NICU=neonatal intensive care unit NL=not listed P value=level of significance PO=by mouth PCG=primary caregiver PCP=primary care provider PEG=percutaneous endoscopic gastrostomy tube PG=parent group PreP=pre-procedure PP=post-procedure RH=regional hospital; SIG=significant SCT=Social Cognitive Theory SLT=Social Learning Theory SNI=systematic nursing intervention SOC=standardization of care SQ=standardized questionnaire T=target population TD=technology dependent TF=tube feeding TT=transition theory

PCG QOL										↑
PCG Anxiety								↓	No Δ	↓
PCG Burden								↓		↓
PCG Satisfaction										↑
Provider Satisfaction									↑	
Constipation			↓							
Diarrhea			↓							
Abdominal Distention			↓							
NGT Adverse Effects							↑			
Incidence of Pediatric NGT's						↑				
NGT Management Differences in PG & HG						X				
Frequent NGT Replacement						X				
Inconsistency in NGT Verification						X				
Misplaced NGT						X				
Need for EB SOC						X				
Location of GT Complication									↑	
Further Educational Need									↓	
Themes										
Absence of Support	X			X						
PCG Burden	X			X			↑			
Disruption of Daily Life	X									
Cancellations	X									

Key: ASD=autism spectrum disorder C=control CG=caregiver CI=confidence interval CBT=Cognitive Behavioral Theory CHT=Cultural Historical Theory CDT=Cognitive Dissonance Theory DV1=dependent variable 1 DV2=dependent variable 2 DD=developmental delay E=experimental EB=evidence-based EF=enteral feeding ELT=experiential learning theory ENS=enteral nutrition support FT=feeding tubes G=gender GJ=gastrojejunostomy tube GT=gastrostomy tube HBM=Health Belief Model HC=historical comparison group HG=home care group HHC=home health care IF=inferred IG=intervention group INT=intervention IOC=incidence of complications IV1=independent variable 1 LOE=level of evidence Q=qualitative QA=quantitative analysis QD=qualitative descriptive QI=quasi-experimental M=mean N=participants NGT=nasogastric tube NICU=neonatal intensive care unit NL=not listed P value=level of significance PO=by mouth PCG=primary caregiver PCP=primary care provider PEG=percutaneous endoscopic gastrostomy tube PG=parent group PreP=pre-procedure PP=post-procedure RH=regional hospital; SIG=significant SCT=Social Cognitive Theory SLT=Social Learning Theory SNI=systematic nursing intervention SOC=standardization of care SQ=standardized questionnaire T=target population TD=technology dependent TF=tube feeding TT=transition theory

Negative Emotions		X								
Post Cognitive Behavioral Efforts		X								
Preparation for Home		X								
Negative Transition Experiences		X								
Positive Transition Experiences		X								
Emotional Stress		X					X			
GT complications				X					X	
GI Function Complications				X						
Lack of Preparation for Complications				X			X			
Maintaining Normal Activity					X					
Responses to the use of tube for feeding					X					
Doing what feels right for the child					X					
Memory Aids/Readiness Tools					X					
Metaphors/Narratives					X					
Repurposed Everyday Objects					X					
Personalized Routines					X					

Key: ASD=autism spectrum disorder C=control CG=caregiver CI=confidence interval CBT=Cognitive Behavioral Theory CHT=Cultural Historical Theory CDT=Cognitive Dissonance Theory DV1=dependent variable 1 DV2=dependent variable 2 DD=developmental delay E=experimental EB=evidence-based EF=enteral feeding ELT=experiential learning theory ENS=enteral nutrition support FT=feeding tubes G=gender GJ=gastrojejunostomy tube GT=gastrostomy tube HBM=Health Belief Model HC=historical comparison group HG=home care group HHC=home health care IF=inferred IG=intervention group INT=intervention IOC=incidence of complications IV1=independent variable 1 LOE=level of evidence Q=qualitative QA=quantitative analysis QD=qualitative descriptive QI=quasi-experimental M=mean N=participants NGT=nasogastric tube NICU=neonatal intensive care unit NL=not listed P value=level of significance PO=by mouth PCG=primary caregiver PCP=primary care provider PEG=percutaneous endoscopic gastrostomy tube PG=parent group PreP=pre-procedure PP=post-procedure RH=regional hospital; SIG=significant SCT=Social Cognitive Theory SLT=Social Learning Theory SNI=systematic nursing intervention SOC=standardization of care SQ=standardized questionnaire T=target population TD=technology dependent TF=tube feeding TT=transition theory

Appendix B

Models and Frameworks

Figure 1

Transition Theory

Figure 2

Rosswurm and Larrabee's Model for Evidence-based Practice

Appendix C

Budget-Cost Management Outline

Phase	Activities/Materials	Direct Cost	Indirect Costs	Potential Funding Sources
Preparation	Use (10) new feeding tube education booklets to distribute potential audiences	Inpatient Floor (10): \$0.15 per page for a 30-page booklet-- \$45		Hospital Funding for Education Purposes
	Design and print pre-test/post-test surveys (20) (10-pre-test) (10-post-test)	(20): \$0.15 per page—5 pages each \$15		Grants Student own money
	Design and print pre-test/post-test surveys for nurses Inpatient Floor: (100) (50-pre-test) (50-post-test) Outpatient Clinic: (30) (15-pre-test) (15-post-test)	Inpatient Floor: (50): \$0.15 per page—1 page--100 pages-- \$15 Outpatient Clinic: (30): \$0.15 per page—1 page--100 pages-- \$4.50		Grants Student's own money
	Create a poster presentation to present education to nurses	Posterboard and materials \$25		Grants Student's own money

Delivery	Decreased Productivity r/t longer clinic appointments to teach parents the education.		30-minute appointments instead of 15-minute appointments-- \$100/visit x10 visits-- \$1000	Hospital
	Train inpatient GI nurses x30 minutes Inpatient: 50 Outpatient: 15		Inpatient: \$0 Outpatient: \$0 Will be unpaid training	N/A
Evaluation	Utilize SPSS software to analyze results (student edition)	\$60		Student's own money
	Review and analysis of results by hospital financial advisors (2hrs @ \$30/hr)	\$60		Hospital

Justification: This project will increase parental education therefore, decreasing unnecessary clinic visits, ED visits, and hospital admissions.

Total Cost: \$1,224.50

Revenue Savings:

Potential avoided level 1 ED visits (3) (\$350 each) -**\$1050**

Potential avoided level 2 ED visits (6) (\$500) -**\$3000**

Avoided one night hospital admission (3) (\$2,500) -**\$5,000**

Cost vs. Revenue Savings:

Cost-Revenue= \$9,050-\$1224.50=\$7,825.50

Appendix D



DEFERRAL

[Diana Jacobson](#)

[EDSON: DNP](#)

602/496-0863 DIANA.JACOBSON@asu.edu

Dear [Diana Jacobson](#):

On 3/3/2022 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Bridging the Gap in Gastrostomy Tube Education
Investigator:	Diana Jacobson
IRB ID:	STUDY00015634
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • ASU Local Context Review Form, Category: Other; • ASU Local Context Review Form, Category: IRB Protocol; • Bridging the Gap in Gastrostomy Tube Education_PCH Initial Application, Category: IRB Protocol; • Bridging the Gap in Gastrostomy Tube Education_PCH Protocol , Category: IRB Protocol; • Data Collection Spreadsheet, Category: Other; • Education Intervention Booklet Cover, Category: Resource list; • Education Intervention Part II, Category: Resource list; • Friedl_A_CITI training certificate, Category: Other; • Friedl_A_CITI Training Report, Category: Other; • Friedl_A_Conflict of Interest Statement, Category: Other; • Friedl_A_Curriculum Vitae, Category: Vitaes/resumes of study team;

	<ul style="list-style-type: none"> • Friedl_A_Informed Consent Training, Category: Other; • Gibson_K_CITI Training Report, Category: Other; • Gibson_K_Conflict of Interest Statement, Category: Other; • Hospital Department Acknowledgement Form, Category: Other; • Informed Consent Form, Category: Consent Form; • Introduction Script, Category: Recruitment Materials; • IRB Independent Authorization Ethics Committee Authorization Agreement, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc); • PCH IRB Approval Letter, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc); • PCH Site Delegation Log, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc); • Post Test Survey, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Pre-Test Survey, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);
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The ASU IRB deferred review and oversight of this project to PCH IRB and the associated IRB protocol number is IRB-22-044.

REMINDER – Effective January 12th 2022, in-person interactions with human subjects require adherence to all current policies for ASU faculty, staff, students and visitors. Upto-date information regarding ASU’s COVID-19 Management Strategy can be found [here](#). IRB approval is related to the research activity involving human subjects, all other protocols related to COVID-19 management including face coverings, health checks, facility access, etc. are governed by current ASU policy.

Sincerely,

IRB Administrator cc: Anne Friedl
 Diana Jacobson
 Danielle Sebbens
 Anne Friedl

Appendix E

Bridging the Gap in Gastrostomy Tube Education

Survey 1

Please do not write your name on this survey. Create your own personal 6-digit identification number by using the first two digits of the month you were born and the last 4 digits of your phone number. Example: A person born in June and the last 4 digits of their phone number would be 062476.

Write your personal ID number here: _____

Directions: Please read the following questions and write the response that best applies to you.

1. What is the age of your child? _____

2. What is the reason your child had a gastrostomy tube put in?

3. Please list all of your child’s health problems here?

4. Who is the primary caregiver(s) that will care for the gastrostomy tube?

Please circle all that apply.

Mother Father Family Members Babysitter

Other: _____

5. Which of the following insurances cover your child’s medical expenses?

Public Private Both Public and Private

The following questions have to do with your child’s gastrostomy tube and feeding. Please circle your best response.

6. I can describe the function of each part of my child’s gastrostomy tube.

I can describe no parts.	I can describe some parts.	I can describe half of the parts.	I can describe most parts.	I can describe all parts.
0	1	2	3	4

7. I can show you how to inflate and deflate the balloon of my child’s feeding tube.

Yes No

8. I can show you how to give my child’s medicine through his feeding tube.

Yes No

9. I can tell you how to bathe my child with his gastrostomy tube.

Yes No

10. I can tell you how my child can safely sleep with their feeding tube during a feeding.

Yes No

11. I can tell you what to do if my child starts vomiting.

Yes No

12. I can tell you the steps of how to give my child a feeding through their tube.

I do not know how to give my child a feeding through their tube.	I know <u>some</u> of the steps of how to give my child a feeding through their tube.	I know <u>half</u> of the steps of how to give my child a feeding through their tube.	I know <u>most</u> of the steps of how to give my child a feeding through their tube.	I know <u>all</u> of the steps and am confident in how to give my child a feeding through their tube.
0	1	2	3	4

13. I can tell you how to provide care for the skin around my child’s gastrostomy tube.

I do not know how to provide care for my child’s skin.	I know <u>some</u> of the steps to provide care for my child’s skin.	I know <u>half</u> of the steps to provide care for my child’s skin.	I know <u>most</u> of the steps to provide care for my child’s skin.	I know <u>all</u> of the steps to provide care for my child’s skin.
0	1	2	3	4

14. I can tell you the steps of what to do if my child’s feeding tube falls out.

I do not know what to do if my child’s feeding tube falls out.	I know <u>some</u> of the steps of what to do if my child’s feeding tube falls out.	I know <u>half</u> of the steps of what to do if my child’s feeding tube falls out.	I know <u>most</u> of the steps of what to do if my child’s feeding tube falls out.	I know <u>all</u> of the steps of what to do if my child’s feeding tube falls out.
0	1	2	3	4

15. I can tell you what to do if my child’s feeding tube is clogged.

I do not know what to do if my child's feeding tube is clogged.	I know <u>some</u> of the steps of what to do if my child's feeding tube is clogged.	I know <u>half</u> of the steps of what to do if my child's feeding tube is clogged.	I know <u>most</u> of the steps of what to do if my child's feeding tube is clogged.	I know <u>all</u> of the steps of what to do if my child's feeding tube is clogged.
0	1	2	3	4

The following questions have to do with your confidence in caring for your child. Please circle your best response.

16. I feel confident in caring for my child's gastrostomy tube.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

17. I feel confident in feeding my child through a gastrostomy tube.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

18. I feel confident in leaving my child with his or her a gastrostomy tube with another caregiver while I go to work or am away from home.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

19. I feel confident that I could take my child with a gastrostomy tube on vacation.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

20. I feel confident that I know what to do if my child's gastrostomy tube falls out.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

21. I worry that I will not be able to care for my child's gastrostomy tube once I get home.

I worry <u>every day</u> about how to care for my child's feeding tube at home.	I worry on <u>most days</u> about how to care for my child's feeding tube at home.	I worry on <u>some days</u> about how to care for my child's feeding tube at home.	I <u>rarely worry</u> about how to care for my child's feeding tube at home.	I <u>never worry</u> about how to care for my child's feeding tube at home.
0	1	2	3	4

THANK YOU FOR COMPLETING THIS SURVEY.

Appendix F

Bridging the Gap in Gastrostomy Tube Education

Survey 2

Please do not write your name on this survey. Create your own personal 6-digit identification number by using the first two digits of the month you were born and the last 4 digits of your phone number. Example: A person born in June and the last 4 digits of their phone number would be 062476.

Write your personal ID number here: _____

The following questions have to do with your child’s gastrostomy tube. Please circle your best response. Please circle your best response.

1. I can describe the function of each part of my child’s gastrostomy tube.

I can describe no parts.	I can describe some parts.	I can describe half of the parts.	I can describe most parts.	I can describe all parts.
0	1	2	3	4

2. I can show you how to inflate and deflate the balloon of my child’s feeding tube.

Yes No

3. I can show you how to give my child’s medicine through his feeding tube.

Yes No

4. I can tell you how to bathe my child with his gastrostomy tube.

Yes No

5. I can tell you how my child can safely sleep with their feeding tube during a feeding.

Yes No

6. I can tell you what to do if my child starts vomiting.

Yes No

7. I can tell you the steps of how to give my child a feeding through their tube.

I do not know how to give my child a feeding through their tube.	I know <u>some</u> of the steps of how to give my child a feeding through their tube.	I know <u>half</u> of the steps of how to give my child a feeding through their tube.	I know <u>most</u> of the steps of how to give my child a feeding through their tube.	I know <u>all</u> of the steps and am confident in how to give my child a feeding through their tube.
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0	1	2	3	4
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8. I can tell you how to provide care for the skin around my child’s gastrostomy tube.

I do not know how to provide care for my child’s skin.	I know <u>some</u> of the steps to provide care for my child’s skin.	I know <u>half</u> of the steps to provide care for my child’s skin.	I know <u>most</u> of the steps to provide care for my child’s skin.	I know <u>all</u> of the steps to provide care for my child’s skin.
0	1	2	3	4

9. I can tell you the steps of what to do if my child’s feeding tube falls out.

I do not know what to do if my child’s feeding tube falls out.	I know <u>some</u> of the steps of what to do if my child’s feeding tube falls out.	I know <u>half</u> of the steps of what to do if my child’s feeding tube falls out.	I know <u>most</u> of the steps of what to do if my child’s feeding tube falls out.	I know <u>all</u> of the steps of what to do if my child’s feeding tube falls out.
0	1	2	3	4

10. I can tell you what to do if my child’s feeding tube is clogged.

I do not know what to do if my child’s feeding tube is clogged.	I know <u>some</u> of the steps of what to do if my child’s feeding tube is clogged.	I know <u>half</u> of the steps of what to do if my child’s feeding tube is clogged.	I know <u>most</u> of the steps of what to do if my child’s feeding tube is clogged.	I know <u>all</u> of the steps of what to do if my child’s feeding tube is clogged.
0	1	2	3	4

The following questions have to do with your confidence in caring for your child. Please circle your best response.

11. I feel confident in caring for my child’s gastrostomy tube.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

12. I feel confident in feeding my child through a gastrostomy tube.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

13. I feel confident in leaving my child with his or her gastrostomy tube with another caregiver while I go to work or am away from home.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

14. I feel confident that I could take my child with a gastrostomy tube on vacation.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

15. I feel confident that I know what to do if my child’s gastrostomy tube falls out.

Not Confident at all	Somewhat Confident	Mostly Confident	Very Confident	Extremely Confident
0	1	2	3	4

16. I worry that I will not be able to care for my child’s feeding tube once I get home.

I worry <u>every day</u> about how to care for my child’s feeding tube at home.	I worry on <u>most days</u> about how to care for my child’s feeding tube at home.	I worry on <u>some days</u> about how to care for my child’s feeding tube at home.	I <u>rarely worry</u> about how to care for my child’s feeding tube at home.	I <u>never worry</u> about how to care for my child’s feeding tube at home.
0	1	2	3	4

The following questions ask for your opinion about the teaching you received on how to care for your child’s gastrostomy tube. Please write your response in the space provided.

17. Was there anything that you thought was missing from the gastrostomy tube education that you received in the hospital or outpatient clinic?

18. What did you think was the **most helpful** part of the gastrostomy tube education?

19. What did you think was the **least helpful** part of this education?

20. What advice would you give to another parent or caregiver whose child is going to receive a feeding tube?

THANK YOU FOR COMPLETING THIS SURVEY.