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Pediatric Discharge G-Tube Toolkit

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PEDIATRIC DISCHARGE G-TUBE TOOLKIT

by

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Paper submitted in partial fulfillment of the
requirements for the degree of

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I would like to thank my family for their support throughout the DNP program. I would like to thank the NICU nurses and discharge planners who helped me identify potential participants for this project. I would like to thank Dr. Mary DeLetter for her guidance and support throughout this DNP project.

Dedication

To my mother, without your love and encouragement this would not have been possible.

To my son, you are the reason I love what I do and you inspire me daily.

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Abstract

Surgically placed gastrostomy tubes (G-tubes) are used in pediatric patients to provide proper nutrition and hydration when illness or trauma renders the child unable to consume adequate oral intake. Parents/caregivers are given education and training on their child's G-tube, which varies from hospital to hospital. Parents/caregivers are responsible for all aspects of the G-tube once discharged from the hospital. Studies have shown that after discharge, ER visits and/or unscheduled clinic visits are necessary for G-tube complications, many of which could be dealt with at home given the proper education and resources. The aim of this project was to provide a Pediatric Discharge G-tube Toolkit to parents/caregivers of children with newly placed G-tubes which would help prevent unnecessary ER visits and/or unscheduled clinic visits for G-tube complications. The kit consists of all necessary supplies for G-tube care and a quick reference guide on managing common complications. Participants were identified by bedside nurses and discharge planners in the Neonatal Intensive Care Unit. The student project leader delivered the toolkit to five parents/caregivers, discussed the contents, and made follow-up calls at one and four weeks post-discharge, using the phone assessment and administering the Modified Version of the Post-Discharge Coping Difficulty Scale (PDCDS). The participants' PDCDS scores ranged from 16-39, with a mean of 29 ± 7.9 indicating they were coping well. Only one of the project participants made an ER visit for a G-tube complication within the first month post-discharge, none made an unscheduled clinic visit, and none were readmitted to the hospital. The pre-project cohort made three ER visits within the first month post-discharge and had two hospital readmissions for G-tube complications.

Key words: G-tube discharge, pediatric G-tube toolkit, pediatric G-tube discharge, G-tube toolkit

Pediatric Discharge G-tube Toolkit

Surgically placed gastrostomy tubes (G-tubes) are necessary for many pediatric patients who have complex medical conditions and are unable to orally intake necessary nutrition to grow and thrive (Crosby & Duerksen, 2005). Pediatric intestinal failure caused by “short bowel syndrome, intestinal motility disorders and mucosal enteropathies” frequently necessitate the use of a feeding tube (Kosar, Steinberg, de Silva, Avitzur, & Wales, 2016, p. 798). Schweitzer, Docherty, Thompson, & Sullivan (2014, p. 421) list “birth defects, traumatic brain injuries, neurologic deficits, and esophageal injuries” as other reasons for feeding tube placement. Once a G-tube has been placed and the patient is ready to be discharged from the hospital, the patient’s parents or caregivers are responsible for the care of the feeding tube. At our children’s hospital we have different methods of teaching parents and caregivers how to manage their child’s care at home. These may include bedside training with show back/teach back, educational videos, education classes, and home care instruction booklets. For those children going home with tracheostomies and/or a g-tube, we also have practice g-tube and trach dolls.

Despite parent and caregiver education, emergency department (ED) visits and unscheduled clinic visits are common for children with G-tubes. The cost of these ED visits varies based on acuity, with low acuity pediatric ED visits averaging \$798 for males and \$812 for females, and high acuity pediatric ED visits averaging \$2,388 for males and \$2,480 for females (Florida Center for Health Information and Policy Analysis, 2014). Not only is the actual ED visit costly, but the families also incur travel, food, and lodging expenses as well as a disruption in their life routine.

The cost of an actual G-tube varies by diameter (French units), depth, brand, type (button vs. catheter-like), and the company providing it to the family. A catheter-like gastrostomy tube can typically be purchased online for \$25-\$40. The button type gastrostomy tube, which is usually preferred by caregivers for its low-profile, typically ranges from \$120 to \$230 at online retailers. Insurance often allows for a new G-tube every three months; sometimes the patient's medical supply company can provide an additional one if there is a malfunction or accidental pull out. Otherwise, parents/caregivers pay out of pocket and if a spare is not available at the time of dislodgement, then they must go to the ED for replacement. The most common gastrostomy tube complications that result in an ED visit are dislodgment, leaking, obstruction, granulation tissue development, and irritation of skin surrounding stoma (Saavedra, Losek, Shanley, & Titus, 2009). Correa et al. (2014) suggested that education prior to discharge that includes prevention and treatment of common complications at home may help avoid these ED visits.

Previous research indicates that G-tube complications are numerous and frequently lead to unplanned healthcare utilization. Alivizatos, Gavala, Alexopoulos, Apostolopoulos, & Bajruevic (2012) conducted a retrospective review of medical records of 31 patients who recently had a gastrostomy or jejunostomy tube insertion for long-term enteral nutrition. During the 17-month review period, there were 92 unscheduled visits for tube complications, with an average of 2.9 visits per participant. The most common complications were accidental tube removal, tube dysfunction, leakage, dermatitis of the stoma, and diarrhea.

Goldin et al. (2016) used the Pediatric Health Information System (PHIS) database to evaluate 15,642 patients under 18 years old who were discharged between 2010 and 2012 from 38 hospitals after G-tube placement. The investigators evaluated the type of surgery used to

place the G-tube; demographics, including sex, race, age, type of residence child resided, and type of insurance; whether the patients had gastroesophageal reflux disease (GERD), neurological issues, or a chronic complex condition (CCC); and whether they had a fundoplication. They found that 8.6% of their sample had a G-tube-related ER visit within 30 days of being discharged; 3.9% were admitted through the ER for G-tube-related issues. The most common reasons for ER visits were gastrostomy tube infection (26.6%), malfunction (22%), and dislodgment of tube necessitating replacement (19.4%). The odds of readmission were increased for Hispanics, non-Hispanic African Americans, children with more than three CCCs, and those with GERD. Patients who had undergone a fundoplication had a lower chance of readmission than those who had not.

Saavedra et al. (2009) conducted a retrospective review of medical records of 77 ER pediatric patients under the age of 18 years who had a gastrostomy or gastro-jejunostomy tube and were seen in the ED. During a 23-month period (1/2003-11/2004), the patients made 181 ER visits related to complications with their G-tube or gastro-jejunostomy tube. Saavedra et al. (2009) also evaluated the type of procedure used for tube placement, indications for initial tube placement, patients' medical disorders or diseases, the chief complaint for the ED visits, the physical state of the tube (dislodged, obstructed, cracked/broken, balloon rupture), abdominal findings, whether there was a need for dilatation, tests or radiological studies performed in the ED, the ED diagnosis, discharge disposition, and tube complications. The mean number of ED visits per patient was 2.4. Tube dislodgement was the chief complaint for 65% and replacement was needed 119 times. Admission was needed for 5% of those visits. The chief complaints consisted of tube dislodgement (65%), obstruction (9%), malfunction (21%), balloon rupture

(8%), granulation tissue (4%), bleeding (3%), infection (6%), and vomiting (6%); some of the complaints occurred concurrently.

Twenty-nine children who had their G-tubes surgically placed at an urban children's hospital during 2018 made 49 ED visits between January 2018 and October 2018 for G-tube complications (B. Combs, personal communication, November 14, 2018). The most common complication was dislodgment, followed by granulation tissue formation, leaking, and clogs (B. Combs, personal communication, November 14, 2018). Including patients who had G-tubes placed prior to January 2018, there were 169 ED visits made for G-tube complications between January 2018 and November 2018; the most common complication was dislodgment, followed by leaking, skin irritation, and granulation tissue (B. Combs, personal communication, November 14, 2018). The most common G-tube problems or complications seen at the hospital's G-tube Clinic are redness at the site, granulation tissue formation, leaking, rash/itching, and drainage that is thought to be infection (B. Combs, personal communication, October 17, 2018).

Theoretical Framework

Meleis developed the Transitions Theory that chronicles the relationships and interactions that nurses have with patients who are experiencing a transition in their lives (Meleis & Trangenstein, 1994). Figure 1 illustrates the use of Transitions Theory to guide this project. The theory consists of six key concepts: (a) types and patterns of transitions; (b) properties transition of experiences; (c) transition conditions (facilitators and inhibitors); (d) process indicators; (e) outcome indicators; and (f) nursing therapeutics (Im, 2006). There are four types of transitions in Meleis theory: developmental transitions, situational transitions, health illness transitions, and organizational transitions (Schumacher & Meleis, 1994).

Parents and caregivers of children with newly placed G-tubes are experiencing a health and illness transition which includes their child's diagnosis with a chronic illness or injury, their child's recovery process, and the eventual discharge from the hospital. There are multiple types of patterns of transitions and people can experience a number of patterns simultaneously rather than a single transition (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). The patterns in the Transitions theory are single, multiple, sequential, simultaneous, related, and unrelated (Meleis et. al, 2000). Parents and caregivers of children with G-tubes may be experiencing multiple transitions based on the reason for the G-tube and not just the placement itself. If their child suffered a traumatic injury then their parental role may have shifted to that of a total caretaker in addition to the transition from hospital to home.

Another simultaneous transition may be from employed to unemployed status due to their child's caretaking needs. Meleis et. al (2000) discussed the multiple properties of the transition experience, including (a) awareness; (b) engagement; (c) change and difference; (d) time span; and (e) critical points and events. Parents and caregivers may be experiencing all of these and be in different stages of each. Awareness is the parent's or caregiver's recognition and understanding of the transitions experience (Meleis et al.). Engagement relates to the extent in which the parent or caregiver is immersed in the transition. Changes refers to a change in the parent or caregiver's identity, role, relationship(s), ability, and patterned behavior (Im, 2006). Differences refers to the ways that parents/caregivers see themselves differently, are viewed by others differently, and how they view their environment differently (Meleis et. al, 2000). Time span refers to the start of the transition, the G-tube placement, to the end of the transition where a stable new normal has developed (Meleis et. al, 2000).

In this project, critical points and events refers to the diagnosis of the chronic illness or traumatic injury, the placement of the G-tube, and discharge home. Transition conditions are the situations that impact a person's ability to navigate through a transition, and that enable or impede their ability to successfully make a healthy transition (Schumacher & Meleis, 1994). This can include "personal, community, or societal factors" that impact the process and outcome of reaching a healthy transition (Im, 2006, p. 421). Though all these play a part in the transition home with a newly placed G-tube, the specific aim of this project was focused on knowledge and preparedness. The G-tube toolkit and education prepared parents/caregivers with supplies and information they need to deal with g-tube complications at home.

Process indicators are steps by which parents/caregivers "move through the transition either toward the direction of healthy or toward vulnerability and risk" (Im, 2006, p. 422). Here, nurses can assess and intervene to help facilitate a healthy outcome for their patient. A goal of the G-tube discharge toolkit is to help parents feel confident in dealing and coping with G-tube complications after hospital discharge. This refers to the parents/caregivers' demonstrated mastery of the skills and behaviors needed to manage their new situation in multiple environments. Finally, Nursing Therapeutics/Intervention defines how nurses help prepare the parents/caregivers for the transition home from the hospital. The Pediatric Discharge G-tube Toolkit intervention is a major component facilitating this transition.

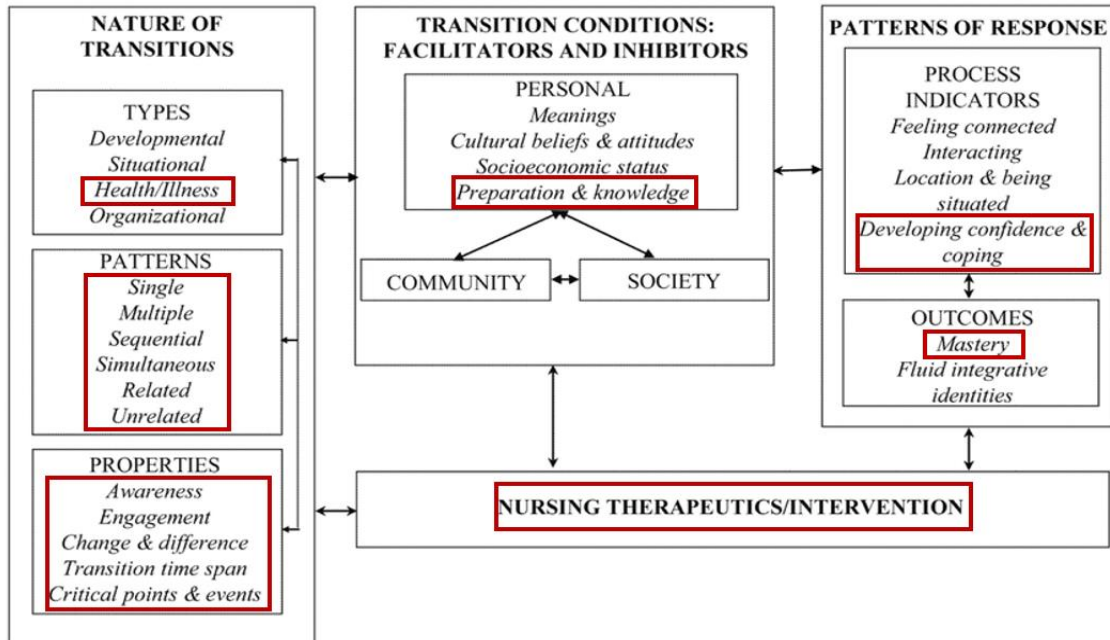


Figure 1. Transition Theory. Project Relevance Highlighted (Meleis et. al, 2000)

Setting and Organizational Assessment

The setting for this project was an urban children's hospital in Louisville, KY which serves more than 170,000 children a year and has 300 inpatient rooms. The unit included in this project is the 100-bed Level IV Neonatal Intensive Care Unit (NICU). The toolkit and coinciding education were distributed to parents/caregivers shortly before discharge. Follow-up phone calls to the patients' parent/caregiver were made at one week and four weeks post-discharge. Bedside nurses, discharge planners, and unit managers were all very supportive of this quality improvement project. Critical factors identified early in the project planning phase included (a) approval by the NICU Practice Council; (b) identification nurse G-tube champions who would track G-tube patients on the unit, assemble their toolkits, and finalize their G-tube

Quick Reference Guide with the appropriate patient specific information; and (c) monetary cost of toolkit bags and G-tube Quick Reference guide printing.

The project was approved by the University of Louisville Institutional Review Board and the hospital's Research Council. Stakeholders in this project included the children, bedside nurses, unit manager, discharge planners, parents/caregivers of children with newly placed G-tube, the ED staff, and the G-tube Clinic staff.

Purpose

The purpose of this project was to implement provision of Pediatric Discharge G-tube Toolkit just prior to discharge for patients with newly placed G-tubes. The project aims were to help parents/caregivers manage G-tube care and minor complications at home and reduce unnecessary ED visits or urgent G-tube Clinic appointments. The toolkit contains all necessary supplies and information for inserting a new G-tube, G-tube care, managing complications, ordering supplies, and contacting appropriate health providers for assistance. In addition to augmenting home care, the toolkit is compact enough to accompany the child to school or day care, community outings, long-distance travel, doctors' appointments, clinic visits, and ER visits.

Intervention

The Pediatric Discharge G-tube Toolkit contains a standardized set of supplies and information and is given to the parent/caregiver prior to discharge. The container is a ready-made and easily accessible bag with all needed supplies for a G-tube change and care, whether it be emergent or planned (see Table 1).

Table 1

Contents of Pediatric Discharge G-tube Toolkit

Contents

New G-tube
Lubricating jelly
Drain sponges/dressing supplies
Barrier cream
Sterile water
Paper Tape (1 roll)
Q-tips
2 G-tube extension sets
Catheter tip syringe for venting
G-tube Quick Reference Guide

The student project leader was notified by NICU bedside nurses and discharge planners of patients with a newly-placed G-tube who were close to discharge. The student project leader provided each parent or caregiver with their personalized G-tube Toolkit and arranged two follow-up phone calls related their child's G-tube. The G-tube Quick Reference Guide was customized for each patient, including G-tube size, amount of water in the balloon, date of surgery, and name of surgeon who placed the G-tube. It also includes contact information for the G-tube Clinic Nurse/Surgery, the provider of supplies, and contains tips for dealing with common G-tube complications (e.g., leakage, redness, granulomas, dislodgement) (Appendix A). Parents/caregivers were instructed to always have the toolkit with their child, including such locations as school/daycare, community outings, long distance trips, doctors' appointments, and ED/clinic visits. This would ensure they had the necessary supplies to address complications, including replacing the G-tube.

Participants

The participants in this project were parents/caregivers of pediatric patients from 2-6 months old that were discharged with first-time newly placed G-tubes. Patients discharged to palliative care or a long-term care facility were excluded. All parents/caregivers were at least 18 years old, able to read, write, and understand the English language, and had access to a working phone.

Data Collection

Demographic data collected included patient age in months, patient gender, reason for G-tube placement, and caregiver relationship to patient (see Table 2).

Parent/Caregiver Data Collection

Parents/caregivers received a follow-up call at one week and four weeks post-discharge to assess home care, determine if they had experienced any G-tube complications, identify how those complication were handled, identify any advice sought (e.g., phone the G-tube nurse, surgeon, or clinic), and determine whether they had any ED or unscheduled clinic visits or hospitalizations related to their child's G-tube. During the four-week follow-up call, the Post-Discharge Coping Difficulty Scale (PDCDS) was administered.

EHR Data Collection

Data on four outcomes were collected from the EHR: (a) number of unplanned clinic visits related to G-tube complications; (b) number of ED visits related to G-tube complications; (c) number of hospital admissions for G-tube complications; and (d) number and type of G-tube complications (see Appendix B). Data collected on five patients prior to the intervention were compared to data from protocol patients. De-identified data were recorded on a computer with facial recognition login and stored on an encrypted USB drive.

Instrument

Parents'/Caregivers' Coping with G-tube Care

A modified version of the Post-Discharge Coping Difficulty Scale (PDCDS) (Weiss & Piacentine, 2006) was administered during the four-week follow-up call to determine how parents/caregivers were coping with caring for their child's new G-tube. Permission to use the PDCDS was obtained by the student project leader from its creator, Dr. Marianne Weiss. The 10-item measure assesses coping of parents/caregivers after their child's hospital discharge. Several scale items were slightly modified to fit parents/caregivers of children who had their first gastrostomy with G-tube insertion and had been discharged from the hospital. The original PDCDS items were developed by nurse clinicians, clinical specialists, and nurse managers at the study hospitals (Weiss & Piacentine, 2006). Some items were refined based on the experts' input. The content validity index for all items across all raters was .72 in that study. Each item is rated on an 11-point scale of 0 (*not at all*) to 10 (*a great deal or extremely*). Items 8, 9, and 10 are reverse scored, all items are summed to form a cumulative score ranging from 0-120. The higher the score, the more difficulty coping the parent/caregiver is experiencing. Cronbach's alpha was .84 in a sample of parents of children post-hospitalization (Lerret & Weiss, 2011) and .76 in a sample of parents of children who received a solid organ transplant (Weiss, Johnson, Malin, Jerofke, Lang, & Sherburne, 2008). Exploratory factor analysis yielded a unidimensional structure (Weiss & Piacentine, 2006). Predictive validity was supported by a positive association between PDCDS scores and post-discharge healthcare utilization in children (Weiss et al., 2008).

Results

Sample Description

There was a total of five parents/caregivers who received the G-tube Toolkit. Data were collected from the EHR of ten children-five before toolkit implementation and five after implementation. All patients were between 1 month and 6 months of age. The mean age of the project participants was 2.8 ± 2.2 months and the mean age of those in the pre-project group was 3.8 ± 1.5 months. Both the project group and the pre-project group had three boys and two girls. The reason for G-tube placement varied, but all participants fell of both groups fell into four categories: (a) Pierre Robin Sequence; (b) Short Bowel Syndrome; (c) aspiration; and (d) feeding difficulties. In the project group, there were two infants with Pierre Robin Sequence, one with Short Bowel Syndrome, one with aspiration, and one with feeding difficulties. In the pre-program group there was one infant with aspiration and four with feeding difficulties. All caregivers that participated in the project were mothers.

Table 2

Demographic Characteristics of Infants N=10

Characteristic	<u>Project n=5</u>	<u>Pre-Project n=5</u>
<u>Gender</u>		
Male	3	3
Female	2	2
<u>Diagnosis For G-tube</u>		
Pierre Robin	2	0
Short Bowel Syndrome	1	0
Aspiration	1	1
Feeding Difficulties	1	4
<u>Mean Patient Age at Discharge in Months</u>	2.8±2.2	3.8±1.5

During the first month following discharge, only one participant reported a complication which led to an ED visit. Within one month post-discharge in the prior to the project group, three participants had made an ED visit for a G-tube complication; two of those resulted in a hospital admission.

Table 3

Comparison of Infants' ED and Clinic Visits Related to G-tube Complications and Subsequent Hospital Readmissions (N=10)

Type	<u>Pre-G-tube Toolkit (n=5)</u>	<u>G-tube Toolkit (n=5)</u>
<u>ED/Complication</u>	3 Leaking/drainage Granulation Tissue Complication of G-tube	1/Dislodgement
<u>Clinic/Complication</u>	0	0
<u>Hospital Readmission</u>	2	0

Parent/Caregiver Report of G-tube Issues and Complications

A script was used for the one-week phone call (Appendix C). Only one of five parents reported a complication during the four weeks post-discharge. In this case, the G-tube had been accidentally pulled out. Parents followed their education/instruction and placed a new G-tube from the toolkit, taped it down, and went to their outlying ED for placement verification. This parent reported that the ED visit was quick and simple. No parents reported urgent complications during the follow-up calls that required referral to ED or emergently to the G-tube clinic. Themes reported during the assessment calls included: (a) Security and positivity having

the toolkit for their child; (b) Contents of toolkit were used and replaced as needed; (c) The Quick Reference Guide provided easy access to needed phone numbers; and (d) No changes for any toolkit contents were recommended.

Post-Discharge Coping Difficulty Scale

Each of the five infants' mothers answered the modified version of the PDCDS. Their total scores ranged from 16-39, with an overall mean score of 29 ± 7.9 out of a possible 120 (Figure 2). These lower scores indicate that these parents were coping well with their child's G-tube and impact it had on home life.

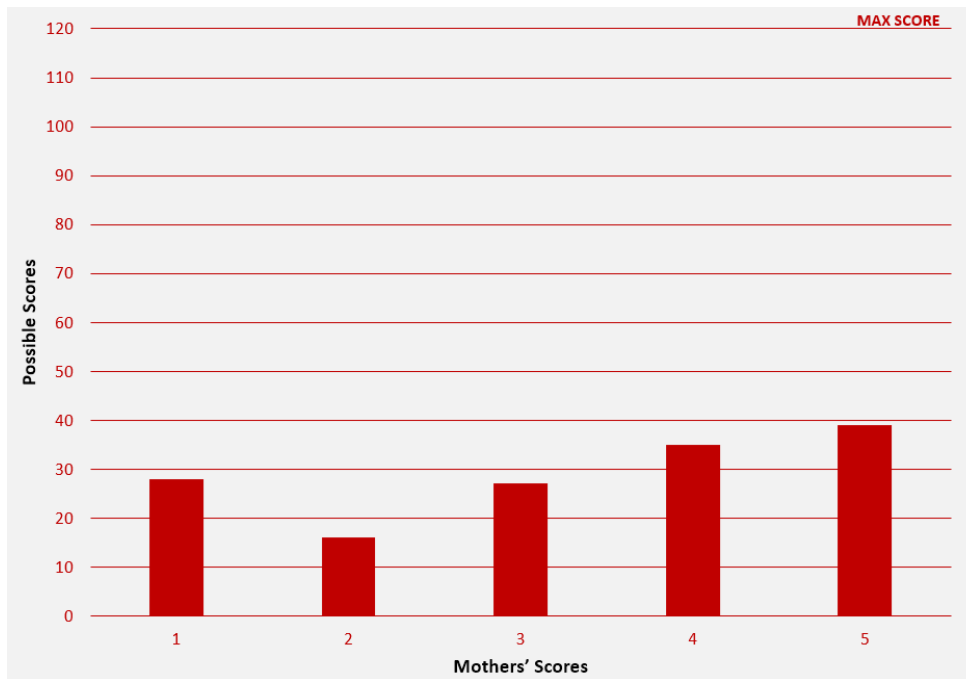


Figure 2. Mothers' Score on the PDCDS. This figure indicates the mothers' scores on the PDCDS out of the max score of 120.

Discussion

Interpretation

The project was positively received by parents/caregivers, bedside nurses, discharge planners, and unit managers. Parents appreciated having a readymade kit that they knew had all they needed to deal with any care or complications of their child's G-tube. The five mothers who received the G-tube Toolkit reported that it was helpful and had low coping difficulty scores one month after being discharged from the hospital. The pre-project group made more ED visits and had two hospital admissions, compared to the project group. The five patients in the pre-project group were selected from recent NICU discharges, but they were not matched to any characteristics of the project group; therefore, this data cannot be generalized. One family who received the toolkit provided important anecdotal data. When their child's G-tube dislodge shortly after discharge, they were able to replace the G-tube with the correct size tube in their toolkit. A trip the local ED was uncomplicated; the providers needed only to assess correct placement and inflate the tube balloon. Without the toolkit, neither the family or local ED would have had the correct G-tube; the child would have required a long distance and much more extensive ED visit.

Feasibility

The toolkit is easy to assemble, and cost is minimal at less than \$3.50 apiece. With the exception of the Quick Reference Guide, all of the kit contents are items that are easily found in the stock room or Pyxis and are already standard items provided to patients at discharge. Educating parents about the kit is made simple with G-tube Quick Reference Guide to follow. Discussing all the topics on the Quick Reference Guide reinforces what parents have learned

throughout their stay about their child's G-tube and can prompt any questions they may have about home care.

Sustainability

The Pediatric Discharge G-tube Toolkit was positively received by bedside nurses in the NICU. A member of the NICU Unit Based Council and the student project leader will present this to the Council to have it added into the NICU standards of care for G-tube education and discharge. If adopted and approved by the Council, the student project leader will provide education on the Pediatric Discharge G-tube Toolkit to three nurses who will be G-tube Discharge Champions. These champions will be responsible for teaching all NICU nurses how to assemble the kit and how to educate parents/caregivers using it as a guide.

Limitations

There are some limitations to this project. First, the sample size was small; therefore, strongly supported data-based conclusions are not able to be drawn. Secondly, PCDCS responses were self-reported. Thirdly, in EHR records review was subject to documentation variances. G-tube complications may not have been listed as a patients' chief complaints during ER presentation; therefore, some patients with recidivism may have been inadvertently excluded. Lastly, there was limited time for follow-up assessment to see if the Pediatric Discharge G-tube Toolkit would impact ED and clinic visits and/or hospital readmissions for multiple months post-discharge.

Conclusion

The student project leader assembled a Pediatric G-tube Toolkit for all participants and disseminated to parents/caregivers of children with newly placed G-tube shortly before their discharge. Education was provided on the use of toolkit and the information on the G-tube

Quick Reference Guide. Each of the participants were contacted one week and four weeks after discharge to assess any G-tube complications that may have occurred or whether they needed to contact or visit a medical provider (pediatrician, ED, G-tube Clinic). During the four-week follow-up call, the PDCDS was administered to determine how well the parents were coping with their child's care at home. All participants reported appreciation about having the additional education and found the Pediatric Discharge G-tube Toolkit to be helpful. The participants' scores on the PDCDS indicated that they were coping well with their child home. This G-tube Toolkit will be easy to sustain in the future due to its low cost, availability of contents in the unit Pyxis or stock room, and availability of the Quick Reference Guide. The next step is to present this project and its findings to the NICU Unit Based Council to discuss the merits of it being added to the standard discharge and teaching for parents/caregivers of infants with a G-tube. The student project leader will enlist the help of three G-tube Discharge Toolkit Champions and provide education on the use of the G-tube Toolkit. Between these Champions and the student project leader, all bedside nurse could learn how to properly assemble the kits and individualize the Quick Reference Guides. It would be beneficial to determine the success the toolkit has on decreasing the recidivism rate, by following more parents/caregivers for a longer period of time and would allow generalizability of the impact of the toolkit.

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Appendix A

G-Tube Quick Reference Guide

NAME: _____ **DATE G-TUBE PLACED:** _____

SURGEON: _____ **SIZE/TYPE:** _____

PHONE #: _____ **AMT OF WATER IN BALLOON:** _____

G-Tube Clinic Nurse Practitioner: Barbara Combs, PNP (502)629-8596 or email her with questions and/or pictures at barbara.combs@nortonhealthcare.org

My G-tube Supply Company is: _____

Phone Number: _____

- If you change your child's G-tube, call your supply company for a replacement G-tube the same day or if at night call first thing in the morning.

Contents of the G-tube Toolkit



Call the Doctor When:

- The G-tube site (stoma) is reddened, skin is broken down, or there is bleeding at the site.
- Your child is not tolerating feedings.
- The G-tube came out and you are unable to replace it.
- Your child's belly looks bloated and larger than normal even after you have unclamped the tube and left it open for one hour.
- Your child is vomiting and unable to tolerate more than two feedings.
- The G-tube is clogged and you have not been able to unclog it.
- Formula is leaking from or around the G-tube.
- There is a bad odor coming from the G-tube site
- The G-tube site has any swelling.
- The site has yellow or green drainage.

Keep the G-tube Toolkit with your child at all times.

Take it to school/daycare, doctor's appointments, community outings, when traveling, and to G-tube Clinic or Emergency Room visits.

Daily Care:

- Clean site twice a day with mild soap and water.
- Pat dry with clean, dry towel.
- Check skin under and around the G-tube every time for any signs of redness or irritation.
- Your child can take a bath or shower after the site has healed (usually 3-5 days) or when directed by your doctor.

Common Skin Issues Around the G-tube

- **Redness:** This can happen when your child gets sick. It may be caused by the illness itself and usually disappears when they get well. You can apply Aquaphor or bacitracin ointment two times a day to the reddened area. These can be bought at most drug stores.
- **Rash:** A rash can be caused by drainage if the G-tube does not fit well. A rash might also appear after an illness that was treated with antibiotics. If the rash does not get better within 2 weeks, call your child's pediatrician. This may be a yeast rash which can be treated with oral antifungal medicine or cream per your pediatrician's recommendations.
- **Skin Breakdown:** Usually this happens when the G-tube does not fit well or there is a problem with the balloon. Check the amount of water in the balloon first to stop any leaking. If the balloon has no water, remove the G-tube and replace it with a new one. To treat the skin breakdown, you need to apply a cream that will create a barrier and protect the skin, allowing it heal. You can use diaper creams such as Barrier Paste, Magic Butt Cream, A&D ointment, Desitin or Calmosseptine. If this does not help after using it for two weeks, call your child's pediatrician to evaluate the skin and tube.



- **Granulation Tissue (Granulomas):** This is extra tissue that may appear around the G-tube site. It is the body's way of trying to heal the G-tube site. The tissue is usually red or pink, moist, and may have some drainage or slight bleeding. This is most common when the tissue is irritated. If this appears, keeping it clean and placing a drain sponge around it will help. If this tissue becomes bothersome it can be treated by your child's doctor using steroid cream at home or silver nitrate sticks in the office.

Common Issues and What to Do

Leaking: Leaking may occur for a few reasons and can usually be fixed easily.

1. First, check the water level in the balloon. It should have the same amount of water that is listed on the front of this guide, usually 3-5 ml. If not, add enough water to equal that amount. Wait 1-2 two hours and check the balloon again. If it less than the correct amount, the balloon is leaking and you need to replace the G-tube. Follow what you were taught or refer to the home care booklet (pg 15).
2. **Illness** can be another cause of leaking. When your child is ill, sometimes the stomach does not empty as well or as quickly which can cause leaking. Try slowing down the feedings or feed smaller amounts more frequently throughout the day. If this does not help, call your pediatrician for help.
3. **Coughing spells** from a respiratory illness cause increase leaking around the G-tube. This is normal and will continue until they are well. Use a drain sponge to absorb the drainage and keep the skin from getting irritated.
4. **Improper fit** from your child growing can cause the tube to not fit properly. If you think this could be the cause of the leakage, call your Surgeon's office to make a G-tube Clinic appointment to get a different size.

Clogged Tube: Best way to prevent clogs is to flush after feedings and medicines as instructed. If the tube becomes clogged follow these steps.

1. Attach the syringe and pour warm water (not hot) into the tube. Let this sit for a few minutes.
2. Try to pull back to see if it has unclogged. If not go onto step 3.
3. Try using room temperature Diet Coke as you did with water in step 1 & 2. **DO NOT** use regular coke, it has so much sugar, it will clog the tube further.
4. If steps 1-3 did not work, you will need to change the tube.

G-tube Comes Out: Remain calm, remember what you have been taught and refer to your home care booklet (pg.15). Replace tube immediately and insert appropriate amount of water in the balloon. If you do not know how to replace tube, it has been less than four weeks since your child got the G-tube, or you can not get it to go back in, go immediately to the nearest hospital emergency room. Before you use the new tube make sure that stomach contents (formula or spit) are able to come out. If you think the tube is in the wrong place call your Surgeon before use.

Appendix B

EHR Data Collection Form

Pre-intervention

ID #	Unplanned clinic visits related to G-tube complications (Provide dates, number of visits, and types of G-tube complications)	ED visits related to G-tube complications (Provide dates, number of ED visits, and types of G-tube complications)	Hospital admissions for G-tube complications (Provide dates, number of hospital admissions, and types of G-tube complications)	Total number of unplanned clinic/ED visits, and/or hospitalizations for G-tube complications
1				
2				
3				
4				
5				

Post-intervention

ID #	Unplanned clinic visits for G-tube complications (Provide dates, number, and types of G-tube complications)	ER visits related to G-tube complications (Provide dates, number, and types of G-tube complications)	Hospital admissions for G-tube complications (Provide dates, number, and types of G-tube complications)	Total number of unplanned clinic/ED visits, and/or hospitalizations for G-tube complications
1				
2				
3				
4				
5				

Appendix C

G-tube Follow-up Phone Call Assessment

1. Has your child had any G-tube complications since discharge? Yes_____ No_____

If Yes: What were the complications and how did you deal with them?

2. Have you needed to contact a healthcare provider about your child’s G-tube complications?

Yes_____ No_____

If Yes: Who did you contact? _____

How many times did you contact _____? _____ (number of times)

3. Has your child had any ER visits because of G-tube complications? Yes_____ No_____

If Yes: How many times did you take your child to the ER for G-tube complications?

_____ (number of times)

If Yes: What were the complications?

4. Has your child had any unscheduled clinic visits because of G-tube complications?

Yes_____ No_____

If Yes: How many times did you take your child to the clinic for G-tube complications?

_____ (number of times)

5. Have you had any difficulties with your child’s G-tube at home?

Yes_____ No_____

If Yes: What difficulties have you had?

6. Have you used the G-tube toolkit since being home? Yes_____ No_____

If Yes: Was the toolkit helpful? Yes_____ No_____

Why or why not? _____

7. Is there anything you would add or take out of the G-tube Toolkit? Yes____ No____

If Yes: What would you add or take out of the G-tube Toolkit? _____

(For Student Project Leader to Answer)

8. During the phone assessment were any urgent complications identified that required intervention and were parents advised to take the child to the ED or G-tube Clinic, as appropriate?

Yes____ No____