EVALUATION OF A COMPREHENSIVE DISCHARGE PLANNING PROGRAM FOR YOUNG CHILDREN WITH NEWLY PLACE TRACHEOSTOMY TUBES

By

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A Master's Paper submitted to the faculty of
the University of North Carolina at Chapel Hill
In partial fulfillment of the requirements for
the degree of Master of Public Health in
the Public Health Leadership Program.

Chapel Hill

Spring 2010

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31 Mar 2010
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Abstract

Infants and children with newly placed tracheostomies present unique challenges for healthcare providers coordinating hospital discharge. Parental education and discharge planning needs can be complex; disease, parental, societal and healthcare related factors can create barriers prolonging hospitalization beyond medical readiness for discharge. I conducted a retrospective chart review to examine the effectiveness of the discharge process, including staff and family education, for 69 children less than 3 years of age who underwent tracheotomy at North Carolina Children's Hospital over a 4 year period. Children enrolled in the study had an overall mean length of hospital stay following tracheotomy of 44 days. The median length of stay (LOS) was 28 days with a minimum stay of 4 days and a maximum stay of 203 days. The LOS was ≤ 44 days for 49 (71.0%) of the children. Barriers to timely discharge were present for all of the 20 (29.0%) of children with LOS > 44 days. This study demonstrates that a highly structured, multidisciplinary approach to tracheostomy education and discharge planning may reduce LOS following tracheotomy. More importantly, this paper shows that early identification of factors prolonging length of stay, adaptation to changing parental needs for education and support, and the establishment of trusting relationships between healthcare providers and families may reduce the impact of some barriers that prevent timely hospital discharge for children undergoing tracheostomy placement.

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Abbreviations

ATS – American Thoracic Society

C5 – Center for Children with Complex and Chronic Conditions

EMR – Electronic Medical Record

HCUP – Healthcare Cost and Utilization Project

LOS – Length of Stay

LTC – Long Term Care

NCCC – Newborn Critical Care Center

NCCAC – North Carolina Children's Airway Center

NCCH – North Carolina Children's Hospital

OHNS – Otolaryngology and Head and Neck Surgeons

PICU – Pediatric Intensive Care Unit

UNCH – University of North Carolina Hospitals

Introduction

This paper examines the hospital discharge planning process for children undergoing tracheostomy placement at the North Carolina Children's Hospital (NCCH). Discharge planning for children with tracheostomies at NCCH occurs within a framework of a structured education program incorporating a dedicated pediatric nurse practitioner specializing in the care of children with tracheostomies and a multidisciplinary children's airway center program. The main components of the discharge planning process are 1) staff, patient and family education, 2) establishment of an appropriate discharge location, 3) establishment of community supports. I will describe the structure of the NCCH tracheostomy discharge planning process including a description of the roles of the nurse practitioner and the North Carolina Children's Airway Center (NCCAC) multidisciplinary team. In addition, I will evaluate the overall discharge panning process for children undergoing tracheostomy placement at NCCH. My goals are to:

(1) Evaluate the effectiveness of the discharge process by measuring the duration of children's hospital stay at NCCH in days following tracheostomy placement and comparing length of stay (LOS) to data reported by other hospitals

(2) Examine factors affecting LOS following tracheostomy placement and identify potential barriers to timely hospital discharge

(3) Suggest opportunities for improvement in the NCCH discharge planning process for children with newly placed tracheostomies

A *tracheotomy* is an incision into the trachea (windpipe) that forms a temporary or permanent opening which is called a *tracheostomy.* A tube is inserted through the stoma (opening) to allow passage of air and removal of secretions. Instead of breathing through the nose and mouth, the child will now breathe through the tracheostomy tube. *Decannulation* refers to the procedure for permanent removal of the tracheostomy tube. Decannulation does not require a surgical procedure; when the tracheostomy tube is removed from the trachea the stoma closes spontaneously within a few days (Aaron's Tracheostomy Page, 2002).

Children with newly placed tracheostomies present unique challenges for healthcare providers attempting to facilitate transition from hospital to an appropriate discharge location. In the past, when tracheostomies in children were more likely to be placed for infectious etiologies, tracheostomy duration was short and children generally remained hospitalized until decannulation (Arcand & Granger, 1998; Lewis, Carron, Perkins, Sie & Feudtner, 2003; Whetmore, Marsh, Thompson & Tom, 1999). Multiple studies have demonstrated changing indications for tracheostomy in young children over the past 30 years primarily as a result of the decrease in infectious etiologies of airway compromise requiring tracheostomy. Many children now successfully leave the hospital to be cared for in the parental home with a tracheostomy (Amin & Fitton, 2003; Arcand & Granger, 1998; Carron, Derkay, Strope, Nosonchuk & Darrow 2000; Carr, Poje, Kingston, Kielma & Heard, 2001; Donnelly, Lacey & Maguire, 1996; Graf, Montagnino, Huekel & McPherson, 2008(1); Lewis et al., 2003; Whetmore et al., 1999). Infants and children with congenital abnormalities and those requiring long term ventilation currently make up the majority of young patients requiring tracheostomy placement. Infants and young children who undergo tracheostomy have a higher incidence of congenital anomalies, prematurity or pulmonary disorders than older children, who are more likely to require tracheostomy placement as a result of injury or neurologic disorders (Amin & Fitton, 2003; Lewis et al., 2003). The US Department of Health and Human Services 2006 Healthcare Cost and Utilization Project report estimated that 55% of children discharged from hospitals in the United States with tracheostomy listed as the primary procedure performed were between the ages of zero and four years (Healthcare Cost and Utilization Project [HCUP], 2006). Older children who undergo tracheostomy following injury or in conjunction with a neurologic disorder may have different patterns of hospitalization, length of stay and discharge disposition than infants and young children undergoing tracheostomy for congenital or pulmonary indications (HCUP, 2006; Lewis et al., 2003).

Infants and young children with tracheostomies represent a subgroup of medically fragile, technology dependent individuals who tend to suffer disproportionately long hospital stays, incur high hospital costs and consume extensive community resources and medical care services following hospital discharge. (Buescher et al., 2006; Cross, Leonard, Skay & Rheinberger, 1998; Duncan, Howell, de Lorimer, Scott Adzik, & Harrison, 1992; Lewis et al., 2003; Wang & Barnard, 2004**)**. As the indications for tracheostomy in children have changed over time, so have the challenges of: providing discharge education for patients, families and hospital staff; establishing an appropriate discharge location and integrating children into their local communities.

The initial step in the discharge preparation process is to help families understand and accept the unique needs of their child with a newly placed tracheostomy. Equally important is providing assistance to the family making the difficult decisions associated with determining the most appropriate discharge location. Options for discharge location may include the parental or a foster home, a long term care (LTC) facility, a rehabilitation facility, or a local hospital close to the parental home. When the family chooses discharge home, parents require information and education to achieve proficiency in the skills necessary to provide care and create a safe and stable home environment. Integrating acceptance, assistance with decision making and education into a comprehensive program can help most families achieve their goal of welcoming and successfully caring for their child with a newly placed tracheostomy in the parental home. For other families, the goal of locating a safe and comfortable environment other than the parental home where they feel secure knowing their child will receive appropriate care can also be achieved through a comprehensive tracheostomy discharge program.

Methods

This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board, study number 09-1443. It is a retrospective chart review of children who received a tracheostomy at the University of North Carolina Hospitals (UNCH) between September 1, 2005 and September 1, 2009. Children whose hospital records were selected for review were identified through the NCCH pediatric bronchoscopy and NCCAC databases as having undergone tracheostomy placement at UNCH during the four year period under review. Children over three years of age at the time of tracheostomy placement were excluded to decrease variability in the primary indication for tracheostomy. Data collected from review of hospital electronic medical records (EMR) was used to determine the children's demographic information, age at tracheostomy placement, LOS in days following tracheotomy, discharge disposition, and reasons for delay of discharge. Description of the family education and discharge processes were obtained through interviews conducted in December 2009 and January 2010 with the tracheostomy nurse practitioner and airway center program social worker. Hospital LOS following tracheostomy placement was determined by review of EMR admission notes, daily progress notes and discharge summaries. Mean and median length of hospital stay in days were calculated for the study population. The decision was made prior to data analysis to more closely examine cases with LOS greater than the mean for the study population. Children whose hospitalization following tracheostomy placement was longer than the overall mean LOS for the study population underwent further review of EMR to identify commonalities and factors associated with prolonged LOS. To identify potential barriers to discharge, I conducted an extensive review of EMR narrative entries including daily physician progress notes, NCCAC weekly discussion notes, and daily care management reports produced by the assigned case manager or social worker. Entries documenting anticipated discharge dates, parental visits and missed appointments, economic assistance provided to families, changes in patient health status, contact with funding and community resource agencies, home nursing companies, and medical equipment suppliers were scrutinized for their impact on the discharge process. Potential barriers to discharge were independently characterized by me and the tracheostomy nurse practitioner (who maintained frequent contact with the subjects during hospitalization and was knowledgeable of each subject's hospital course). We then compared our efforts and discrepancies identifying or characterizing barriers to discharge were discussed and resolved. Barriers to discharge were characterized using the four broad categories of contributing factors to extended hospital stay for technology dependent children described by Cross et al. (1998). The categories and contributing factors utilized in this study of barriers to discharge are described as follows:

(1) Societal

- Private and/or public funding approval process
- Available placement options in the community

(2) Health care

- Ability of the health care team to coordinate complex discharge needs
- Availability of adequate home nursing care

(3) Parental

- Level of commitment for caring for the child
- Involvement in learning necessary skills
- Ability to provide care and master necessary technology
- Family psychosocial and economic considerations

(4) Presence of disease

- Change in the child's medical condition
- Need for additional treatment or intervention

Discharge education

A highly structured process guides tracheostomy education for families and staff at NCCH (Drake & Henry, 2002; Shiley, 2005). A pediatric nurse practitioner specializing in the care of children with tracheostomies is included in the initial family discussions and decision making concerning tracheostomy placement. Although discharge disposition and identified home caregivers may change during the child's hospitalization, initial teaching and discharge planning are begun as soon as the decision is made to proceed with tracheostomy and the family expresses interest in taking the child home at discharge. At least two family members or home caregivers are expected to undergo extensive tracheostomy training and demonstrate competency in caring for the child prior to discharge to the parental home. The nurse practitioner serves as an expert resource for staff and for families until the time the child is successfully decannulated. Nurse practitioner responsibilities include training multidisciplinary teams of staff nurses, respiratory therapists and medical staff in tracheostomy care and education techniques to ensure that families receive consistent, thorough training and education at the bedside. Ongoing, consistent training is a hallmark of the education process. One informal staff education technique utilized by the nurse practitioner, and enthusiastically embraced by hospital staff, is a weeklong “trach or treat” exercise held annually in October. The nurse practitioner, wearing a witch hat and carrying a Halloween bag full of candy, visits each of the pediatric areas in the hospital and offers treats to staff in exchange for correct answers to tracheostomy care related questions (Appendix A). The Newborn Critical Care Center (NCCC) and the NCCH nursing service have each formed tracheostomy education committees to provide assistance to the nursing staff with developing tracheostomy teaching competencies, maintaining tracheostomy care skills and monitoring staff teaching performance. The nurse practitioner is an active member of these committees.

The discharge education process incorporates written and audiovisual caregiver educational materials as well as life size, customized infant dolls with tracheotomy stomas that will accommodate standard size tracheostomy tubes for hands on simulation and role playing exercises. The dolls, wearing clothes made by hospital volunteers, are given to the child at discharge and in addition to being a valuable teaching tool, frequently become the child’s cherished toy. Teaching checklists are utilized to ensure that all components of the family training process including: cardiopulmonary resuscitation; tracheostomy suctioning; tracheostomy tube change; and cleaning tracheostomy equipment have been completed prior to discharge. The training process continues throughout the child’s hospital stay with timelines modified to meet the needs of the child and designated caregivers. Interpreter services are available day and night to accommodate the needs of non-English speaking families. When questioned about the expected duration of family training, the nurse practitioner explained:

> The inpatient teaching continues until the moment the child leaves the hospital. A teaching checklist will indicate that parents have demonstrated competence in the required tasks such as suctioning and tracheostomy tube changes, but it does not really show how comfortable the family is. I may stop by a room to visit with a family as the discharge date is nearing and the checklist has been completed. I test the family skills and level of comfort by removing the child’s

> tracheostomy tube in a controlled setting and handing it to them. I want to see how comfortable they are responding to a sudden scary situation that may happen at home (C. Reilly personal communication January, 15, 2010).

In addition to simulations of real life experiences, families planning to take their child home are encouraged to room–in with their child and become familiar with home care equipment prior to discharge. Representatives of the medical equipment company and home nursing agency selected by the family frequently meet with the family in the hospital prior to the child's discharge to facilitate a smooth transition from hospital to parental home. In order to further facilitate the transition process, infants transitioning from the NCCC to home may initially be accompanied home or to the first community pediatrician visit by a staff nurse who cared for the child during hospitalization.

North Carolina Children's Airway Center

In response to increasing challenges of meeting the needs of children with a variety of airway disorders, and the recognition that effective communication among providers is key to coordinating complex patient care, NCCH created The North Carolina Children's Airway Center (NCCAC) in 2007, with the funding support of a Duke Endowment grant. Through the NCCAC, a multidisciplinary team was developed to coordinate and improve care for children with a variety of complex airway disorders including those with tracheostomies. The team includes pediatric pulmonologists, pediatric otolaryngology and head and neck surgeons (OHNS), nurses, a speech therapist, social worker and respiratory therapist coordinating care and securing community services for enrolled children and their families. Children enrolled in the NCCAC and included in the database are those treated at NCCH as inpatients or through the outpatient clinics and diagnosed with a complex airway or breathing problem that is managed by more than one of the NCCAC specialty care providers. At weekly conferences, the team discusses patient care concerns, formulates treatment strategies, and reviews discharge plans. The NCCAC approach to discharge planning includes early identification of potential barriers to successful discharge. As part of the process, the NCCAC social worker performs thorough family assessments to identify strengths and weaknesses that may impact LOS or create barriers to timely discharge. The inclusion of the social worker on the team also ensures that insurance coverage, financial resources and reimbursement sources are optimized to meet care needs. The nurse practitioner and social worker collaborate with hospital staff and family members to explore discharge options, engage home nursing care and community services, and to secure home medical equipment and supplies.

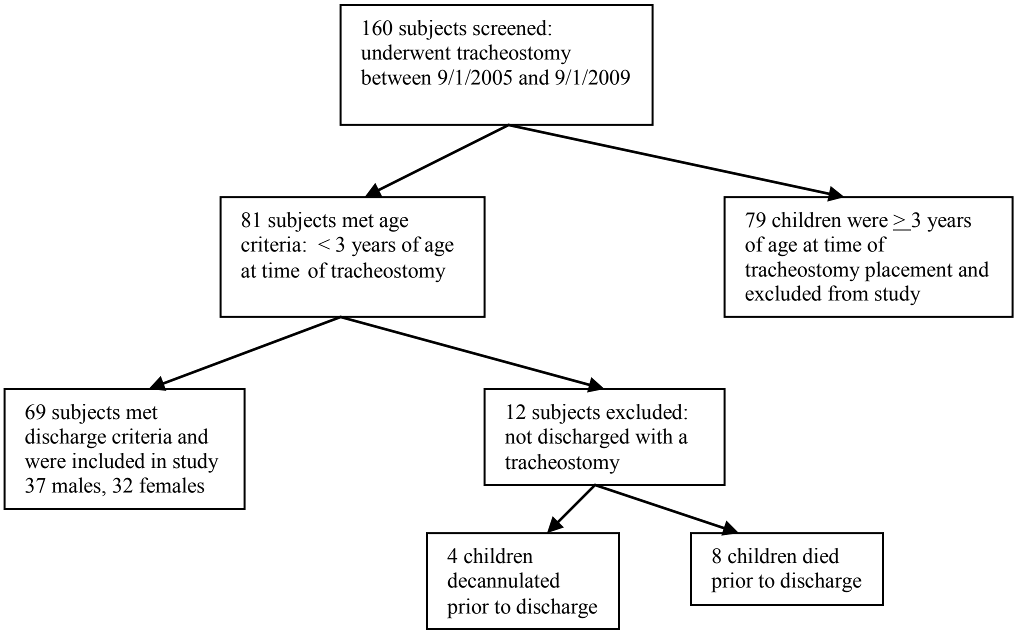
Results

UNCH is a 757 bed public, academic medical center serving all 100 counties of North Carolina and the southeast region of the United States. Located within the medical center, NCCH is a 140 bed facility including three floors of pediatric inpatient beds, a 48 bed NCCC and a twenty bed Pediatric Intensive Care Unit (PICU). Following tracheostomy surgery, all children are initially admitted to the PICU or NCCC and remain there at least until the first tracheostomy tube change, occurring five to seven days after surgery. Following the initial tracheostomy change, performed by a pediatric OHNS, the child may be considered for transfer to one of the inpatient floors.

Of the 160 children who received tracheostomies at NCCH between September 1, 2005 and September 1, 2009, 81 children were less than three years of age at the time of tracheostomy placement and were therefore eligible for inclusion in the retrospective chart review. Excluded from this group were twelve children who were not discharged after tracheostomy placement: four were decannulated prior to leaving the hospital and eight children died prior to discharge.

The remaining 69 children eligible for inclusion in the study consisted of 37 (53.7%) males and 32 (46.3%) females. The mean age at tracheostomy placement was six months and the median was three months with a range of two weeks to 27 months. One set of twins, both undergoing tracheotomy, were included in the study and the 68 families of children with tracheostomies resided in 27 of the 100 counties in North Carolina at the time of the child's initial hospital admission. The three counties surrounding NCCH: Orange, Durham and Wake were most frequently represented as home to 22 (31.9%) of the families (Appendix B).

Figure 1. Children Enrolled in Tracheostomy Discharge Study and Reasons for Exclusion



Of the 69 children included in the study, sixteen (23.2%) were discharged on mechanical ventilation. This subset will be described in further detail later. Children in the study had an overall mean length of hospital stay following tracheostomy placement of 44 days (Table 1). The median LOS was 28 days with a minimum stay of four days and a maximum stay of 203 days. The LOS was ≤ 44 days for 49 (71.0%) of the children. The subset of twenty (29.0%) children with LOS > 44 days will be described in further detail in a subsequent section. Children were discharged from three units within the hospital: twenty (29.0%) were discharged from the NCCC, seventeen (24.6%) were discharged from the PICU and 32 (46.4%) were discharged from an inpatient pediatric floor (Appendix B).

The subset of twenty infants discharged from NCCC had a mean length of stay of 70 days with a median stay of 55 days and a range of six to 203 days. Overall, infants discharged from NCCC remained hospitalized two times longer than children discharged from PICU or an inpatient floor. The seventeen infants and children discharged from the PICU had a mean length of stay of 35 days with a median of nineteen days and range of four to 145 days. The mean length of stay for the 32 children discharged from an inpatient floor was 33 days with a median of 26 days and range of nine to 192 days (Table 1).

Table 1. Number and Percent of Patients Discharged, and Characteristics of LOS by Discharging Unit

Discharge Unit	# Discharged	% Discharged	Length of Stay in Days following Tracheotomy		
			Mean	Median	Range
NCCC	20	29.0%	70	55	6 - 203
PICU	17	24.6%	35	19	4 - 145
Inpatient Floor	32	46.4%	33	26	9 - 192
Total	69	100%	44	28	4 - 203

Children in this study were discharged to a parental home, long term care facility, local hospital closer to home, or a rehabilitation facility. Table 2 lists the discharge disposition, number of patients discharged and mean length of hospital stay for patients discharged from each unit identified in the study population.

Table 2. Number, Percentage and Mean Length of Hospital Stay in Days by Discharging Unit and Discharge Disposition for All Children

Discharge Unit	Parental Home		LTC Facility		Local Hospital		Rehab Facility		Total	
	# (%)*	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS
NCCC	9 (13.0%)	70	4 (5.8%)	145	7 (10.1%)	28	0 (0%)	0	20 (28.9%)	70
PICU	4 (5.8%)	78	1 (1.4%)	n=1 LOS 74	10 (14.5%)	18	2 (2.9%)	12	17 (24.6%)	35
Inpatient Floor	28 (40.6%)	34	2 (2.9%)	37	2 (2.9%)	11	0 (0%)	0	32 (46.4%)	33
Total	41 (59.4%)	47	7 (10.1%)	104	19 (27.5%)	21	2 (2.9%)	12	69 (100%)	44

*** % reflects the total for all children**

For the purposes of this paper, prolonged LOS is defined as hospital discharge > 44 days following tracheostomy placement, representing a LOS of longer duration than the mean of the study population. Hospital records of the twenty children with prolonged LOS were selected for further review to identify and characterize potential barriers to discharge. These twenty children with a LOS > 44 days represent 29.0% of the total study population. As shown in Table 3, the mean LOS for this group was 96 days with a median of 80 days and a range of 47 - 203 days. Infants discharged from NCCC accounted for twelve of the twenty (60.0%) children with a LOS > 44 days. Of the twelve infants discharged from NCCC after a prolonged hospital stay, seven went to the parental home, four were discharged to a long term care facility and one was transferred to a hospital closer to the family's home. Of the four children discharged from the PICU after a prolonged LOS, two went home, one went to a long term care facility and one to a local hospital. Of the four children discharged from an inpatient floor after a prolonged stay, three went home and one went to a long term care facility (Table 3).

Table 3. Number, Percent and Average Length of Hospital Stay in Days by Discharging Unit and Discharge Disposition for Children with LOS > 44 days

Discharge Unit	Parental Home		LTC Facility		Local Hospital		Total		
	# (%)*	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS	Median LOS Range
NCCC	7 (35.0%)	80	4 (20.0%)	145	1 (5.0%)	n=1 LOS 76	12 (60.0%)	101	102 47- 203
PICU	2 (10.0%)	115	1 (5.0%)	n=1 LOS 74	1 (5.0%)	n=1 LOS 51	4 (20.0%)	89	79 51 - 145
Inpatient Floor	3 (15.0%)	98	1 (5.0%)	n=1 LOS 62	0 (0%)	0	4 (20.0%)	89	58 48 - 192
Total	12 (60.0%	90	6 (30.0%)	119	2 (10.0%)	63	20 (100%)	96	80 47 - 203

*** % reflects the total for subset of 20 children with LOS > 44 days**

Of the sixteen children who were discharged from the hospital on mechanical ventilation, nine were discharged to the parental home, five were transferred to a local hospital and two were discharged to a long term care facility. The mean LOS for the subgroup of children discharged on mechanical ventilation was 74 days with a median of 76 days and a range of six - 145 days (Table 4).

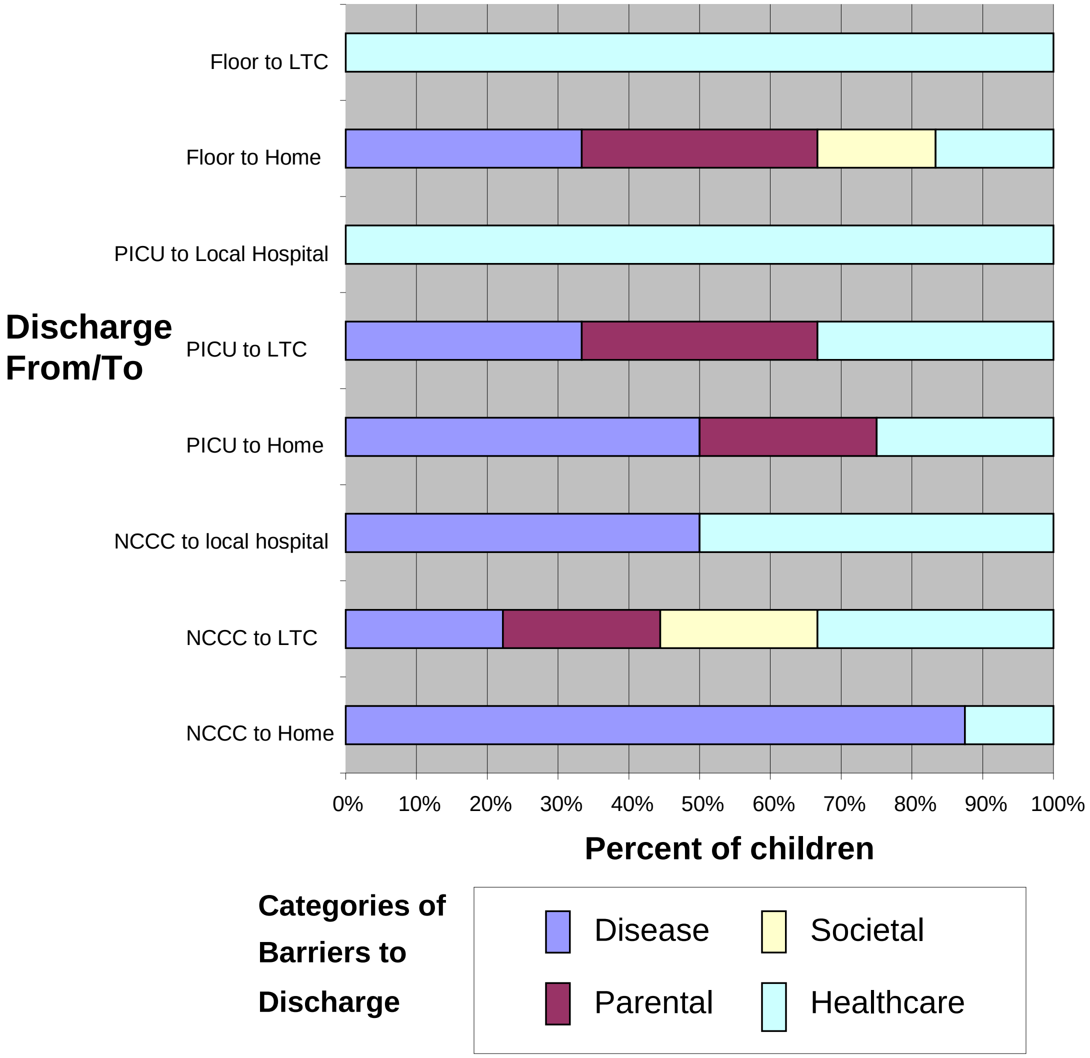
Table 4. Number, Percent and Average Length of Hospital Stay in Days by Discharging Unit and Discharge Disposition for Children Discharged on Mechanical Ventilation

Discharge Unit	Parental Home		LTC Facility		Local Hospital		Total		
	# (%)*	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS	# (%)	Mean LOS	Median LOS Range
NCCC	5 (31.2%)	91	1 (6.2%)	n=1 LOS 128	2 (12.6%)	53	8 (50.0%)	86	87 31-128
PICU	4 (25.0%)	79	1 (6.2%)	n=1 LOS 74	3 (18.7%)	36	8 (50.0%)	62	59 6-145
Total	9 (56.3%)	85	2 (12.4%)	101	5 (31.2%)	43	16 (100%)	74	76 6-145

*** % reflects the total for subset of 16 children discharged on mechanical ventilation**

Each of the four barriers to discharge described by Cross: societal, health care, parental and presence of disease were represented, individually or in combination, by the twenty children with a LOS > 44 days following tracheostomy and are displayed in Figure 2 (Cross et al., 1998).

Figure 2. Barriers to Discharge by Unit Discharged from and Discharge Location for Children with LOS > 44 days Following Tracheotomy



Of the twenty children identified as having prolonged LOS, eight (40.0%) had presence of disease as the single associated barrier to discharge. The mean LOS for this group of eight children was 78 days with a median of 70 days and a range of 47 – 203 days. Of the eight children whose only barrier to discharge was presence of disease, six (75.0%) were discharged from the NCCC to the parental home while one was discharged from the NCCC to a long term care facility and one child was discharged from an inpatient floor to the parental home (Table 5).

Table 5. Number, Percent and LOS Characteristics for Children with Presence of Disease as the Single Barrier to Discharge and LOS > 44 Days Following Tracheotomy

Discharge From/To	Number Discharged	Percent Discharged	LOS Following Tracheotomy		
			Mean	Median	Range
NCCC to Home	6	75.0%	76	70	47 -110
NCCC to LTC	1	12.5%	n=1 LOS 203	N/A	N/A
Floor to Home	1	12.5%	n=1 LOS 48	N/A	N/A
Total	8	100%	78	70	47 - 203

The remaining twelve (60.0%) of children experienced barriers other than, or in addition to, presence of disease as contributing factors to LOS > 44 days. The mean LOS for this group of twelve children was 101 days with a median of 91 and a range of 51 – 192 days. Of these twelve children, five were discharged from NCCC, with one infant discharged from NCCC to the parental home, one discharged from NCCC to a local hospital, and three infants discharged from NCCC to long term care facilities. In addition, four were discharged from PICU with two children discharged from PICU to the parental home, one discharged from PICU to a long term care facility and one discharged to a local hospital. Of the three children discharged from an inpatient pediatric floor, two were discharged to the parental home and one was discharged to a long term care facility (Table 6).

Table 6. Number, Percent and LOS Characteristics by Discharge Unit and Discharge Location for Children with Barriers Other Than, or in Addition to, Presence of Disease and Prolonged LOS > 44 Days Following Tracheotomy

Discharge Unit	**Parental Home**		**LTC Facility**		**Local Hospital**		**Total**		
	# (%)*	**Mean LOS**	**# (%)**	**Mean LOS**	**# (%)**	**Mean LOS**	**# (%)**	**Mean LOS**	**Median Range**
NCCC	1 (8.3%)	n=1 LOS 97	3 (25.0%)	150	1 (8.3%)	n=1 LOS 76	5 41.7%)	110	107 76 - 141
PICU	2 (16.7%)	115	1 (8.3%)	n=1 LOS 74	1 (8.3%)	n=1 LOS 51	4 (33.3%)	89	79 51 - 145
Floor	2 (16.7%)	123	1 (8.3%)	n=1 LOS 62	0 (0%)	0	3 (25.0%)	103	62 54 - 192
Total	5 (41.7%)	115	5 (41.7%)	117	2 (16.7%)	63	12 (100%)	101	91 51 -192

***% reflects the total for subset of 12 children with barriers other than or in addition to disease and LOS > 44 days**

Appendix C describes in detail the parental, societal and healthcare related factors described in the EMR contributing to delays in discharge for the twelve children who experienced a prolonged hospital stay > 44 days for reasons other than or in addition to presence of disease.

Discussion

Length of stay

The 44 day mean LOS for children at NCCH compares favorably to other studies reporting findings on overall time to discharge for children with new tracheostomies. Recent reviews report overall mean LOS for children following tracheostomy of 42 to 66 days with infants' mean LOS reports as high as 86 days following tracheostomy (Carr et al., 2001; Duncan et al., 1992; Graf et al., 2008(1); HCUP, 2006; Lewis et al., 2003). Results of this study indicated that (1) a highly structured tracheostomy discharge education program incorporating a dedicated nurse practitioner specializing in the care of children with tracheostomies, (2) a focus on staff and family education, (3) and utilization of a multidisciplinary children's airway center team approach may contribute to decreased LOS for many children preparing for discharge following tracheostomy placement. Others have reported a structured, comprehensive family and home caregiver education program may play a role in decreasing mortality among children with tracheostomies, decreasing hospital readmission rates and allowing more technology dependent children to be discharged home rather than remain hospitalized or be discharged to long term care facilities (Carr et al., 2001; Duncan et al., 1992; Fiske, 2004; Graf et al., 2008(1); Graf, Montagnino, Huekel & McPherson, 2008(2); Lewis et al., 2003).

The American Thoracic Society (ATS) consensus guidelines for the care of the child with a tracheostomy include a thorough description of the necessary components of a comprehensive tracheostomy training program for caregivers (American Thoracic Society [ATS], 2000). ATS guidelines provide the basis for development of a structured education program that includes mastery of technical as well as decision making skills. Prior to discharge, education can be incorporated into the daily care routines as well as provided through formal training sessions. Opportunities for parents to observe, receive instruction, and demonstrate competence in suctioning, tracheostomy tie and tube changes occur whenever the parents are present at their child's bedside. Evenings, nights and weekends may present optimal educational opportunities, and trained staff should be available to educate families who may be unable to spend weekday time at the hospital due to work or child care obligations. In a hospital setting where children may be discharged from different units and caregiver education may be provided by physicians, physician assistants, nurse practitioners, nurses and respiratory therapists, all staff should provide consistent educational messages to families and take full advantage of "teaching moments." A dedicated advanced practice nurse responsible for overseeing staff and family education and serving as an expert resource for families during hospitalization and following discharge may improve the quality of the educational program and decrease anxiety for families anticipating discharge home with their child.

A multidisciplinary approach to discharge planning and family education provides opportunities for informed discussion and decision making by the healthcare team involved in the care and discharge planning of children with tracheostomies (Fiske, 2004). Neonatologists, pediatricians, surgeons, pediatric subspecialists, nurses, therapists, case managers, social workers and family play important roles in discharge planning. Team meetings of healthcare providers provide a forum for thoughtful discussion and review of progress towards discharge, engaging team members in cooperative and creative problem solving that can result in comprehensive treatment strategies addressing disease management and discharge planning. Multidisciplinary discussion may aid in early identification and securing of community resources including early childhood intervention programs and case management services (Cross et al., 1998). Exploring opportunities to link families of children who have recently undergone tracheostomy placement with those who have previously undergone similar experiences may provide support and valuable advice for families who are preparing for discharge (Carnevale, Alexander, Davis, Rennick, Troini, 2006). In addition to creating a forum for discussion between multidisciplinary teams, the NCCAC developed an informal partnership with the Center for Children with Complex and Chronic Conditions (C5) at Pitt County Memorial Hospital in eastern North Carolina. C5 provides case management services for children living within their 25 county catchment area (Center for Children with Complex and Chronic Conditions [C5], 2008). After obtaining consent from the parents or legal guardian, the NCCAC and C5 can collaborate to facilitate the transition from NCCH to the discharge location for a child with a tracheostomy. The relationship between these two groups serves as the basis for communication and early establishment of community resources for children and families transitioning from NCCH to parental or foster homes, long term care facilities and local hospitals in eastern North Carolina.

Although a comprehensive tracheostomy discharge education program may have a positive impact on decreasing LOS for many children, for some critically ill children with presence of disease as the only barrier to discharge, improvements in the discharge process may have minimal impact on LOS following tracheostomy placement. Eight children in this study, representing 12% of the total study population, incurred a LOS > 44 days due to presence of disease alone. This group, with a mean LOS of 76 days, represents the most critically ill children included in the study. All but one of these eight children eventually were discharged to their parental home, with four going home on mechanical ventilation. One child was discharged to a long term care facility after a LOS of 203 days, the longest LOS for any child in the study. When this subgroup of eight critically ill children with a LOS > 44 days due to presence of disease is removed from the LOS calculations, the overall mean LOS for the remaining 61 (88%) children decreased from 44 to 39 days.

While estimates of one to three weeks have been proposed as the time required for parents to complete thorough tracheostomy training, multiple factors can preclude completion of family education (Graf et al., 2008(2)). Physicians, nurses and respiratory therapists assume responsibility for providing thorough family training, but depending on the severity of the child's illness, initiating and completing a structured education program may be difficult even when families are readily available and eager to learn. Family members may complete the audiovisual and simulation components of an education program but the opportunity to demonstrate skills in suctioning or changing their child's tracheostomy tube may be deferred until the child is medically stable. As the child nears medical readiness for discharge, the family can learn to perform tracheostomy care and participate in rooming–in prior to discharge home. Utilization of a skills checklist, training multiple healthcare providers as educators and taking advantage of "teaching moments" allows flexibility the education process allowing training to be tailored to the timeline for the child's discharge. This study demonstrates that despite institution of a structured discharge planning program that meets the needs of most children with tracheostomies, disease severity may prolong LOS especially for critically ill infants preparing for discharge from the NCCC to the parental home.

Barriers to discharge

Findings of this study suggest that identifying barriers to discharge other than presence disease of may result in identifying opportunities for improvement in the discharge process. Although 57 (83%) of children discharged from NCCH following tracheostomy placement had a mean LOS $\leq$ 44 days or had a LOS > 44 days with presence of disease as the only barrier to discharge, twelve (17%) children endured prolonged LOS due to non-disease related factors characterized as: societal, healthcare, and/or parental related. Examination of barriers to discharge affecting these twelve children may provide insight into gaps in the discharge process. This group represents the children who stand to benefit most from, and should be the focus of process improvement efforts.

While it is difficult to individually address the complex and frequently intertwined non-disease related barriers to discharge, it is important to explore these barriers in depth in an attempt to develop meaningful ways to improve the discharge process.

Societal factors

The societal factors prolonging LOS identified in this study may be reflective of statewide economic conditions. Lack of stable, reliable housing options or LTC facilities equipped to provide complex care may indicate that available state resources are not meeting the demands of the population. Policy changes at the local, state and national levels may be required to alleviate conditions that prevent families from securing safe and affordable housing. Advocacy by healthcare professionals may increase awareness about the lack of LTC facilities in state that meet the needs of technology dependent, medically fragile children. Failure to complete paperwork to obtain public insurance may reflect the complexity of the task. Families may struggle to navigate the complex processes associated with securing public or private insurance and additional funding for home supplies and equipment required to care for a child with a tracheostomy in the parental home. Fragmented and unsupportive health and social services networks may be complicated and frustrating for families with limited personal and material resources (Carnevale et al., 2006). On an individual level, removing barriers prolonging LOS may be addressed through a multidisciplinary approach to discharge planning that allows for early intervention when societal barriers arise. Recognition of potential problems with housing or ability to complete complex paperwork early in the discharge planning process may provide opportunities to intervene. Social workers and case managers can assist families with completion of complex paperwork and identify additional funding sources for medical and other supplies. A multidisciplinary approach to securing resources may help families identify public housing options. Reluctance on the part of families to share information about substandard housing or difficulties completing a complex task such as insurance paperwork may persist until the problems threaten to delay or prevent discharge. Development and nurturing of trusting relationships between families and healthcare team members may facilitate early and frank discussion of issues that could potentially develop into barriers to timely discharge.

Healthcare factors

Healthcare related barriers to discharge identified in this study include: lack of bed space at local hospitals and LTC facilities, delays in final approval for acceptance by LTC facilities and inability to secure home nursing. These barriers demonstrate how the limited availability of discharge placement options for children with tracheostomies can impact LOS. While caring for a child with a tracheostomy at home may be the goal for some families, this may not be a realistic option for others. EMR notations indicate that some families in this study initially felt strongly that discharge to the parental home was preferred. Over time, as the complexities of assuming care for their child at home became apparent, and date of anticipated discharge approached, some families recognized their inability to provide a safe, secure, and stable environment for their child. Some considered options such as transfer to a LTC facility or a hospital close to home, although in North Carolina very few LTC facilities exist for technology dependent children. One facility located in eastern North Carolina has the capability to care for children receiving mechanical ventilation, but has a limited number of beds for children requiring this level of care. Families are informed of options for LTC at the time of preparation for tracheostomy and those families who struggle with the demands of tracheostomy education and adjustment to caring for their medically fragile child are further encouraged to consider all available discharge options and to tour a LTC facility. Healthcare providers supporting families throughout their child’s hospitalization can provide information, guidance and positive reinforcement as families work through the difficult decision making processes associated with discharge planning. Prolonged LOS in this study for some patients resulted from waiting until close to the time of discharge to choose LTC facility placement or transfer to a local hospital. Delays in discharge were associated with getting approval for acceptance to a LTC facility or delays waiting for a bed to become available at the desired facility. Barriers to discharge associated with inability to secure home nursing coverage can be multifactoral. Statewide nursing shortages affecting the availability of private duty nurses reflects a societal barrier that may be overcome through aggressive intervention by policymakers, while delays in contacting home nursing agencies by the healthcare team may result in avoidable prolonged LOS while arrangements are undertaken to secure and train home nurses (North Carolina Institute of Medicine, 2007).

Parental factors

In examining the parental factors associated with prolonged LOS: failure to keep training appointments, resistance to learning care and not coming to the hospital regularly were mentioned in the EMR of several patients. Because NCCH serves the entire state, long driving distances may present a barrier to frequent visits for some families. Of the twelve children with prolonged LOS resulting from non-disease related barriers to discharge, four (67%) lived outside of the three counties immediately surrounding NCCH. Lack of reliable transportation, financial constraints, and family or job responsibilities may contribute to limited hospital visits for training. To meet the immediate needs of NCCH families struggling to attend training sessions, the NCCAC social worker identifies resources to fund family transportation expenses and arranges temporary affordable local housing in an effort to alleviate some of these burdens.

Stress and burdens of home care

Multiple studies have identified the various stressors associated with caring for a technology dependent child at home and the burden these stressors place on the entire family. Issues of financial burden, social isolation, loss of privacy, anxiety, fear, exhaustion, and role conflict have been associated with caring for a technology dependent child and place increased strain on family finances and emotional stability in the household (Carnevale et al., 2006; Cohen, 1999; Lantos & Kohrman, 1992; Levine, 2005; Ratliffe, Harrigan, Haley, Tse & Olson, 2002; Wang & Barnard, 2004). Findings of this study may reflect the early impact of these stressors on family function. Missed training appointments, lack of regular visits, resistance to teaching, and delays in completing paperwork by some families may reflect their response to the enormity of the task of caring for their technology dependent child. Resistance to learning tracheostomy care and failure to keep scheduled training appointments may also reflect some ambivalence on the part of families who have previously chosen to pursue discharge to the parental home. Some families may have strong moral beliefs that their child should be cared for at home and believe that options such as LTC facility placement represent child abandonment. Initially they may be overwhelmed with learning the technical skills necessary to care for their child, but over time, shift concern to other aspects of the care burden (Ratliffe et al., 2002). As families confront new parental responsibilities they may experience personal conflicts between wanting to provide their child with the perceived benefits of being cared for at home while struggling with the personal and financial strains accompanying this decision (Carnevale et al., 2006; Lantos & Kohrman, 1992). They may struggle to create a new normality, face criticism of their decision by other family members or their community, and experience feelings of social isolation (Carnevale et al., 2006; Levine, 2005). Family members undergoing tracheostomy training may begin to feel that they are alone in the experience of learning the complex technical skills required to care for their child. As they to attempt to model the care behaviors of hospital nurses while observing the constant nature and continuous vigilance of care provision, they may come to believe they must be constantly available to their child. The most frequently reported burden by families is the sense that as a parent, one is never off duty (Ratliffe et al., 2002). Realization of new and overwhelming parental responsibilities may result in behaviors such as training avoidance or delays that serve to prolong the child's hospitalization while the family adjusts to new realities and role expectations. There are many resources to help a parent learn the technical skills necessary for providing care for their medically fragile child, but there are very few to help them know how to be a parent in these special circumstances (Ratliffe et al., 2002).

This study identified several instances where families reevaluated previous decisions to care for their child in the parental home and instead opted for discharge to a long term care facility. As the time to discharge approached they questioned their own abilities and availability of resources to provide adequate care for their child. The resulting changes in the placement decision ultimately lead to prolonged LOS for these children. Delays in decision making or reevaluation of previous choices may represent the process some families need to undergo in order to fully understand and accept the realities of their new lives. Attempts to rush decision making or decrease the time required by families to make informed decisions may be detrimental to the child and the family. Periodic conversations with the family and ongoing assessments of discharge options as the child's care needs evolve and the family achieves a better understanding of the care burden may help families understand that their initial choices can be modified based on their own needs and the needs of their child. The underpinning of all discharge decision making is the goal of achieving the best outcome for the child.

In recent years researchers have begun to examine more closely the impact of home based care on the family of the medically fragile, technology dependent child. Families of some children dependent on ventilators have described their feelings of stressful and sometimes overwhelming responsibility, desire to seek normality, conflicting social values, living in isolation, concern for the views of the child and questioning of the moral order of their lives.

Families have been described as living with daily experiences of distress and enrichment (Carnevale et al., 2006; Ratliffe et al. 2002). While the central ethical principle guiding decision making in pediatrics is that decisions should reflect the best interest of the child, benefits of home care for the child are influenced by family stability, parental motivation, community support and economic resources (Lantos & Kohrman, 1992). The literature suggests that home caregivers can become physically and emotionally overburdened experiencing symptoms of anxiety, stress and depression (Wang & Bernard, 2004).

While care of many technology dependent children has been reported to be less costly when provided in the parental home, actual cost comparisons between caring for a technology dependent child in the hospital, at home or in a LTC facility have not been accurately assessed (Office of Technology Assessment, 1987; Mentro, 2003). It may be that when nurses, rather than parents, care for children dependent on ventilators in the home, the cost may equal or exceed the cost of hospital care for the same child. The loss of income for a parent who cannot work outside the home due to care giving responsibilities, transportation, pharmaceutical and insurance expenses, utility, telephone and unreimbursed medical supply expenses are some of the hidden costs that must be considered in any comparative analyses. In addition the costs of stress and emotional burden cannot be underestimated. A clear understanding of the complex needs of families confronting discharge decisions and the limitations of healthcare providers and systems to meet those needs may help reshape thinking about discharge goals for technology dependent children (Lantos & Kohrman, 1992).

A full evaluation of the discharge planning process currently in place at NCCH is limited by the lack of comparison LOS data prior to the creation of the NCCAC and inclusion of a nurse practitioner in the discharge education program. In addition, I did not examine readmission rates for tracheostomy related problems following the initial hospital discharge for children enrolled in this study. Early hospital readmission may reflect deficits in the discharge education process. Because the population served by the NCCH extends across the state and southeast region, readmission may occur at hospitals other than NCCH, making it difficult to accurately collect readmission data. A retrospective chart review limits the researcher's ability to clarify incomplete data or retrieve missing data. A prospective study of the discharge planning process with interviews of staff and families participating in tracheostomy education and decision making about discharge location would potentially yield additional useful information to evaluate and improve the discharge planning process.

Conclusion

Effectiveness of the discharge planning process for children with tracheostomies is enhanced by a multidisciplinary focus that incorporates a dedicated nurse practitioner specializing in the care of children with tracheostomies and a team approach to discharge planning. Length of Stay (LOS) following tracheostomy placement is affected by multiple factors, some of which may be amenable to early team intervention with families while others reflect a lack of community services and available discharge options. Recommendations for improvements in the discharge planning process include early and ongoing assessment of family dynamics and provision of support and guidance as families adapt to the new realities of parenting a medically fragile child dependent on technology.

Appendix A.

Trach or Treat Scenarios 2009

(use the dolls for demonstration and participation. get out all the trach supplies)

1. Bobby Joe is a 2 month old direct admit from home yesterday. His history includes Pierre Robin syndrome, intrauterine growth retardation (IUGR) and a significant cleft palate necessitating a GT (which is leaking significantly). His birth wt was only 2.4 Kgs. On admission, his weight is only 2.8 Kgs. He had a trach placed before going home in order to keep his airway open. He is here for a g/j tube revision. Bobby has a 3.0 neo shiley trach. What items will you need to set up the room for this admission?

Answer: 3.0 neo shiley trach and a 2.5 ETT, suction catheters, suction set up, small child bag and mask, trach placard and trach identification sheet (info sheet), pulse oximetry and cardiac monitoring, HME, trach mist collar set up. Other hospital's carry the neo 2.5 we do not.
* All patients are required to have humidification overnight. display sheets.

Continue scenario: It is time for Bobby to go to surgery for this GT revision. His 15 yr old mother decided not to stay with him over night, instead she went back home to Cary. She said she would be in later after the surgery. You go in the room and notice that Bobby has kicked off his pulse ox probe. His HR is 182; he is agitated and acting like he is choking. What do you do?

Answer: attempt to pass the catheter

Continue scenario: you pass the suction catheter with some difficulty, you suction for large amount of milky looking secretions. Bobby still seems to be struggling to breath. Sats are now in the mid 80's. He is dusky looking. HR is now 100. What do you do?

Answer: You switch out the trach with the one in the emergency supply (extra at bedside) and it doesn't go. Attempt to insert ET tube instead. Attempt to bag. Call a RRT.

Alternate scenario: You attempt to switch out the trach with the one in the emergency supply (extra at bedside) and discover that the box is empty. You have no backup trach. What do you do?

Alternate scenario Answer: You have no back up trach to replace, press Staff assist button. You attempt to bag from above and cover the stoma. Call a code blue.

Continue scenario: You are unable to reinsert the new trach back into the stoma. Sats are now 75; HR is 80 and failing rapidly. What do you do?

Answer: You attempt to bag from above and cover the stoma. Call a code blue.

Continue scenario: You are starting to have some chest rise and continue bagging. HR is now up to 100, color is starting to improve. After a few minutes, the code team arrives. Give them a report using a SBARQ.

2. Richie Jr, a 4 yo, is a well know pt "frequent flyer" to all the floors. He has a 4.0 peds shiley trach. He is considered to have a "stable trach" and usually does not require any oxygen just

humidification overnight. Richie Jr. is going to the playroom with his family. Does he need a doctor's order before he can go?

Answer: Yes, policy says he must have an order to be off the monitor for legal reasons. The order needs to include being off pulse oximetry and cardiac monitoring to go off floor to playroom. Only one order is required per admission.

Continue scenario: Richie is in the playroom and starts to have difficulty breathing. He is cold and ashen and is having difficulty moving air. His mother starts screaming for help. What should you do?

Answer: Send someone to get the code cart in the playroom, call RRT (64111), suction once code cart is there, give 02. Have someone attend to family to give you room to work on the child.

Continue scenario: When you attempt to suction, you cannot pass the catheter. Richie is now cyanotic. Heart rate is now 45. His mother is now crying for someone to help her child. What do you do?

Answer: Call a code blue, attempt to ambu bag to increase oxygenation, switch out trach with supply that is stored on the code cart. Have someone reassure his mother that everything is being done possible to help her child.

Continue scenario: After switching out the trach, you are able to ambu Richie easily.
His color is slowing returning to pink. HR is now 80. The code team just arrived. What do you do?

Answer: Continue to provide support as needed to Richie and allow his mom to be at his side. Give report using SBARQ to code team. Place Richie on a stretcher and take him back to his room for close observation.

S=Situation
B=Background
A=Assessment
R=Recommendations
Q=Questions

Appendix B. Demographic Characteristics of 69 Children Meeting Study Inclusion Criteria (< 3 years old, undergoing tracheostomy between 9/1/2005 and 9/1/2009 and discharged with tracheostomy) and a Subset of 20 Children with LOS > 44 days Following Tracheotomy

Demographic Characteristics	**All Children** **n = 69** **Value**	**LOS > 44 Days** **n = 20** **Value**
Age at tracheostomy in months, mean	6.0	3.2
Male, %	53.7	60.0
Ethnicity, %		
White, non – Hispanic	44.9	45.0
African American	40.6	45.0
Hispanic	10.2	10.0
Other	4.3	0
Insurance, %		
Public	84.0	90.0
Private/health maintenance organization	8.7	0
Other/unknown	7.3	10.0
County of Parental Residence, %		
Orange, Durham, or Wake	31.9	35.0
Discharged on Ventilator, %	23.2	55.0
Unit Discharged from, %		
NCCC	29.0	60.0
PICU	24.6	20.0
Inpatient floor	46.4	20.0
Discharge Disposition, %		
Parental home	9.4	60.0
Long term care facility	10.1	30.0
Local hospital	27.5	10.0
Rehabilitation facility	3.0	0

Appendix C. Societal, Healthcare and Parental Related Factors Described in the EMR Contributing to Delays in Discharge for the Twelve Children With Prolonged LOS > 44 Days for Reasons Other Than or in Addition to Presence of Disease

Societal

- Family initially lacked stable, consistent, and reliable housing
- Long term care facility refused to accept patient due to complexity of care
- Family delayed completion of paperwork required to apply for public insurance coverage

Healthcare

- Lack of available bed space at long term care facility
- Long term care facility delayed final approval for acceptance into the facility
- Inability to secure adequate hours of home nursing care coverage
- Lack of bed space availability at local hospital chosen for transfer

Parental

- Family failed to keep training appointments
- Family did not come to hospital regularly
- Family initially refused long term care, as discharge date approached, felt inadequate and doubted their ability to provide care at home, requested long term care facility placement
- Family refused home nursing, were resistant to learning care, delayed training, failed to keep training appointments
- Family acknowledged unstable home situation close to discharge date, unable to identify 2 caregivers

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