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## A quality study of family-centered care coordination to improve care for children undergoing tracheostomy and the quality of life for their caregivers



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### ABSTRACT

**Importance:** Approximately 4000 U.S. children undergo tracheostomy yearly [1], and these surgeries often result in hospital re-admissions that have definite cost and caregiver burdens due to complications that are avoidable with proper training and support.

**Objective:** To assess the impact of a Family-Centered Care Coordination (FCCC) program on the quality of care received by children undergoing tracheostomy and their caregivers.

**Design:** Caregivers of children undergoing tracheostomies from January 2012 to January 2013 and then a different set of caregivers of children undergoing tracheostomies from January 2015 to January 2016 completed both the Pediatric Tracheostomy Health Status Instrument (PTHSI) 1 month after discharge and the Medical Complications Associated with Pediatric Tracheostomy (MCAT) questionnaire 6 months after initial tracheostomy. To assess complication rates, these same sets of caregivers were asked to complete the MCAT and only those who provided complete medical data for all 6 months were included for comparative analysis.

**Setting:** The PTHSI and MCAT were administered at Massachusetts Eye and Ear in a hospital setting.

**Participants:** Ten caregivers of children undergoing tracheostomies completed the PTHSI before FCCC program implementation and 12 caregivers then completed the PTHSI after FCCC implementation. For each of the 2 groups, 5 caregivers provided complete data on the MCAT questionnaires.

**Exposures:** FCCC is a collection of programs, policies, and tools designed to ensure safe transition home for children undergoing tracheostomies, reduce re-admission rates, and minimize “caregiver burden”.

**Main outcomes and measures:** The PTHSI is a validated caregiver quality of life instrument that was supplemented by the MCAT which records post-discharge medical issues following tracheostomy that relate specifically to the tracheostomy placement.

**Results:** The time to first follow-up appointment decreased from 6.4 weeks (SD = 1.52) to 6 days (SD = 0.18) with FCCC implementation. The total MCAT scores decreased from 15.2 (SD = 1.1) to 1.3 (SD = 1.3) (Wilcoxon sum rank test:  $P < 0.016$ ) whereas neither PTHSI scores ( $P = 0.32$ ) nor the specific caregiver burden domain ( $P = 0.18$ ) demonstrated a significant change.

**Conclusions:** and Relevance: By reducing the time to first follow-up after tracheostomy and by optimizing caregiver tracheostomy tube care and teaching, children's quality of care and caregiver burden can be significantly improved.

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Approximately 4000 U.S. children undergo tracheostomy each year [1], for a variety of reasons, including genetic conditions such as Robin sequence or Crouzon's syndrome [2], chronic lung disease of prematurity requiring ventilator dependence, and laryngeal trauma resulting in subglottic stenosis. The mean age for a child to

undergo tracheostomy is 5 years, and the median age is 1 year [1,3]. Therefore, most children who are discharged home after the initial placement of a tracheostomy are infants or young toddlers, and tracheostomy care at home is delivered by primary caregivers.

Although children typically heal from tracheostomy surgery within 5 days, the length of stay in the hospital is usually 3 weeks or longer [1] because the preparation to live at home with a tracheostomy is challenging. Feeding regimens and home nursing support need to be established. Durable medical equipment needs to be procured. Most importantly, caregivers must be trained to care for the tracheostomy at home. This not only involves daily maintenance (e.g., suctioning and changing the tracheostomy tube) but also knowing with whom and when to follow-up for their children's tracheostomy care, knowing the warning signs of an impending issue (such as infection or accidental decannulation), and what to do if and when this happens. Home routines change according to the needs of not only the child with tracheostomy but the family as a whole, which, therefore, makes proper training and education prior to hospital discharge imperative.

Nearly 10 years ago, we formed a partner group for families of children with tracheostomy with the goal of identifying ways to improve our care. Together, we designed a program to streamline post-tracheostomy care and caregiver education. We implemented the program hospital-wide over several months in 2014. The program aimed to achieve 3 goals that were identified by caregivers themselves: 1) to reduce length of hospital stay after tracheostomy placement, 2) to feel better prepared and supported while caring for the tracheostomy at home, and 3) to reduce complications after tracheostomy (by teaching proper tracheostomy care including suction changing techniques). Caregivers of the children undergoing tracheostomies identified concerns over tracheostomy care such as these as major factors affecting "caregiver burden", or the stress, worry and limitations on family life experienced by caregivers due to having a child with a tracheostomy. Our Quality Report describes the components of the Family Centered Care Coordination Program, the context and implementation process, as well as the pre- and post-measurements to evaluate the program and how it affected medical complications and issues that could be influenced by proper caregiver training, and, in turn, measure how this affected overall caregiver burden.

## 1. Methods

### 1.1. FCCC program

Over the past 10 years at Massachusetts Eye and Ear Infirmary (MEEI) and the Massachusetts General Hospital for Children (MGHfC), a dedicated group of caregiver partners has inspired and directed the development of a FCCC initiative that has evolved to become a collection of programs, policies, and tools designed to ensure safe transition home, reduce re-admission rates, and minimize "caregiver burden".

Our first caregiver luncheon was held in 2012 to solicit interest from caregivers in helping us formalize a peer-to-peer mentoring program based on peer support efforts that had been ongoing since 2007. The enthusiastic reception led to a successful implementation of the mentoring program, and feedback indicated that this component of the FCCC program was incredibly valuable for new parents and personally rewarding for our mentor parents. From the initial focus group, and contributions through quarterly luncheons, it became apparent that the parents were eager to participate and propose their own programs in a collaborative manner [4,5]. Continued engagement with parents has led to proposals that have been subsequently implemented and now form the core components of FCCC at MEEI: a website for parents and members of the

community (e.g., teachers and neighbors who want to understand more about caring for children with tracheostomies), structured teaching methods among health care professionals, and video teaching. Parents requested to meet more frequently (bi-monthly rather than quarterly) and at facilities that could accommodate their children (e.g., Boston Children's Museum). Over the past 5 years, we added Skype calls (a software application using web cameras to communicate via the internet) to supplement the in-person focus group meetings to accommodate those parents unable to attend meetings but still wish to contribute to the program.

Purposeful engagement with hospital staff caring for children post-tracheostomy was vital for successful implementation of the FCCC program [6]. Program elements that required staff participation involved 4 hospital units (the pediatric intensive care unit (PICU), neonatal intensive care unit (NICU), general ward, and the outpatient airway clinic) and several disciplines including nursing, respiratory therapy, care coordination and unit medical teams—all of which had integral roles in guaranteeing the program's success. Specific changes included a daily schedule of teaching, discharge planning changes in the child's treatment, near-continuous caregiver training at the bedside by the child's nurse, peer-to-peer mentor assignments with other families who can share their experiences and training videos for use once a child is home.

### 1.2. The Pediatric Tracheostomy Health Status Instrument (PTHSI)

The primary outcome measure is the 17-item caregiver burden domain (Table 1) within the 34-item self-administered survey for caregivers, the Pediatric Tracheostomy Health Status Instrument (PTHSI). This instrument was developed, refined, and validated with a series of focus groups of caregivers of children with tracheostomies (both parents and health care professionals) [4]. Total PTHSI scores range from 0 to 100, with higher scores reflecting a worsening overall quality of life and caregiver burden.

### 1.3. Medical Complications Associated with pediatric tracheostomy (MCAT) questionnaire

As part of the qualitative work done to develop the FCCC program, caregivers were asked to define the medical issues and complications that they felt affected their child's health, the quality of care they received, and the factors that influenced their own quality of life as caregivers. The MCAT questionnaire was developed from this work. Additionally, time to first follow-up visit after discharge as well as a mean summary score of medical complications in the first 6 months following discharge were then quantified (Table 2).

Caregivers of all children who received tracheostomies from January 2012 to January 2013 at MEEI and then a different set of caregivers whose children received tracheostomies from January 2015 to January 2016 completed both the PTHSI no earlier than 1 month after discharge and the MCAT questionnaire no earlier than 6 months post-discharge after initial tracheostomy. To assess complication rates, these same two sets of caregivers were asked to complete the MCAT. The scores for those caregivers who provided complete medical data for all 6 months were included for comparative analysis.

This work was deemed exempt by the MEEI Institutional Review Board.

## 2. Results

The mean age for the 22 children who received a tracheostomy during this time period was 2.1 years (SD = 1.0) and the gender distribution was 60% male (n = 14) and 40% female (n = 8). Fifty-

**Table 1**  
17-item caregiver burden domain from the Pediatric Tracheostomy Health Status Instrument (PTHSI).

|     |  |
|-----|--|
| 1.  | How would you describe your overall quality of life?   |
| 2.  | How often are you able to perform activities to manage your home?  |
| 3.  | How often are you worried or concerned about your child's safety when you perform a tracheostomy change?   |
| 4.  | How often are you worried or concerned about your child's safety when you suction the tracheostomy?  |
| 5.  | How often are you worried or concerned about your child's safety with regard to your child's overall ability to breathe?                             |
| 6.  | How often over the past week have you been able to take your child out of the house (i.e. to run errands, for recreation)?                           |
| 7.  | During the past 4 weeks, how often have you been worried or concerned about your child's physical health?  |
| 8.  | During the past 4 weeks, how often have you been worried or concerned about your child's emotional well-being or behavior?                           |
| 9.  | During the past 4 weeks, how often have you been limited in fulfilling your own needs because of your child's physical health?                       |
| 10. | During the past 4 weeks, how often have you been limited in fulfilling your own needs because of your child's emotional well-being or behavior?      |
| 11. | During the past 4 weeks, how often has your child's condition affected your health?  |
| 12. | During the past 4 weeks, how often has your child's condition affected your emotional state?   |
| 13. | During the past 4 weeks, how often has your child's condition affected your sleep?   |
| 14. | During the past 4 weeks, how often has your child's condition affected your relationship?  |
| 15. | During the past 4 weeks, how often has your child's condition interrupted various everyday family activities? (eating meals, watching TV, going out) |
| 16. | Over the past four weeks, how often did you need help from skilled medical personnel?  |
| 17. | Over the past four weeks, how often did you get help from skilled medical personnel?   |

**Table 2**  
Medical complications associated with pediatric tracheostomy (MCAT) administered to caregivers.

|    |   |
|----|---|
| 1. | After discharge from the hospital after your child had his/her tracheostomy placed, how many weeks/months was it to your first postop doctor's visit (approximately)?   |
| 2. | Over the six months after discharge from the tracheostomy placement, how often did you have a question which your pediatrician could not answer?  |
| 3. | Over the six months after discharge from the tracheostomy placement, how often did you have to bring your child to the Emergency room or be admitted due to tracheitis (an infection around the tracheostomy hole)?   |
| 4. | Over the six months after discharge from the tracheostomy placement, how often did you have to bring your child to the Emergency room or be admitted due to bleeding from the tracheostomy (perhaps from suctioning)? |
| 5. | Over the six months after discharge from the tracheostomy placement, how often did you have to bring your child to the Emergency room or be admitted due to plugging of the tracheostomy?                             |
| 6. | Over the six months after discharge from the tracheostomy placement, how often did you have to bring your child to the Emergency room or be admitted due to difficulty changing the tracheostomy?                     |
| 7. | Over the six months after discharge from the tracheostomy placement, how often did you have to bring your child to the Emergency room or be admitted due to some other reason?  |

nine percent (59%) ( $n = 13$ ) of children underwent tracheostomy for isolated subglottic stenosis, 27% ( $n = 6$ ), tracheomalacia, and 14% ( $n = 3$ ) for other reasons.

### 2.1. Time to first follow-up appointment

The mean time from discharge following tracheostomy to first follow-up appointment decreased from 6.4 weeks ( $SD = 1.52$ ) when there was no FCCC program to 6 days ( $SD = 0.189$ ) following implementation (Wilcoxon sum rank testing ( $P = 0.0131$ )).

### 2.2. PTHSI

For the 10 caregivers of children with tracheostomies who did not receive FCCC, their mean PTHSI score was 107.4 ( $SD = 19.8$ ) and the PTHSI specific caregiver burden domain score was 59.8 ( $SD = 11.3$ ). In contrast, for the 12 caregivers of children with tracheostomies who did receive FCCC, their mean PTHSI score was 96.9 ( $SD = 13.8$ ) and the PTHSI specific caregiver burden domain score was 51.7 ( $SD = 10.2$ ). Neither the PTHSI scores nor the mean caregiver burden domain of the PTHSI demonstrated a significant change ( $P = 0.32$  for PTHSI;  $P = 0.18$  for domain specific PTHSI caregiver burden) following implementation of the FCCC program.

### 2.3. MCAT

The mean total MCAT score for those who did not receive FCCC was 15.2 ( $SD = 1.1$ ) and 1.3 ( $SD = 1.3$ ) for those who did receive FCCC. Wilcoxon sum rank testing was performed to compare the two groups and revealed a two-sided t approximation ( $P = -value$ ) of 0.016.

## 3. Discussion

This research aims to outline a Quality Improvement project directed towards establishing a complex, multi-faceted Family Centered Coordinated Care (FCCC) Program with a goal of improving the quality of care these children and caregivers receive and potentially diminishing caregiver burden. The underlying theory behind such a FCCC program is that by improving caregiver teaching regarding optimal tracheostomy care and decreasing the time to first follow-up post discharge, caregivers would have their questions and concerns addressed more promptly and would not require frequent emergency room visits and hospital admissions for complications such as tracheostomy infections, tracheostomy bleeding, and difficulty changing the tracheostomy, thereby improving the quality of care these children receive. In these two small cross-sectional cohorts of children and caregivers, a FCCC program appeared to significantly improve the quality of care they received. Interestingly, although caregivers involved in the creation and establishment of the FCCC program identified the MCATs as significant influences on overall caregiver burden, there was not a significant decrease in caregiver burden between the cohorts as measured by the PTHSI and the subdomain specifically addressing caregiver burden. This disparity between the change scores for the MCAT and PTHSI can be explained either due to too small a sample size to see a significant change in the PTHSI scores, or because the PTHSI is not a sensitive enough instrument to measure changes in caregiver burden as it has been shown to have little to no correlation with the physical health of the caregiver and only poor correlation with his or her mental health [7].

The optimal approach to transitioning families from the hospital to home after tracheostomy is unknown, and no studies have examined interventions to facilitate transition from hospital to

home for children with tracheostomy. Due to this practice and knowledge gap, it has been estimated that upwards of 11% of children require 4 or more hospitalizations within 6 months after tracheostomy [8,9], and approximately 56.4% of children experience at least one hospital admission in the 2 years following tracheostomy [10]. Seemingly simple issues such as how often to change the tracheostomy have neither best practice data or consensus information [11]. In one well cited study, only 41% of children discharged after a tracheostomy had a post-operative appointment scheduled within several months of their discharge and approximately 19% had yet to see a primary care pediatrician within 2 years following discharge [10,12]. Careful inspection of these re-admissions suggests that upwards of 21% may be attributed to ambulatory care sensitive conditions (ACSCs) such as asthma and gastroenteritis (or in the case of patients undergoing tracheostomy, MCATs) that, if treated in conjunction with a well prescribed systematic care plan, may have been less severe and have required fewer re-hospitalizations [13]. Clearly, such re-admissions will affect caregiver burden due in part to their child's increased days missing from programs or school as well as due to their own time away from work. It also has an enormous economic dimension. In 2009 alone, there were approximately 4523 readmissions for children with tracheostomies for ACSCs and the total cost of care for these re-admissions approximated \$294 million [10]. Our pilot work suggests that an established FCCC program, 1) by improving caregiver training with tracheostomy care and 2) providing earlier, more timely follow-up with health care practitioners upon discharge, it can significantly diminish the number of MCATs and the number of readmissions after discharge from pediatric tracheostomy.

This project represents pilot work to study the initial efficacy of a FCCC program that combined physicians, nurses, case workers, and caregivers to create a coordinated program which addressed the needs of caregivers with children after tracheostomy as they transitioned home. We studied two cohorts of caregivers at different time periods – before and after the design and implementation of a FCCC program. The inherent weakness of following two small distinct cohorts over different periods of time is that there well may have been other factors that played a role in the differences seen, and, in the case of the PTHSI, the sample size may simply have been too small to identify significant differences. A larger longitudinal multi-center study would help address these weaknesses and answer such questions.

Larger, multi-center longitudinal studies will also allow us to look more closely at how socioeconomic factors and other factors such as whether the caregivers are engaged in a partnership or whether there is just one primary caregiver may affect caregiver burden and medical outcome. Such studies should also include data on length of stay as well as cost data as the value of health care is

defined both by quality as well as cost. Further evaluation of this program would also benefit from an evaluation of the implementation process; it is a complex intervention and the hospital and health system context may impact efficacy.

#### 4. Conclusion

In summary, we believe our Quality Improvement project to develop a Family Centered Care Coordination program for children with tracheostomies and their caregivers suggests a model for improving the quality of care these vulnerable children and their caregivers receive which is worth further investigation.

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