



Medical Professionals and Patient Families Collaborate to Improve Survival Rates for Infants with Tracheostomies

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Babies born very prematurely face a variety of challenges to their survival. Among them are difficulties to breathe properly because of immature lungs. As a result, preterm infants often require prolonged respiratory support and develop [bronchopulmonary dysplasia \(BPD\)](#), a chronic lung disease. Babies with the most severe forms of BPD may require long term mechanical ventilation and for that a tracheostomy is necessary.

A tracheostomy is a surgically created opening in the windpipe for the insertion of tube that will be connected to a ventilator and provide air artificially into the lungs.

Infants with severe lung disease or congenital malformations blocking the airway can be discharged home with a tracheostomy on respiratory support such as mechanical ventilation. They usually have lengthy hospitalizations and require close medical supervision due to dependency on technology for survival. Yet, mortality among these complex and vulnerable patients is high, currently ranging

from 14% for the non-extremely preterm and up to 18% for extremely preterm babies.

[Joanna Machry, M.D.](#), a neonatologist specializing in [newborn medicine](#) at the [Johns Hopkins All Children's Hospital](#) in St. Petersburg, Florida, and her colleagues, thought they could do better. Accordingly, they devised a revolutionary innovative, multidiscipline, interventionist “protocol” — a procedure devised to carry out the most scientifically proven actions known to best improve the course of medical treatment. Their protocol aimed at improving survival rates for infants with tracheostomies in need for respiratory support beyond hospitalization.

“We wanted to change the culture for caring for complex, preterm infants for whom tracheostomy becomes a treatment option,” Machry explains. “The culture change required moving from a single provider’s care and decision-making to a multidisciplinary, institution-level, approach. A ‘trach team,’ or committee, that would regularly do rounds and discuss cases together. We also developed an educational program to ensure that every doctor, nurse, and ancillary provider, would be well-trained in trach care and in managing trach emergencies.”

The protocol also involved training patients’ family members who would be caring for the child after discharge to home, but with the child continuing on mechanical ventilation at home.

A Personal Passion

Machry, who also serves as the program director for the Johns Hopkins All Children’s [Neonatal-Perinatal Medicine Fellowship Program](#), has had a lifelong passion for pediatric care, and especially respiratory care for preterm infants.

“My father is a retired pediatrician and was always very active in emergency medicine,” recalls Machry, a native of Brazil. “I grew up in his medical environment. He used to take me to the hospital, and I often did rounds with him. Occasionally, I even watched him do procedures.”

Following in her father’s footsteps, Machry graduated from medical school in Brazil and completed a pediatric residency in Brazil. She then came to the United States in 2003 to do pediatric residency and fellowship in neonatal-perinatal medicine at Jackson Memorial Hospital at the University of Miami Miller School of Medicine.

“During that fellowship, I took care of many complicated pediatric patients, including an infant with a tracheostomy,” she says. “Although we did everything we could at the time, unfortunately the baby did not survive a tracheostomy emergency event.”

For Machry, that loss was devastating, but encouraged her to seek opportunities for improving care for pediatric patients with tracheostomies. Several years ago, she placed her hopes for better success on work carried out by the [Global Tracheostomy Collaborative \(GTC\)](#).

GTC's Five Key Drivers

According to Machry, GTC partners with hospitals, health care professionals, patients and families around the world to improve the care, safety, and quality of life for everyone with a tracheostomy.

“GTC is concerned with developing safe, effective tracheostomy care on a global scale through data-driven innovations of interprofessional teams of physicians, nurses, respiratory therapists, speech therapists, patients and families,” she says.

The protocol Machry and her colleagues eventually devised for improving tracheostomy care for pediatric patients was built on five “key drivers” developed by GTC.

The five key drivers include:

- Developing a new, multidisciplinary approach aimed at changing the “culture” for tracheostomy care from a single provider care and decision-making approach to a multidisciplinary collaborative approach
- Standardizing a “clinical pathway” for tracheostomy care
- Initiating broad staff education to ensure that every doctor, nurse, and ancillary provider is well-trained in trach care and in managing trach emergencies
- Including patient and family involvement in care improvement efforts through tracheostomy care training and getting regular feedback from patient families
- Entering data, tracking performance; bench-marking data and sharing data with other institutions

Creating a Multidisciplinary Team

In September 2016, a multidisciplinary “NICU Tracheostomy Team” was established at Johns Hopkins All Children’s within the Maternal, Fetal & Neonatal Institute. Co-led by a neonatologist and a respiratory therapist, the team comprised all caregivers, including the patients’ family members, physicians and advance practice providers from neonatology, pulmonology, anesthesiology,

pediatric otolaryngology, respiratory therapy, neonatal intensive care (NICU), nursing, speech pathology, social work, dietary and case management.

Kathy Renn, R.N., a “quality improvement nurse specialist,” and Angela Green, Ph.D., R.N., vice president of safety and quality at the Johns Hopkins Health System responsible for advancing clinical excellence across the continuum of care and helping set new operational standards of care delivery, were included. Green, who holds a faculty appointment in the Johns Hopkins University School of Nursing, also served as senior author of the subsequent study publication.

“In January 2017, multidisciplinary bedside rounds were implemented to formulate recommendations for NICU patients being considered for tracheostomy and for those with a tracheostomy already in place,” Machry explains.

Family Education, Training and Simulation

Education for tracheostomy caregivers — both hospital staff and patient family members — employed existing clinical practice guidelines on procedures, such as skin assessment, suction practices and tracheostomy tube changes. Standard practices were reviewed by tracheostomy team members and updated as necessary to reflect the most current evidence-based literature. Team members also reviewed and updated a tracheostomy parent booklet detailing information on tracheostomy care after their child’s discharge.

Clinical pathway development

In keeping with the second key driver, over a two-year period the trach team also developed a standardized, clinical pathway titled “Tracheostomy Related Care for Patients In the NICU.”

The pathway was based on input from all disciplines involved in tracheostomy care. All evidence-based recommendations were agreed upon after extensive review of the literature and available published guidelines to offer detailed guidance on discharge criteria for a safe transition to the home environment, says Machry.

“Bedside nursing staff members interested in caring for tracheostomy patients and who self-identified with desire to become a “tracheostomy champion, “were recruited by the NICU Tracheostomy Team,” Machry explains.

The “tracheostomy champions” were provided with education to ensure consistency in staff education at the time a new patient was enrolled and education materials and patient-specific reference cards with information on tracheostomy tube type, size, proper suction depth, and due date for tube exchange, were placed at each patient’s bedside.

The Study

The team recently published a study, titled [“The NICU tracheostomy team: multidisciplinary collaboration for improvement in survival of complex patients”](#) in the *Journal of Perinatology*.

As a “qualitative improvement article,” the journal article describes the details of the protocol as well as examines its effectiveness in improving outcomes.

“Our overall objective was to improve survival rates for any of our pediatric patients undergoing a tracheostomy placement during NICU hospitalization,” says study first author Machry. “The specific, measurable, attainable and relevant aim was to increase survival of NICU infants with a tracheostomy by 20 percent over a five-year period and to evaluate the key driver improvement strategies, which included implementing multidisciplinary bedside rounds to discuss all NICU patients under consideration for a tracheostomy or those with a tracheostomy in place. The study also examined the standardization of clinical practices as well as the success of staff and family education and training.”

Study Results and Conclusions

“Our quality improvement project demonstrated that multidisciplinary collaboration and a standardized institutional approach to neonatal tracheostomy care is feasible, and resulted in improved patient survival. Interventions addressing the five key drivers, as identified by the GTC, were beneficial to an overly complex and vulnerable population of infants without sustained impact on hospital length of stay (LOS),” concluded the study authors.

“Our data suggests that multidisciplinary collaboration and a standardized approach to tracheostomy care in neonatal patients are associated with improved in-hospital survival without a sustained increase in LOS. Efforts to improve optimal timing for tracheostomy placement, and prevention of infectious complications in patients with BPD, are opportunities for further quality improvement efforts to impact patient outcomes along with the potential for reduction in length of hospitalization.”