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Health Care Resource Utilization for Children Requiring Prolonged Mechanical Ventilation via Tracheostomy

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BACKGROUND: More children are discharged from ICUs on prolonged mechanical ventilation (PMV) via tracheostomy than ever before. These patients have long hospitalizations with high resource expenditure. Our objective was to describe the characteristics of these resource-intensive patients and to evaluate their costs of care. We hypothesized that subjects requiring PMV for neurologic diagnoses would have higher costs, longer hospital length of stay (LOS), and worse outcomes than those with primarily respiratory diagnoses. METHODS: We identified 50 pediatric subjects between January 2015 and December 2017 at our institution who had a new tracheostomy placement and were enrolled in a home mechanical ventilation program. Collected data included demographics, indication for tracheostomy, LOS, hospital costs, readmissions, and outcomes. We also compared subjects who required PMV for respiratory diagnoses versus neurologic diagnoses. RESULTS: Of 50 subjects, 41 were < 12 months old at the time of tracheostomy. Thirty-four subjects had a respiratory diagnosis requiring PMV, 14 had a neurologic diagnosis, and 2 had a cardiac diagnosis. The total initial hospitalization cost was $31,133,582, which averages to $622,671 per subject. The average initial hospitalization LOS was 155 d. Respiratory subjects had longer LOS and higher average costs than neurologic subjects. The average readmission rate was 2.16 per subject in the first year after discharge, and the average readmission cost per subject was $73,144. Eight subjects died in the first year after discharge, and 4 suffered a serious morbidity. CONCLUSIONS: This descriptive study evaluated the social and medical characteristics of subjects being discharged from the pediatric ICU with PMV via tracheostomy, as well as quantified the financial impact of their care. Those requiring PMV for neurologic diagnoses had shorter hospital LOS and lower hospital costs than those with respiratory diagnoses. No definitive differences in outcomes were found. *Key words: pediatrics; tracheostomy; home ventilation; chronic ventilation; resource utilization.* [Respir Care 0;0(0):1–•. © 0 Daedalus Enterprises]

Introduction

An increasing number of children with complex medical conditions survive their critical illness with the support of prolonged mechanical ventilation (PMV) via tracheostomy tubes.[1-5] Medical advancements over the past few decades have made this a safe and effective approach to managing these patients, either at home or in long-term health care facilities.[4,6-9] Previous studies have reported that patients who require PMV have a high rate of complications and hospital readmissions, and the financial costs

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associated with caring for them can be a large burden to the health care system.[3,10-15]

There are insufficient data describing the health care utilization of pediatric patients requiring PMV. The typical initial hospitalization includes a long initial ICU admission followed by considerable additional hospital time dedicated to arduous training of the caregivers to safely care for these patients at home.[14,16] Although hospital length of stay (LOS) has been described previously,[13,14] few studies have quantified the total health care utilization. For many patients, despite prolonged hospitalizations and the utilization of large amounts of health care resources, readmissions are a frequent occurrence and long-term outcomes are often poor.[10,13,14,17] It has been proposed that there is a difference in both costs and outcomes associated with different underlying conditions leading to the need for PMV, but a comparison between these subjects has been described in only a few studies.[18-20]

Our objective was to describe the social and medical characteristics of these resource-intensive patients and to evaluate the cost of caring for them, both for the initial hospital admission and for readmissions in the first year after discharge. We hypothesized that subjects requiring PMV for neurologic diagnoses would have higher costs, longer hospital LOS, and worse outcomes than those with primarily respiratory diagnoses.

QUICK LOOK

Current knowledge

More children than ever are surviving critical illness with prolonged ventilation via tracheostomy tubes. However, these patients have a high rate of complications, and the financial costs of their care represent a large burden to the health care system.

What this paper contributes to our knowledge

This study characterizes subjects requiring PMV, quantifies the financial impact of their care, and describes their outcomes. It also compares these values between subjects with primarily neurologic conditions and subjects with primarily respiratory conditions.

Methods

This was a retrospective cohort study of subjects under 18 years of age who underwent new tracheostomy placement and were discharged on PMV between January 1, 2015, and December 31, 2017, at Riley Hospital for Children in Indianapolis, Indiana. Patients were excluded if they received a tracheostomy but were not discharged on PMV, if they were recannulated after a previous tracheostomy, or if they had a tracheostomy performed at another institution and were then transferred to our institution for initiation of PMV. Patients who died during their initial hospitalization were also excluded from the study. This study plan was submitted to the Indiana University Institutional Review Board and was granted exemption.

Our institution's current process for a patient admitted to the neonatal ICU who is identified as requiring PMV involves transferring the patient to the pediatric ICU prior to tracheostomy placement, and afterwards transitioning from a hospital ventilator to a home mechanical ventilator. Once the patient is stable on a home mechanical ventilator, medical care is transitioned to a chronic ventilation team, which consists of pulmonary nurse practitioners, social workers, respiratory therapists, and pediatric pulmonary attending physicians. Although our program is located within the pediatric ICU, it is cohosted in a special 8-bed space that functions as a chronic ventilation unit where patients are transitioned to home ventilation and caregivers receive training on their child's needs. The staffing is provided by a separate dedicated respiratory therapist as well as dedicated registered nurses with expertise in training these families for home discharge. The regular pediatric ICU registered nurses and respiratory therapists are not included in the staffing pool for this unit. Parents and caregivers are trained in routine and emergent tracheostomy care as well as in home ventilator management. Our institution follows the American Thoracic Society guidelines for discharge to home on PMV, which requires a minimum of 2 full-time caregivers to undergo this training and to be available at all times to care for these patients.[21] Patients who are admitted to the pediatric ICU and then are identified as requiring PMV via tracheostomy tube follow the same process.

All subject data were collected from electronic medical records. Subjects' demographic data included age, gender, ethnicity, primary language of subject or caregivers, marital status of primary caregiver, age of mother at time of subject's birth, mother's employment status, and identity of the second trained caregiver. Some subjects changed their second caregiver; if this occurred more than once, they were classified as having difficulty identifying a second caregiver. Hospital course dates and other dates were obtained, including date of birth, admission date, date of decision to proceed with tracheostomy, date of tracheostomy, date of first tracheostomy tube change, date of pediatric ICU transfer (if applicable), date of transfer to the chronic ventilation team, and date of discharge. Medical data collected for each subject included the subjects' gestational age, primary diagnosis leading to the need for tracheostomy and PMV, and the surgical service performing the tracheostomy. Primary diagnoses were categorized as respiratory, neurologic, or cardiac. Discharge follow-up data included subjects' discharge location (home vs chronic care facility),

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Department of Child Services involvement, which is Indiana's state government agency responsible for addressing child abuse or neglect, and home skilled nursing availability. Outcome data were obtained for the first year after hospital discharge, which included subjects' emergency department visits, number of readmissions, hospital days per readmission, mortality, and serious morbidity, which included survived cardiac arrest, stroke, anoxic brain injury, and unplanned hospital admission requiring surgical intervention. Financial data were also obtained from Medicaid for each subject because all of our cohort subjects were supported by Indiana Medicaid. These data included all Medicaid charges for each subject's initial hospitalization and for subsequent readmissions to Indiana University facilities. Costs to the hospital were also obtained and are defined as a hospital-specified factor of each Medicaid charge. Itemized charges related to nursing, radiology, respiratory, pharmacy, lab, physical and occupational therapy, surgery, pulmonary, and emergency charges were collected. All financial data represent direct costs, which include procedures, medications, imaging, etc., that are directly provided to the subject; the financial data do not include indirect costs such as hospital staff training, insurance, quality-assurance fees, etc. Collected data were stored in REDCap for Health Insurance Portability and Accountability Act compliance. All descriptive statistics were obtained using RStudio 3.4.3 (RStudio, Boston, Massachusetts).

We also performed a subanalysis separating the subjects who required PMV via tracheostomy for primarily respiratory diagnoses from those for primarily neurologic diagnoses. We obtained the same descriptive statistics for these groups as for the full cohort of 50 subjects. This subanalysis excluded the subjects with primarily cardiac diagnoses. Subanalysis comparisons were performed using Mann-Whitney *U* tests in RStudio 3.4.3.

Results

Subjects were identified using lists acquired from the Home Ventilation Program at Riley Hospital. Between January 1, 2015, and December 31, 2017, a total of 87 patients were identified. Fourteen of these patients were excluded because we were unable to obtain a full financial analysis from Medicaid at the time the study was performed because the 1-y follow-up data were not available. Eight patients were excluded due to the patients' tracheostomy being performed at another hospital prior to transfer to our institution. Seven patients had the tracheostomy performed prior to 2015 and were discharged in 2015. Four patients had a tracheostomy placed prior to admission and were only admitted to initiate PMV. Two patients were enrolled in the chronic ventilation program but were discharged on tracheostomy collar only. One patient was admitted only for re-cannulation after previously being de-cannulated. One patient died prior to discharge. Thus, a final cohort of 50 subjects were included in the study analysis.

Table 1. Subject Characteristics

Male	33 (66)
Pre-term	27 (54)
Ethnicity	
White	26 (52)
Black	16 (32)
Hispanic	4 (8)
Other	4 (8)
Primary language of caregiver	
English	47 (94)
Spanish	3 (6)
Marital status of mother	
Married	28 (56)
Single	22 (44)
Average age of mother at time of birth, y	28.3
Mother's employment status at time of birth	
Unemployed	26 (52)
Second caregiver	
Father	36 (72)
Other family member living in the home	6 (12)
Difficulty identifying second caregiver	4 (8)
Non-relative	2 (4)
Relative living outside the home	2 (4)

N = 50 subjects. Data are presented as *n* (%) except average age of mother at time of birth.

Table 2. Subgroup Characteristics

	All	Respiratory	Neurologic	Cardiac
Subjects, *n*	50	34	14	2
Male, *n* (%)	33 (66)	24 (71)	9 (64)	0 (0)
Median age at tracheostomy placement, months	4.5	4.5	24	6
Subject < 12 months old, *n* (%)	41 (82)	32 (94)	7 (50)	2 (100)

Table 1 outlines the general characteristics of our study population. The majority of our subjects (82%) were < 1 y old at the time of their tracheostomy placement, with a median age of 4.5 months. Table 2 displays the characteristics of the subgroups, separated by the primary diagnosis requiring PMV via tracheostomy tube. The majority of our subjects (68%) required PMV via tracheostomy tube for a primarily respiratory diagnosis. Eighteen of these subjects had bronchopulmonary dysplasia as the subject's primary respiratory diagnosis, 5 subjects had chronic lung disease, 4 had congenital diaphragmatic hernias, 3 had ARDS, 3 had pulmonary hypoplasia, and 1 subject had severe obstructive sleep apnea. Of the subjects with primarily neurologic diagnoses, 4 had a neuromuscular

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Table 3. Time to Event

	All	Respiratory	Neurologic	*P*
Subjects, *n*	50	34	14	
Admission to tracheostomy, d	79	91	44.5	<.001
Decision to proceed with tracheostomy placement to surgical procedure, d	8.5	8.2	9.5	.69
First tracheostomy change, d	4.8	5	4.4	.43
Tracheostomy to discharge, d	78	89	50	.02

Table 4. Initial Hospitalization Costs and LOS for New Tracheostomy and PMV

	All	Respiratory	Neurologic	*P*
Subjects, *n*	50	34	14	
Cost, $				
Total	31,133,582	24,090,990	5,231,486	
Average	622,671	708,559	373,678	<.001
LOS, d				
Total	7,762	6,082	1,320	
Average	155	179	94	<.001

LOS = length of stay
PMV = prolonged mechanical ventilation

Table 5. Readmissions and Hospital-Free Days in the First Year After Discharge

	All	Respiratory	Neurologic
Subjects, *n*	50	34	14
Readmissions			
Average, no.	2.16	2.15	2.43
Average cost, $	73,144	72,259	85,587
First month, *n* (%)	19 (38)	17 (50)	2 (14)
First 3 months, *n* (%)	27 (54)	18 (53)	8 (57)
First 12 months, *n* (%)	38 (76)	27 (79)	10 (71)
Hospital-free days, d			
Average	307	319	269
Median	356.5	358	326

disorder, 4 had a genetic or metabolic syndrome, 4 had severe cerebral palsy, and 2 subjects had hypoxic ischemic encephalopathy. On average, the respiratory group was younger at the time of tracheostomy placement than the neurologic group with a median uncorrected gestational age of 4.5 months compared to 24 months, respectively. The 2 cardiac subjects were such a small proportion of our population that they were not analyzed as a separate subgroup, although they are included in the total analysis.

T3,AQ:F Table 3 shows the average time in days between major events in our cohort as they progressed through initial hospitalization. The first time point is the time between hospital admission and the tracheostomy placement. Second is the time between the medical team and family coming to a decision to proceed with a tracheostomy placement and when the procedure occurred. Third is the time between the tracheostomy placement and the first tracheostomy tube change. The final time is between the tracheostomy placement and discharge from the hospital. The comparison *P* value is between the 2 subgroups and indicated that the respiratory group had a significantly longer average time between hospital admission and tracheostomy placement, as well as between tracheostomy placement and hospital discharge. Other hospital characteristics include the majority of subjects being admitted initially to the neonatal ICU rather than to the pediatric ICU (72% vs 26%, respectively), with only 1 subject admitted to the floor. Pediatric ear, nose and throat specialists performed the majority of the tracheostomies compared to pediatric general surgery (78% vs 22%, respectively).

Table 4 illustrates both the initial hospitalization costs and stay data for our subject population. The total data for the whole population is given, as well as the subgroup comparison. The neurologic subjects had significantly lower average hospital costs and stay.

When evaluating the itemized charges for these subjects, we found that the respiratory subjects had significantly higher charges for nursing ($P < .001$), respiratory ($P < .001$), pharmacy ($P = .02$), physical therapy and occupational therapy ($P = .01$), and laboratory care ($P < .01$) than did the neurologic subjects. However, when adjusting for the subjects' overall LOS and calculating these charges per day, these differences were not seen. All itemized charges, when measured per patient day, were found to have no significant difference between the 2 groups. There was no difference in the charges for radiology, surgery, pulmonology, or emergency care between the 2 groups.

Our study population had variability in their discharge destination as well as in the availability of home nursing. Forty-five (90%) of our subjects were discharged to home, and the remaining 5 (10%) subjects were discharged to a long-term care facility. Thirty-six (72%) of our subjects had home nursing approved prior to discharge, and 8 (16%) subjects had Department of Child Services involvement at some point during their initial hospitalization.

Table 5 displays the readmission rates, costs, and hospital-free days of our subject population. Although it appears that the neurologic subjects had higher readmission costs and fewer hospital-free days, these comparisons were not significantly different given our current data ($P = .07$). It is possible, however, that a larger sample size may provide the statistical power to detect a difference.

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Eight subjects died within the first year of discharge, for a 16% mortality rate. The causes of death included 3 compassionate withdrawals of mechanical support (1 in the setting of a newly diagnosed critical illness, and 2 because the families did not appreciate any significant recovery and chose to allow natural death), 2 due to tracheostomy tube dislodgement leading to respiratory and subsequently cardiac arrest, 2 due to cardiac arrests at home of uncertain etiologies, and 1 due to stroke that left the subject brain dead. Mortality rates were 12% in the respiratory group (4 of 34 subjects) compared to 29% in the neurologic group (4 of 14 subjects). These rates were not significantly different on hypothesis testing ($P = .21$). A total of 12 subjects had a serious morbidity, which was defined as either a successfully resuscitated cardiac arrest, tracheostomy dislodgement leading to respiratory arrest, a stroke or hypoxic-ischemic encephalopathy, an unplanned ICU admission requiring a surgical intervention, or death. The serious morbidity rates were also different, with 6 subjects in each group having a serious morbidity. This gives rates of 18% for the respiratory group and 43% for the neurologic group, which was also shown to be nonsignificant on hypothesis testing ($P = .14$). It is likely, however, that both the mortality rates and the serious morbidity rates are different between the respiratory and neurologic groups, but a larger sample size is needed to adequately detect them.

Discussion

This study not only offers a rare epidemiological outline for a unique and growing cohort of pediatric patients requiring PMV, but it also provides quantifiable data regarding the monumental resource burden this emerging patient population can be to the health care system. With regard to the epidemiology of our study, our findings are similar to previous studies in that the majority of these subjects were < 1 y old and they required PMV for the management of primarily respiratory diseases.[20,22] Our financial data indicate that the average cost to the hospital for caring for a single child requiring a tracheostomy and PMV was > $600,000 for the initial admission. Previous studies, and most intensive care providers' anecdotal experience, take note of the lengthy admissions and slow progress of this patient population toward discharge. Although the dramatic hospital LOS have been touted in the literature, seeing the staggering in-patient hospital costs may motivate providers and hospital administrators to find new ways to help these patients navigate their hospital stays more efficiently. It has been reported that several in-patient and out-patient interventions have been successful in providing more efficient and cost-effective care for this patient population.[23,24] The results of our study may help hospital systems prioritize these types of interventions in the future to provide not only more efficient care, but also more effective care for these patients.

The 1-y follow-up data we have described is consistent with previous literature reports. These subjects had frequent and costly readmissions, with > 75% of our subjects being readmitted during the first year. The 1-y mortality rate of these subjects was also relatively high compared to the general population at 16%; although this rate is lower than the rates reported in a few other studies of this population, this is only a 1-y mortality rate, whereas other studies provide mortality rates over 5 or more years.[12,25,26] This continues to emphasize that, despite long hospitalizations requiring rigorous caregiver training and copious resource utilization, these patients continue to struggle with their underlying diseases as well as the risks inherent with managing a home ventilator.

By analyzing the data between respiratory and neurologic subgroups, we identified several differences between the 2 groups. The subjects with neurologic conditions were typically older than those with respiratory conditions. This is likely due to the higher number of premature infants with bronchopulmonary dysplasia who more frequently require tracheostomies and PMV. We also noted that, contrary to our initial hypothesis, children with primarily respiratory illnesses had, on average, longer LOS and higher hospital costs than those with primarily neurologic illnesses. There are likely many underlying reasons for this difference. Again, a large proportion of our subjects who required PMV were premature infants with bronchopulmonary dysplasia who, secondary to their prematurity, require prolonged hospitalization to establish feeding plans, stable growth, and sustained adequate lung function before any attempt at discharge can be made. It can also be difficult for providers to determine which patients with bronchopulmonary dysplasia will require a tracheostomy and PMV because many will have improved lung function over time and can be discharged without the need for PMV. Several of our subjects with neurologic conditions were admitted as teenagers and, due to their declining overall health, required a tracheostomy and PMV. It is often a more straight forward decision for providers to determine whether this population will require PMV, and so these patients are frequently admitted to the pediatric ICU and discharged in far less time than a premature infant with bronchopulmonary dysplasia.

There are significant ethical considerations when determining which patients are appropriate for PMV at home, particularly patients with severe neurologic injury. In our organization, all patients are offered a palliative care consult before proceeding with this decision. Furthermore, these patients are discussed in a weekly multidisciplinary team meeting called Pediatric Ethics and Communication Excellence (PEACE). Palliative care physicians, nurses, respiratory therapists, social workers, medical ethicists, and intensivists attend this meeting. Any concerns that the group

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identifies are discussed by the palliative care and ICU teams with the family.[27]

When evaluating the itemized charges for our subjects, we found no significant differences between the 2 groups when adjusted per subject day. This finding illustrates that the subjects' inherent medical conditions were not necessarily the key drivers of the overall hospital cost, rather the length of the subjects' stay was more likely the primary contributor.

Our study has several limitations. It is a retrospective study, which make it prone to bias. Also, our cohort included only 50 subjects, which limits the statistical power to detect smaller differences between the subgroups. It is of note that several of the subject variables described in this study (ie, timing of tracheostomy placement, transition of care from neonatal ICU to pediatric ICU, discharge education) are all heavily influenced by our institution's specific practices, culture, and unit-specific logistics. As a single center located in the central United States, our findings may not be widely generalizable, particularly to other health care systems outside of the United States. Although our study's generalizability is limited, it does provide an example that can be compared to other institutions' experiences and contributes to the overall knowledge of caring for this patient population. We were unable to gather data on length of stay or hospital costs for any patients who were admitted to a hospital outside of the Indiana University Health system, such as patients living a large geographic distance from our center. We were also unable to accurately track emergency department visits for patients who presented to outside emergency departments. However, the majority of our subjects lived close to our center and were admitted only to our center. A limitation of our cost data is that it does not include physician charges. We were able to identify which subjects had skilled nursing and which did not at discharge, but with the available data we were unable to accurately track the number of hours of skilled nursing available to these families. We also were unable to obtain specific financial data from private insurers for subjects who had private insurance. However, $< 20\%$ of our subjects had any amount of private insurance, and all were eventually enrolled in Indiana Medicaid. A final limitation is that this study was performed from a single center, and Medicaid data may be highly variable at other institutions around the country.

Conclusions

Although the demographics and the medical characteristics of this subject cohort are similar to previous reports in the literature, we offer the first glimpse into the complicated landscape of the health care costs associated with a pediatric cohort of subjects with PMV. We conclude that those requiring PMV for primarily neurologic diagnoses had shorter hospital LOS and lower hospital costs than those with primarily respiratory diagnoses. No definitive differences in outcomes were found. This study opens a great opportunity for consideration of care-effectiveness projects aimed to reduce these patients' length of hospital stay.

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