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Two-Year Mortality, Complications, and Healthcare Use in Children With Medicaid Following Tracheostomy

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Objectives/Hypothesis: To assess patient characteristics associated with adverse outcomes in the first 2 years following tracheostomy, and to report healthcare utilization and cost of caring for these children.

Study Design: Retrospective cohort study.

Methods: Children (0–16 years) in Medicaid from 10 states undergoing tracheostomy in 2009, identified with International Classification of Diseases, Ninth Revision, Clinical Modification procedure codes and followed through 2011, were selected using the Truven Health Medicaid Marketscan Database (Truven Health Analytics, Inc., Ann Arbor, MI). Patient demographic and clinical characteristics were assessed with likelihood of death and tracheostomy complication using chi-square tests and logistic regression. Healthcare use and spending across the care continuum (hospital, outpatient, community, and home) were reported.

Results: A total of 502 children underwent tracheostomy in 2009, with 34.1% eligible for Medicaid because of disability. Median age at tracheostomy was 8 years (interquartile range 1–16 years), and 62.7% had a complex chronic condition. Two-year rates of in-hospital mortality and tracheostomy complication were 8.9% and 38.8%, respectively. In multivariable analysis, the highest likelihood of mortality occurred in children age < 1 year compared with 13+ years (odds ratio [OR] 7.3; 95% confidence interval [CI], 3.2–17.1); the highest likelihood of tracheostomy complication was in children with a complex chronic condition versus those without a complex chronic condition (OR 3.3; 95% CI, 1.1–9.9). Total healthcare spending in the 2 years following tracheostomy was $53.3 million, with hospital, home, and primary care constituting 64.4%, 9.4%, and 0.5% of total spending, respectively.

Conclusion: Mortality and morbidity are high, and spending on primary and home care is small following tracheostomy in children with Medicaid. Future studies should assess whether improved outpatient and community care might improve their health outcomes.

Key Words: Tracheostomy, Truven MarketScan Medicaid Database.

Level of Evidence: 4.

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INTRODUCTION

Over the last decades, tracheostomy has been increasingly performed in children with complex healthcare needs, including children with upper airway obstruction, those unable to breathe independently requiring long-term ventilation, and those with multiple complex and chronic conditions.[1–4] The health problems experienced by these children are associated with ongoing care burden, risk of adverse health outcomes, and significant healthcare utilization.

In adult patients, much is known about the life experience associated with tracheostomy, the potential for adverse outcomes, and associated healthcare costs.[4,5] However, less is known regarding such issues in children following tracheostomy.[6–8] Nearly 8% of children do not survive the hospital stay when tracheostomy is performed.[9,10] The majority of deaths are not tracheostomy-related but rather secondary to the child's underlying chronic conditions.[10,11] Between 15% to 19% of children experience a tracheostomy-related complication.[9,12] Some children experience recurrent hospitalizations because of these complications as well as their fragile health status.[1,9]

Counseling families on the risks and benefits of tracheostomy, and what to expect from the health system afterward for their child, is challenging. This is largely because the children experience a heterogeneous array of relatively rare, chronic conditions that make it difficult to project their prognosis. Most single-centered studies in children with tracheostomy have sample sizes that limit the ability to assess how specific patient characteristics affect health outcomes.[13,14] These studies might

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also be heavily influenced by center-specific practices and reflect regional resource variability. Although it is known that some children with tracheostomy are prone to high hospital use,[1,9] there is a paucity of information on their use of other health services in the system (e.g., primary care, emergency department care, home healthcare).

The objectives of this study were to 1) describe the characteristics of children assisted with tracheostomy captured by a Medicaid database, 2) identify patient characteristics that correlate with adverse outcomes in the first 2 years following tracheostomy, and 3) report healthcare utilization and cost of caring for children in the first 2 years following tracheostomy. Such information may improve our understanding of the comprehensive needs of these children and set a baseline against which to measure the success of future interventions designed to optimize the quality of care and health outcomes of children with tracheostomy.

MATERIALS AND METHODS

Study Design and Setting

This is a retrospective cohort analysis of the Truven Health Medicaid Marketscan Database (Truven Health Analytics, Inc., Ann Arbor, MI) from 2009 to 2011. The Marketscan Medicaid Multistate Database (Truven Health Analytics) contains the pooled healthcare experience of approximately 7 million Medicaid enrollees from 12 contributors; seven state contributors, and five Medicaid health plans from multiple geographically dispersed states. It contains comprehensive claims data across the care continuum, including paid claims and encounter data for health services and prescription drug and durable medical equipment claims. The Truven database is de-identified and fully compliant with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Because this study did not involve the collection, use, or transmittal of individually identifiable data, Boston Children's Hospital Institutional Review Board review was waived.

Study Participants

Children age 0 to 16 years who were discharged from an inpatient facility in 2009 following tracheostomy placement with continuous follow-up through 2011 were identified from International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) procedural coding for tracheostomy (31.1 or 31.2). All children were continuously enrolled in Medicaid for 11 out of 12 months during each year of the follow-up period unless death intervened.

Main Outcome Measures

The main outcome measures were in-hospital mortality and tracheostomy-related adverse events in the first 2 years following tracheostomy, excluding hospitalization when the tracheostomy was performed. Tracheostomy-related adverse events were identified from ICD-9-CM diagnosis codes for tracheotomy infection (519.01), tracheostomy-related hemorrhage or tracheoesophageal fistula (519.09), tracheal stenosis (519.02), and unspecified tracheostomy complication (519.00).

Secondary outcomes were healthcare utilization and spending that were assessed via paid claims data for health services in the first 2 years following tracheostomy, such as inpatient (excluding the hospitalization when the tracheostomy was performed), primary care, laboratory, dental, emergency room, home healthcare, durable medical equipment, specialty care, and retail pharmacy.

Patient Characteristics

Demographic variables included age at tracheostomy placement ($<$ 1 year, 1–4 years, 5–12 years, $\geq$ 13 years), gender, and race/ethnicity (white, black, Hispanic, other, or missing). Indication for tracheostomy was defined as an upper airway anomaly or other. Upper airway anomalies (748.x) included diagnoses such as subglottic stenosis (748.74); vocal cord paralysis (748.34); tracheal stenosis; and other anomalies of larynx, trachea and bronchus (748.3), as identified by ICD-9-CM diagnosis codes. Other indications for tracheostomy included prematurity, chronic lung disease, neurological impairment, and trauma.

Patient complexity was assessed with chronic condition type and number, as well as presence of a disability and use of additional medical technology beyond the tracheostomy. The presence and number of any chronic condition was assessed with ICD-9-CM codes in the Agency for Healthcare Research and Quality (AHRQ) Pediatric Chronic Conditions Indicator (CCI) and Clinical Classifications Software (CCS). The ICD-9-CM codes in the Complex Chronic Conditions (CCC)[15,16] were used to assess the presence of a complex condition. Disability was assessed from the child's eligibility for Medicaid enrollment. Medical technology assistance was assessed as the presence of other technology apart from respiratory (e.g., gastrostomy tube, ventriculoperitoneal shunt) using ICD-9-CM codes.

Statistical Analysis

We assessed patient characteristics (age at tracheostomy, gender, race/ethnicity, chronic condition type, number of chronic conditions, presence of other technology, and disability) with in-hospital mortality and tracheostomy-related adverse events using bivariable (chi-square, Wilcoxon rank-sum) and multivariable (logistic regression) analysis. We used a multivariable model to assess the adjusted odds of mortality with respect to age, race, and disability. Likewise, we assessed the adjusted odds of a tracheostomy-related complication with respect to age, chronic condition type, disability, and other technology. A multivariate model (exponential regression) was also used to assess patient characteristics (chronic condition type, presence of other technology, and disability) and cost. All analyses were conducted with a statistical significance threshold of $P < .05$ and performed using SAS version 9.3 (SAS Institute Inc., Cary, NC).

RESULTS

There were 502 children in Medicaid undergoing tracheostomy in 2009 who were identified in the Marketscan Medicaid Database (Truven Health Analytics). Median age at tracheostomy was 8 years (interquartile range [IQR] 1–16); of those, 42.0% were female and 43.0% were non-Hispanic white. Upper airway anomaly was the primary indication for tracheostomy in 27.9%. Sixty-two percent of children had a complex chronic condition, with 43.4% having $\geq$ three chronic conditions. Thirty-four percent were eligible for Medicaid because of disability. Twenty-eight percent had additional medical technology beyond tracheostomy, including gastrostomy tubes and ventriculoperitoneal shunts (Table I). The in-

TABLE I.
Demographic and Clinical Characteristics of the Study Population.

Characteristic	Finding
Demographic Characteristics	
Median (IQR) age in years at tracheostomy	8 years (1,16)
Age categories (%)	
0–11 months	37.3
1–4 years	37.3
5–12 years	17.9
≥ 13 years	7.6
Female (%)	42.0
Race/ethnicity (%)	
Hispanic	25.0
Non-Hispanic White	43.0
Non-Hispanic Black	25.1
Other	26.9
Enrolled in Medicaid because of disability (%)	34.1
Clinical Characteristics	
Number of chronic conditions (%)	
0	7.8
1	23.9
2	24.9
≥ 3	43.4
Type of chronic conditions (%)	
Non-complex	37.3
Complex	62.7
Technology assistance (%)	27.9

IQR = interquartile range.

hospital mortality rate for children in the first 2 years following tracheostomy was 9% (Table II). In the follow-up period, 38.8% of all children experienced a tracheostomy-related complication (Table III). Hemorrhage/tracheoesophageal fistula was the most common complication (37.9%).

Analysis of Patient Characteristics and Mortality

In bivariable analysis, median age (IQR) at tracheostomy placement was significantly lower in children who died versus in those who survived (1 year [IQR 0, 10] vs. 8 years [IQR 0, 16]; $P < .001$]. Two-year mortality rates varied significantly across children's race/ethnicity. Hispanic children had a higher mortality (28.0%) than non-Hispanic white (7.9%) and non-Hispanic black (8.7%) children, $P = 0.008$. Mortality also varied significantly across the children's type of chronic condition. Mortality rates were higher in children with a complex chronic condition versus in those without a complex chronic condition (12.4% vs. 2.6%, $P < 0.001$). Mortality did not vary significantly ($P \geq 0.1$) by gender, tracheostomy indication (upper airway vs. other), tracheostomy complication type, chronic condition number, eligibility for Medicaid because of disability, or the presence of other medical technology.

In multivariable analysis, the highest likelihood of mortality was observed in infants age < 1 year compared with children ages 13+ years (OR 7.3; 95% CI, 3.2–17.1), children with Hispanic ethnicity compared to non-Hispanic white (OR 4.7; 95% CI, 1.5–14.1), and in children enrolled in Medicaid because of a disability (OR 2.8; 95% CI, 1.3–5.7).

Analysis of Patient Characteristics and Tracheostomy-Related Adverse Events

In bivariable analysis, the median age (IQR) at tracheostomy placement was significantly lower in children who experienced a tracheostomy-related adverse event compared to those who did not (2 years [IQR 1, 8] vs. 12 years [IQR 3, 17]; $P < .001$). Tracheostomy-related adverse event rates varied significantly across children's race/ethnicity. Hispanic children had a higher rate of adverse events (38.9%) than non-Hispanic white (23.6%) and non-Hispanic black (28.7%) children, $P = 0.008$. Adverse event rates increased as the children's number of chronic conditions increased from 0 to ≥ 3 (13.9%–42.9%, $P < 0.001$). Adverse event rates were higher in children with a complex chronic condition versus in children without a complex chronic condition (42.4% vs. 14.8%, $P < 0.001$) and in children enrolled in Medicaid with a disability compared with another reason (45.2% vs. 26.1%, $P < 0.001$).

In multivariable analysis, the highest likelihood of tracheostomy-related adverse events was observed in

TABLE II.
Association of Two-Year Mortality With Patient Demographic and Clinical Characteristics.

	Two-Year Mortality Following Tracheostomy	
Characteristic	Yes (n = 45)	No (n = 457)
Demographic Characteristics		
Median (IQR) age in years at tracheotomy	1 year (0,10)	8 years (0,16)
Female (%)	46.7	41.6
Race/ethnicity (%)		
Hispanic	15.6	3.9
Non-Hispanic White	37.8	43.5
Non-Hispanic Black	24.4	25.2
Other	22.2	27.4
Enrolled in Medicaid because of disability (%)	44.4	33.0
Clinical Characteristics		
Number of chronic conditions (%)		
0	6.7	7.9
1	24.4	23.9
2	24.4	24.9
≥ 3	44.4	43.3
Type of chronic conditions (%)		
Noncomplex	13.3	39.6
Complex	86.7	60.4
Technology assistance (%)	35.6	27.1

IQR = interquartile range.

TABLE III.
Association of Two-Year Tracheostomy-Related Adverse Events With Patient Demographic and Clinical Characteristics.

Characteristic	Two-Year Tracheostomy-Related Adverse Event: Yes (n = 45)	No (n = 457)
Demographic Characteristics		
Median (IQR) age in years at tracheotomy	12 years (3, 17)	2 years (1, 8)
Female (%)	41.7	41.3
Race/ethnicity (%)		
Hispanic	3.5	4.9
Non-Hispanic white	48.4	32.9
Non-Hispanic black	26.1	23.1
Other	22.0	39.1
Enrolled in Medicaid because of disability	71.9	55.9
Clinical Characteristics		
Number of chronic conditions (%)		
0	9.9	3.5
1	28.7	13.3
2	25.5	23.8
≥ 3	35.9	59.4
Type of chronic conditions (%)		
Noncomplex	49.3	18.2
Complex	50.6	81.8
Technology assistance (%)	21.7	39.1

IQR = interquartile range.

children ages 1 to 4 years versus 13+ years (OR 4.0; 95% CI, 2.4–7.5), children with a complex chronic condition versus those without a complex chronic condition (OR 3.3; 95% CI, 1.1–9.9), and children with additional medical technology versus those additional medical technology (OR 2.0; 95% CI, 1.3–3.3), $P < 0.01$ for all.

Healthcare Utilization and Spending

Total healthcare spending in the 2 years following tracheostomy for the 502 children in our study was $53.3 million, of which 64.5% ($34.4 million) was spent on hospital care (not including the hospitalization when tracheostomy occurred) (Table IV). The median (IQR) cost was $27,335 ($1,643–$112,608) over the 2-year period, with 50.3% in the first 6 months, 22.4 % in the second 6 months, and 27.4% in the second year. Fifty-six percent (56.4%) of children experienced at least one hospital admission in the 2 years following tracheostomy; hospitalized children experienced a median of two (IQR 1–4) admissions that collectively cost a median $60,704 (IQR $20,012–$149,016). A tracheostomy complication was listed as the primary diagnosis in only 4.5% of these hospitalizations. Respiratory (41.2%), gastrointestinal (6.5%), neurological (10.4%), and other (37.4%) health problems were the primary diagnoses in the remaining admissions. Beyond hospital care, examples of health services that accounted for the remainder of spending included specialty care (10.8%, $5.7 million), home healthcare (9.4%, $5.0 million), pharmacy (4.7%, $2.5 million), durable medical equipment (1.7%, $.9 million), emergency department (0.6%, $0.3 million), and primary care (0.5%, $0.2 million) (Table IV). Of note, 19.7% of children did not have a visit with a primary care physician, and 62.4% did not use home healthcare services in the 2-year follow-up period (Fig. 1).

In multivariate analysis, the mean cost of children with tracheostomy and a complex chronic condition was 138% higher (92.38; 95% CI, 1.6–3.5) than that of children without a chronic condition, and the mean cost of children with additional medical technology was 68% higher (91.68; 95% CI, 1.4–2.1) compared to children without additional medical technology, $P < 0.01$ for all (Table V).

DISCUSSION

This study complements existing literature by reporting 1) patient characteristics associated with in-

TABLE IV.
Association of Two-Year Tracheostomy-Related Health Service Utilization

Health Service	% of Children Utilizing	Health Service Use: Median (IQR) Number of Visits	Median (IQR) Cost per Patient ($)
Inpatient	56.4	2 [1, 4]	60,703 [20,012, 149,016]
Specialty care	85.1	31 [7, 132]	3,447 [542, 17,865]
Home health	37.6	15 [6, 207]	4,119 [1456, 51,561]
Pharmacy	90.2	11 [6, 19]	1,192 [204, 4,625]
Therapy	69.5	24 [7, 62]	3,291 [1071, 7,432]
Rehabilitation/other care	73.7	9 [3, 20]	651 [241, 1,401]
Medical equipment	60.4	24 [7, 50]	2,210 [645, 4,589]
Testing	84.5	17 [7, 36]	780 [285, 17,77]
Mental health	43.6	12 [4, 36]	1,038 [264, 2,639]
Emergency department	60.8	9 [4, 20]	632 [266, 1,367]
Primary care	81.3	9 [4, 17]	467 [199, 855]
Dental	33.3	5 [3, 11]	159 [80, 445]

IQR = interquartile range.

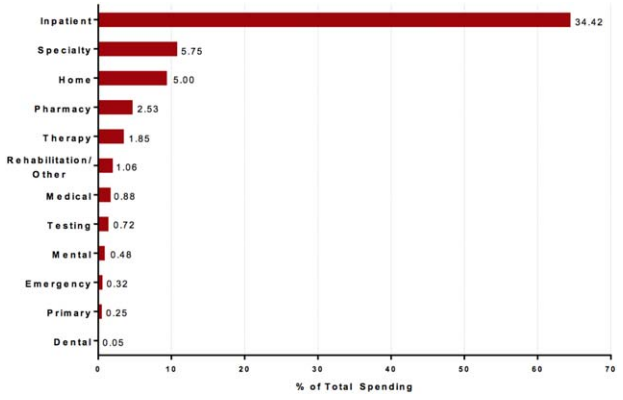

Fig. 1. Percent of total spending for health resource users and total aggregate cost in $millions. [Color figure can be viewed in the online issue, which is available at www.laryngoscope.com.]

hospital mortality and tracheostomy adverse events in children in the first 2 years following tracheostomy, and 2) healthcare use and spending across the care continuum associated with caring for these children during this time. The findings from the study suggest that morbidity and mortality can be high following tracheostomy in children, especially for those children with underlying complex chronic conditions. The findings also suggest that most healthcare spending for children with tracheostomy goes to hospital care, with a much smaller amount spent on outpatient and community care such as primary care and home healthcare.

As evidenced in other studies,[1–4] the children in our cohort were very medically complex, with 62% having a complex chronic condition, 43% having three or more chronic conditions, and 29% having medical technology in addition to tracheostomy. For many of these children, we speculate that tracheostomy may be required for a number of years, if not a lifetime, with a need for long-term, complex tertiary care and labor-intensive home care, especially in those children requiring chronic ventilatory support. Guidance and counseling for the families of these children with multiple chronic diagnoses on what to expect long-term following tracheostomy has always been challenging. The data presented in this study may allow a greater understanding with respect to which children are at higher risk for substandard health outcome, as well as how much healthcare spending is occurring to care for these children in the first 2 years after tracheostomy.

Both in-hospital mortality (9%) and tracheostomy complication (39%) were high following tracheostomy in children with Medicaid. These findings are congruent with other national studies on pediatric tracheostomy, which have reported an overall mortality rate of 7%.[10,14] In the present study, children of younger age (< 1 year) at the time of tracheostomy placement, children of Hispanic ethnicity, and children with more complex chronic condition type all had increased likelihood of death. This was particularly striking in the multivariable analysis with children under the age of 1 year having more than a seven-fold increased odds of mortality compared to older children (OR 7.3; 95% CI, 3.2–17.1). For the first time, we identified that children enrolled in Medicaid due to disability also showed increased mortality in the multivariable analysis (OR 2.8; 95% CI, 1.3–5.7). Previous studies have identified a lower mortality in children with an upper airway anomaly following tracheostomy[9]; however, in our study there was no significant difference between the two groups with mortality rates of 11.4% and 8.0% in the upper airway and other group, respectively.

We were not able to identify the exact cause of in hospital mortality; however, in keeping with other studies, we speculate that the vast majority of deaths in children with tracheostomy are probably not tracheostomy-related but rather secondary to the child's underlying diagnosis and clinical characteristics.[17–21] Of the children who had a tracheostomy complication (38.8%), mortality was low (4.1%), suggesting that death in all children was not tracheostomy-related in the majority of patients. Similar patient characteristics were also associated with tracheostomy-related adverse events, with an increased incidence in children aged 1 to 4 years, children with a complex chronic condition, and also children with additional medical technology. Likewise, in the 56.4% of patients who had a least one-hospital readmission in the 2-year period following tracheostomy, a tracheostomy-related complication was the primary diagnosis for readmission in only 4.5% of these patients, again demonstrating the complexity of this patient group.

This study was performed using healthcare utilization data across the care continuum, allowing us to analyze spending by service types in caring for these children from a comprehensive perspective. The main strength of this approach is the payment information: the actual paid dollars by the insurer. A clear disproportionate allocation of funds was identified, with the majority spent on hospital care following tracheostomy. It is well recognized that children with tracheostomy are at risk for recurrent hospitalizations due to tracheostomy-related complications and respiratory infections.[22–24] One study reported that 11% of children required four or more hospitalizations

TABLE V.
Multivariate Analysis of Patient Characteristics and Costs in Children With Medicaid Undergoing Tracheotomy in 2009.

Effect	Estimate	Lower 95% Confidence	Upper 95% Confidence	*P* Value
Group complex chronic group vs. none	2.3845	1.6308	3.4864	< .0001
Group noncomplex chronic group vs. none	1.2244	0.825	1.8171	0.3141
Group blind/disabled vs. not	1.2679	1.0378	1.549	0.0203
Other technology present vs. not	1.6819	1.3639	2.0741	< .0001

Estimates are ratios of means.

within 6 months after tracheostomy.[1] Another study observed a 30-day readmission rate of 52% in children under 1 year of age after tracheostomy. [25]

As previously noted, children with tracheostomy in the community have increased medical needs due to their medical complexity, and it is expected that the families of these children have a close relationship with their primary care and are availing of necessary home care services. However, to our surprise, 19.7% of children in our study did not have a visit with a primary care physician, and 62.4% did not use home health services in the 2-year follow-up period. Spending on primary (0.5%, $0.2 million) and home care (9.4%, $5.0 million) was extremely small compared with spending on hospital care (64.4%, $34.4 million). Of the 37.6% of patients who received home healthcare services at least once, the median cost per patient was $4,119 (IQR $1456.8, $51561.7), with a median of 15 visits.

The explanation for this disproportionate spending remains unclear. It could possibly be secondary to the inability of claims-based data to provide information on a host of attributes that are presumed more common in the Medicaid population than in the commercially insured, including low income, lower education, and social/financial instability.[26,27] Reported multi-institutional studies on children with tracheostomy do not adjust for these factors; however, disparities in care related to race and income have been widely reported in adult Medicaid studies.[28,29] Additional family and societal costs of the missed work of caregivers during their child's hospitalization (absenteeism) and altered productivity (presenteeism) when parents are coordinating care while in the work place, notable given the lack of primary care contact, also remain unmeasured.

From a policy as well as a quality perspective, the data in this study suggest that more attention on primary, outpatient care, and homecare services might be necessary when caring for children with tracheostomy in Medicaid. It is well reported that there is substantial variability in the surveillance and management of children with tracheostomy, with many receiving disorganized and fragmented care from multiple providers.[30,31] The lack of coordinated multidisciplinary care for these children with Medicaid in the community may undoubtedly be contributing to the increased number of hospitalizations and associated high inpatient hospital claims. Many children with tracheostomy have chronic ventilation support needs and would benefit from enhanced outpatient and community care following discharge after tracheostomy placement. This study does not specifically address the increased needs of children with ventilator dependence, and future studies focused on analyzing this data from administrative database are paramount. It is possible that if greater spending was allocated to these areas, and that if these children experienced effective transitional nursing and homecare, subsequent hospital readmissions, inpatient charges, mortality, and morbidity might be reduced.[32] Multiple studies advocating a multidisciplinary team approach in caring for patients with tracheostomy have shown great success in improvement of health outcomes and reduction of adverse events.[33–36] Although these studies have been reported in adults, it seems plausible that children with tracheostomy would benefit from a similar coordinated approach.

We identified patients of younger age, Hispanic ethnicity, and increasing medical complexity as having increasing risk of mortality and adverse events in the 2 years following tracheostomy. Clinical programs identifying such patients as high risk on hospital discharge and in the community may lead to the avoidance of predictable adverse events with subsequent hospital readmissions.[37,38] A recent study by Mosquero et al. examined how an enhanced medical home setting that provided comprehensive care to prompt effect care versus usual care in high-risk children with chronic illness reduced the incidence of serious illness and hospital costs.[39] Quality of care for children and parent satisfaction were substantially increased in this study, but they reported that the benefits and savings identified seem likely to be achievable only in high-risk populations treated in major academic centers with the necessary subspecialists, resources, and clinician commitment. Such medical homes may potentially be the most cost-effective for high-risk patients, such as children with tracheostomy; however, payments required to develop and sustain such programs may not be forthcoming unless they are shown to improve outcomes with no increase in current costs.[38,40,41] Similar findings were also reported by Berman et al.; enrollment of children with multisystem disorders in a comprehensive primary care program was associated with a decreased length of stay for nonintensive care hospitalizations.[42]

The findings in our study should be interpreted with several limitations in mind. Firstly, this is a retrospective study based on administrative claims data; therefore, the selection of patients is dependent on the accuracy and completeness of diagnostic and procedural ICD-9-CM coding, which may be influenced by variations in coding precision at different institutions and are thus susceptible to coding error and bias.[43] Secondly, administrative claims data are limited in their ability to assess the clinical reason for death, that is, whether it was related to the tracheostomy or a coexisting comorbidity. The true nature and severity of tracheostomy complications are limited to access from ICD-9-CM coding. For example, the tracheostomy ICD-9-CM code 519.09 combines tracheostomy hemorrhage with the extremely rare complication of tracheoesophageal fistula; it is not possible to identify whether bleeding episodes were minor secondary to stomal granulation versus life-threatening hemorrhage.

We were able to identify in-hospital mortality; the Medicaid data does not contain information on death for children who experienced mortality at home or at another community setting. Previous studies have shown that an increasing number of children with complex medical conditions may experience mortality outside of the hospital.[44] Therefore, the in-hospital mortality that we observed may underestimate the mortality rate in these children because we are not capturing those who died at home. It is also important to note that our healthcare costs reflect only Medicaid charges and payments, and thus estimates may be underestimated because some children with this degree of special healthcare need frequently have dual

commercial and Medicaid healthcare coverage. The generalizability of our study findings is thus limited to children with tracheostomy in Medicaid.

Despite these limitations, we hope that the findings in this study may be used by pediatric tracheostomy providers of all types to better inform families on what to expect regarding outcomes and healthcare encounters after their child receives a tracheostomy. Future investigations should consider opportunities to assess 1) how healthcare spending might be reallocated from hospital care to outpatient, community, and home care; and 2) how this reallocation may help optimize health and increase the quality of life for these children and their families while also reducing hospital costs. Additional factors that influence health outcomes and hospitalizations with more clinically detailed inpatient, outpatient, and community data need to be explored to best identify and help children with tracheostomy who are most at risk for substandard health outcomes.

CONCLUSION

Children with tracheostomy are a unique medically complex group of patients. Mortality and morbidity are high and spending on primary and home care is small following tracheostomy in children with Medicaid. Future studies should assess whether improved outpatient and community care might improve their health outcomes and reduce healthcare expenditure.

BIBLIOGRAPHY

1. Graf JM, Montagnino BA, Hueckel R, McPherson ML. Pediatric tracheostomies: a recent experience from one academic center. *Pediatr Crit Care Med* 2008;9:96–100.
2. Berry JG, Graham RJ, Roberson DW, et al. Patient characteristics associated with in-hospital mortality in children following tracheotomy. *Arch Dis Child* 2010;95:703–710.
3. Liu C, Heffernan C, Saluja S, et al. Indications, Hospital course, and complexity of patients undergoing tracheostomy at a tertiary care pediatric hospital. *Otolaryngol Head Neck Surg* 2014;151:232–239.
4. Goldenberg D, Ari EG, Danino J, Netzer A, Joachims HZ. Tracheotomy complications: a retrospective study of 1130 cases. *Otolaryngol Head Neck Surg* 2000;123:495–500.
5. Shah RK, Lander L, Berry JG, Nussenbaum B, Merati A, Roberson DW. Tracheotomy outcomes and complications: a national perspective. *Laryngoscope* 2012;122:25–29.
6. Graham RJ, Rodday AM, Parsons SK. Family-centered assessment and function for children with chronic mechanical respiratory support. *J Pediatr Health Care* 2014;28:295–304.
7. Glass KC, Carnevale FA. Decisional challenges for children requiring assisted ventilation at home. *HEC Forum* 2006;18:207–221.
8. Lindahl B, Lindblad BM. Family members' experiences of everyday life when a child is dependent on a ventilator: a metasynthesis study. *J Fam Nurs* 2011;17:241–269.
9. Berry JG, Graham DA, Graham RJ, et al. Predictors of clinical outcomes and hospital resource use of children after tracheotomy. *Pediatrics* 2009; 124:563–572.
10. Lewis CW, Carron JD, Perkins JA, Sie KC, Feudtner C. Tracheotomy in pediatric patients: a national perspective. *Arch Otolaryngol Head Neck Surg* 2003;129:523–529.
11. Zhu H, Das P, Roberson DW, et al. Hospitalizations in children with preexisting tracheostomy: a national perspective. *Laryngoscope* 2015;125:462–468.
12. Bradley PJ. Management of the obstructed airway and tracheostomy. In: Kerr AG ed. Scott-Brown's Otolaryngology. London, UK: Butterworth & Heinmann; 1997.
13. Kremer B, Botos-Kremer AI, Eckel HE, Schlondorff G. Indications, complications, and surgical techniques for pediatric tracheostomies: an update. *J Pediatr Surg* 2002;37:1556–1562.
14. Berry JG, Lieu TA, Forbes PW, Goldmann DA. Hospital volumes for common pediatric specialty operations. *Arch Pediatr Adolesc Med* 2007;161: 38–43.
15. Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980 –1997. *Pediatrics* 2000;106:205–209.
16. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, Koepsell TD. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics* 2001; 107:E99.
17. Carter P, Benjamin B. Ten-year review of pediatric tracheotomy. *Ann Otol Rhinol Laryngol* 1983;92:398–400.
18. Primuharsa Putra SH, Wong CY, Hazim MY, Megat Shiraz MA, Goh BS. Paediatric tracheostomy in Hospital University Kebangsaan Malaysia: a changing trend. *Med J Malaysia* 2006;61:209–213.
19. Dempster JH, Dykes EH, Brown WC, Raine PA. Tracheostomy in childhood. *J R Coll Surg Edinb* 1986;31:359–363.
20. Rodgers BM, Rooks JJ, Talbert JL. Pediatric tracheostomy: long-term evaluation. *J Pediatr Surg* 1979;14:258–263.
21. Kremer B, Botos-Kremer AI, Eckel HE, Schlondorff G. Indications, complications, and surgical techniques for pediatric tracheostomies: an update. *J Pediatr Surg* 2002;37:1556–1562.
22. Perkins J Mouzakes J, Pereira R, Manning S. Bacterial biofilm presence in pediatric tracheotomy tubes. *Arch Otolaryngol Head Neck Surg* 2004; 130:339–343.
23. Brook I. Bacterial colonization, tracheobronchitis, and pneumonia following tracheostomy and long-term intubation in pediatric patients. *Chest* 1979;76:420–424.
24. Ghose R. Complications of a medically complicated child. *Ann Intern Med* 2003;39:301–302.
25. Edwards JD, Kun SS, Keens TG. Outcomes and causes of death in children on home mechanical ventilation via tracheostomy: an institutional and literature review. *J Pediatr* 2010;157:955–959.e2.
26. Krumholz HM, Normand SL, Spertus JA, Shahian DM, Bradley EH. Measuring performance for treating heart attacks and heart failure: the case for outcomes measurement. *Health Aff (Millwood)* 2007;26:75–85.
27. Keenan PS, Normand SL, Lin Z, et al. An administrative claims measure suitable for profiling hospital performance on the basis of 30- day all-cause readmission rates among patients with heart failure. *Circ Cardiovasc Qual Outcomes* 2008;1:29–37.
28. Jha AK, Orav EJ, Epstein AM. Low-quality, high-cost hospitals, mainly in South, care for sharply higher shares of elderly black, Hispanic, and Medicaid patients. *Health Aff (Millwood)* 2011;30:1904–1911.
29. Joynt KE, Orav EJ, Jha AK. Thirty-day readmission rates for Medicare beneficiaries by race and site of care. *JAMA* 2011;305:675–681.
30. Berry JG, Goldmann DA, Mandl KD, et al. Health information management and perceptions of the quality of care for children with tracheotomy: a qualitative study. *BMC Health Serv Res* 2011;11:117.
31. Zhu H, Das P, Brereton J, Roberson D, Shah RK. Surveillance and management practices in tracheotomy patients. *Laryngoscope* 2012;122:46–50.
32. Berry JG, Hall DE, Kuo DZ, et al. Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals. *JAMA* 2011;16;305:682–690.
33. Mitchell RB, Hussey HM, Setzen G, et al. Clinical consensus statement: tracheostomy care. *Otolaryngol Head Neck Surg* 2013;148:6–20.
34. Garrubba M, Turner T, Grieveson C. Multidisciplinary care for tracheostomy patients: a systematic review. *Crit Care* 2009;13:R177.
35. Cetto R, Arora A, Hettige R, et al. Improving tracheostomy care: a prospective study of the multidisciplinary approach. *Clin Otolaryngol* 2011; 36:482–488.
36. Hettige R, Arora A, Ifeacho S, Narula A. Improving tracheostomy management through design, implementation and prospective audit of a care bundle: how we do it. *Clin Otolaryngol* 2008;33:488–491.
37. Cohen E, Jovcevska V, Kuo DZ, Mahant S. Hospital-based comprehensive care programs for children with special health care needs: a systematic review. *Arch Pediatr Adolesc Med* 2011;165:554–561.
38. Schwenk TL. The patient-centered medical home: one size does not fit all. *JAMA* 2014;311:802–803.
39. Mosquera RA, Avritscher EB, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial. *JAMA* 2014;312: 2640–2648.
40. Agrawal R, Shah P, Zebracki K, Sanabria K, Kohrman C, Kohrman AF. Barriers to care for children and youth with special health care needs: perceptions of Illinois pediatricians. *Clin Pediatr (Phila)* 2012;51:39–45.
41. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med* 2011;165:1020–1026.
42. Berman S, Rannie M, Moore L, Elias E, Dryer LJ, Jones MD Jr. Utilization and costs for children who have special health care needs and are enrolled in a hospital-based comprehensive primary care clinic. *Pediatrics* 2005;115:e637–e642.
43. Miller ML, Wang MC. Accuracy of ICD-9-CM coding of cervical spine fractures: implications for research using administrative databases. *Annu Proc Assoc Adv Automot Med* 2008;52:101–105.
44. Feudtner C, Feinstein JA, Satchell M, Zhao H, Kang TI. Shifting place of death among children with complex chronic conditions in the United States, 1989–2003. *JAMA* 2007;297:2725–2732.