Title

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Children and young adults who received tracheostomies or were initiated on long-term ventilation in pediatric ICUs

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Abbreviations

CCC	complex chronic condition
CPAP	continuous positive airway pressure
CRF	chronic respiratory failure
IQR	interquartile range
IV	invasive ventilation
LOS	length of stay
NIV	noninvasive ventilation
PCPC	Pediatric Cerebral Performance Category
PIM	Paediatric Index of Mortality
PICU	pediatric intensive care unit
POPC	Pediatric Overall Performance Category
VPS	Virtual Pediatric Intensive Care Unit Systems

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Abstract

Objectives: To characterize patients who received tracheostomies for airway compromise or were initiated on long-term ventilation for chronic respiratory failure in pediatric intensive care units (PICU), and to examine variation in the incidence of initiation, patient characteristics, and modalities across sites.

Design: Retrospective cross-sectional analysis.

Settings: Seventy three North American PICUs that participated in the Virtual Pediatric Intensive Care Unit Performance System.

Patients: PICU patients admitted between 2009 and 2011.

Interventions: None.

Measurements and Main Results: Among 115,437 PICU patients, 1.8% received a tracheostomy or were initiated on long-term ventilation; 1034 received a tracheostomy only, 717 were initiated on invasive ventilation (IV), and 381 were initiated on noninvasive ventilation (NIV). Ninety percent had substantial chronic conditions and comorbidities, including more than 50% with moderate or worse cerebral disability upon discharge. Seven percent were initiated after a catastrophic injury/event. Across sites, there was variation in incidence of tracheotomy and initiation of long-term ventilation, ranging 0–4.6%. There also was variation in patient characteristics, time to tracheotomy, number of extubations prior to tracheostomy, and the use of IV versus NIV.

Conclusions: While the PICU incidence of initiation of tracheostomies and long-term ventilation was relatively uncommon, it suggests that thousands of children and young adults receive these interventions each year in North American PICUs. The majority of them have conditions and comorbidities that impose on-going care needs, beyond those required by artificial airways and long-term ventilation themselves.

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Introduction

Technology-dependent children require a device to compensate for the loss of a vital body function and daily skilled care to avert further disability, hospitalization, and death (1). Tracheostomies for airway patency and invasive ventilation (IV) and noninvasive ventilation (NIV) for chronic respiratory failure (CRF) may be the most demanding and precarious of dependencies. In many instances, these interventions improve and prolong the child's life. However, these dependencies and their associated care needs can also impact their families and the healthcare system (2-5). Determining which children are appropriate candidates for tracheostomies or long-term ventilation (LTV) can sometimes be controversial, especially when the children have profound disabilities and/or life-limiting conditions (6-7). Because children who require these interventions are often survivors of critical illness, they are often initiated in intensive care settings, such as pediatric intensive care units (PICU).

Most studies of children receiving tracheostomies or initiated on LTV have been from a single-institution (8-10) or focused on patients receiving tracheostomies (11-14). Previous studies often group patients that received tracheostomies together without differentiating those supported by IV or patients receiving LTV without differentiating those using IV and NIV. They also group these complex patients into overly broad diagnostic categories and provide limited detail about their comorbidities and the circumstances around their initiation. Thus, relatively little is known about how frequently these interventions are initiated in patients, about what types of patients are initiated, or about the variation of practice around their initiation. Examining these topics is necessary to better understand practice patterns, be capable of examining trends, and gauge the scale of potential controversial scenarios. Therefore, we conducted a multi-institutional, retrospective cross-sectional analysis of PICU patients who received tracheostomies or were initiated on long-term IV or NIV. We present their demographic and clinical characteristics, including their underlying and comorbid conditions. To explore variation of practice, we describe how the incidence of initiation and severity of disabilities among initiated patients varied across institutions and how different modalities of LTV were used. This information provides a detailed picture of a major subset of these patients and the current state of practice.

Material and Methods

Data Source and Hospitals

We performed a cross-sectional analysis of patients discharged from North American PICUs that participated in the Virtual Pediatric Intensive Care Unit Performance System (VPS, LLC, Los Angeles, CA) (15) between January 2009 and December 2011. Participating institutions submitted demographic and clinical data for every discharge. Many sites voluntarily submitted additional data for every discharge. We included sites that voluntarily reported the use of tracheostomies and noninvasive ventilation. Mechanical ventilation was a mandatory data element. To identify patients with diagnoses associated with CRF, we excluded sites that did not report secondary diagnoses. Institution-specific data on the number of licensed pediatric and PICU beds, the proportion affiliated with medical schools and pediatric critical care fellowship programs, and the quarters of data that were contributed was reported.

Tracheostomies and Initiation of Long-Term Ventilation

Included VPS sites recorded every utilization of tracheostomies, assisted mechanical ventilation (and whether it was via endotracheal tube or tracheostomy), and NIV for every respective patient. Each utilization included start and end dates/times, as well as “Present on Admission” and “Present on Discharge” flags. Criteria used to identify patients initiated on tracheostomy alone, long-term IV, or long-term NIV are listed in Table 1. While there is no universally accepted definition of CRF, we ascribed to the one in Rogers’ Textbook of Pediatric Intensive Care—“The diagnosis of CRF is usually made once repeated attempts to wean from assisted ventilation have failed for at least 1 month in a child without superimposed acute respiratory disease or a patient who has a diagnosis with no prospect of being weaned from the ventilator (such as high spinal cord injury)” (16). To establish if patients met the month of assisted ventilation criterion, length of ventilation prior to PICU discharge was determined using start and end dates/times of assisted ventilation. Patients discharged to home, chronic care facilities, non-pulmonary rehabilitation facilities, or hospice on IV or NIV were considered to be supported by LTV, regardless of their PICU length of ventilation. Presumably, patients were not aggressively weaned from assisted ventilation in these settings. We presumed that patients did not have a superimposed acute respiratory disease because the PICU team determined them to be clinically appropriate for transfer to

lower acuity care. To identify diagnoses conferring "no prospect of being weaned from the ventilator," three co-authors (JDE, TGK, HBP) scrutinized *a priori* over 2000 VPS diagnosis codes. Seven diagnoses for patients using IV and four for those using NIV were agreed upon as meeting this criterion (Table 1).

Patients and their characteristics

We included all patients regardless of age, as adults are cared for in PICUs (17). We reported characteristics of patients grouped by those who received a tracheostomy alone, those initiated on IV, those initiated on NIV, and all interventions combined. Demographic and baseline characteristics included sex, age, race (selected by data entry personnel at sites), insurance, number of complex chronic conditions (CCC), and baseline disability. Kernel Density plots were made to illustrate the overall distribution pattern of age at PICU admission for patients initiated on technologies. CCCs were defined using Feudtner's definition (18) and identified among VPS diagnoses codes using a list developed by Edwards et al (19). For functionality/disability status, VPS used Pediatric Overall and Cerebral Performance Categories (POPC and PCPC) (20). Categories range from 1 (normal function) to 6 (brain death). Scores of 2, 3, and 4 indicate mild, moderate, and severe disability, respectively; 5 indicates coma or vegetative state. Admission and discharge characteristics included planned, perioperative, patient origin and disposition, risk of PICU mortality as a proxy for severity of illness at admission, length of PICU stay, and discharge disability. Predicted mortality was estimated using Paediatric Index of Mortality (PIM) 2 (21). We reported the size of the PICUs and presence of a pediatric critical care fellowship program where patients were initiated. To identify patients likely receiving tracheostomies or initiated on LTV due to catastrophic events, we reported the number admitted for head/neck/face/spinal cord injuries, cardiac arrest, cerebrovascular events, and burns.

Next, we identified the proportion of patients with specific chronic conditions. Conditions relevant to our study population were selected based on our experience, with an emphasis on neuromuscular and pulmonary conditions. "Less" relevant conditions were combined into their organ subcategories. As a comparison group, we reported the prevalence of these same conditions among PICU patients who were not initiated/already using a tracheostomy or LTV.

Data are presented as proportions +/- 95% confidence intervals, medians with ranges, or means with standard deviations. When information was available for only a subgroup of the patients, we noted this in the text or tables.

Variation of practice

To examine variation in the incidence of initiation of tracheostomies and LTV across sites, we calculated the median proportion and ranges of patients initiated on each technology. We constructed box plots of the time from PICU admission to tracheotomy and number of planned and unplanned extubations prior to tracheotomy to explore variability across sites. To examine the prevalence and variability of prevalence of static encephalopathy and/or generalized developmental delay in initiated patients across sites, we calculated their median proportion and ranges. More granularly, we assessed the distribution of baseline and discharge POPC and PCPC by sites; only sites that initiated ≥5 patients on a respective device were represented in order to avoid skewing data with sites that initiated very few patients. Next, we examined the utilization of IV and NIV among PICUs by depicting the number of patients initiated on IV versus NIV by site. We repeated this analysis focusing on children <3 years with neuromuscular disease and no craniofacial/airway abnormalities (ie, conditions that would make caregivers favor IV over NIV). Whether to offer LTV and what modality to offer these children are debated (7, 22-24). To help ensure counts could be reasonably compared across sites, these latter two analyses included sites that contributed 10 or more quarters of data. In these analyses, sites were grouped by ICU bed size, as a surrogate marker of more tertiary units that might care for more complex patients.

Because data were deidentified, this study qualified for exemption status by the University of California, San Francisco Committee on Human Research. Stata version 13 (StataCorp LP, College Station, TX) was used for analyses and figures.

Results

Sites and patients

After excluding 66,185 patients (81,910 admissions) from 35 units, 73 PICUs contributed the required data on 115,437 patients (140,927 discharges) for analysis. Institutional characteristics of included PICUs are shown in Supplemental Digital Content Table 1. Of those patients, 1034 (0.9%) received a tracheostomy alone, 717 were initiated on IV (0.6%; 168 had a tracheostomy already in place, 549 had a tracheostomy placed during the same admission as initiation of IV), and 381 (0.3%) began NIV. Their demographic and baseline clinical characteristics are presented in Table 2. Among all three groups, 68% had $\geq$2 CCC, and 62% were enrolled in public insurance. There was a bimodal distribution of age (infants/toddlers and adolescents) for all three groups (Figure 1). Those receiving a tracheostomy alone or initiated on IV were generally younger than those initiated on NIV.

Admission and discharge characteristics of initiated patients are presented in Table 3. For all three groups, 72% of patients had unplanned PICU admissions. Eighteen patients in the tracheostomy group (1.7%) and 8 in the IV group (1%) had their tracheostomy placed within the first two days of a planned PICU admission, suggesting their initiation was planned. Fifty-seven patients who received a tracheostomy alone (5.5%) were admitted for head/neck/facial/spinal cord injuries; 19 (1.8%) for cardiac arrest; 16 (1.6%) for cerebrovascular events; and 5 (0.5%) with burns. Thirty-two (4.5%) of those initiated on IV were admitted for head/neck/facial/spinal cord injuries; 8 (1.1%) for cardiac arrest; 13 (1.8%) for cerebrovascular events; and 2 (0.3%) for burns. No patients initiated on NIV were admitted for similar injuries or events. Ten patients in the tracheostomy alone group and 23 in the IV group were previously supported by long-term NIV.

Twenty percent of IV patients and 16% of NIV patients were discharged to a chronic care or rehabilitation facility from a PICU. Just <1% of IV and NIV patients were discharged to a hospice facility. Six percent of patients in the tracheostomy group died during their PICU admission; 30% of whom met criteria for CRF. Of the 40% of patients with Pediatric Performance Categories reported, 66% and 83% had moderate or worse overall disability at baseline/admission and upon discharge, respectively. About a quarter had no cerebral disability, whereas 54% had moderate or worse cerebral disability upon discharge. Four percent of patients receiving a tracheostomy alone and 3% of those initiated on IV were discharged in a coma or vegetative state.

Chronic conditions of children receiving a tracheostomy or initiated on LTV are presented in Table 4. Forty percent of patients with tracheostomies alone and 22% of those initiated on IV had a craniofacial/airway abnormality. A quarter of patients initiated on NIV had obstructive apnea. More patients with spinal muscular atrophy and muscular dystrophies were initiated on NIV than IV. Relatively common comorbidities among all three groups included genetic syndromes, cerebral palsy, epilepsy, static encephalopathy/generalized developmental delay, and spine deformities.

Variation of practice

While the median incidence of initiating tracheostomies and LTV across sites was low, there was variability in the ranges (0–4.6%) of incidences (Table 5). Thirteen sites initiated <1% on any device; 25 sites initiated >2%. Also there was no discernable pattern of initiation comparing PICUs of different sizes or by having affiliated fellowship programs. There was variability among sites regarding the timing of tracheotomy and number of extubations prior to tracheotomy (Supplemental Digital Content Figures 1 and 2).

The prevalence of static encephalopathy/generalized developmental delay among initiated patients varied across sites. The median proportion of tracheostomy patients with these comorbidities was 12.5% (IQR 0-28.6%; range 0-100%); the median proportion among IV patients was 14.3% (IQR 0-29.3%, range 0-100%); and the median proportion among NIV patients was 9.8% (IQR 0-33.3%, range 0-100%). Supplemental Digital Content Figure 3 and 4 shows the prevalence of overall and cerebral disabilities at baseline and upon discharge, respectively, among patients for whom Performance Categories were reported. There was variation between units in the severity of disabilities in their initiated patients.

Supplemental Digital Content Figure 5 depicts the number of patients initiated on long-term IV versus NIV by sites grouped by ICU bed size, as well as the subgroup analysis of patients with early-onset neuromuscular disease. There were differences between sites in the total number of patients initiated on LTV and the number initiated on IV versus NIV. Most units more commonly initiated patients on IV, but a few initiated more on NIV.

Discussion

With improving care of critically/chronically ill children, increasing numbers are living with tracheostomies and on LTV to support airway compromise and CRF, respectively (5, 9, 25-26). Increasingly, pediatric critical care medicine is focusing on morbidity after critical illness as an outcome of interest (27). Our analysis of patients in 73 PICUs who received tracheostomies or were initiated on LTV provides details of how often these interventions occur and to whom in PICUs. Among our cohort, 1.8% of PICU patients received a tracheostomy or was initiated on LTV. Relatively few patients were initiated after catastrophic events. Very few patients were admitted for a planned tracheostomy. Rather, the majority had CCC that presumably led or contributed to their airway compromise or CRF, and most were initiated during unplanned PICU admissions and after acute/acute-on-chronic critical illness. Many chronic conditions that are commonly associated with these CRF (eg, spinal muscular atrophy and muscular dystrophy) were not highly prevalent, suggesting that the conditions that put children at risk for CRF are heterogeneous. The bimodal distribution of age of initiation of LTV is consistent with the pathophysiology of CRF where increased respiratory load or diminished ventilation capacity manifest especially in young childhood and adolescence (16, 28). Certain comorbidities (eg, epilepsy, static encephalopathy, and spine deformities) were more prevalent. Subgroup analysis showed that about a third to a half of initiated patients had severe or worse disability upon discharge, depending on the intervention. Our findings also suggest that there may have been variation in practice around how and in whom these interventions were initiated across PICUs. Collectively, this means thousands of chronically ill children and young adults receive tracheostomies or are initiated on LTV each year in North American PICUs.

Previous studies of children who receive tracheostomies or LTV reported comparable findings. Lewis et al estimated that 4861 tracheotomies were performed in U.S. pediatric patients in 1997 (0.07% of all pediatric admissions) and found that practice varied by region (11). A study of United Kingdom PICUs found a 2% incidence of tracheostomy; institutional incidence varied from 0.13 to 5.66% (12). Wakeham et al. studied tracheostomies in children in PICUs who required mechanical ventilation for ≥3 days (13). They found 6.6% of these patients received a tracheostomy (48% of whom were also

discharged on mechanical ventilator support) and significant variation in the use and timing of tracheostomy across units. Berry et al found that 48% of patients who received a tracheostomy at major children's hospitals had neurological impairment (14). Our study augments previous ones by 1) including children and young adults cared for in larger and smaller PICUs/institutions; 2) differentiating patients who received a tracheostomy alone and those initiated on long-term IV; 3) differentiating patients who were initiated on long-term NIV from those on IV; 4) being the first to apply criteria for CRF, as opposed to including all patients receiving mechanical ventilation for days or discharged on it; 4) providing greater detail on patients' chronic and comorbid conditions; and 5) providing greater detail on the variation around who and how patients were initiated.

It is important to highlight that, for many patients, these interventions improve and prolong life and are sometimes temporary (eg, patients with isolated upper airway abnormalities, bronchopulmonary dysplasia, and congenital central hypoventilation syndrome). For others, these dependencies are life-long, do not mitigate the patients' other conditions, confer their own risks (29-30), and, in some cases, can impose substantial care demands on families and the healthcare system (2-5). As a result, questions of who are appropriate candidates sometimes arise (7, 23, 31-33). Understanding who are initiated is a necessary first step to scrutinize these concerns and the care patients/families receive, as well as to analyze future trends.

This study has several limitations. First, VPS cannot identify patients with airway compromise or CRF for whom these interventions were not chosen or offered. These data are especially needed to further enlighten variation of practice. Second, we could only comment on patients initiated in PICUs. But many neonates receive tracheostomies or undergo initiation of LTV in neonatal ICUs (34-35), and many children using long-term NIV are initiated in non-ICU settings (9, 36). Nevertheless, our study captured a large, important subset of these patients. Third, unless they had previous admissions to reference, patients admitted with a tracheostomy, requiring acute mechanical ventilation, and discharged using long-term IV were considered already supported by long-term IV because we could not be certain they were not using long-term IV on admission. Similarly, patients admitted and discharged using NIV were considered to be already dependent on long-term NIV. Fourth, we could not discern between patients initiated on full- and part-time LTV. Fifth, some rehabilitation facilities may aggressively wean patients off

positive pressure ventilation, but in VPS only pulmonary rehabilitation is differentiated from more general rehabilitation and chronic care facilities. Sixth, variation in who was initiated (and how) certainly reflects many PICU and non-PICU factors, including patient factors and institutional practices to transfer patients to other hospitals with pediatric otolaryngological expertise and home mechanical ventilation programs, that could not be studied. Small numbers of patients admitted could make substantive changes in incidence numbers. Variation may also reflect differences in patient populations that presented to different sites. We attempted to address this by picking one major subgroup (children with early-onset neuromuscular disease) and stratifying sites by institutional characteristics (eg, ICU bed size, associated pediatric critical care fellowship). Seventh, discharge POPC may have been biased towards worse disability because patients were discharged dependent on a tracheostomy and/or a ventilator. Eighth, multiple sites and many admissions were excluded because they did not voluntarily report on the use of tracheostomies and noninvasive ventilation. These sites tended to be smaller units that started participating in VPS towards the end of the study period. These exclusions may bias our results towards patients seen in larger PICUs. Finally, because this was not a longitudinal cohort study, the numbers of patients who were transitioned from natural to artificial airway or one ventilation modality to another are likely under represented.

Conclusions

Tracheotomy and initiation of LTV among PICU patients was relatively uncommon, but other PICU outcomes are similarly rare (eg, mortality). Given the increasing attention on morbidity as a PICU outcome (27), these interventions, which can prolong the child's life but can also substantially impact their families and the healthcare system, are worthy of further study. This study provides multi-institutional descriptive and incidence data on children and young adults receiving tracheostomies or initiated on LTV in PICUs that may be used as a foundation for future examinations of trends of these interventions and deeper examinations of variation of practice.

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Figure Legend:

Figure 1. Kernel Density plots of age of patients receiving tracheostomies or initiated on chronic invasive or noninvasive ventilation at PICU admission.

Supplemental Digital Content Table 1 Hospital and unit characteristics of participating sites

Supplemental Digital Content Figure Legend:

Figure 1. Box plots of time from PICU admission to tracheotomy by PICU sites. A) Tracheostomy alone group. B) Chronic invasive ventilation group.

Figure 2. Box plots of number of planned and unplanned extubations prior to tracheotomy among patients initiated on chronic invasive ventilation.

Figure 3. Bar graphs of the prevalence of baseline disabilities upon PICU admission among patients receiving tracheostomies or initiated on chronic ventilation by PICU sites. Overall disability (ie, POPC) is on the left; cerebral disability (ie, PCPC) is on the right. Sites (ie, bars) are sorted by proportion of initiated patients with no disability for each graph. A) Tracheostomy alone group. Includes 372 patients from 17 sites and only patients discharged alive from the PICU. B) Chronic invasive ventilation group. Includes 260 patients from 17 sites. C) Chronic noninvasive ventilation group. Includes 165 patients from 9 sites.

Figure 4. Bar graphs of the prevalence of disabilities upon PICU discharge among the same patients receiving tracheostomies or initiated on chronic invasive or noninvasive ventilation by PICU sites. Overall disability (ie, POPC) is on the left; cerebral disability (ie, PCPC) is on the right. Sites (ie, bars) are sorted by proportion of initiated patients with no disability for each graph. A) Tracheostomy alone group. B) Chronic invasive ventilation group. C) Chronic noninvasive ventilation group.

Figure 5. Bar graphs of the number of patients initiated on chronic invasive ventilation versus chronic noninvasive ventilation by PICU sites between July 2009 and December 2011. A) All patients. B) Patients who were <3 years with neuromuscular disease and no craniofacial/airway abnormalities.

Table 1. Criteria used for identifying patients receiving tracheostomies or initiated on chronic ventilation

Group	Criteria
Tracheostomy alone	• Patient admitted postoperatively after tracheotomy or had a tracheostomy intervention that was not present on admission • Tracheostomy that was present on discharge
Chronic respiratory failure	• Repeated attempts to wean from assisted ventilation have failed for at least 1 month • No superimposed acute respiratory disease or • Patient has a diagnosis that confers no prospect of being weaned from the ventilator: spinal muscular atrophy type 1[a] hereditary myopathies/muscular dystrophies[a] Arnold-Chiari malformation with hydrocephalus[a] vertebral fracture with spinal cord injury and paralysis[a] diaphragm paralysis[b] spina bifida[b] cystic fibrosis[b]
Invasive ventilation	• Above criteria for tracheostomy or admitted with a tracheostomy but not on mechanical ventilatory support • Met criteria for chronic respiratory failure • Discharged using mechanical ventilation or invasive continuous positive airway pressure
Noninvasive ventilation	• Not admitted using noninvasive ventilation • Met criteria for chronic respiratory failure • Discharged using bilevel positive airway pressure or noninvasive continuous positive airway pressure

[a] Considered as implying “no prospect of being weaned” for patients using invasive and noninvasive ventilation

[b] Considered as implying “no prospect of being weaned” for patients using invasive ventilation only

Table 2. Demographic and baseline clinical characteristics of patients receiving tracheostomies or initiated on chronic ventilation

Characteristic, % (95% CI)	Tracheostomy alone n=1,034	Invasive ventilation n=717	Noninvasive ventilation n=381	Any device n=2,132
Male sex	59.8 (56.7–62.7)	55.9 (52.2–59.5)	60.1 (55.1–64.9)	58.6 (56.5–60.6)
Age, months, median (IQR)	42 (9–138)	27 (6–143)	143 (74–192)	54 (10–158)
Race[a]				
Caucasian	49.8 (46.5–53)	51.9 (48–55.8)	60.6 (55.1–65.9)	52.4 (50.2–54.7)
African American	22.6 (20–25.4)	16.6 (13.8–19.7)	16.8 (13.1–21.4)	19.6 (17.8–21.4)
Hispanic	17.9 (15.5–20.5)	20.6 (17.6–23.9)	13.7 (10.3–17.9)	18.1 (16.4–19.9)
Asian/Indian/Pacific Islander	2.3 (1.5–3.5)	2.3 (1.3–3.8)	3.8 (2.2–6.6)	2.5 (1.9–3.4)
Other/mixed	6.1 (4.8–7.9)	6.1 (4.5–8.3)	3.5 (1.9–6.2)	5.6 (4.6–6.7)
Unspecified	1.3 (0.7–2.3)	2.6 (1.6–4.2)	1.6 (0.7–3.8)	1.8 (1.3–2.5)
Number of complex chronic conditions				
None	15.1 (13–17.4)	5.4 (4–7.4)	5.5 (3.6–8.3)	10.1 (8.9–11.5)
1	26.2 (23.6–29)	13.2 (11–15.9)	25.2 (21.1–29.8)	21.6 (19.9–23.4)
2	17.6 (15.4–20)	19.2 (16.5–22.3)	21.3 (17.4–25.7)	18.8 (17.2–20.6)
≥ 3	41.1 (38.1–44.1)	62.1 (58.4–65.6)	48 (43–53.1)	49.5 (47.3–51.6)
Baseline POPC[b]				
No disability	19.6 (16–23.9)	16.8 (12.9–21.7)	4.7 (2.5–8.9)	15.4 (13.2–18)
Mild disability	21.9 (18.1–26.3)	15.8 (11.9–20.6)	8.9 (5.6–14)	17.1 (14.7–19.7)
Moderate disability	37 (32.3–41.9)	31.5 (26.3–37.3)	33.2 (26.8–40.2)	34.4 (31.3–37.6)
Severe disability	20.9 (17.2–25.2)	35.8 (30.4–41.7)	53.2 (46–60.2)	32.9 (29.8–36.1)
Coma/vegetative state	0.5 (0.1–2)	–	–	0.2 (0.1–0.9)
Baseline PCPC[b]				
No disability	43.6 (38.8–48.6)	39 (33.5–45)	28.9 (22.9–35.9)	38.9 (35.7–42.2)
Mild disability	18.1 (14.6–22.3)	20.4 (16.1–25.6)	21.1 (15.8–27.5)	19.5 (17–22.3)
Moderate disability	19.6 (16–23.9)	19.7 (15.4–24.8)	12.6 (8.6–18.2)	18.1 (15.7–20.8)
Severe disability	18.1 (14.6–22.3)	20.8 (16.4–26)	37.4 (30.7–44.5)	23.2 (20.5–26.2)
Coma/vegetative state	0.5 (0.1–2)	–	–	0.2 (0.1–0.9)
Insurance[c]				
Medicaid/Medicare/government	60.8 (56.7–64.8)	65.7 (60.6–70.4)	61.3 (54.9–67.2)	62.4 (59.6–65.2)
Commercial	33.1 (29.3–37.1)	30.7 (26.2–35.7)	36.7 (30.8–43)	33.1 (30.4–35.9)
Self-Pay	3 (1.9–4.8)	1.7 (0.7–3.7)	0.4 (0–2.9)	20.7 (13.9–30.7)
Other	3 (1.9–4.8)	1.9 (0.9–4)	1.7 (0.6–4.4)	2.4 (1.7–3.5)

CI, confidence interval; IQR, interquartile range; PCPC, Pediatric Cerebral Performance Categories; POPC, Pediatric Overall Performance Categories

[a] Race data available for 1851 (87%) patients from 61 (82%) sites

[b] Pediatric Performance Categories available for 863 (40%) patients from 28 (38%)

[c] Insurance data available for 1162 (54%) patients from 36 (47%) sites

Table 3. Admission and discharge characteristics of patients receiving tracheostomies or initiated on chronic ventilation

Characteristic, % (95% CI)	Tracheostomy alone n=1,034	Invasive ventilation n=717	Noninvasive ventilation n=381	Any technology n=2.132
Unplanned admission	68.7 (65.8–71.4)	75.6 (72.3–78.6)	75.9 (71.3–79.9)	72.2 (70.3–74.1)
Peri-operative	48.6 (45.6–51.7)	25.5 (22.5–28.9)	28.6 (24.3–33.4)	37.3 (35.3–39.4)
Origin				
Emergency department	28 (25.4–30.9)	37.2 (33.8–40.8)	41.2 (36.3–46.2)	33.5 (31.5–35.5)
General ward	18.7 (16.4–21.2)	15.8 (13.3–18.6)	18.1 (14.5–22.3)	17.6 (16–19.2)
OR/PACU/procedure suite	38 (35.1–41)	18.4 (15.7–21.4)	25.2 (21.1–29.8)	29.2 (27.3–31.1)
Intermediate unit	4.2 (3.2–5.7)	7.3 (5.6–9.4)	2.4 (1.2–4.5)	4.9 (4–5.9)
Another ICU	8.6 (7–10.4)	16 (13.5–18.9)	5.2 (3.4–8)	10.5 (9.2–11.8)
Chronic/rehabilitation facility	0.5 (0.2–1.2)	2.1 (1.3–3.4)	0.5 (0.1–2.1)	1 (0.7–1.6)
Pulmonary rehabilitation facility	0.1 (0–0.7)	0.1 (0–1)	0.3 (0–1.9)	0.1 (0–0.4)
Home/outpatient	1.6 (1–2.6)	2.5 (1.6–4)	6.3 (4.2–9.2)	2.8 (2.2–3.6)
Other	0.3 (0.1–0.9)	0.6 (0.2–1.5)	0.8 (0.3–2.4)	0.5 (0.3–0.9)
Admitted from another hospital	17.9 (15.7–20.4)	23.3 (20.3–26.5)	16.5 (13.1–20.6)	19.4 (17.8–21.2)
PIM2 risk of mortality, %, mean (SD)	6 (13.2)	8.4 (15)	5 (8.2)	6.6 (13.2)
Admitted to PICU with				
ICU beds				
≤17	17.9 (15.7–20.4)	21.8 (18.9–24.9)	17.8 (14.3–22)	19.2 (17.5–20.9)
18-24	46.8 (43.8–49.9)	47.1 (43.5–50.8)	59.3 (54.3–64.2)	49.2 (47.1–51.4)
≥25	35.3 (32.4–38.3)	31.1 (27.8–34.6)	22.8 (18.9–27.3)	31.6 (29.7–33.6)
Affiliated fellowship program	66.2 (63.2–69)	61.6 (58–65.1)	68.2 (63.4–72.7)	65 (62.9–67)
Disposition				
General ward	51 (47.9–54)	24.3 (21.3–27.5)	24.5 (21.3–30.1)	37.4 (35.4–39.5)
Intermediate unit	19.5 (16.7–22.8)	17 (14.4–20)	6.6 (4.5–9.5)	16.4 (14.7–18.5)
OR	0.2 (0–0.8)	0.6 (0.2–1.5)	–	0.3 (0.1–0.6)
Another ICU	5 (3.4–7.3)	5.6 (3.6–8.6)	4.4 (2.4–7.6)	5.2 (3.9–6.7)
Home	9.4 (7.7–11.3)	30.1 (26.9–33.6)	45.9 (40.9–50.8)	24.7 (22.9–26.6)
Chronic/rehabilitation facility	7.4 (5.9–9.1)	17.4 (14.8–20.4)	12.9 (10.6–15.2)	9.9 (8.7–11.3)
Pulmonary rehabilitation	0.9 (0.5–1.7)	3.1 (2–4.6)	3.4 (2–5.8)	2.1 (1.5–2.8)
Hospice	–	0.8 (0.4–1.9)	0.8 (0.3–2.4)	0.4 (0.2–0.8)
Morgue	6.2 (4.9–7.8)	–	–	–
Other	0.6 (0.3–1.3)	0.3 (0.1–1.1)	0.5 (0.1–2.1)	0.5 (0.3–0.9)
Discharged to another hospital	3 (2.1–4.2)	3.3 (2.3–4.9)	1 (0.4–2.8)	2.8 (2.2–3.6)
Discharge POPC[a]				
No disability	3 (1.7–5.4)	0.7 (0.2–2.8)	3.2 (1.4–6.9)	2.2 (1.4–3.4)
Mild disability	16.7 (13.2–20.7)	8.2 (5.5–12.1)	7.4 (4.4–12.1)	11.4 (9.4–13.7)
Moderate disability	42.9 (37.9–48)	37.3 (31.8–43.1)	35.8 (29.2–42.9)	38.2 (35–41.5)
Severe disability	32.8 (28.1–.37.8)	50.6 (44.5–56.4)	53.7 (46.5–60.7)	42 (38.8–45.4)
Coma/vegetative state	4.6 (2.9–7.4)	3.2 (1.6–5.9)	–	2.9 (2–4.3)

Discharge PCPC[a]				
No disability	25.4 (21.2–30.1)	21.1 (16.7–26.4)	28.4 (22.4–35.3)	23.9 (21.2–26.9)
Mild disability	17.2 (13.7–21.5)	23.7 (19–29)	20 (14.9–26.4)	19.4 (16.9–22.2)
Moderate disability	24.6 (20.4–29.3)	24.4 (19.7–29.8)	13.2 (9–18.8)	21.3 (18.6–24.1)
Severe disability	28.1 (23.8–33)	27.6 (22.6–33.1)	38.4 (31.7–45.6)	29.3 (26.3–32.4)
Coma/vegetative state	4.6 (2.9–7.4)	3.2 (1.6–5.9)	–	2.9 (2–4.3)
Discharged on CPAP[b]	–	6.1 (4.6–8.2)	15.7 (12.4–19.8)	–
Length of PICU stay, median days (IQR)	18 (8–31)	33 (16–57)	20 (15–32)	25 (14–46)

CI, confidence interval; CPAP, continuous positive airway pressure; PACU, post-anesthesia care unit; ICU, intensive care unit; IQR, interquartile range; LOS, length of stay; MV, mechanical ventilation; OR, operating room; PIM, Paediatric Index of Mortality; PCPC, Pediatric Cerebral Performance Categories; POPC, Pediatric Overall Performance Categories; PPV, positive pressure ventilation; SD, standard deviation

[a] Pediatric Performance Categories available for 863 (40%) patients from 28 (38%), but reported for 837 patients because of 26 tracheostomy alone patients that died prior to discharge.

[b] As opposed to conventional mechanical ventilation for patients on chronic IV or BiPAP for patients on chronic NIV.

Table 4. Chronic conditions of PICU patients receiving tracheostomies or initiated on chronic ventilation

Condition, % (95% CI)	Tracheostomy alone n=1034	Invasive ventilation n=717	Noninvasive ventilation n=381	Admissions without tracheostomy or chronic ventilation[a] n=130,847
Cardiac				
Congenital heart disease, non-complex	6.1 (4.8–7.7)	8.1 (6.3–10.3)	3.4 (2–5.8)	5.5 (5.4–5.6)
Congenital heart disease, complex	9.1 (7.5–11)	13.9 (11.6–16.7)	7.1 (4.9–10.2)	10.5 (10.3–10.7)
Pulmonary hypertension	4.4 (3.3–5.9)	10.7 (8.7–13.2)	3.7 (2.2–6.1)	1.8 (1.8–1.9)
Other cardiac condition	1.4 (0.8–2.3)	4.5 (3.2–6.2)	3.9 (2.4–6.4)	1.3 (1.3–1.4)
Endocrinologic	6.6 (5.2–8.3)	11 (8.9–13.5)	10.5 (7.8–14)	8 (7.9–8.2)
Immunologic	2.7 (1.9–3.9)	3.6 (2.5–5.3)	4.5 (2.8–7.1)	1.8 (1.7–1.9)
Gastroenterologic[b]	4.9 (3.8–6.4)	7.9 (6.2–10.2)	14.7 (11.5–18.6)	3.7 (3.6–3.8)
Genetic syndrome	15.3 (13.2–17.6)	18.7 (16–21.7)	15 (11.7–18.9)	6.7 (6.6–6.9)
Hematologic	2.1 (1.4–3.2)	2.2 (1.4–3.6)	2.6 (1.4–4.8)	2.7 (2.6–2.8)
Metabolic	5 (3.9–6.5)	6.7 (5.1–8.8)	10 (7.3–13.4)	2.7 (2.6–2.8)
Neuromusclar				
CCHS	0.4 (0.1–1)	1.1 (0.6–2.2)	1 (0.4–2.8)	0 (0–0)
Cerebral palsy	9.9 (8.2–11.8)	8.4 (6.5–10.6)	22.6 (18.6–27.1)	3.9 (3.8–4)
Chiari malformation	0.6 (0.2–1.3)	1.7 (1–2.9)	1 (0.4–2.8)	0.6 (0.5–0.6)
Ventricular shunt or other CNS device	4.6 (3.5–6.1)	5.3 (3.9–7.2)	6.8 (4.7–9.8)	2.7 (2.6–2.8)
Epilepsy	18.4 (16.1–20.9)	16.3 (13.8–19.2)	31.2 (26.8–36.1)	8.9 (8.7–9)
Hydrocephalus	6.6 (5.2–8.2)	8.2 (6.4–10.5)	7.6 (5.3–10.8)	4 (3.9–4.1)
Muscular dystrophy	0.9 (0.5–1.7)	8.1 (6.3–10.3)	21.3 (17.4–25.7)	0.4 (0.4–0.5)
Spina bifida	1.6 (1–2.6)	4.6 (3.3–6.4)	5.8 (3.8–8.6)	1.7 (1.6–1.7)
Spinal muscular atrophy type 1	0.6 (0.3–1.3)	5.7 (4.2–7.7)	13.1 (10.1–16.9)	0.3 (0.2–0.3)
Static encephalopathy or generalized developmental delay	20.2 (17.9–22.8)	18.7 (16–21.7)	22.3 (18.4–26.8)	7.2 (7–7.3)
Other neuromuscular	9.2 (7.6–11.1)	10.3 (8.3–12.8)	17.6 (14.1–21.8)	3.9 (3.8–4)

condition				
Oncologic				
CNS tumor	4.3 (3.2–5.7)	3.2 (2.1–4.8)	1.3 (0.5–3.1)	3.5 (3.4–3.6)
Other oncologic conditions[c]	6.5 (5.1–8.2)	3.3 (2.3–4.9)	1.8 (0.9–3.8)	5.9 (5.7–6)
Orthopedic				
Scoliosis/kyphosis	5.9 (4.6–7.5)	11.2 (9–13.7)	33.6 (29–38.5)	4.5 (4.4–4.6)
Otolaryngologic				
Craniofacial or airway abnormality[d]	39.7 (36.8–42.8)	22.2 (19.3–25.4)	9.7 (7.1–13.1)	4.6 (4.5–4.7)
Obstructive sleep apnea[e]	6.6 (5.2–8.3)	4.2 (2.9–5.9)	26.5 (22.3–31.2)	2.2 (2.1–2.3)
Prematurity	7.5 (6.1–9.3)	9.3 (7.4–11.7)	2.4 (1.2–4.5)	4.2 (4.1–4.3)
Pulmonary				
Asthma	5.6 (4.4–7.2)	6.1 (4.6–8.2)	18.9 (15.3–23.2)	11.1 (11–11.3)
Bronchopulmonary dysplasia	5 (3.9–6.5)	9.5 (7.4–11.9)	1 (0.4–2.8)	1.2 (1.1–1.3)
Cystic fibrosis	0.3 (0.1–0.9)	1.3 (0.7–2.4)	0.8 (0.3–2.4)	0.5 (0.4–0.5)
Diaphragm paralysis	0.6 (0.3–1.3)	3.3 (2.3–4.9)	1.6 (0.7–3.5)	0.2 (0.2–0.2)
Pulmonary hypoplasia	0.3 (0.1–0.9)	1.7 (1–2.9)	1 (0.4–2.8)	0.2 (0.2–0.3)
Other pulmonary conditions	8.7 (7.1–10.6)	14.2 (11.9–17)	22 (18.1–26.5)	2.6 (2.5–2.7)
Renal	2.1 (1.4–3.2)	3.1 (2–4.6)	4.2 (2.6–6.8)	2 (2–2.1)
Rheumatologic	0.3 (0.1–0.9)	0.6 (0.2–1.5)	1.6 (0.7–3.5)	0.6 (0.5–0.6)

CCHS, congenital central hypoventilation syndrome; CI, confidence interval; CNS, central nervous system; GI, gastro-intestinal**;** PICU, pediatric intensive care unit

Patients may have had more than one condition

[a] Excludes patients who were admitted with a tracheostomy or already on chronic ventilation and/or died during their PICU admission

[b] Does not include patients with feeding intolerance or dependence on feeding tubes

[c] Includes "benign" oncologic conditions

[d] Includes patients with upper and lower airway malacia

[e] Excludes patients with documented anatomical upper airway abnormality

Table 5. Incidence of tracheotomy and initiation of chronic ventilation by ICU characteristic

Technology by ICU bed size	Median (%)	Interquartile range	Range
Tracheostomy alone			
≤17 beds	0.6	0.4 – 0.9	0 – 1.3
18-24 beds	0.8	0.4 – 1.1	0.2 – 2.5
≥25 beds	0.8	0.6 – 1.2	0.1 – 1.7
No PCCM fellowship	0.7	0.5 – 0.9	0 – 2.5
Affiliated PCCM fellowship	0.7	0.5 – 1.1	0.1 – 2.1
Invasive ventilation			
≤17 beds	0.5	0.2 – 0.8	0 – 2.5
18-24 beds	0.6	0.5 – 0.9	0.2 – 1.7
≥25 beds	0.6	0.4 – 0.9	0.3 – 1.8
No PCCM fellowship	0.6	0.4 – 0.7	0 – 1.7
Affiliated PCCM fellowship	0.6	0.4 – 0.9	0 – 2.5

Noninvasive ventilation			
≤17 beds	0.2	0 – 0.4	0 – 0.9
18-24 beds	0.3	0.1 – 0.4	0 – 2
≥25 beds	0.3	0.1 – 0.5	0 – 1.7
No PCCM fellowship	0.2	0 – 0.4	0 – 0.9
Affiliated PCCM fellowship	0.2	0.1 –0.4	0 – 0.2
Any technology			
≤17 beds	1.3	0.9 – 2.1	0 – 3
18-24 beds	1.8	1.4 – 2.4	0.5 – 4.6
≥25 beds	1.8	1.2 – 2.3	0.6 – 3
No PCCM fellowship	1.5	1.1 – 1.8	0 – 4.6
Affiliated PCCM fellowship	1.9	1.2 – 2.4	0.5 – 3.4

Percentiles are of PICU patients (as opposed to admissions)

Supplemental Table 1. Hospital and unit characteristics

	n=73 (100%)
Number of licensed pediatric beds	
≤ 110	22 (30)
111–249	22 (30)
≥ 250	29 (40)
Number of licensed pediatric ICU beds	
≤ 17	31 (42)
18–24	27 (37)
≥ 25	15 (21)
Affiliated PCCM fellowship program	36 (49)
Separate intermediate care unit	20 (27)
Number of quarters for which data was contributed	
1-4	26 (36)
5-8	11 (15)
9-12	36 (49)
Initiated patients on	
Tracheostomy alone	70 (96)
Invasive ventilation	68 (93)
Noninvasive ventilation	56 (77)

ICU, intensive care unit; PCCM, pediatric critical care medicine