RESEARCH ARTICLE

Longitudinal Prevalence of Tracheostomized Children in Minnesota

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ABSTRACT

OBJECTIVES: To identify the annual prevalence of tracheostomized children over an 11-year span in Minnesota. Secondary objectives included decannulation and mortality rates.

METHODS: Retrospective review from 2008 to 2018 of a pediatric home care company database that provides home care services for ≥95% of tracheostomized children in Minnesota. The study group was divided into 2 cohorts: tracheostomized children that never required invasive home mechanical ventilation (iHMV) and tracheostomized children that required iHMV. Outcome measures included prevalence rates of tracheostomized children with or without iHMV, primary diagnoses, decannulation, and death rates.

RESULTS: Prevalence rates for tracheostomized children ≤16 years of age per 100 000 population increased 39% from 12.3 in 2008 to 17.2 in 2018. This upward trend was primarily associated with an increase in tracheostomized children receiving iHMV. This prevalence trend was inversely correlated with age. There was no significant change in the decannulation rate. The annual all-cause death rate declined over the study period and was primarily associated with decreased mortality in children receiving iHMV. If national prevalence rates in 2018 were comparable to Minnesota, the results suggest there were 2839 pediatric home care patients with tracheostomies not requiring iHMV and 9024 children receiving iHMV.

CONCLUSIONS: The population of tracheostomized children in Minnesota is expanding at a disproportionate rate relative to the population of children at large. This increase is predominantly associated with an increase in iHMV. Although the annual all-cause death rate has declined over the past decade, there was no change in the decannulation rate.

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The population of children with medical complexity (CMC) is increasing and uses a disproportionate amount of pediatric health care expenses.[1,2] As the population of CMC expands, health care resources must be commensurate with the need.[3] Children with tracheostomy often require invasive home mechanical ventilation (iHMV) and home health care, and 12% of CMC are tracheostomy dependent.[4] There are increasing inpatient services for children with tracheostomy[5] and those dependent on long-term iHMV.[6] This may translate into an increasing prevalence of tracheostomized children because there is no national database tracking this population. Studies from single centers have shown that increased numbers of patients receiving iHMV[7–9] had reduced mortality,[10,11] and more hospital discharges to iHMV[12] suggests that prevalence increased over time. Recent trends in decannulation and all-cause mortality rates need to be better elucidated. We designed this retrospective study to analyze the longitudinal prevalence of tracheostomized children in Minnesota, decannulation rates, and all-cause death outcomes over an 11-year span.

METHODS

Setting and Objective

With this retrospective chart review, we assessed the annual prevalence of tracheostomized children aged ≤16 years from 2008 to 2018. The database was provided by a Minnesota pediatric home care company with 400 employees and >30 years of experience. It provides services and durable medical equipment to ~6000 children in the upper Midwest. The objective was to show the change in annual prevalence for tracheostomized children from 2008 to 2018. Two subgroups were studied, those with and without iHMV. Secondary objectives included prevalence trends by age, trends in the decannulation, and all-cause death rates. All-cause mortality for the study population and age-specific mortality in 3 age groups (0–2, 3–8, 9–16) were analyzed from 2008 to 2018. Since 2014, the home care database ascribed primary diagnosis as the underlying medical condition that most likely contributed to a need for tracheostomy and/or iHMV. Because of the limitations of the database before this, only primary diagnoses of new entries into the database are represented for 2014 to 2018.

The Children's Minnesota institutional review board determined this study to be institutional review board exempt.

Data

A retrospective chart review included all tracheostomized children receiving services in the home care database. This was done for 2008, 2010, and each year from 2012 to 2018. The database was improved in 2011, but extraction of data before 2012 was substantially more labor intensive. Hence, data were extracted for 2008 and 2010 to facilitate a 10-year prevalence trend over an 11-year span. For each year, the number of existing patients aged ≤16 years at the beginning of the year and residing in Minnesota was determined, including the number of new patients receiving services, moves or transfers, deaths from all causes, and decannulations throughout each study year. Data included the age distribution (age on January 1 for continuing patients, and age at the time services started for new patients). Information for gender, race, home care nursing (HCN), and Medicaid status at the start of home care were extracted from 2012 to 2018. Data for these latter variables were not available for 2008 and 2010. Data were stratified into 2 groups: tracheostomized patients who never received iHMV and patients who required iHMV anytime during their home care. The database was updated by clinical staff doing regularly scheduled visits on all tracheostomized patients, with the exception of some long-time patients with patient-owned equipment. This latter group was tracked in the database by supply and prescribers' orders.

Prevalence

Estimation of the statewide prevalence rate relied on the assumption that ≥95% of tracheostomized children in Minnesota were captured in the home care services database. To validate that the database adequately captured this population, a survey of health care personnel was conducted that included discharge planners, case managers, and respiratory therapists involved in the care and discharge of tracheostomized children at the 4 children's hospitals in Minnesota. Furthermore, pulmonologists from 3 different pediatric pulmonary practices in Minnesota were surveyed. Respondents included health care personnel from each of the children's hospitals (6 respondents) as well as pediatric pulmonologists from each of the independent practices (4 respondents).

This inquiry validated that ≥95% of tracheostomized children cared for in these institutions over the past 10 years were receiving, in part, home care services that would be documented in the database used for the study and that this pattern did not appreciably change over time. In addition, if the study's database correctly identified 95% of tracheostomized children in Minnesota, these children could be used to estimate total statewide number of tracheostomized children by dividing the number of tracheostomized patients by 95%. As the home care database employed for analysis was estimated to be inclusive of 95% to 100% each year of tracheostomized children residing in Minnesota, we estimated statewide children simply as the number of tracheostomized children in the database. Hence, our estimate of statewide children is a conservative estimate because it does not inflate tracheostomized patient numbers to account for children cared for by other home care providers.

To estimate the statewide prevalence rate, we computed the number of tracheostomized children per 100 000 people in Minnesota ≤16 years of age for each year. Minnesota population estimates by age are approximated as of July 1 of each year and obtained from the US Census Bureau. To correlate these midyear population estimates, we approximated midyear tracheostomized patient population as patients at the beginning of the year plus 50% of new patients receiving services for the year less 50% of the year's moves and transfers, deaths, and decannulations. We estimated the US home care tracheostomized population assuming Minnesota's prevalence rate is reflective of the national prevalence rate and using US population data from the US Census Bureau.

Statistical Analysis

We used ordinary least squares regression to estimate yearly trend in prevalence rates, all-cause death rates, and decannulation rates for all patients. Patients were stratified into 2 groups, with and without iHMV. We also made these estimates stratifying patients 0 to 2, 3 to 8, and 9 to 16 years of age using Stata version 15 (StataCorp, College Station, TX). The χ^2 and t tests analyzed differences between patients with and without iHMV.

RESULTS

Between 2008 and 2018, the average annual number of tracheostomized children in Minnesota was 175.9, 70% of which had iHMV. These children accounted for 14.5 out of every 100 000 people aged 0 to 16 years. Patients with iHMV were more likely to be younger, white, and have HCN and insurance other than Medicaid at the start of care compared with patients without iHMV (Table 1). There were no significant differences in gender, annual death rate, or annual decannulation rate between patients with iHMV compared with those without iHMV.

In Supplemental Table 3, we show primary diagnoses and the classification scheme of tracheostomized patients newly entered in the database during 2014 to 2018. Over this period, 72.1% received iHMV. The most common primary diagnosis was respiratory followed by neuromuscular or central nervous system (CNS). A subanalysis of new patients referred for iHMV during the 2014 to 2018 period identified that 34.3% were former premature infants with bronchopulmonary dysplasia (BPD) and chronic respiratory failure. Patients with a primary respiratory diagnosis had the greatest need for iHMV, followed by patients with a primary cardiac diagnosis. Approximately one-third of patients entered in the 2014 to 2018 database had a syndrome and/or chromosomal disorder and/or genetic disorder.

Prevalence rates for tracheostomized children per 100 000 population increased 39% from 12.3 in 2008 to 17.2 in 2018 (Fig 1). Regression results reveal the annual increase in the prevalence rate over this period was 0.42 and statistically significant (Table 2). Stratifying these patients by iHMV, to those without iHMV, showed that the upward trend was associated with patients with iHMV. Specifically, the prevalence rate for those with iHMV increased from 8.0 per 100 000 population in 2008 to 13.0 per 100 000 population in 2018. This is a 62% increase over the 2008 to 2018 period, and the 0.44 yearly increase in the prevalence trend was statistically significant. In contrast, there was no significant change in yearly prevalence rate for those without iHMV over this same period.

On average for 2008 to 2018, results showed that prevalence rate was a decreasing function of age. Specifically, patients aged 0 to 2 years had the highest prevalence rate of 31.4 per 100 000 (95% confidence interval [CI]: 29.6–33.2) compared with 13.0 per 100 000 (95% CI: 12.2–13.9) and 9.4 per 100 000 (95% CI: 8.7–10.1) for patients aged 3 to 8 and 9 to 16 years, respectively (Fig 2). In addition, between 2008 and 2018, the prevalence rate increased significantly at

TABLE 1 Demographic and Clinical Characteristics

	Tracheal Tube Without iHMV	Tracheal Tube With iHMV	All	*P* for Difference Between, Without, and With iHMV
Average daily patient census	52.7 (2.9)	123.3 (20.7)	175.9 (20.8)	—
Prevalence per 100 000	4.3 (0.2)	10.1 (1.6)	14.5 (1.6)	—
Age group, %, y				.015
0–2	32.7	39.7	37.6	—
3–8	33.8	30.8	31.7	—
9–16	33.5	29.4	30.6	—
Male, %	55.6	56.8	56.5	.663
Race, %				<.001
White	59.3	66.2	64.3	—
African American	25.0	16.3	18.8	—
Asian American	5.4	4.1	4.5	—
AI or AN	0.9	3.8	3.0	—
Other or unknown	14.0	12.6	13.0	—
Received home care nursing, %	65.7	78.0	74.5	<.001
Medicaid at start of care, %	58.4	51.6	53.5	.017
Death rate, %	4.4	4.6	4.5	.886
Decannulation rate, %	11.4	11.4	11.4	.978

The number of yearly observations is 9. SDs for nonbinary variables are in parentheses. Data are for 2008, 2010, and 2012–2018. Annual patients are computed as the number of patients at midyear. This was computed as patients on January 1 aged 0 to 16 y plus 50% of the year's new patients receiving services less 50% of the year's deaths, decannulations, and transfers. Male sex, race, home care nursing, and Medicaid data are based on 2012–2018 data. As patient insurance may change for any patient and typically trends toward Medicaid over time, we included the percentage of patients with Medicaid at the start of home care. AI, American Indian; AN, Alaskan Native; —, not applicable.

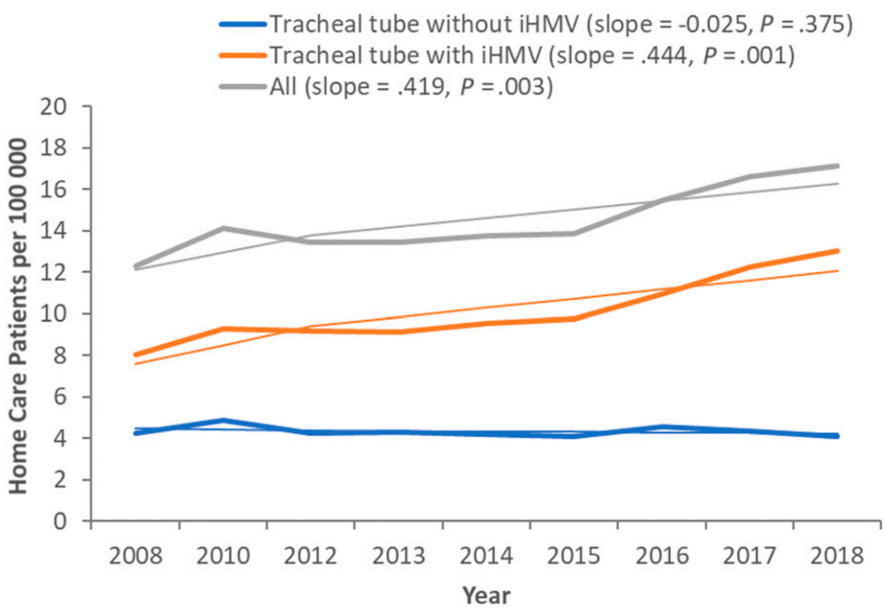

FIGURE 1 Prevalence rates by tracheal tube combined, with, or without iHMV.

the $P = .05$ level for the 3 to 8 and 9 to 16 age groups, although not significantly ($P = .165$) for the 0 to 2 age group (Table 2). Stratifying these age groups with and without iHMV shows different prevalence trends. For patients with iHMV, there is a statistically significant increase in the prevalence rate for each of the 3 to 8 and 9 to 16 age groups at the $P = .05$ level and nearly so for the 0 to 2 age group ($P = .052$). In contrast for patients without iHMV, no age group had a statistically significant increase in the yearly prevalence rate. For all patients (with and without iHMV), the yearly increase in the prevalence trend tends to decline with age. It is highest for patients 0 to 2 years of age (0.87 per year although not statistically significant) and lowest (0.31 per year) for patients 9 to 16 years of age (Table 2).

The results reveal a statistically significant decline in the annual all-cause death rate over the 2008–2018 period from 8.8% to 3.3% (Table 2, Fig 3). Stratifying with and without iHMV shows that this yearly downward trend of 0.5 percentage points was statistically significant for those with iHMV but not for those without iHMV. On the basis of the annual mortality rates, the 5- and 10-year survival rates were 83% and 60%, respectively. The all-cause mortality rate during the 2008 to 2018 study period for tracheostomized children with and without iHMV was 13% and was comparable between children without iHMV (12.73%) and those with iHMV (13.11%). Note that this 13% rate is the mortality rate of all children in our study regardless of how many years they were at risk. Limitations exist in the interpretation of age-specific mortality trends during this same study period because of smaller numbers when stratified into 3 age groups. Recognizing this limitation, there is a significant downward trend in the death rate for the 0 to 2 age group ($P = .043$) but not for the 3 to 8 age group ($P = .085$) or the 9 to 16 age group ($P = .470$). There was no significant difference in overall mortality rate among the 3 age groups during the study period.

Regarding the annual decannulation rate over the 2008 to 2018 period, there was neither a significant trend across all patients nor when stratified based on need for iHMV.

We estimated the size of the national tracheostomized population ≤16 years of age (Supplemental Table 4). If prevalence rates in Minnesota are representative of national prevalence rates, it is suggested that in 2018 there were 9024 children requiring iHMV and 2839 children with tracheostomies not requiring iHMV.

TABLE 2 Time Trends in Annual Prevalence, Death, and Decannulation Rates: 2008–2018

	Tracheal Tube Without iHMV		Tracheal Tube With iHMV		All	
Age group	Coefficient	P	Coefficient	P	Coefficient	P
Prevalence rate	−0.0251	.375	0.4445	.001**	0.4194	.003**
Age group, y						
0–2	−0.2640	.076	1.1374	.052	0.8734	.165
3–8	0.0691	.291	0.3036	.014*	0.3727	.027*
9–16	−0.0016	.971	0.3148	.001**	0.3133	.009**
Death rate	−0.0048	.160	−0.0055	.024*	−0.0052	.036*
Decannulation rate	0.0001	.990	−0.0024	.368	−0.0020	.376

Coefficients represent the annual change (or time trend) in the prevalence rates. Coefficients and *P* values are based on regressions of prevalence rates as a function of years since 2008.
* $P = .05$ and ** $P = .01$ for statistical significance.

DISCUSSION

Increasing numbers of children with tracheostomy are being discharged from hospital to home,[6] and we show in our study that the increase is primarily associated with iHMV. Researchers of another study demonstrated an increase in prevalence for children ≤16 years of age requiring iHMV.[13] Our predominate population is children 0 to 2 years of age. This is not surprising considering that 34% of new patients receiving iHMV are former premature neonates with BPD and that the most common diagnosis in our study population was respiratory. Prevalence rates for the 3 to 8 and 9 to 16 age groups were comparable. A bimodal population for tracheostomy based on age was previously reported.[14] The second most common diagnosis was neuromuscular and CNS, whereas others reported this as the most common.[15]

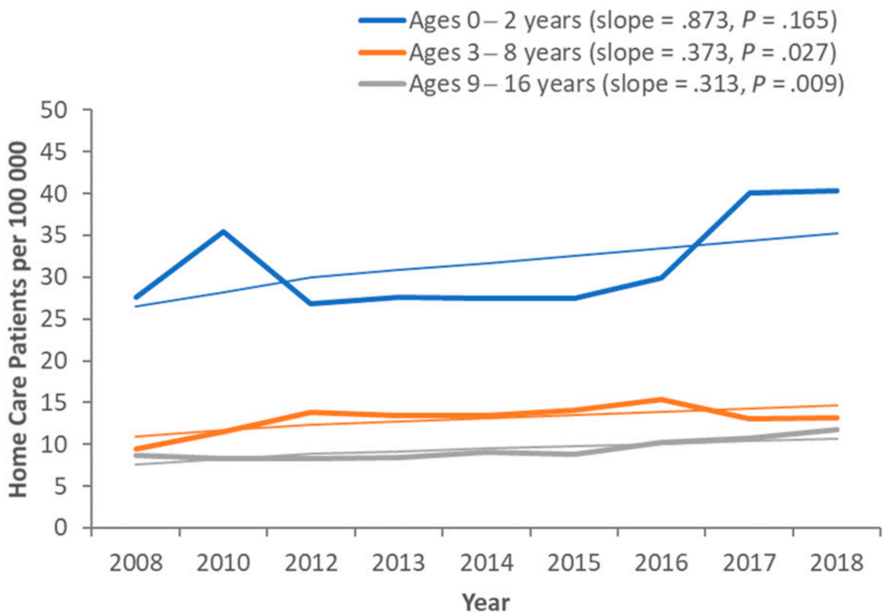

FIGURE 2 Prevalence rates by age group with and without iHMV combined.

The prevalence of tracheostomized children never requiring iHMV is unknown. Data available on tracheostomy rates in the United States between 2000 and 2012 revealed a decrease from 6.8 to 6 per 100 000 children ≤18 years.[14] No differentiation was made on the need for iHMV at discharge.

An analysis between 2006 and 2012 revealed a 31% increase in tracheostomy in extremely premature neonates, presumably associated with severe BPD and iHMV.[5] With our data, we support that the increased prevalence of tracheostomized children is weighted by the iHMV cohort, and our subanalysis of new patients receiving iHMV over 2014 to 2018 revealed 34.3% were former premature infants with BPD and chronic respiratory failure. In a previous Minnesota report, researchers found that the tracheostomy rate for premature infants with <1000-g birth weights was 6.9%.[16] Recent increases in the percentage of premature births in the United States (10.02% in 2018 compared with 9.63% in 2014) may put additional upward pressure on iHMV prevalence.[5,16] In Minnesota between 2008 and 2018, the average annual prevalence of tracheostomized children ≤16 years of age not requiring iHMV was 4.3 per 100 000 children. Over the same period, there was no statistically significant change in this prevalence rate. In contrast, the Minnesota prevalence rate over this timeframe increased 5.0 per 100 000 (8.0–13.0) for tracheostomized children requiring iHMV. Extrapolating Minnesota to national data, we estimated that in 2018 there were 2839 tracheostomized children living at home annually during the same time period that never required iHMV and 9024 that required iHMV (Supplemental Table 4).

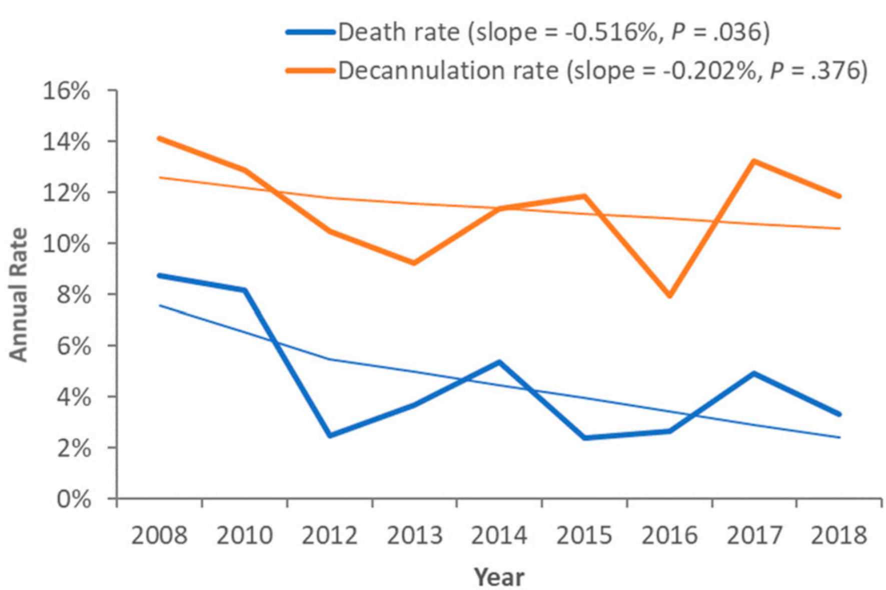

FIGURE 3 Annual death and decannulation rates with and without iHMV combined.

Some state-level data are available for iHMV and have been used to approximate iHMV prevalence in the United States. In 2004, there was an estimated prevalence rate of 6.3 per 100 000 children <16 years of age receiving iHMV in Utah,[13] extrapolated to 4100 children in the United States. Another report[7] used data from Massachusetts[8] and Pennsylvania[9] to estimate prevalence of iHMV in children ≤18 years of age. Using 2005 census data, the prevalence of children on iHMV in Massachusetts was estimated at 4.7 per 100 000 children, which extrapolated to 3526 children in the United States. The 2006 data for Pennsylvania estimated a prevalence rate of 6.4 per 100 000 children, which extrapolated to 4802 children on iHMV in the United States. In our study, we estimated a prevalence rate in Minnesota of 8.0 per 100 000 children on iHMV in 2008, which extrapolates to 5596 children in the United States and compares favorably considering our findings are from a latter year and included children ≤16 years of age.

It appears that the United States has a higher prevalence of children on iHMV than other countries. Austria[10] and Italy[11] reported prevalence rates for children <18 at 2.4 and 1.84 per 100 000, respectively. Researchers in a report from

Korea identified a prevalence of children on iHMV of 2.1 per 100 000.[17] Researchers of a Canadian study found that between 2005 and 2009 the prevalence of iHMV was 1.3 per 100 000 and, in contrast to our study, reported no significant increase in iHMV[18] but a significant increase in noninvasive HMV. A Dutch study[19] revealed an increase in tracheostomies to support iHMV as did our study.

Annual mortality during tracheostomy-associated hospitalization is 8%.[14] Candidates for iHMV have a 4% death rate before hospital discharge.[15] We found the annual all-cause death rate after hospital discharge was 4.6% in the iHMV cohort. A review on outcomes for children on iHMV found variable survival rates,[20] and the authors also found 5- and 10-year cumulative survival rates from their institution were 80% and 63%, respectively. This equated to an overall death rate of 21%. Investigators from Utah found a 17% death rate over their study period.[13] Researchers of a Canadian study described survival rates for children receiving iHMV at 5 and 10 years as 84% and 77%, respectively.[18] Investigators in Holland reported a 29% death rate for children on iHMV over 30 years (1979–2009).[19] Survival rates and death rates for our study are comparable with 5- and 10-year survival rates of 83% and 60%, respectively, and a 13% death rate in our study over the 2008 to 2018 period. What we contribute with our study is that death rates for the iHMV population statistically declined during the study period. This did not hold true for the cohort that never received iHMV, for which no significant trend (up or down) was detected. The role of HCN, which was present with 78.0% of children receiving iHMV, in decreasing mortality over the study period is indeterminate.

In our study, we looked at the annual decannulation rate over the study period for all children as well as separately for the cohorts with and without iHMV. There was no difference between the cohorts regarding decannulation rates and the combined rate averaged 11.4% over the study period. Researchers of a Utah study[13] looked at 2 different cohorts in 1996 and 2004 and identified decannulation rates of 33% and 4.5%, respectively. Researchers in other studies report variable rates for successful weaning from mechanical ventilation.[20] Authors of two of these reports describe liberation from mechanical ventilation at 14%[18] and 18%,[20] but these figures may not equate to decannulation. To the degree that the pediatric home care population is expanding and increasing in complexity over time, maintaining a constant decannulation rate may be considered a quality improvement.

As with regional differences in tracheostomy rates,[14] there may also be geographical variations in the population of tracheostomized children in the United States. We extrapolated Minnesota data to estimate the US population of tracheostomized children. This assumes that the average national approach to tracheostomy and supporting tracheostomized children in home care is comparable to Minnesota. Accordingly, with our data, we suggest that $>$11 000 tracheostomized children $\leq$16 years of age resided in the United States in 2018. Approximately 75% of these children required iHMV at some time. The other 25% were managed at home without the need for iHMV.

Limitations included a retrospective database from a Minnesota company that provides, in part, services for $\geq$95% of children with tracheostomies. This database should be representative and nearly comprehensive for Minnesota children with tracheostomies. Factors not studied that could impact prevalence rates are decreased use of noninvasive ventilation or prolonged hospitalization with decannulation before hospital discharge. Extrapolating data from Minnesota to the United States has limitations because it requires the assumption that Minnesota is nationally representative. Given that variation by geographic regions in the United States only varied between 5.4 and 7 tracheostomies per 100 000 person-years,[14] this assumption seems reasonable.

CONCLUSIONS

The increase in the population of tracheostomized children is attributed to iHMV. Approximately 25% of children never required iHMV. The annual all-cause death rate declined over 11 years without change in the decannulation rate. These results may influence the allocation of future health care resources and expenditures for this expanding population of technology-dependent children.

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