










# Healthcare service use and medical outcomes of tracheostomy-dependent children: a nationwide study

In Gyu Song <sup>1</sup>, You Sun Kim <sup>2,3</sup>, Min Sun Kim <sup>3,4</sup>, Ji Weon Lee <sup>4</sup>, Yoon-Min Cho <sup>5</sup>, Youna Lim <sup>6</sup>, Seong Keun Kwon <sup>7</sup>, Dong In Suh <sup>3</sup>, June Dong Park <sup>3</sup>

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IGS and YSK are joint first authors.

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## ABSTRACT

**Background** Despite the rising trend of tracheostomies in children, there is a lack of comprehensive resources for families to navigate the challenges of living with a tracheostomy, emphasising the need for evidence-based support in understanding postoperative care and long-term adjustments. This study aimed to examine the pattern of using healthcare services and nationwide medical outcomes in children who underwent a tracheotomy before the age of 2 years.

**Methods** This retrospective study used the National Health Insurance System database from 2008 to 2016 and included all children codified with tracheotomy procedure codes before their second birthday. Healthcare utilisation, such as medical costs, number of hospital visits, home healthcare nursing and medical diagnoses on readmission, in the first 2 years after tracheotomy was evaluated. Multivariable logistic regression analysis was used to determine the factors affecting mortality.

**Results** In total, 813 patients were included in this study. Their use of healthcare services and the accompanying expenses were higher than the national medians for similar age groups; however, both metrics decreased in the second year. The major causes of admission within 2 years of surgery were respiratory and neurological diseases. The mortality rate within 2 years was 37.8%. Higher risks of mortality were associated with having two or more complex chronic conditions. Use of home healthcare nursing services was associated with a lower mortality risk.

**Conclusion** Paediatric patients with more complex chronic conditions tended to have higher mortality rates within 2 years after surgery. However, receiving home healthcare nursing was significantly associated with a reduced risk of death. Many causes of hospitalisation may be preventable with education and supportive care. Therefore, further research for establishing an integrated care system for these patients and their caregivers is required.

## INTRODUCTION

With the development of medical science, the number of medically complex and technology-dependent children has steadily increased. Paediatric tracheotomy is technically difficult, with a higher risk of mortality

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Children under the age of 2 who undergo tracheotomy experience high morbidity and significant complications and place a substantial burden on their families.

## WHAT THIS STUDY ADDS

⇒ Many causes of hospitalisation may be preventable with education and supportive care.  
⇒ Receiving home healthcare nursing was significantly associated with a reduced risk of mortality.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings of this study can serve as empirical evidence for establishing new systems, such as home healthcare services, in countries with weak support systems for children who undergo tracheotomy.

and perioperative complications than that in the adult population,<sup>1 2</sup> particularly for younger children. Data from the National Surgical Quality Improvement Program of the American College of Surgeons indicate that children aged <2 years with tracheostomy have higher morbidity, with 24.3% experiencing a major complication within 30 days of tracheotomy.<sup>3</sup> Nonetheless, the procedure is becoming more prevalent in paediatric populations with complex medical conditions or chronic illnesses, such as airway obstruction, cardiopulmonary disease and neurological impairment.<sup>1 2 4</sup>

Living with a tracheostomy poses significant challenges to both patients and their families; therefore, they should receive comprehensive information before the procedure. Providing practical insights into the journey after tracheotomy can empower parents to make informed decisions about the surgery and prepare for the required long-term adjustments. It becomes imperative to develop family-centred resources grounded in robust, evidence-based data on contemporary

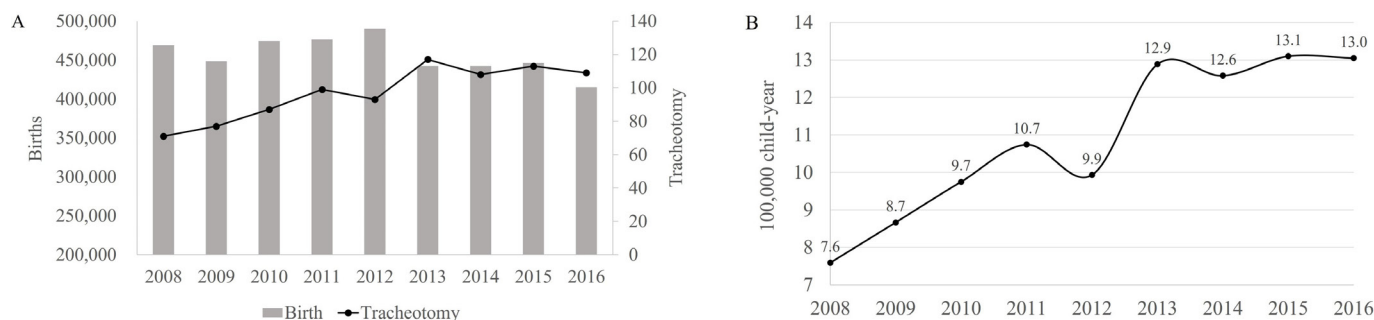


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For numbered affiliations see end of article.

**Correspondence to**  
Professor Min Sun Kim;  
mskim81@snu.ac.kr

Dr In Gyu Song; pedigms@gmail.com



**Figure 1** Trend in (A) the number of births and tracheotomies between 2008 and 2016 and (B) the incidence rate of tracheotomies per 100 000 child-years in the Republic of Korea.

tracheotomy-related healthcare and outcomes. While there is a wealth of literature on paediatric tracheotomy procedures, indications and complications, studies focusing on the enduring experiences of patients and their families after tracheotomy are lacking.<sup>1 5–7</sup> This study leveraged the Korean National Health Insurance System (KNHIS) database to examine nationwide healthcare utilisation and outcomes among children who underwent tracheotomy before their second birthday.

## METHODS

### Data source and study design

This retrospective study analysed the data of children born between 2008 and 2016 using a nationwide database from the Republic of Korea and followed their records until 2018. The KNHIS database collects mandatory information on beneficiaries of national health insurance and medical aid in a unified manner. This database comprises several linked data sets such as social and economic qualifications, medical treatment, results of medical check-ups and costs.<sup>8</sup> Diagnostic codes are based on the WHO's International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10). Information on population census

and national annual medical fees was obtained from the Korean Statistical Information Service.<sup>9</sup>

Children who underwent tracheotomy before the age of 2 were included to focus on a population where tracheotomy complications are more prevalent.<sup>3</sup> We excluded children who died during hospitalisation to ensure that the study assessed progress after elective tracheotomy, which would be more informative in terms of long-term implications.

### Terminology

Tracheotomy cases were defined as those with a corresponding procedural code (O1300, O1301, O1303, O1305, O1306, M5830). Complex chronic conditions (CCCs) are defined as:

any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center.<sup>10</sup>

The list of categories was adopted from CCC version 2.<sup>11</sup> Patients living with CCCs were defined as individuals

**Table 1** Number of births and tracheotomies between 2008 and 2016 in the Republic of Korea

	Birth (n)	Tracheotomy (n)	Death within tracheotomy episode*, n (%)	Death within 2 years after first discharge, n (%)
2008	469 248	71	5 (7.0)	24 (36.4)
2009	448 459	77	10 (13.0)	26 (38.8)
2010	474 435	87	3 (3.4)	43 (51.2)
2011	476 710	99	5 (5.1)	29 (30.9)
2012	490 472	93	3 (3.2)	31 (34.4)
2013	442 418	117	6 (5.1)	36 (32.4)
2014	442 341	108	9 (8.3)	36 (36.4)
2015	446 160	113	8 (7.1)	36 (34.3)
2016	415 083	109	12 (11.0)	46 (47.4)
Total	4 105 326	874	61 (7.0)	307 (37.8)

\*Number of children who died during hospitalisation for tracheotomy and these were excluded in this study.

**Table 2** Demographics of patients who underwent tracheotomy before 2 years of age, n (%)

Total	N=813	100%
Sex		
Male	461	56.7
Female	352	43.3
Age at tracheotomy (years)		
0	701	86.2
1	112	13.8
Level of income		
Medical aid and first (lowest)	123	15.6
Second	173	21.9
Third	286	36.2
Fourth (highest)	208	26.3
Residence		
Metropolitan city*	370	41.0
Other regions	533	59.0
Categories of CCC		
Respiratory	441	54.2
Neurological and neuromuscular	331	40.7
Premature and neonatal	274	33.7
Cardiovascular	187	23.0
Metabolic	135	16.6
Gastrointestinal	132	16.2
Other congenital or genetic defect	99	12.2
Renal and urological	28	3.4
Malignancy	12	1.5
Haematological or immunological	11	1.4
Miscellaneous	1	0.1
Number of CCCs		
0	70	8.6
1	217	26.7
2	260	32.0
≥3	266	32.7
Two-year mortality	307	37.8
Median (interquartile) day to death	144 (52–313)	–
Patients who died during hospitalisation for tracheotomy were excluded.		
*Metropolitan city: Seoul, Busan, Incheon, Daegu, Daejeon, Gwangju and Ulsan.		
CCC, complex chronic condition.		

assigned CCC disease codes in either the primary or additional diagnosis field for hospital visits. The number of CCCs was defined as the number of CCC categories designated for each patient.

Ambulatory care sensitive conditions (ACSCs) refer to clinical conditions where the likelihood of an unplanned hospitalisation can be diminished through prompt and efficient outpatient care. Hospitalisation stemming from ACSC may signify a lost opportunity for prevention and an

adverse encounter for a child and their family. Additionally, it may signal a deficiency in, or limited access to, high-quality outpatient healthcare services. We defined ACSCs using the patients' ICD-10 codes, according to previous studies.<sup>12 13</sup>

The relevance index indicates the number of patients in a certain area who used hospitals in the same region. This was calculated by dividing the number of patients who underwent tracheotomy in a hospital located in the same residential area by the total number of patients who underwent tracheotomy residing in that area for the same year. Therefore, a lower relevance index in a specific region indicated that more patients moved to a remote area for treatment.<sup>14 15</sup>

### Variables

Demographic characteristics included patients' sex, age at tracheotomy, income level, categories and number of CCCs, address of the patient's residence and the medical institution where tracheotomy was performed. The insurance type (national health insurance or medical aid) and the KNHIS premium based on income levels were used as proxy indicators for financial status. The lowest income category was designated as those receiving medical aid. KNHIS income levels were divided into four groups: category 1 (<25% premium), category 2 (25%–50% premium), category 3 (50%–75% premium) and category 4 (>75% premium). Medical aid and category 1 patients were merged for analysis due to the small number receiving medical aid. The country was divided into administrative districts, and patients' residential districts were classified as metropolitan (Seoul, Busan, Incheon, Daegu, Daejeon, Gwangju, Ulsan) or other regions.

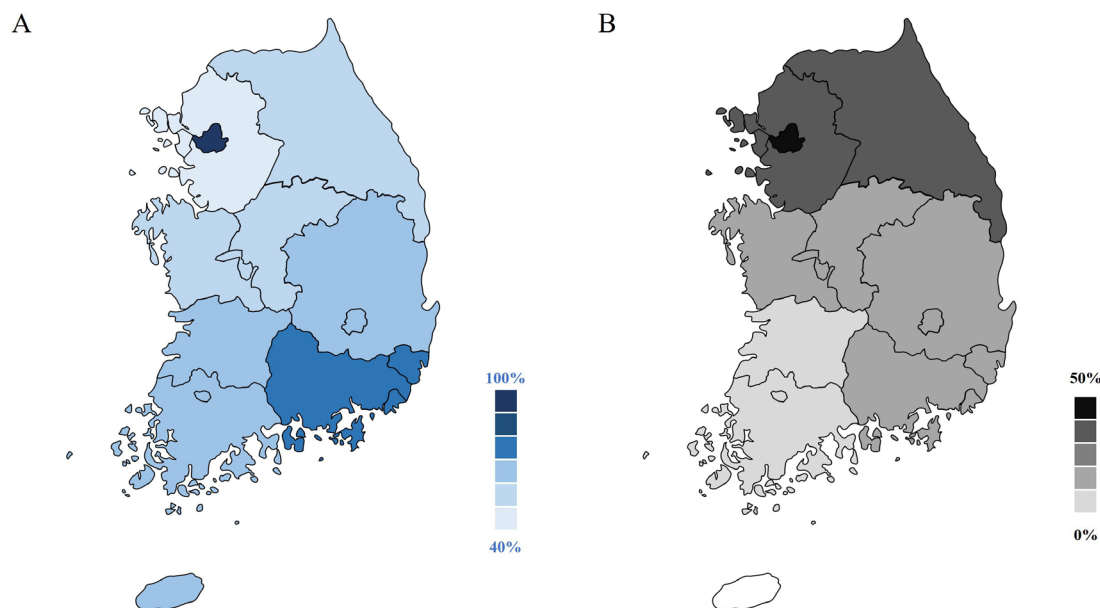
For 2 years following tracheotomy, healthcare utilisation indicators included medical expenses and the combined count of hospitalisations, outpatient visits and use of emergency medical services. Notably, admissions through the emergency room were recorded under hospitalisations in the database, precluding a separate tally for emergency department visits. Additionally, home care nursing utilisation was identified by assignment of procedure codes (AN200, AN300, AN400, AN500).

### Outcome measures

The main outcome measure was mortality within 2 years of tracheotomy. The primary and top five secondary diagnoses for admission were identified using ICD-10 diagnostic codes. The top 20 codes were selected after excluding codes relating to health status/services (tracheostomy status) and underlying medical conditions, such as hypoxic ischaemic encephalopathy.

### Statistical analysis

The annual difference in the 2-year mortality rate after tracheotomy was examined using Pearson's  $\chi^2$  test. Multivariate logistic regression was used to evaluate the association between the main outcome and predictive factors. All analyses were performed using SAS software (V.9.4). P values of <0.05 were considered statistically significant, and ORs with



**Figure 2** (A) Relevance index and (B) home healthcare nursing utilisation ratio for children who had a tracheotomy in the Republic of Korea. The relevance index is the ratio of children who underwent tracheotomy in a certain residential district to children dwelling in that area who underwent tracheotomy. The home healthcare nursing utilisation ratio is defined as the ratio of children using home healthcare nursing. The national territory is divided into eight areas. The map was downloaded from the Republic of Korea editable map template (<https://yourfreetemplates.com/free-south-korea-editable-map>) and modified by the Microsoft PowerPoint 2016 program after confirming the 'Terms-of-use'.

95% CIs were calculated to elucidate the strengths of the associations.

### Patient and public involvement

The public nor patients were involved in this study.

## RESULTS

### Trends in the number of tracheotomies and mortality rates

In total, 4105326 infants were born between 2008 and 2016, with a downward trend (figure 1A, table 1).

However, the number and incidence rate of tracheotomies in patients <2 years also increased over the years (figure 1B). 61 children who died during hospitalisation for tracheotomy were excluded, and 813 were included. 307 patients died within 2 years after tracheotomy. The overall mortality rate was 37.8%. There were no significant annual differences in the 2-year mortality rates ( $p=0.099$ ).

### Demographic characteristics

Most patients underwent tracheotomy before 1 year of age. The majority (91.4%) had at least one CCC, and

**Table 3** Healthcare service utilisation per person among patients who received it more than once

	First year after tracheotomy (n=566)			Second year after tracheotomy (n=507)		
	First quartile	Median	Third quartile	First quartile	Median	Third quartile
Medical cost (US\$)	5854	14 542	36 820	2673	6468	16 241
Hospitalisation						
Total duration (days)	9	23	37.5	5	10	26
Number of hospitalisations	2	3	5	2	3	4
Cost	3644	12 680	38 728	1695	4941	16 102
Outpatient clinic						
Number of visits	14	23	30	17	25	34
Cost	966	1974	3563	786	1639	3364
Emergency room						
Number of visits	2	3	5	1	2	4
Home healthcare nursing						
Number (%)	147 (26.0)			91 (17.9)		
Cost is valued in US dollars. Those admitted through the emergency room were classified into ‘admission’.						



**Table 4** List of the top 20 diagnoses in patients who were readmitted after tracheotomy

ICD-10 code	Diagnosis	n
J18.9	Pneumonia*	116
J45.9	Asthma*	82
J21.9	Acute bronchiolitis*	76
R56.8	Other and unspecified convulsions*	53
R50.9	Fever	45
J69.0	Pneumonitis due to food and vomit*	43
G40.9	Epilepsy, unspecified*	40
J38.6	Stenosis of larynx	40
A09.9	Gastroenteritis and colitis of unspecified origin*	35
A41.9	Sepsis, unspecified	35
J20.9	Acute bronchitis*	35
R06.0	Dyspnoea	30
K21.9	Gastro-oesophageal reflux disease without oesophagitis*	26
N39.0	Urinary tract infection*	25
I46.0	Cardiac arrest with successful resuscitation	22
R13	Dysphagia	20
I46.9	Cardiac arrest, unspecified	17
R060	Other forms of dyspnoea	17
D65	Disseminated intravascular coagulation (defibrination syndrome)	17
J39.8	Other specified diseases of upper respiratory tract	15

Codes on health status/services and underlying medical conditions were omitted.  
 \*Diagnosis corresponding to ambulatory care sensitive conditions.  
 ICD-10, International Statistical Classification of Diseases and Related Health Problems 10th Revision.

approximately two-thirds had multiple CCCs (table 2). Approximately half (48.0%) of the surgeries were performed in Seoul, which showed the highest relevance index (92.6%). The relevance index for Busan and the surrounding area was 75.2% (figure 2A). 42% of children residing in Seoul used home healthcare nursing services. On the other hand, <30% children residing distant from the capital city used home healthcare nursing services (figure 2B).

### Healthcare utilisation after tracheotomy

Table 3 shows the data of the patients with at least one service used in the first 2 years after tracheotomy. The spend on medical services was more in the first year than in the second year; the median total medical costs were US\$14542 and US\$6468 per capita, respectively (US\$1=1115.7 Korean won). The total hospital stay, number of emergency room visits and use of home healthcare nursing also decreased. While 26.0% of

patients received home healthcare nursing in the first year, only 17.9% did so in the second year.

### Causes of hospitalisation after tracheotomy

Table 4 summarises the top 20 causes of hospitalisation within 2 years after tracheotomy. Respiratory illnesses, such as pneumonia (n=116) and asthma (n=82), and neurological illnesses, including convulsions and epilepsy, were frequent diagnoses for admission. 10 of the 20 diagnoses were considered ACSCs.

### Risk factors for mortality

The median time to death within 2 years after tracheotomy for 307 patients was 144 days (IQR: 52–313). In multivariable analyses, three CCCs indicated the highest likelihood of mortality (OR 2.654; 95% CI 1.462 to 4.819), and two CCCs were also associated with increased mortality (OR 1.971; 95% CI 1.084 to 3.585). Home healthcare nursing was significantly associated with a reduced mortality risk (OR 0.613; 95% CI 0.433 to 0.869) (table 5).

## DISCUSSION

To our knowledge, this is the first study that identified the nature of healthcare utilisation and outcomes of children who underwent tracheotomy before 2 years of age in Korea. The number of infants requiring tracheotomy increased despite a declining national birth rate. Most paediatric patients underwent surgery in their first year of life and had at least one CCC. Presence of more CCCs was associated with higher mortality within 2 years after surgery. Home healthcare nursing utilisation was associated with lower mortality.

The increasing trend in tracheotomies observed in this study has also been observed in other studies. A single-tertiary centre study revealed that surgeries have been increasing over the last 30 years.<sup>4</sup> A study of 14155 participants registered in the Pediatric Health Information System database of 52 children's hospitals in the USA from 2010 to 2018 also showed an increase in the annual number of tracheotomies.<sup>16</sup> This tendency could be attributed to improvements in paediatric critical care technologies and the increased life expectancy of medically complex children.<sup>1</sup>

Children who underwent tracheotomy had higher healthcare utilisation than did the general population of children. The median total admission durations were 23 days and 10 days in the first and second years after tracheotomy, respectively; these were substantially higher than the reported median of 6.8 days and 7.5 days, respectively, for same-age Korean children.<sup>17</sup> The annual median total medical costs per capita in both years were also far above those for same-age Korean children (US\$917.5).<sup>17</sup> As the benefit coverage rate in Korea was approximately 60% during the study period, higher actual medical expenses were estimated.<sup>18</sup> These results were consistent with previous findings.<sup>19 20</sup> A study including 502 children in

**Table 5** Associated factors of mortality of patients who underwent tracheotomy before 2 years old

	Death, n (%)	OR (95% CI)	Adjusted OR (95% CI)*
Number of CCCs			
0	19 (27.1)	Reference	Reference
1	62 (28.6)	1.074 (0.587 to 1.963)	1.151 (0.621 to 2.133)
2	102 (39.2)	1.732 (0.967 to 3.102)	1.971 (1.084 to 3.585)
≥3	124 (46.6)	2.343 (1.313 to 4.182)	2.654 (1.462 to 4.819)
Sex			
Female	137 (38.9)	Reference	Reference
Male	170 (36.9)	0.917 (0.689 to 1.220)	0.985 (0.730 to 1.331)
Age at tracheotomy (years)			
0	265 (37.8)	Reference	Reference
1	42 (37.5)	0.987 (0.654 to 1.490)	0.937 (0.602 to 1.457)
Level of income			
Medical aid and first	58 (47.2)	1.291 (0.824 to 2.023)	1.209 (0.759 to 1.924)
Second	59 (34.1)	0.749 (0.493 to 1.138)	0.688 (0.448 to 1.058)
Third	97 (33.9)	0.743 (0.513 to 1.074)	0.684 (0.467 to 1.002)
Fourth	85 (40.9)	Reference	Reference
Residence			
Metropolitan area	123 (37.2)	Reference	Reference
Non-metropolitan area	183 (38.2)	1.045 (0.783 to 1.396)	0.983 (0.725 to 1.333)
Home healthcare nursing			
Yes	67 (30.9)	0.663 (0.476 to 0.923)	0.613 (0.433 to 0.869)
No	240 (40.3)	Reference	Reference

Patients who died during hospitalisation for tracheotomy were excluded.  
 \*Adjusted with number of CCCs, sex, age at tracheotomy, level of income, residence and home healthcare nursing.  
 CCC, complex chronic condition.

the USA who underwent tracheotomy in 2009 found that the total healthcare spending for hospitalisation during the 2 years after the surgery was over US\$75 000.<sup>21</sup>

In the current study, approximately 48.0% of patients underwent surgery in Seoul, and the relevance index for other regions was lower than that for the capital city. Moreover, the home care nursing utilisation rate was higher in Seoul. Patients living in remote areas of the capital city may have difficulties with not only undergoing surgery but also receiving postoperative supportive care. A survey reported that caregivers of medical technology-dependent children in Korea had substantial problems taking care of their sick children and managing medical devices at home.<sup>22</sup> Studies have urged the establishment of a well-equipped environment and a partnership between hospitals and community care systems for successful tracheostomy management after discharge.<sup>23–24</sup> To provide proper care after discharge, a referral system and home healthcare services must be developed throughout the country. For example, the American Academy of Pediatrics has called for fostering family provider–community partnerships.<sup>25</sup> Establishment and implementation of comprehensive measures, such as standardised education protocols, systematic communication between tertiary

care centres and primary care providers, and activation of visiting home healthcare, respite care and school-based specialised services, are encouraged.<sup>26–27</sup>

In this study, most hospitalisations after tracheotomy were due to respiratory or neurological conditions. Notably, among the top 10 conditions, 7 were identified as ACSCs, and 8 among the top 20 conditions were respiratory problems. The aforementioned comprehensive measures could help minimise avoidable hospitalisations.<sup>12–13–26–27</sup> In order to reduce respiratory problems at home, caregivers should be educated on adequate secretion management, clean techniques for aspiration and the importance of vaccination.<sup>28</sup> The American Thoracic Society guidelines also emphasise the importance of education. Continuous efforts to obtain, strengthen and improve skills are encouraged to ensure patient safety and clinical benefits. The guidelines presented detailed educational objectives in various domains.<sup>29</sup> The utilisation of telemedicine can be an additional option for supporting parents, especially those with limited medical resources. 27% of hospitalisations were shown to be prevented by telemedicine in a prospective clinical study of tracheostomy-dependent children, with caregivers reporting improved safety and quality of life.<sup>30</sup>

In this study, the mortality rate within 2 years after surgery was 37.8%, higher than that previously reported. A retrospective single-centre study including 68 children who underwent tracheotomy before age 2 found that 23.5% of patients died.<sup>31</sup> Other recent studies reported that approximately 13%–27% of paediatric patients who underwent tracheotomy died.<sup>32–35</sup> The higher mortality rate may be attributed to the broader indications for tracheotomy in Korea, where doctors sometimes perform the procedure even when it may not significantly alter the prognosis. This can be inferred from the higher population-based tracheotomy incidence rate in Korea (10.9 per 100 000 child-years vs 6.0 per 100 000 child-years in the USA) and deserves further study.<sup>6</sup> To minimise avoidable tracheotomies in infants, a multidisciplinary approach involving evidence-based guideline development, specialised training for healthcare professionals, clear communication with families about prognosis and treatment options, and early discussions on advanced care planning is crucial. Additionally, regular case reviews and data analysis can contribute to improved decision-making and outcomes.

The greater the number of CCCs present among patients who underwent tracheotomy, the higher the association with mortality. Since the specific cause of death for each patient was not ascertainable in this study, caution is warranted in the interpretation of our findings. However, our findings could be used in shared decision-making when deciding to proceed with tracheotomy. It would be beneficial to share with parents that the risks/burdens of the procedure, particularly the risk of mortality due to underlying conditions, must be considered.

Those receiving home care nursing demonstrated lower odds of mortality in this study. Home care nursing has been shown in previous studies to assist with transitioning safely from the hospital to home and reducing the risk of readmission. Additionally, research has demonstrated its ability to decrease family burnout and enhance the quality of life for children.<sup>36–38</sup> Furthermore, cost-effectiveness analyses have revealed significant cost-saving effects associated with home care nursing.<sup>36–39</sup> Establishing supportive systems like home healthcare could potentially contribute to reducing mortality rates and alleviating the burden on families.

This study had limitations. First, the KNHIS is based on claims data and we could not obtain detailed clinical data or identify the patient's medical condition. Although we used CCC codes to identify the disease severity, it may not have reflected the patient's actual medical condition. Moreover, we could not ascertain the specific reasons for tracheotomy or underlying causes of mortality. Therefore, prospective cohort studies should be conducted to determine preoperative and postoperative conditions and prognoses in the future. Second, as a retrospective cohort study, this study examined associations rather than causal relationships, thus precluding the determination of cause–effect relationship. This aspect could also be further addressed in a prospective cohort study.

Nevertheless, this study had several strengths. First, it was a nationwide study that identified children who underwent tracheotomy within 2 years after birth. Because 97% of individuals are covered by a unified national health insurance system,<sup>40</sup> our findings could be generalised to the entire population and minimise bias. Second, because the KNHIS database contains healthcare utilisation variables, a nationwide analysis of healthcare expenditure and admission days was possible. Thus, our study can be used as a reference for preoperative counselling and parental preparation during the postoperative phase.

In conclusion, children with tracheostomies often experience complex conditions. Traditional healthcare models have difficulty meeting the high healthcare needs of these patients, and they frequently receive fragmented and disorganised care.<sup>41</sup> An integrated care system that links hospital-based specialists with community-based healthcare can be helpful. It is necessary to continue studying the characteristics, needs and outcomes of this population as the information gathered will be beneficial to patients and caregivers.

#### Author affiliations

<sup>1</sup>Pediatrics, Yonsei University College of Medicine, Seodaemun-gu, Korea (the Republic of)

<sup>2</sup>Department of Paediatrics, National Medical Center, Jung, Korea (the Republic of)

<sup>3</sup>Department of Paediatrics, Seoul National University College of Medicine, Seoul, Korea (the Republic of)

<sup>4</sup>Seoul National University Children's Hospital Integrated Care Center, Seoul, Korea (the Republic of)

<sup>5</sup>National Health Insurance Service, Wonju, Korea (the Republic of)

<sup>6</sup>Seoul National University, Gwanak-gu, Korea (the Republic of)

<sup>7</sup>Department of Otorhinolaryngology-Head and Neck Surgery, Seoul National University College of Medicine, Seoul, Korea (the Republic of)

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**Contributors** Conceptualisation: MSK, IGS, YSK. Data curation: IGS, Y-MC, YL. Formal analysis: Y-MC, YL. Investigation: MSK, IGS, YSK, JWL. Methodology: MSK, IGS, YSK, Y-MC, YL. Software: IGS, Y-MC, YL. Validation: IGS, Y-MC, YL. Visualisation: IGS, Y-MC, YL. Writing—original draft: IGS, YSK. Writing—review and editing: MSK, IGS, YSK, JWL, SKK, DIS, JDP. Guarantors: MSK, IGS

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**Data availability statement** The data supporting the conclusions of this study can be obtained from NHIS. However, access to this data is subject to restrictions as it was utilized under license for this specific study and is not accessible to the



public. Nevertheless, the authors can provide the data upon reasonable request and with the approval of NHIS.

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#### ORCID iDs

In Gyu Song <http://orcid.org/0000-0002-3205-9942>  
 You Sun Kim <http://orcid.org/0000-0002-7687-2687>  
 Min Sun Kim <http://orcid.org/0000-0001-5323-9857>  
 Ji Weon Lee <http://orcid.org/0000-0003-4012-0843>  
 Yoon-Min Cho <http://orcid.org/0000-0002-6970-938X>  
 Youna Lim <http://orcid.org/0000-0002-0325-0246>  
 Seong Keun Kwon <http://orcid.org/0000-0001-9218-7666>  
 Dong In Suh <http://orcid.org/0000-0002-7817-8728>  
 June Dong Park <http://orcid.org/0000-0001-8113-1384>

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