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Tracheostomy in children with severe neurological impairment: A single-centre review

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Abstract

Objective: To determine the characteristics and the clinical course of the children with severe neurological impairment who require tracheostomy and long-term in-patient care. ***Design:*** Retrospective case series. ***Patients:*** 36 patients with severe neurological impairment and tracheostomy, having received in-patient care from Department of Paediatrics and Adolescent Medicine, Caritas Medical Centre, from 1 January 2010 to 30 September 2015. ***Main outcome measures:*** Post-tracheostomy survival time and rate, complications and mortality related to tracheostomy, decannulation rate, types of bacteria found in the lower respiratory tract specimens after tracheostomy creation. ***Results:*** The mean age at which their tracheostomy was created is 6.9 years (range 4 weeks to 18 years). The indications for their tracheostomy include upper airway obstruction (58%), recurrent pneumonia (33%), and prolonged invasive mechanical ventilation (31%). Twenty-six (72%) patients were still alive at the end of the study. Their mean age is 13.8 years, and the mean duration of time elapsed since their tracheostomy was created is 8.2 years. Ten (28%) patients had passed away at the end of the study. Their mean age at death is 15.1 years, and their mean post-tracheostomy survival time is 5.0 years. The overall 1-year and 5-year post-tracheostomy survival rates are 100% and 81.2% respectively. None of them had decannulation, or tracheostomy-related death. The 3 most prevalent bacteria found in the lower respiratory tract specimens after tracheostomy creation are *Pseudomonas aeroginosa*, non-typeable *Haemophilus influenzae* and *Moraxella catarrhalis*. ***Conclusion:*** Although tracheostomy is an invasive procedure and carries risk of complication, it can facilitate better care of the children with severe neurological impairment, physical disability and respiratory complications, including upper airway obstruction, recurrent pneumonia, and respiratory failure requiring prolonged invasive mechanical ventilation. They can have long survival after tracheostomy. The decannulation rate is extremely low in them.

Keywords: Children, Complication, Indication, Neurological impairment, Survival, Tracheostomy

Introduction

Children with severe neurological impairment are prone to respiratory co-morbidities and complications. Moreover, a large proportion of the mortality of this group is related to the deterioration of respiratory condition. Tracheostomy is one of the long-term management options, aiming to facilitate respiratory care, improve respiratory function, reduce respiratory complications, and improve survival and quality of life. However, tracheostomy is also an invasive procedure with its own complications which could be life-threatening. Data about the outcome of these children undergoing tracheostomy is lacking. Our goal is to evaluate the indications and outcome of tracheostomy in this group of patient through the use of our patient information collected over the past 6 years.

Setting, patients and methods

The cohort in this study includes all the patients with severe neurological impairment and tracheostomy, who were cared for long term at Paediatric Department, Caritas Medical Centre (including Developmental Disabilities Unit (DDU), Ventilator-assisted Care Unit (VACU) and general ward) between 1 January 2010 and

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30 September 2015. The DDU is the only centre in Hong Kong providing long-term in-patient care to children with severe neurological impairment and complex medical problems. The VACU looks after children requiring long-term invasive ventilatory support. Both units accept territory-wide referrals from other instituitions in Hong Kong. We retrospectively evaluated their medical records, including the medical notes from our hospital, the electronic medical summaries from other hospitals and the record of the tracheostomy surgery. The information from the other hospitals is retrieved from the Electronic Patient Records (ePR) of Hospital Authority. If the patient had more than one tracheostomy surgery in his / her life, only the first one is analysed.

The information recorded included: patient demographics, causes of their neurological impairment, gross motor functional status, co-existing medical problems (severe / profound intellectual disability or developmental delay, cerebral palsy, hypotonia, epilepsy, gastroesophageal reflux), the need for artificial tube feeding or long-term positive pressure ventilatory support, information about the tracheostomy surgery (date, the institution where it was performed, indications for tracheostomy), any complications related to the tracheostomy, and the date of death for those who had passed away.

We also looked into the types of bacteria found in their lower respiratory tract specimens (tracheal aspirate or broncho-alveolar lavage) taken since their tracheostomy was created. We assumed that these specimens were collected during their acute illnesses (e.g. increased sputum production, cough or respiratory distress; fever), intending to investigate whether lower respiratory tract infections account for these symptoms.

An analysis was performed to assess the relationship of age of tracheostomy creation and survival. The patients were divided into 2 groups in accordance with their age at which the surgery was performed, using 5 years as the dividing line. Cumulative survival rates, with respect to the date of the tracheostomy surgery and of birth respectively, were calculated.

Statistical analysis was performed using SPSS software version 22. Differences between groups were compared using Chi-square test for categorical variables. Two-tailed t-test was used to test for differences between means from groups. We used Kaplan Meier Method to analyse the survival function. Individuals are censored if they were alive at the end of the study period. The overall differences between estimated survival curves of different groups of patient were calculated by the log-rank test. Values of *P* less than 0.05 were considered significant.

Results

Thirty-six patients with severe neurologically impairment and tracheostomy had received long-term in-patient care in our unit between January 2010 and September 2015. All of them have severe or profound intellectual disability (or developmental delay), and are dependent on others

Table 1. Characteristics of patients

Sex	Male: 19 (53%); Female 17 (47%)		
Grade of MR / DD	Severe / Profound: 36 (100%)		
GMFCS	Level 5: 36 (100%)		
Status at the end of the study	Alive: 26 (72%) • In our hospital: 21 • Transferred out: 5	Death: 10 (28%) • Died in our hospital: 7 • Died in other hospitals: 3	
Cerebral palsy vs hypotonia	Cerebral palsy: 26 (72%) • Spastic: 13 (36%) • Dystonia: 4 (11%) • Mixed: 9 (25%)	Hypotonia: 10 (28%)	
Epilepsy	Yes: 30 (83%)	No: 6 (17%)	
GERD	Yes: 18 (50%)	No: 18 (50%)	
Feeding mode	Gastrostomy: 29 (81%)	Nasogastric tube: 7 (19%)	Oral: 0
Long-term positive pressure ventilatory support	No: 24 (67%)	Yes: 12 (33%)	

MR: mental retardation (intellectual disability); DD: developmental delay; GMFCS: Gross Motor Function Classification System; GERD: gastroesophageal reflux disease

for mobility (Gross Motor Function Classification System, GMFCS Level 5). Seventy-two percent (26/36) of them have cerebral palsy (13 are of spastic type, 4 dystonic, 9 mixed), while the remaining 28% (10/36) have hypotonia. Most of them have co-existing epilepsy (30/36, 83%). Half of them (18/36) were diagnosed to have gastroesophageal reflux disease (GERD). All patients (36/36) require artificial tube feeding through either a gastrostomy tube (29/36, 81%) or nasogastric tube (7/36, 19%). Thirty-three percent of them (12/36) require long-term positive-pressure ventilatory support through their tracheostomy.

At the end of this study, 26 (72%) of them were still alive. The mean age of this group of patients was 13.8 years (range 2.4-25.1 years; median 13.3 years). Twenty-one patients in this group were under the care of our department. Their mean age was 12.2 years (range 2.4-24.2 years; median 11.1 years). Five had been transferred to adult service since they reached 18 years old. Their mean age was 20.5 years (range 18.2-25.1 years; median 19.7 years).

The remaining 10 (28%) patients had passed away at the end of this study. The mean age at death was 15.1 years (range 1.9-20.4 years; median 16.3 years). Seven of them died during the care in our unit, and the remaining 3 after being transferred to adult service.

There is no tracheostomy-related mortality. None of them had decannulation.

There is a great variety of the underlying conditions leading to their severe neurological impairment and intellectual disability. The most prevalent condition is hypoxic-ischemic encephalopathy (12/36, 33%), followed by idiopathic cause (8/36, 22%), metabolic / genetic / chromosomal conditions (5/36, 14%), neuromuscular diseases (3/36, 8%), and other causes (Table 2).

The indications of their tracheostomy surgery include: upper airway obstruction (21/36, 58%), recurrent pneumonia (12/36, 33%) and prolonged invasive mechanical ventilation (11/36, 31%). Patients can have more than one indication for tracheostomy. For one patient who had the tracheostomy done in another hospital, the indication is not well-documented in the Electronic Patient Record (Table 3).

The age at which the tracheostomy surgery was performed varied between the fourth week of life to 18 years. The mean age is 6.9 years (median 4.7 years).

Thirteen (36%) patients had their tracheostomy surgery performed in our hospital. The mean age at which it was performed is 14.1 years (range 8.3 years-18.0 years; median 14.2 years), which is later in their lives than in those who had the tracheostomy done in other hospitals before transferal. The latter group had it performed at the mean age of 2.8 years (range 0.1 years -10.5 years; median 2.1 years). The difference in the mean age of tracheostomy creation between these 2 groups is significant (P<0.001).

For the group who were alive at the end of this study, the mean duration of time elapsed since the tracheostomy was created is 8.2 years (range 0.7 years -17.6 years; median 8.2 years). For those who had passed away, the mean duration that they were on tracheostomy is 5.0 years (range 1.2 years-12.4 years; median 3.4 years).

The overall 1-year survival rate after the tracheostomy surgery is 100%, 5-year 81.2%, and 10-year 72.5% (Figure 1). For the subgroup of patients who had their tracheostomy done in our hospital, the 5-year survival rate is 68.4% and 10-year 38.0%. They are significantly lower than the corresponding rates of those who had their tracheostomy done in other hospitals (P=0.022).

Those who had their tracheostomy created at or before 5 years of age ('earlier' group) are more likely to have upper airway obstruction as the indication for tracheostomy than those after ('later' group). The 'earlier' group is also more likely to have gastrostomy (Table 4).

Table 2. Underlying neurological impairment

Disease type	No.	Disease type	No.
Hypoxic-ischaemic enchepalopathy	12	CNS infection	2
Idiopathic	8	Demyelinating disorders of the CNS	2
Metabolic / genetic / chromosomal	5	Cerebral malformation	1
Neuromuscular diseases	3	Brain tumour	1
Cerebral haemorrhage	2		

CNS: central nervous system

They generally have higher post-tracheostomy survival rate than the 'later' group (*P*=0.024). The 5-year post-tracheostomy survival rates are 94.1% ('earlier' group) and 68.4% respectively (Figure 2). However, there is no significant difference in the life span between the 2 subgroups (*P*=0.787) (Figure 3).

The complications related to the tracheostomies include dislodgement, blockage, stenosis, tracheitis, tracheal haemorrhage, granuloma and abscess. A few of them needed another tracheostomy surgery following stoma stenosis or accidental dislodgement of tracheostomy tube. We are not able to quantify how frequent the complications occurred because the corresponding information in the records is patchy. There were 2 serious life-threatening complications in our series. One patient had accidental tracheostomy tube dislodgement during the first week after the tracheostomy surgery. Re-insertion at bedside was in vain, and surgical emphysema occurred after the attempt. That patient had to have the tube re-inserted in the operating theatre. Another patient suffered from hypoxic-ischemic brain damage after disconnection from ventilator following accidental tracheostomy tube dislodgement.

Table 3. Indications leading to their tracheostomy surgery

Upper airway obstruction	21/36 (58%)
Recurrent pneumonia	12/36 (33%)
Prolonged invasive mechanical ventilation	11/36 (31%)
Indications not well-defined	1/36 (3%)

Most patients had *Pseudomonas aeroginosa* (33/36, 92%), non-typeable *Haemophilus influenzae* (27/36, 75%) and *Moraxella catarrhalis* (27/36, 75%) found in their specimens of tracheal aspirate or bronchoalveolar lavage taken during acute illnesses (including fever, increased cough, increased respiratory distress) at certain time points after the creation of tracheostomy. Other commonly found bacteria in their lower respiratory tract during acute illnesses include *Proteus* species, *Staphylococcus aureus* (methicillin-sensitive and -resistant), *Acinetobacter* species, *Stenotrophomonas maltophilia*, *Corynebacterium striatum* (diphtheroids), *Escherichia coli* and *Serratia* species. The complete list

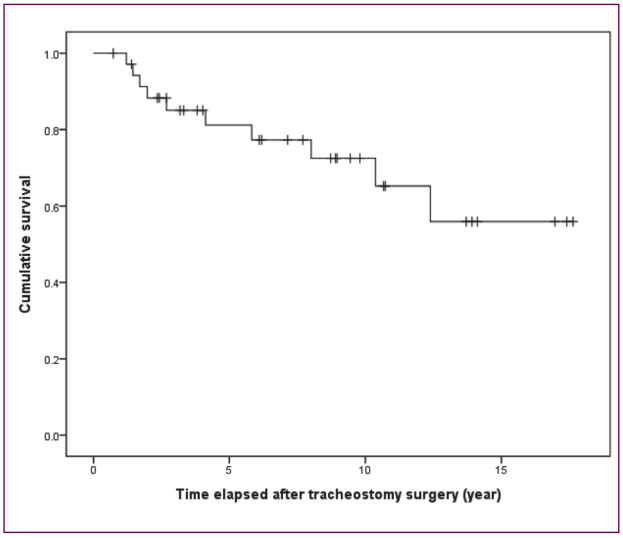

Figure 1. Cumulative post-tracheostomy survival of the whole group.

Table 4. Characteristics and indications for tracheostomy of the 2 subgroups, defined by the age at which the tracheostomy was created

Variables			'Earlier' group (n=18)	'Later' group (n=18)	P value
Characteristics	Sex	Male	8 (44%)	11 (61%)	0.317
	Cerebral palsy (CP) vs hypotonia	Spastic CP	4 (22%)	9 (50%)	0.107
		Dystonic CP	1 (6%)	3 (17%)	
		Mixed CP	7 (39%)	2 (11%)	
		Hypotonia	6 (33%)	4 (22%)	
	Gastro-esophageal reflux disease	Yes	9 (50%)	9 (50%)	1.0
	Epilepsy	Yes	13 (72%)	17 (94%)	0.074
	Feeding mode	Gastrostomy	17 (94%)	12 (67%)	0.035
		Naso-gastric tube	1 (6%)	6 (33%)	
	Positive-pressure ventilatory support	Yes	4 (22%)	8 (44%)	0.157
Indications for tracheostomy	Recurrent pneumonia	Yes	4 (22%)	8 (44%)	0.157
	Upper airway obstruction	Yes	14 (78%)	8 (44%)	0.040
	Prolonged invasive mechanical ventilation	Yes	5 (28%)	5 (28%)	1.0

of bacteria that were found in these lower respiratory tract specimens is shown in Table 5.

Discussion

Children with severe neurological impairment are more likely to have respiratory co-morbidities and prone to respiratory diseases. Their respiratory dysfunction is resulted from several factors: respiratory muscle weakness due to the underlying neurological condition or prolonged immobility; destruction of the airway and lung parenchyma due to recurrent infection and inflammation; restriction of the respiration due to kyphoscoliosis; upper airway obstruction; and hypoventilation.

In patients with cerebral palsy, there is a disruption of the tone and control of the pharyngeal muscles which maintain the patency of the pharynx when negative pressure is generated during inspiration.[1] Those with neuromuscular diseases have hypotonic airway, which is prone to collapse. Both groups of patients have high risk of upper airway obstruction, which can get worse by mucosal swelling and increased secretions during acute upper or lower respiratory tract infection.

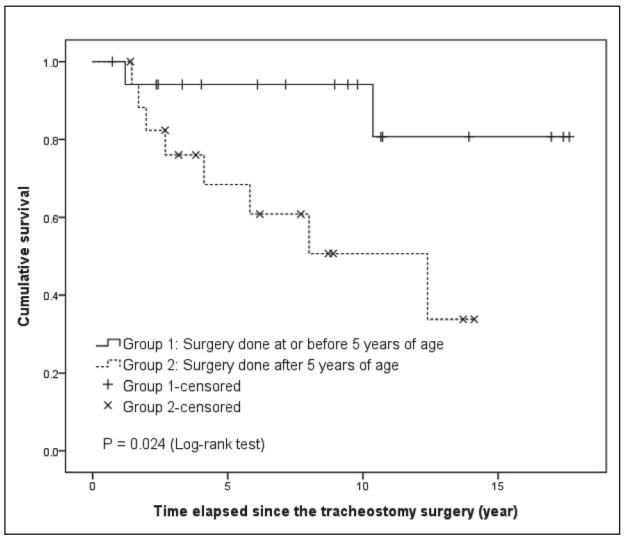

Figure 2. Cumulative post-tracheostomy survival of the 2 subgroups, defined by the age at which the tracheostomy tube was created.

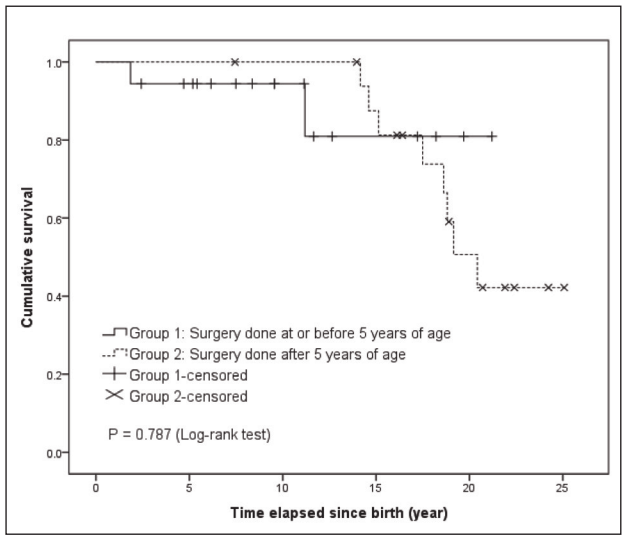

Figure 3. Cumulative survival, with respect to the date of birth, of the 2 subgroups, defined by the age at which the tracheostomy tube was created.

Table 5. Number of patients having the organism found in their tracheal aspirate / bronchoalveolar lavage at certain time points after the tracheostomy was created (assumed to be taken during acute illnesses, e.g. fever or respiratory symptoms)

Organism	n	Organism	n	Organism	n
Pseudomonas aeroginosa	33	*Serratia* spp.	12	*Achromobacter (Alcaligenes) xylosoxidans*	2
Haemophilus influenzae	27	*Streptococcus pneumoniae*	11	Alpha-haemolytic *Streptococcus*	2
Moraxella catarrhalis	27	Group G/C *Streptococcus*	11	*Citrobacter* spp.	1
*Staphylococcus aureus**	24	*Morganella morganii*	7	*Burkholderia cepacia* complex	1
Proteus spp.	22	*Klebsiella pneumoniae*	7	*Haemophilus parainfluenzae*	1
Acinetobacter spp.	19	Enterobacter spp.	5	Group B *Streptococcus*	1
Stenotrophomonas maltophilia	13	*Neisseria meningitidis*	4	*Streptococcus pyogenes*	1
Corynebacterium striatum (diphtheroids)	13	Coliform	4	*Delftia acidovorans*	1
Escherichia coli	12	*Providencia* spp.	3	Bacterioides	1

*Methicillin-susceptible: n = 20; methicillin-resistant: n = 11

Disruption of the swallowing mechanism (due to muscle weakness in neuromuscular conditions and poor coordination in cerebral palsy), gastro-esophageal reflux, and loss of protective cough mechanism contribute to the recurrent aspiration of the content of the upper oro-digestive tract into the lower airway. As a result, there is chronic inflammation and increased secretion in the lower respiratory tract. On the other hand, profound immobility and poor cough mechanism result in ineffective clearing of the sputum. All these factors predispose them to recurrent bronchitis, pneumonia and bronchiectasis.[2]

Tracheostomy helps in the care of these patients through several ways. It bypasses the upper airway obstruction and maintains a secure path for breathing. It improves the airway toileting by providing an easily accessible route for sputum suction, which is an important element of the routine care and the management during acute respiratory illnesses. If patients need positive-pressure ventilation, both acutely or long term, tracheostomy can serve as a secure airway for the ventilator machine. It markedly reduces the need for emergent placement of endotracheal tube, and the risk of morbidity and mortality caused by unsuccessful or delayed placement of endotracheal tube in emergency situations. Although non-invasive ventilation is an alternative, some of these patients have excessive secretions and are prone to aspiration, and are not good candidates for non-invasive ventilation. The physiological death space for breathing is reduced by tracheostomy, thereby lowering the work of breathing.[3] Diagnostic and therapeutic endoscopic manoeuvres of the lower respiratory tract can be performed with lower risk through the tracheostomy because of the presence of a secure airway.

This study summarises the characteristics and the long-term outcome of the paediatric patients with severe neurological impairment, requiring tracheostomy, and staying in hospital for long. It is a recent and relatively large cohort of such patients in our local population. Although they have a great variety of neurological conditions, they all have profound intellectual disability and immobility. Most of them also have epilepsy. They all require an artificial tube for feeding, which reflects that swallowing dysfunction is very common in this group of patients. However, they do not necessarily have gastro-esophageal reflux disease. The majority of them (69%) do not need long-term positive-pressure ventilatory support through their tracheostomies.

The indications for performing a tracheostomy are similar to those reported in the literature,[4-8] which include upper airway obstruction (anatomical or functional), recurrent pneumonia, and prolonged invasive mechanical ventilation. There is a wide range of age at which their tracheostomies were created, from a few weeks to 18 years.

Those patients having their tracheostomies created in other hospitals before being transferred to our centre were younger when the surgery was performed. They had severe upper airway obstruction (most commonly tracheomalacia) and respiratory failure requiring prolonged endotracheal intubation and invasive mechanical ventilatory support early in their lives, leading to early tracheostomy creation. On the other hand, those patients having their tracheostomies done in our hospital were older at the time of the surgery. Although their respiratory functions were relatively stable early in their lives, they gradually deteriorated due to the natural progression of their neurological conditions, prolonged immobility, and recurrent lower respiratory infection.

The survival rate is 100% at 1 year after the tracheostomy creation. The overall 5-year survival rate is 81.2%, which is comparable with that (76-89%) of those children requiring long-term positive-pressure ventilation at home, who have neuromotor dysfunction or chronic lung diseases.[9-11] The chance of survival beyond 10 years after tracheostomy is still quite high (72.5%). Although from this study we cannot tell whether tracheostomy can lengthen their life spans, they can survive relatively long after the procedure.

The overall time-defined survival rates in this study may overestimate the general post-tracheostomy survival of the children with severe neurological impairment requiring the surgery, because this cohort does not include those who had died in other hospitals after the tracheostomy surgery, presumably early in their lives.

The time-defined survival rates (except 1-year) for the sub-group who had their tracheostomy done after admission to our centre are lower than those with the procedure done in other hospitals. We suggest it is due the fact that the surgery was performed later in their lives, when their general and respiratory conditions had deteriorated to a certain level already. Moreover, as stated above, early deaths in other hospitals are not included in this cohort.

Tracheostomy can affect frequency of pneumonia in both ways. On one hand, better airway toileting can reduce pneumonia. On the other hand, presence of

tracheostomy will lead to bacterial colonisation which makes respiratory infection more frequent. When we were contemplating this study, we tried to devise a way to assess the relationship of tracheostomy and the frequency of pneumonia. However, we find it difficult to quantify that because it involved extensive examination of the detailed records and there was frequently inadequate documentation of the pneumonia episodes in the records.

Complications related to tracheostomy are not uncommon, although most of them are mild. The rates of complication reported in the literature range from 47 to 77%,[4,5,12,13] depending on the types of complication included for analysis. The most commonly encountered complication is granulation, followed by keloid formation, cannula obstruction, accidental dislodgement or decannulation, tracheal bleeding, and stenosis of stoma or trachea. There can be life-threatening consequences following accidental obstruction and dislodgement of the tracheostomy cannula. Other serious complications related to tracheostomy reported in other studies include pneumothorax, pneumomediastinum, creation of false passage following insertion of tracheostomy cannula, pressure necrosis of the tracheal wall, innominate artery erosion, tracheoesophageal fistula, and trachea-innominate artery fistula.[4-6,12-14] The rates of mortality directly related to tracheostomy reported in other studies are low, ranging from 0-3.6%.[4,5,12] Following decannulation, tracheocutaneous fistula may occur as a complication.[12,14]

Decannulation rates of 17-51% were reported in other studies of paediatric tracheostomy.[4,5,11,15] However, there is no decannulation in our group. This is likely due to the fact that they all have severe neurological and physical impairment (GMFCS Level 5). The progressive deterioration of their general condition and respiratory function necessitates permanent tracheostomy. This observation is in line with the trend reported by other authors, that nowadays the cannulation time is longer and the decannulation rate is lower than a few decades ago, as tracheostomy is performed more on children with chronic debilitating conditions like severe neurological impairment.[12]

After creation of tracheostomy, many bacteria can colonise the trachea and the upper bronchial tree,[16,17] predisposing them to symptomatic lower respiratory tract infection and potential serious consequences. They include the colonisers of the naso-oropharyneal airway and the digestive tract, and the ubiquitous bacteria in the environment. These bacteria are commonly detected in the lower respiratory tract specimens (tracheal aspirate and bronchoalveolar lavage) taken not only when they are relatively well, but also during acute respiratory illnesses. The 3 most prevalent bacteria found in our cohort are *Pseudomonas aeroginosa*, non-typeable *Haemophilus influenzae* and *Moraxella catarrhalis*.

Formulating anti-bacterial treatment for these patients during lower respiratory tract infection is not straightforward. Firstly, as in our cohort, they stay in hospital for long. Their airways are frequently colonised with multidrug-resistant bacteria acquired from the hospital environment. Secondly, polymicrobial colonisation of their airway is common in these patients,[18] and there is a large drift in the bacterial flora of their tracheobronchial tree over time.[19] We cannot decide the empirical antibiotic therapy for acute respiratory exacerbations in these children based on the previous culture result. Last but not least, interpretation of the positive bacterial growth in the tracheal aspirate (and sometimes bronchoalveolar lavage) is complicated. It is difficult to differentiate whether the growth merely represents coloniser of the upper airway, or true pathogen causing lower respiratory tract infection.

In order to have a more accurate description of the bacteriology of chest infection in these children, we need to have prospective studies with comprehensive definition and accurate documentation of the acute lower respiratory infections. Bronchoalveolar lavage, with measures preventing contamination from the upper tract, is superior to tracheal aspirate in reflecting the lower tract pathogens.

Conclusion

Although tracheostomy is an invasive procedure and carries risk of complication, it can facilitate better care of the children with severe neurological impairment, physical disability and respiratory complications, including upper airway obstruction, recurrent pneumonia, and respiratory failure requiring prolonged invasive mechanical ventilation. They can have long survival after tracheostomy. Decannulation rate is extremely low in them.

This study summarises the clinical characteristics and the clinical course of a group of young patients with severe neurological impairment and physical disabilities, who had tracheostomies because of their respiratory co-morbidities. It provides information for decision-

making when we need to consider tracheostomy on similar patients in the future, and to formulate a comprehensive plan of care for them after the surgery.

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