

Peer Review File

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Reviewer A

This is an important study highlighting the varied management of these complex patients and their families.

The paper is well-written and has a reasonable response rate, albeit a small absolute number. This, as well as the retrospective nature of the paper, is acknowledged in the discussion.

I assume that the lack of an MDT prior to tracheostomy placement was due to the urgent nature of some tracheostomies.

Would ASPORLS consider developing a consensus statement on the management of paediatric tracheostomy and also making videos and multimedia adjuncts as an aid to surgical teams managing tracheostomy patients?

Response 1: We anticipate that the results of this study would serve as a starting point for discussions about the value of developing a consensus statement on paediatric tracheostomy care in Australia and New Zealand. The overseas experience suggest that there is still a wide variation in the way paediatric tracheostomies are managed. The development of evidence-based clinical practice guidelines and specialty group consensus statements may help improve overall outcomes by standardising the delivery of tracheostomy care.

More importantly, our study has identified potential areas that can be optimised to improve the management practices surrounding paediatric tracheostomies, especially in relation to the adequate the preparation of patients and families for the tracheostomy.

The use of videos and multimedia adjuncts has been shown to improve parental engagement with the tracheostomy process. If there is interest in their use by the wider medical community, exploring the production of such resources with the Australian and New Zealand Society of Paediatric Otolaryngology could be a valuable consideration.

My only comment is that perhaps more graphical representation of the findings and less text would be beneficial for the reader.

Response 2: We have endeavoured to include a comprehensive summary of the findings from our cross-sectional survey and, as a consequence, the “Results” section of our manuscript is comprised of rather dense text. We have now summarised some of these findings, namely the demographics of the

otorhinolaryngologists surveyed and the long term outpatient care of tracheostomised patients, into two tables. We have also included two additional figures to help better illustrate the findings from our study. This brings the total number of figures to three, and the total number of tables to five.

Changes in the text: We have made changes to the manuscript as described below. All figures will be supplied as a separate .pptx file and all tables will be provided separately. They have been included as picture below to help with ease of review.

In the results section, we have created Table 1 to summarise respondent demographics:

“Twenty-six of 75 (36.1%%) ANZSPO members responded. Demographics of otorhinolaryngologists included in the survey can be seen in Table 1. The majority (57.7%) worked at institutions where >10 paediatric tracheostomies were performed each year, while another 23.1% worked at institutions where between 6-10 paediatric tracheostomies were performed each year. None of the respondents worked at a hospital where percutaneous tracheostomies were performed in children” – Results, page 5, line 19.

Table 1. Demographics of otorhinolaryngologists

	Number of respondents
Number of years in practice	
<5 years	6 (23.1%)
5-10 years	8 (30.8%)
>10 years	12 (46.2%)
Fellowship in paediatric otorhinolaryngology	
Yes	23 (88.5%)
No	3 (11.5%)

We have also created Figure 1 to summarise other health professionals involved in preparing the family for a tracheostomy.

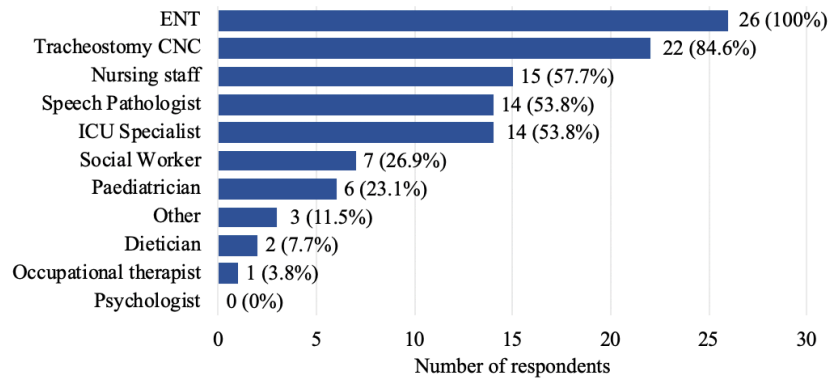


Figure 2. Health professionals involved in preparing the family for a tracheostomy

We have also created Table 5 to summarise the airway evaluation and long term care of children with stable, long term tracheostomies to replace part of the body of the text. The final paragraph of the results section now reads as follows:

“For children with stable, long-term tracheostomies, the recommended frequency of routine outpatient reviews and laryngotracheobronchoscopies is summarised in Table 5. The majority (20/26; 76.9%) of respondents had a standardised protocol for decannulation” – Results, Page 8, Line 20

Table 5. Summary of airway evaluation and long term care

	Number of respondents
Frequency of routine outpatient review	
Monthly	2 (7.7%)
Every 2-3 months	9 (34.6%)
Every 6 months	11 (42.3%)
Annually	3 (11.6%)
Variable	1 (3.8%)
Frequency of routine laryngotracheobronchoscopy	
Every 6 months	4 (15.4%)
Annually	7 (26.9%)
Only if indicated	15 (57.7%)

We have also added in Figure 3 to help highlight the variation in preoperative, inpatient and outpatient MDT input into tracheostomy care. We have included this in the discussion section of the manuscript as follows:

“Despite such evidence supporting the benefits of a multi-disciplinary approach to tracheostomy care, less than half (46.2%) of the respondents in our survey routinely held a multi-disciplinary team meeting prior to placement of a tracheostomy in a child, and less than a quarter (23.1%) routinely conducted weekly reviews of paediatric inpatients with tracheostomies (Figure 3). This is in contrast to a Canadian study (18), where the majority of respondents (69.4%) held a multidisciplinary, inpatient, tracheostomy team discussion at their institution. Furthermore, less than two thirds of respondents (61.5%; 16/26) in our study had an outpatient multi-disciplinary outpatient tracheostomy service at their institution.” – Discussion, Page 14, Line 2.

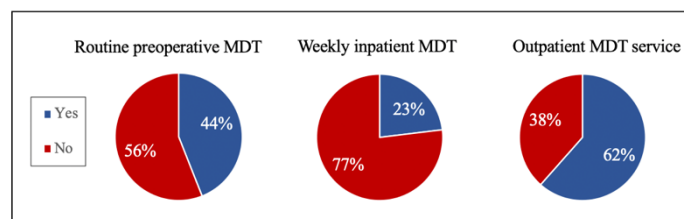


Figure 3. Comparison of preoperative, inpatient and outpatient MDT input into tracheostomy care

Reviewer B

Overall, an important and excellent article that has value to add.

The main article is well-written and relatively succinct. The discussion points are set out nicely.

1. The following need to be considered:

- Page 8: Line 9 A comment on manufacturers recommendation for re-use would be relevant.

Response 1: We have included a comment on the manufacturers recommendation for re-use in the results section.

Unsurprisingly, the manufacturers recommendations for re-use varies between companies. For example, Biovona tracheostomy tubes may be cleaned, reprocessed/sanitized and reused up to 5 times in a single patient, but can remain in place for up to 29 days. Likewise, the manufacturers of Shiley tracheostomy tubes suggest that they should be changed every 29 days, although no mention is made of how frequently they can be reprocessed. (White et al, 2010). On the other hand, the manufacturer’s recommendation is that TRACOE mini tracheostomy tubes are to be used for no longer than 14 days. However TRACOE Silicosoft tubes can be reprocessed up to 7 times during the 29 days it is in use for a single patient.

Routine cleaning without the use of mechanical abrasion or sanitising (eg washing in warm water with a mild soap solution) is not intended to be classified as “reprocessing”.

Biofilm on the surface of the tube may not only be a source of infection for the patient, but may also lead to the degradation of the tube, leading to the loss of structural integrity and subsequent increase risk of tube fracture or failure (Björling et al, 2007).

Although a manufacturer may recommend using a tracheostomy tube for only a finite number of days, there is no clear scientific evidence supporting the frequency with which tracheostomy tubes should be replaced. Indeed, the smaller diameter of paediatric tracheostomy tubes and the lack of disposable inner cannulas in most paediatric tracheostomy tubes means that more frequent changes than recommended by the manufacturer is often necessary to ensure that the tube does not become blocked by secretions or coated in secretions.

References:

Björling G, Axelsson S, Johansson UB, et al. Clinical use and material wear of polymeric tracheostomy tubes. *Laryngoscope*. 2007;117(9):1552-1559.

White AC, Kher S, O'Connor HH. When to change a tracheostomy tube. *Respir Care*. 2010;55(8):1069-1075.

Changes in the text: A comment on the manufacturers recommendation for reuse has been added to the results section.

“Manufacturers generally recommend the use of a tracheostomy tube for no more than 29 days, with some tracheostomy tubes being suitable for reprocessing up to 5 -7 times within that period (Hess and Altobelli 2014, St-Laurent et al 2023)” – Results, page 8
Line 16.

References added to manuscript (please note that all subsequent references have been renumbered using EndNote to account for the addition of these two references into the text)

“4. Hess DR, Altobelli NP. Tracheostomy tubes. *Respir Care*. 2014;59(6):956-71; discussion 71-3.” - References

“5. St-Laurent A, Zielinski D, Qazi A, AlAwadi A, Almajed A, Adamko DJ, et al. Chronic tracheostomy care of ventilator-dependent and -independent children: Clinical practice patterns of pediatric respirologists in a publicly funded (Canadian) healthcare system. *Pediatr Pulmonol*. 2023;58(1):140-51.”- References

- Page 9 Line 15 Pre-operative: Reference to a paper that found 50% of parents regret placement of tracheostomy tube is made, presumably due to ongoing QOL of child and family being of low standard. Later mention is made of introducing parents to a tracheostomized patient and family. Have you considered that "setting realistic expectations" may sway parents to decline a tracheostomy? Is the intent that parents can make a fully informed decision to proceed or not with a tracheostomy? Declining a tracheostomy may be a very appropriate decision: in that case what would the impact be on the treating team. A comment should be made as to the pros and cons of such an introduction.

Response 2: Parents need to be able to make a fully informed decision when faced with the decision of whether to proceed with placement of a tracheostomy for their child, especially considering the significant impact such a decision has on the child's and family's quality of life in the long run.

The paper by October et al found that over 50% of parents experienced regret following insertion of a tracheostomy and that the reasons for regret could broadly be categorized into three main themes: i) parents feeling uninformed ii) lamenting the timing of the decision iii) disappointment in the medical care received. The study also reported that parents had expressed a desire for more information, both during the decision making process, and after the decision was made.

A more recent study by Yan et al in 2021 based on semi-structured interviews conducted with parents who recently faced a tracheostomy decision found that parents often seek emotional support from other parents who had undergone similar experiences.

Introducing parents to a tracheostomised patient and their family has several benefits. Firstly, it may help parents better understand the challenges of caring for a tracheostomised child firsthand, and allow them to make a more informed decision should they wish to proceed. Furthermore, seeing other families successfully managing life with a tracheostomy can provide reassurance to parents facing similar decision. In addition, meeting a tracheostomised patient and their family may help provide a support network for parents for navigating future challenges.

However, there are also drawbacks to consider. Witnessing another family's struggles may cause emotional distress and anxiety for some parents, potentially influencing their decision-making process. Furthermore, depending on the specific circumstances and experiences of the introduced family, parents may develop biased perceptions of tracheostomy care and this may reinforce unrealistic expectations, as each patient's situation is unique and outcomes may differ.

Meeting a tracheostomized child and their family allows parents to witness firsthand the challenges and adjustments involved in caring for a tracheostomized child. This is not to say that all parents must meet with a tracheostomized patient and their carer prior to surgery; rather parents should be given the option to do so if they so wish, in order to help better prepare them for what caring for a child with a tracheostomy entails.

For some parents, such a meeting may bring about more questions, and this provides the opportunity for the treating team to address any new concerns raised. For other parents, it may reaffirm their decision to proceed with a tracheostomy, and reassure them that they have the skills and support necessary to care for a child with complex needs.

It is also possible that meeting a tracheostomized patient and their family may dissuade some parents from proceeding with a tracheostomy. However, it is important for the treating team to recognize that forgoing a tracheostomy may be a more appropriate decision for some families. Parents do not make such a decision lightly, especially since the placement of a tracheostomy is often the last resort when all other alternatives have been exhausted. The treating team must therefore respect the parent's decision regarding their child's management and continue to provide support for the parents following such a difficult decision.

These complexities surrounding the parental decision making process for the placement of a tracheostomy highlight the importance of providing appropriate psychological and social support to parents, regardless of the final outcome of the decision regarding placement of a tracheostomy.

References:

October TW, Jones AH, Greenlick Michals H, Hebert LM, Jiang J, Wang J. Parental Conflict, Regret, and Short-term Impact on Quality of Life in Tracheostomy Decision-Making. *Pediatr Crit Care Med*. 2020 Feb;21(2):136-142

Yan H, Cynthia A-E, Pituch K, Deldin P, Kukora S. Parent Experiences And Considerations When Facing Tracheostomy Decisions For A Critically Ill Child. *Pediatrics*. 2021;147(MeetingAbstract):543-4.

Changes in the text: A discussion on the advantages and disadvantages of introducing parents to tracheostomised child and their family has been added to the manuscript as part of the discussion on preoperative considerations. The paragraphs that have been amended are as follows:

“In addition, fewer than half of all respondents in our study routinely offered to connect patients and their families with a tracheostomised patient and/or their carers prior to surgery. Although this is not a critical part of the consent process, the

opportunity to meet a tracheostomised patient may allow parents to better understand the challenges of caring for a child with a tracheostomy and help set realistic expectations for patients and their caregivers.

Previous studies have suggested that parents are often inadequately counselled about the long-term negative consequences of having a tracheostomy, with the benefits of a tracheostomy emphasized more than risks (Herbert et al 2017, Nageswaran et al 2018). While, seeing another family successfully manage a child with a tracheostomy may provide some parents with reassurances regarding their ability to acquire the skills and support necessary to care for a child with complex needs, witnessing the significant adjustments that are often required may dissuade other parents from proceeding with a tracheostomy. This decision not to proceed with a tracheostomy may be the more prudent decision for some families, considering the significant burden of care and well-recognised psychosocial impact associated with caring for child with a tracheostomy.

The opportunity to be introduced to another family who have faced a similarly difficult decision should therefore be offered to parents as it may help promote a more balanced discussion of risks and benefits, so that parents are better prepared for the ongoing management needs of their child and can make a fully informed decision about tracheostomy placement.” – Discussion, page 10, starting from line 16.

References added to manuscript (please note that all subsequent references have been renumbered using EndNote to account for the addition of these two references into the text”

“13. Hebert LM, Watson AC, Madrigal V, October TW. Discussing Benefits and Risks of Tracheostomy: What Physicians Actually Say. *Pediatr Crit Care Med*. 2017;18(12):e592-e7” - References

14. Nageswaran S, Golden SL, Gower WA, King NM. Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *The Journal of pediatrics*. 2018;203:354-60. e1.” - References

2. Acronyms:

-Page 6 Line 7: Need to write in full what CNC stands for and put the acronym in brackets. Also "ICU" is a place: Should put "Intensive Care Unit (ICU) representative/specialist"

-Each 1st mention of anything with an acronym in an article should be written in full with the acronym in brackets. There are a few exceptions

Response 3: Thank you for bringing to our attention the acronyms we have overlooked in our manuscript.

Changes in the text: We have amended the manuscript as suggested so that all acronyms are written in full when first mentioned. The changes are as follows:

“..while a tracheostomy clinical nurse consultant (CNC) (22/26; 84.6%) nursing staff (15/26; 57.7%), Intensive Care Unit (ICU) specialist (14/26; 53.8%) and speech pathologists (14/26; 53.8%) were also commonly involved” – Results, page 6, line 10

“The American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNS) Foundation consensus statement also endorses the provision of a checklist of emergency supplies that should remain with the patient at all times” – Discussion, page 13, line 2

“the International Pediatric Otolaryngology Group (IPOG) consensus statements do not make specific recommendations for routine laryngotracheobronchoscopies following insertion of tracheostomies” – Discussion, page 16, line 4