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Balancing Safety, Practicality, and Equity in Pediatric Tracheostomy Guidelines

In this Complex Care Journal Club podcast episode, Drs. Reshma Amin and Christopher Baker discuss a clinical practice guideline from the American Thoracic Society on the care of infants and children with tracheostomies. They describe the role of interprofessional and family-centered decision-making, safety- and ethics-driven recommendations, and next steps for implementation across diverse healthcare settings.

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Kilby Mann *00:04*
Hello and welcome to the Complex Care Journal Club Podcast. My name is Kilby Mann. I'm a pediatric rehabilitation medicine physician at Children's Hospital Colorado, and your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and its implications for practice. I'm delighted to have Reshma Amin Professor in the Department of Pediatrics and Health Policy Management and Evaluation at the University of Toronto, and the Director of Sleep Medicine and Long-Term Ventilation as well as Dr Christopher Baker, Professor of Pediatrics and Pulmonary Medicine and the Director of the Ventilator Care Program for Children's Hospital Colorado. They are two of the main authors on the new American Thoracic Society Clinical Practice Guideline "Care of Infants and Children with Tracheostomies", published in November of this year. Thank you both so much for being here today.

Christopher D. Baker *00:49*
Thanks, Dr Mann, it's exciting.

Kilby Mann *00:51*
I should tell everyone that I get to work with Baker, and we've actually been working on the same unit this week. And Reshma, it's great to meet you for the first time. So, I wanted to start with how these guidelines came to be?

Christopher D. Baker *01:05*
Back in 1999 there was a clinical consensus statement from the American Thoracic Society called "Care of the Child with a Chronic Tracheostomy" that was by Sherman and colleagues that we had all referred to for many, many years. It addressed a lot. As time goes by, there's more evidence available, there's a changing landscape of clinical care, and we felt like new recommendations were needed. And back in 2016 there was a ATS clinical practice guideline, that's the American Thoracic Society, that for children with the need for chronic home ventilation, and so that addressed the kids that have tracheostomies for mechanical ventilation. But really nothing had come out since probably 2013 looking at all kids with trachs. So, we put a proposal into the ATS to revisit the topic of infants and children who need tracheostomies in their care. Yeah, it's exciting for us to be able to put this out.

Kilby Mann *02:21*
I think that's great. I wonder, do either one of you want to talk a little bit about the group. I look at the list, you've got pulmonologists or respirologists. You've got some ENT [ear, nose and throat] doctors on there, I think some nurses. How did that group get together?

Reshma Amin *02:36*
That's a great question, Kilby and I think that one of the things about tracheostomy care, and one of its strengths is that it's a very interprofessional field, and I think we really wanted to ensure that we had good representation from all of those key stakeholders, including patients and families, who are key partners in care for these children. So right from the respirology/ pulmonology perspective to head and neck/ otolaryngology, respiratory therapy, speech and language pathology, nurse practitioners. And not only did we want to be inclusive in terms of the interprofessional nature, but also, as someone from north of the border, we also wanted to ensure that we really had an international representation. So, we were fortunate to have membership from the United States and Canada, but also all the way from Australia and then also South America.

Kilby Mann *03:28*
Can either one of you can speak a little bit more about that process as you came up with the final recommendations?

Christopher D. Baker *03:36*
The standard process that we utilize is called GRADE methodology. It's Grading, Recommendations, Assessment, Development and Evaluation, where it involves a careful, thorough, comprehensive literature search of a topic and then all the literature that's there is first weeded through to see what's the most relevant. And then, the outcomes are examined as well as the strength of the evidence based on "Is it a randomized control trial?", "Is it a case series that's just observations?" In many of our recommendations, there's not a very, incredibly strong research topic. And sometimes that's like, you know, due to the fact that there's never been a study of "whether parachutes work or not, by randomizing who gets to jump out of a plane with one or without." There's a lot of safety-based care that is straightforward. And, children will be harmed if we did a randomized study. But nevertheless, you know, when there is literature, we want to account for that and be comprehensive. And so, this results in our methodology team reviewing 1000s of papers, literally, and whittling it down to dozens of papers that we all review for each recommendation. And then, once we know what the literature says, we form our recommendation and then talk about both the strength of the recommendation, how much evidence there is, and how strongly we feel about the certainty. And so, things where we made a strong recommendation were in most cases because there was a big safety component for patients. In almost all of them, there was a low or very low certainty of evidence, because these things haven't been studied in randomized trials. But that's where we felt like having a big interdisciplinary panel of experts really was important to make sure we're coming to consensus and making recommendations that we could all agree with, knowing that still, ultimately, everything comes down to a patient's discussion with their physician and making individual, customized care plans that make sense in the clinical setting. So, these aren't meant to be "brought down from on high", but hopefully do raise the bar and improve care.

Kilby Mann *06:13*
I think that's so great, because there's a lot of things where there's just not a lot of evidence out there, but we know this is the best things for the patient. So, I think that's where I was really interested in how you build the system, and that way of saying, There aren't all these studies out there, and still, we as this big group can stand behind this recommendation, that this is the best care for these kids.

Christopher D. Baker *06:35*
Yeah, our methodologist that was provided through the ATS. His name is Narayan Iyer, and he is a neonatologist and then works with the ATS as a methodologist. So, we kind of got a double benefit there, of his clinical expertise, but more importantly for this, his methodology expertise, so he could really guide through with his team getting everything ready for the meetings. We would have to come to consensus on what our recommendations would be, and then making sure the process was standardized in the way that's in accordance with the clinical practice guideline development approach.

Kilby Mann *07:16*
That sounds like a great resource. What are some other opportunities and challenges that were identified while y'all were developing and conducting the creation of these guidelines?

Reshma Amin *07:26*
One of the strengths of the guideline, as we had talked about, is really that interprofessional experience, but also the experience from individuals who are working across different healthcare systems – in terms of rural/urban and also publicly versus privately funded healthcare systems. And I think with that, we really learned, as we were going through these meetings, just what the diverse experiences are, as well as the barriers to the care of these families. And I think, just to build on what Baker said, I think that we were quite opportunistic and pragmatic in our choice of these PICOs [Patient/Intervention/Comparator/Outcome, a framework to formulate research questions], both initially when they were put forward after a systematic review by Baker and I, and also just in terms of hearing from the rest of the panel what the priorities are. This was an opportunity for us to help set a standard, an opportunity through clinical practice guidelines, whereby smaller less resourced centers can use these to their advantage to advocate for resources. We want to ensure that we were firm enough for these to help support those smaller institutions, but not so rigid such that these guidelines could then potentially disadvantage clinicians who are trying to be quite flexible and supportive and provide care from a patient-centered, bespoke view, where sometimes we do have to think about the nuances of the individual situations. That's how we chose the topics. Especially in some situations when safety was so paramount, we really had to be quite thoughtful in the strength of our recommendations to make these as useful of a tool internationally as possible.

Christopher D. Baker *09:12*
I think it's true that applicability is huge, and even some of the reviewers pointed this out, "This is great for those of you that are in your big, free-standing children's hospitals that have all these resources. But what about providers that are working as a single provider in a small town or in very resource-strained areas, where really access to care is limited?" And so, one of the things we're working on now is following up on how these guidelines could be implemented in low- and middle-income countries. We've already started reaching out to colleagues in Sub-Saharan Africa, Argentina, and Pakistan, to discuss the guidelines, and then we're trying to publish follow-up papers describing how it might look different in these settings. We care about the healthcare of children around the world, everywhere, and so we want our guidelines to be applicable, and hopefully it helps point to needs and helps obtain resources for areas that need them. And yet, it's certainly a challenge for providers in those settings to even care for children with medical complexity, much less when life is on the line with a tracheostomy and sometimes a ventilator and oxygen.

Kilby Mann *10:37*
As a Peds rehab where we are taking care of kids with new treatment needs, I assure our trainees that, like, we have a whole system in place to make sure all this training gets done and the family is going to be set up. I also think this is great for the pediatrician, the complex care physician, to know that these are the guidelines and how well-prepared families and caregivers can be for taking kids home. I wonder if you want to talk a little bit about what some of the recommendations are.

Christopher D. Baker *11:04*
One that really addresses what you just talked about is the importance of a standardized process for discharge. We emphasize that it's important and some key components of that standardized process. But we didn't say, "Here's what it should be in your hospital in a system that we don't practice in." You know? We said that part of what is important is developing that process to fit in your system, and so it's going to look differently in different hospitals – that's what works here in Colorado might not be what

works in Toronto. So, we have to pay attention to the local systems, the local family needs, and all of those things. And, even once our individual center has a standardized process, it still, of course, has to be customized for each patient discharge to make sure specific needs are addressed. Nevertheless, that whole approach is what we recommend and feel strongly that it's important to care, to not "invent the wheel" every time. The more that can be kind of organized, it not only helps teams provide the best care, but it helps families know what to expect and, in a very long and stressful hospitalization, hopefully feel like they at least know where things are going and that they're staying on track. And families (we involved families in so much of this), they would tell us, "That makes a huge difference!"

Reshma Amin *12:28*
Patient safety is paramount for this patient population, given there's so much inherent risk of morbidity and mortality, because a tracheostomy is, you know, really a high stakes intervention for many of our patients. And so, as Baker said, that was really a focus of that PICO question. And the other one that really, I think, came shining through as something that was very important to our stakeholders, was the application of ethical principles to the decision-making around tracheostomy. And the reason I think we all value that and prioritize that so highly is that, if you ask any one of our patients and their families, they will always remember the way in which a tracheostomy was first introduced. They'll remember the setting, they'll remember how it was said, and unfortunately, it's often not said or their memory and recollection of it is not that it was presented in an accurate, realistic, supportive way. I think that really has stuck with us and many of the panelists. Although each clinical situation is unique, we really wanted to arm readers with a framework. What are key principles to think about when you are embarking on these discussions, to families, really to help sort of scaffold them to provide patient-centered care? Because this is what patients remember.

Christopher D. Baker *13:51*
It was a really hard recommendation to develop. Sarah Sobotka is a developmental pediatrician at the University of Chicago that helped us take the lead on that. She's published a lot of other papers in the space. We involved PICU and NICU and ENT in that subcommittee. How do we help in hard situations to make sure that families know what they're signing up for, that they have all the information, that we are benefiting patients, and not harming them? And you know, of course, we couldn't make a table that says, "These patients should get a trach and these patients should not get a trach." It's messier than that. Of course, these are hard decisions. But really, like Reshma mentioned, the ethical principles that can be utilized to help the shared decision-making process with families. That's huge. So, we got to where we felt like, "Okay, there's some important guidance here that does help the conversation and the thought process."

Kilby Mann *14:52*
I think it's also your first recommendation in the guidelines. So, I think it like speaks to how important it is.

Christopher D. Baker *15:00*
Yeah. We kind of tried to order them in a logical way. Like you decide to do a trach, and then you discharge, and then you decide what care is going on at home. The next one is about trach cultures. And then who needs bronchoscopy? And then sleep studies often come up in the process of trying to reduce [ventilator] settings or take the tracheostomy out. So hopefully the recommendations flow in an order that patients experience the care.

Kilby Mann *15:26*
One of the recommendations is about awake trained caregiver, but you also talk about the watcher role. And so, I wonder if one of you could speak a little bit more to that? Because I think that is so helpful, we want to empower you to be able to train someone else at home, so you have a bigger community, you can have more of your village that we all need as parents, no matter the complexity.

Reshma Amin *15:46*
I think that the care of these children in the community is really where we want these children to be. We want them in the community with their families - full stop. But these kids require care by trained caregivers around the clock, and that is incredibly challenging for families where there's two caregivers. Nonetheless, when we have to think about situations where there's only one primary caregiver. We really lean on home care professionals to help support those patients. Unfortunately, post-pandemic, it really has completely changed the landscape of what is available in terms of resources for these families. And so, a lot of healthcare systems had to re envision what this means in terms of healthcare professionals and who are available to be providing this care. And so, in different healthcare systems, like in the United Kingdom, they have essentially "carers", which are not nurses. They're really the equivalent of like a personal support worker that gets trained in all aspects of the care of this child and that's the care provider. that's where this concept of "watchers" or even the concept of paying families to be the trained caregiver is coming from so it's a need to innovate, to meet really the limited healthcare resource availability to support these children at home, because we know that family caregivers cannot do this alone.

Christopher D. Baker *17:16*
And you know, credit where credit is due, families figured this out before we did already. A lot of times they will have somebody, "I'm going to catch up on some sleep a little bit, but just watch the machine." And, like, they tell them things. And so then they're not leaving them solely in the care of somebody that's not fully trained, but they're able to be the "eyes and ears" and then get the fully-trained caregiver if something's going on, so that caregiver could sleep or do daily life things, laundry, cooking, you know, things where you're maybe not paying full attention to your child, but somebody else is. And then we said, "Does everyone need this?" You know, for kids on a ventilator, this is a life support machine that's hooked up to you through the tracheostomy. But you know, a lot of kids with trachs are high functioning, and older kids that, if there's a problem with the trach, they can get help. They can run into the other room and ask somebody to help or pound on a wall or hit a buzzer, all sorts of things to communicate, even if their voice is taken away because there's a problem with the trach. So we said, "Maybe not every kid with a trach needs an awake and alert caregiver 24/7, but those that are at the highest risk of a severe acute event probably do." So, we've left that judgment call there. So much of this is a judgment call, and so much of it is a shared decision about risk. Some families are incredibly risk averse and want to monitor every single thing. Others are comfortable living life with a little more risk, but a little more freedom. And that's true for healthy kids whose parents let them, you know, go play down the street or not. We have to allow parents to be parents in this process. And, there's no such thing as zero risk. So, it's all about managing risk and clear communication about what we're training families for and what everyone understands are the possibilities.

Kilby Mann *19:17*

I wonder if there's anything or any of the recommendations, we haven't specifically referenced yet that either one of you wants to call out when we think about that clinical implication of these guidelines?

Reshma Amin *19:29*
Baker mentioned it a little bit just in terms of sleep studies, that maybe we could just talk through it a little bit more. That's probably the most contentious of all of the PICOs. And I think one real strength of our panel is that we actually brought otolaryngologists together with sleep physicians who do sleep studies and also with ventilation docs who typically don't use sleep study resources as much, both, again, across various healthcare systems. So, we really were able to have a very fulsome conversation about what's practical and what's necessary. And I think that we're all quite happy with what we've landed on, because it gives people flexibility. If you have these resources, then you can use them, but if you don't have these resources, there's still other ways to go about doing things, because everything doesn't end with a sleep study. We have limited access to sleep studies in many places, therefore we can't make a blanket recommendation that every child that needs to be decannulated with the tracheostomy needs a sleep study, because that's not practical and that's not really a fair, reasonable recommendation. So, we gave suggestions within the guidelines in terms of which patients we think will really benefit from a sleep study in the setting of those who are probably more complex, who are sort of failing other traditional methods, and maybe those that were transitioning from invasive to noninvasive ventilation. But for other patients, it's very reasonable to use other methods of gas exchange and also direct observation. So, I think we're hopeful that what we've put forward is a recommendation that's a guide to help sort of streamline the different buckets of patients and to guide sort of these really high needs resources with those high need complex patients. But to be very clear that this is not "one size fits all" and we need to be thoughtful about which patients will need what, because we don't have unlimited resources for all of these patients in all settings.

Kilby Mann *21:25*
Absolutely. I know you talked a little bit about you had patients and families and those key voices that need to be heard in developing it. I wonder if there's any things you've learned in working with patients and families moving forward?

Christopher D. Baker *21:39*
We were lucky to have family members contribute to the panel that weren't afraid to speak their mind, and speak truth to power. They were brave to say, "Look, you guys in your room with all your academic stuff, recommend this thing. But like, in reality, there's this." But also, the lived experience of the hospital stay is hard. It's traumatizing being there that long. And then going home… it's great to finally be out of the hospital, but now there's this pressure. Parents figure it out, and they're heroes in this process, but they have to be heard. If we make all these medical recommendations, but they're not reality-based, then it's just us trying to speak to the physiology and the academics without really understanding the struggles and what really works and doesn't work at home. So, that family perspective was huge. And I would say to families listening to this, you deserve a doctor that will hear you and listen to those concerns and hopefully be candid and push back if there's something that's safety related, that will say "There's evidence for this. There's a reason we do this," but at the same time really hear the struggle and feel like you're partners in this. Because, I mean, you deserve that. And really, we as doctors are better when we get that information from families.

Reshma Amin *23:06*

We were so privileged to have the very vocal and experienced patients and families join us. And I think it really was important for us to hear what the priorities are, but also for them to weigh in on these different recommendations. And I think it helped to inform how they were written, in terms of the guidelines, it influenced the voting, it influenced the strength of the recommendations. It influenced some of the comments around implementation and those considerations. What we're proud of is that we really worked to make sure the patient and family voice was heard in these guidelines. And I think the other way that we hope these will help patients and families is that if they are in a challenging situation where they really feel not supported, now there's a document that they could use and bring forward to individuals to really help support them in advocacy for the care of their child.

Kilby Mann *23:57*
I think this is also a great document from building a new program for someone to say this is what we need to be doing. So, I think there's so many ways to take them moving forward.

Christopher D. Baker *24:07*
There were a couple recommendations, like one about tracheal aspirate cultures, like getting the bacterial culture when kids are sick, and bronchoscopy, where we tempered those. There's times where they're absolutely needed. Like somebody is acutely sick and coming into the hospital, knowing what bacteria is predominant can really help guide treatment. But for a long time, I think some practices have just every clinic visit, grab a culture, because then we know what bugs are there. And a lot of literature has shown that that isn't helpful to patients. It's not really guiding care. And, you could do a lot with clinical management in the outpatient setting without those cultures. Often we're starting empiric antibiotic therapy when kids are sick based on what grew the last time they were sick and not waiting for the culture to come back anyway. It's a part of the body that stays open to the outside, just like our noses and mouths. You never treat the nose or mouth to get rid of all the bacteria there. So, testing at the end of treatment to make sure you got it all also isn't beneficial. So, toning down the importance of that culture. What's way more important is clinical symptoms than what the culture shows. And so hopefully that's both cost-effective, but helps guide clinical care to be better. And with bronchoscopy, the same thing. If there are clinical symptoms that warrant an airway evaluation, then it's important. And we all agree that before trach decannulation, a full airway evaluation, either by otolaryngology or by pulmonary (or both), is critical. But, you know, "Oh, it's that time of year again for our scope." - probably we don't need to be doing that. If it doesn't change patient care, then we said there are these cases where it's not indicated. So, hopefully, these guidelines are helpful in that sense too.

Kilby Mann *26:07*
Yeah, I think that's great. Any other important next steps that you're thinking about for this work, or any lessons learned? I don't know if y'all have been involved in guideline creation before, if this was your first time?

Christopher D. Baker *26:21*
We've both been doing guidelines for a while. So, Reshma, you want to talk about past experiences? I sometimes I feel like we're "gluttons for punishment", because it is really hard work. But it is so important. And even to say, "You don't need to be doing this." Sometimes the most senior pulmonologist at an institution, that has 40 years worth of experience, might not need a guideline, but there's a lot of people that are new to the care or in smaller centers and sometimes just having

streamlined recommendations really does help us avoid waste and not do things that are unnecessary, as well as making sure we do the things that are necessary.

Reshma Amin *27:01*
You know, I think sometimes we practice in our own microcosms of our institution, and we think that this is how we're doing it, because this is the way we've always done it at our institution. This was a wonderful opportunity, just to really level-set with a broad group of really expert clinicians that share perspectives to ensure that you're coming together and following what's really being put forward as best practice. I think the implementation work around this is going to be quite exciting and fun. And then I'll let Baker speak a little bit more of just about some of our thoughts translating this into the low- and middle-income countries.

Christopher D. Baker *27:38*
Yeah, we want to do a global survey of providers around the world to really examine how and where are these relevant, and where are there areas of the world where it's really just impossible. One of my colleagues that helped us out already in Pakistan, she was here in Denver most of her career and retired. Her name is Tania Khan. She moved back to Pakistan and does almost a primary care clinic, but with a pulmonary focus in very rural Pakistan. In the setting she's in, she can check pulse oximetry in her clinic, but there's not really home oxygen available. So, if a child were to need a tracheostomy or to even need oxygen, she'd be referring them into the bigger city to be at the larger hospital. Trying to have a patient come back to that rural area where, even basic things like fresh water and reliable electricity might not be possible. So how do you have monitors and ventilators and suction machines and all these things? And yet, there's handheld suction machines that are manual, that don't require any electricity at all. We don't want to hold people back - but we want to, like I said before, we want to be reality-based in our recommendations. And we certainly care about very much the care around the world, not just at the big academic centers.

Kilby Mann *29:11*
I look forward to learning more about this implementation and next steps. I think it will resonate with a lot of our listeners.

Christopher D. Baker *29:18*
You know, there's one other thing we did with these guidelines that was a first for the ATS. This was one of the first guidelines where, after making each recommendation, there's a section called "Health Equity" that importantly addressed how a recommendation can both help address areas of care where there's some disparities that are real and exist in different populations, and also sometimes recommendations create new disparities. So, I'm personally very proud that these guidelines have that component to them, which hadn't previously been a routine subsection for recommendations in the ATS clinical practice guidelines. But they welcomed that, and so I really appreciate the organization being willing to do that, and I think they add to the value a lot.

Kilby Mann *30:13*
I agree. I really appreciated those sections as well. Thank you so much for your time Reshma and Baker and thank you to you and your team for advancing the field of complex care. Thank you all for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has the potential to be practice-changing, that values patient, family engagement, is relevant across disciplines and

diagnoses and uses high quality or novel research methods. We invite you to join the conversation by suggesting an article that you would like to see discussed in this podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

Journal Club Article

Amin R, Agarwal A, Chiang J, Collaco JM, Cristea AI, Propst EJ, Sobotka SA, Balakrishnan K, Benscoter D, Brenner MJ, Castro-Codesal ML, Cuevas Guaman M, Daines CL, Dawson JA, Edwards JD, Graham RJ, Henningfeld JK, Hoekstra NE, Jackson AJ, Johnson RF, Kam K, Kun SS, Napolitano N, Pacheco A, Panitch HB, Prager JD, Shi JY, Soma M, St-Laurent A, Syed F, Watters KF, Zielinski D, Ho ATN, Velagapudi RK, Zeba F, Knight SL, Iyer N, Baker CD. Care of Infants and Children with Tracheostomies: An Official American Thoracic Society Clinical Practice Guideline. Am J Respir Crit Care Med. 2025 Nov;211(11):2001-2020. doi: 10.1164/rccm.202508-2055ST. PMID: 41123183; PMCID: PMC12618984.

Other Resources

Sherman JM, Davis S, Albamonte-Petrick S, Chatburn RL, Fitton C, Green C, Johnston J, Lyrene RK, Myer C 3rd, Othersen HB, Wood R, Zach M, Zander J, Zinman R. Care of the child with a chronic tracheostomy. This official statement of the American Thoracic Society was adopted by the ATS Board of Directors, July 1999. Am J Respir Crit Care Med. 2000 Jan;161(1):297-308. doi: 10.1164/ajrccm.161.1.ats1-00. PMID: 10619835.

Sterni LM, Collaco JM, Baker CD, Carroll JL, Sharma GD, Brozek JL, Finder JD, Ackerman VL, Arens R, Boroughs DS, Carter J, Daigle KL, Dougherty J, Gozal D, Kevill K, Kravitz RM, Kriseman T, MacLusky I, Rivera-Spoljaric K, Tori AJ, Ferkol T, Halbower AC; ATS Pediatric Chronic Home Ventilation Workgroup. An Official American Thoracic Society Clinical Practice Guideline: Pediatric Chronic Home Invasive Ventilation. Am J Respir Crit Care Med. 2016 Apr 15;193(8):e16-35. doi: 10.1164/rccm.201602-0276ST. PMID: 27082538; PMCID: PMC5439679.):257-265. doi: 10.1542/hpeds.2019-0153.