*Palliative and Supportive Care*

**cambridge.org/pax**

**Original Article**

**Cite this article:** Nageswaran S, Gower WA, King NMP, Golden SL (2024) Tracheostomy decision-making for children with medical complexity: What supports and resources do caregivers need? *Palliative and Supportive Care* **22**(4), 776–782. https://doi.org/10.1017/S1478951522001122

Received: 31 March 2022
Revised: 16 May 2022
Accepted: 29 July 2022

**Key words:**
Children; Decision making; Supports; Tracheostomy

**Author for correspondence:**
Savithri Nageswaran,
Department of Pediatrics, Wake Forest School of Medicine, 1 Medical Center Blvd, Winston-Salem, NC 27157, USA.
E-mail: snageswa@wakhealth.edu

# Tracheostomy decision-making for children with medical complexity: What supports and resources do caregivers need?

Savithri Nageswaran, M.D., M.P.H.[1,2], William A. Gower, M.D., M.S.[1,3], Nancy M. P. King, J.D.[2] and Shannon L. Golden, M.A.[4]

[1]Department of Pediatrics, Wake Forest School of Medicine, Winston-Salem, NC; [2]Department of Social Science and Health Policy, Wake Forest University, Winston-Salem, NC; [3]Department of Pediatrics, University of North Carolina School of Medicine, Chapel Hill, NC and [4]Goldsmith Research Group, Winston-Salem, NC

## Abstract

**Objectives.** Caregivers of children with medical complexity (CMC) face decisions about life-sustaining interventions, such as tracheostomy. Our objective is to describe the support needs of caregivers of CMC and the resources they use surrounding tracheostomy decision-making (TDM) for their children.

**Methods.** This qualitative study, conducted between 2013 and 2015, consisted of semi-structured interviews with 56 caregivers of 41 CMC who had tracheostomies, and 5 focus groups of 33 clinicians at a tertiary care children's hospital. Participants were asked about their perspectives on the TDM process. Qualitative data were transcribed, coded, and organized into themes.

**Results.** Caregivers used five domains of resources surrounding TDM: (1) social network including extended family members, friends, and clergy; (2) healthcare providers including physicians and nurses; (3) other parents of children with tracheostomy; (4) tangible materials such as print materials, videos, tracheostomy tubes, mannequins, and simulation labs; and (5) internet including websites, social media, and online health communities. Caregivers used these resources for (1) decision-making, (2) becoming knowledgeable and skillful about child's diagnosis, tracheostomy, and home care, and (3) emotional and spiritual well-being. Caregivers agreed that they received enough support, but there were gaps. Clinicians were knowledgeable about these resources, discussed social network and internet less often than the other domains, and identified gaps in supporting caregivers.

**Significance of results.** Caregivers' need for support and use of resources surrounding tracheostomy placement for CMC extended beyond decision-making, and included becoming knowledgeable and getting emotional/spiritual support. Healthcare providers exploring these resources with caregivers could improve the quality of TDM communication.

## Introduction

Children with medical complexity (CMC), also known as children with life-limiting illnesses, medically fragile children, or technology-dependent children, are a heterogeneous group with many different medical conditions (Cohen et al., 2011). These conditions include genetic disorders, extreme prematurity, perinatal ischemic encephalopathy, trauma, infection, degenerative disorders, and malignancy. Whereas these conditions once inevitably led to death in the near term, CMC are living longer because of advances in technology (Feudtner et al., 2001). CMC are hospitalized often and for long periods, and have high readmission rates (Simon et al., 2010; Berry et al., 2011). Parents/Caregivers of CMC often face decisions about life-sustaining treatments including tracheostomy (Jonas et al., 2021).

In the US, there is a shift in the indication for tracheostomy for children from being offered only for conditions that are reversible, to now include conditions that are life limiting. CMC constitute a larger proportion of children for whom tracheostomy is offered compared to several decades ago (Campisi and Forte, 2016; Muller et al., 2019). Placement of tracheostomy in CMC has significant consequences for the health of the child including death and hospitalizations (Berry et al., 2009; Edwards et al., 2010; McPherson et al., 2017), and for caregivers of CMC as well (Callans et al., 2016). Hence, supporting families when they make decisions about tracheostomy for their CMC is an important role for healthcare providers caring for these children. Yet, very little is known about how best to support caregivers during the tracheostomy decision-making process (TDM). To address this gap, in a qualitative study, we interviewed parents/caregivers of CMC and conducted focus groups of healthcare providers (HCPs) about TDM for CMC. While we have published on different aspects of TDM — decisional satisfaction, religion and spiritual factors, and HCPs' roles — from this project

**Table 1.** Characteristics of children [$n = 41$]

| Characteristic | Median (Range) or Number (%) |
|---|---|
| Age[a] | 2.5 *years* (5 *months* – 18 *years*) |
| Sex | |
| Boys | 21 (51%) |
| Girls | 20 (49%) |
| Race | |
| White | 29 (71%) |
| Black | 10 (24%) |
| Multiracial | 2 (5%) |
| Hispanic | 7 (17%) |
| Health insurance | |
| Medicaid | 31 (76%) |
| Private | 7 (17%) |
| Both | 3 (7%) |
| Annual household income | |
| <$20,000 | 17 (42%) |
| $20,001 to $40,000 | 12 (29%) |
| $40,001 to $80,000 | 11 (27%) |
| Missing | 1 (2%) |
| Primary diagnostic categories | |
| Prematurity | 6 (15%) |
| Anoxic brain injury | 5 (12%) |
| Myopathy, muscular dystrophy | 7 (17%) |
| Neurological malformations | 4 (10%) |
| Lung or heart defects | 4 (10%) |
| Genetic conditions | 8 (20%) |
| Malignancy | 1 (2%) |
| Other | 6 (15%) |
| Age at tracheostomy | 10 *months* (4 *days* – 17 *years*) |
| Duration of tracheostomy[b] | 1.5 *years* (2 *months* – 5 *years*) |
| Type of Intervention | |
| Tracheostomy only | 25 (61%) |
| Tracheostomy and chronic mechanical ventilation | 16 (39%) |
| Decanulation | |
| Decanulated prior to interview | 8 (20%) |
| Decanulated and 2nd tracheostomy | 1 (2%) |
| Died prior to interview | 3 (7%) |

[a] Date of birth to date of interview/date of death.
[b] Date of tracheostomy to date of interview/date of decannulation/date of death.

(Nageswaran et al., 2018; Gower et al., 2020; Nageswaran et al., 2022), the objective of this paper is to describe the support needs of and resources used by caregivers of CMC when making decisions about tracheostomy and preparing for home care of their children.

## Methods

This study was conducted at Brenner Children's Hospital (BCH), the tertiary care children's hospital of Wake Forest Health Sciences (WFHS) in western North Carolina, and involved: interviews with parents/caregivers of CMC (referred to as "caregivers") who had a tracheostomy, and focus groups of HCPs experienced in pediatric TDM (referred to as "clinicians"). This study has a phenomenological orientation. Methodological details are provided in the Consolidated Reporting of Qualitative Studies Checklist (Tong et al., 2007) in Supplementary Appendix A and described previously (Nageswaran et al., 2018, 2022; Gower et al., 2020). WFHS Institutional Review Board approved the study. Informed consent was obtained from each participant.

### Interviews

Caregivers were eligible if their children were <18 years old, had a chronic condition, defined as health condition that lasted or was expected to last ≥12 months, had the tracheostomy performed ≤5 years before the interview, and were current patients at BCH or patients at time of death. Caregivers had to be ≥18 years old, English- or Spanish-speaking, and the primary caregiver. Bereaved caregivers were included except within 6 months of the child's death. Children were identified from the hospital's administrative database using procedure codes for tracheostomy, a list maintained by the otorhinolaryngology department of children who received tracheostomy, and a list of children referred to the pediatric palliative/complex care program. Caregivers were recruited by the research associate (SG) through telephone contact; Spanish-speaking caregivers were recruited by the bilingual social worker of the palliative/complex care program.

Between December 2013 and November 2014, 41 in-depth, semi-structured interviews (35 English; six Spanish) of 56 caregivers were conducted by trained interviewers. An interview guide was developed to elicit information about the TDM process (Supplementary Appendix B) and was revised for relevance as interviews progressed. A $30 incentive was provided to participants.

### Focus groups

Clinicians were eligible if they worked in the neonatal or pediatric intensive care or step-down units, and were involved in the TDM process. We invited clinicians through three sources: (1) physicians (neonatologists, and pediatric hospitalists, intensivists, pulmonologists, and otorhinolaryngologists) via email, (2) flyers distributed on the pediatric floors, and (3) personal invitation of clinicians who were identified in caregiver interviews. Five focus groups were conducted with 33 clinicians between September and October 2015; two groups included physicians only (seven and eight participants); and three groups included nurses, social workers, a care coordinator, and a respiratory, speech and physical therapist (nine, five, and four participants). Focus groups were moderated using guides designed to elicit clinician perspectives on TDM (Supplementary Appendices C and D). Focus groups were conducted after caregiver interviews were complete. The focus group guide comprised questions similar to those we asked caregivers, as well as vignettes for discussion based on caregiver interviews. Participants received food and $25 incentives.

**Table 2.** Participant characteristics

| Characteristic | Median (Range) or *N* (%) |
|---|---|
| Caregivers who participated in 41 interviews [*n* = 56] | |
| Age | 36 *years* (19 *years* – 53 *years)* |
| Relationship to the child | |
| Mother | 38 (68%) |
| Father | 13 (23%) |
| Grandmother | 3 (5%) |
| Grandfather | 1 (2%) |
| Grandmother figure | 1 (2%) |
| Education | |
| <High School | 9 (16%) |
| High School | 16 (29%) |
| Some College | 11 (20%) |
| College | 17 (30%) |
| Missing | 3 (5%) |
| Clinicians who participated in 5 focus groups [*n* = 33] | |
| Nonphysician focus groups (3) | |
| Nurse | 11 (33%) |
| Social Worker | 3 (9%) |
| Respiratory Therapist | 1 (3%) |
| Physical Therapist | 1 (3%) |
| Speech Therapist | 1 (3%) |
| Care Coordinator | 1 (3%) |
| Physician focus groups (2) | |
| Otorhinolaryngologist | 2 (6%) |
| Pediatric Pulmonologist | 2 (6%) |
| Pediatric Intensivist | 4 (12%) |
| Neonatologist | 3 (9%) |
| Pediatric Hospitalist | 4 (3%) |
| Sex | |
| Female | 26 (79%) |
| Male | 7 (21%) |
| Age category, in years | |
| ≤36 | 5 (15%) |
| 36–45 | 15 (45%) |
| ≥46 | 12 (36%) |
| Missing | 1 (3%) |
| Years of service | |
| <10 years | 10 (31%) |
| 10–20 years | 11 (33%) |
| >20 years | 11 (33%) |
| Missing | 1 (3%) |

### *Qualitative data analysis*

Interviews and focus groups were audio-recorded and transcribed verbatim. Spanish transcripts were translated into English. Separate interview and focus group codebooks were developed inductively and revised for accuracy as coding progressed. We used ATLAS.ti (v.7) software (2013) for data management and analysis. All four investigators coded the first two transcripts as a group to ensure the consistent understanding and application of codes and their meanings. For the remaining transcripts, two investigators independently coded each transcript, then compared them and reconciled coding differences to arrive at a consensus. Coded data were summarized by an investigator and then verified by a second investigator. Caregiver interviews were coded prior to focus group conduct. This sequential design allowed us to both probe deeper into the phenomenon while corroborating or negating our developing findings during ongoing analysis (saturation and triangulation). During synthesis, we compared and contrasted caregiver and clinician data. Using thematic content analysis (Green and Thorogood, 2018), investigators identified and verified themes by their prevalence and salience across datasets.

### *Quantitative data*

Child-level data including diagnosis, dates of tracheostomy, birth and death, and insurance type were abstracted from medical records. Before the interviews, caregivers completed surveys eliciting demographic information. Before focus groups, clinicians completed surveys eliciting age categories and years of service.

## Results

The characteristics of children are presented in Table 1. The characteristics of caregivers and clinicians are presented in Table 2. Qualitative results are presented below. Three themes, related to the resources and supports that caregivers needed in the tracheostomy decision-making process, were identified.

### *Theme 1: Caregivers described five different fundamental resource domains that did help, or would have helped them, to address their needs surrounding TDM*

Support of all kinds was important to caregivers since the TDM process was an emotionally charged experience for them. Caregivers identified areas where support was needed: (1) decision-making, (2) becoming knowledgeable and skillful about child's diagnosis, tracheostomy, and home care, and (3) emotional and spiritual well-being. These needs culminated in tremendous caregiver stress. Caregivers used five domains of resources to meet their support needs (illustrative quotes in Table 3) during TDM.

1) *Social network:* Spouses, extended family members, friends, and clergy helped in the TDM process and provided emotional support. Family support was variable. Some did not have any family member with whom they could discuss TDM. While most often parents made the decision together, some mothers mentioned that fathers did not agree to the tracheostomy initially. Single mothers sometimes did not involve the father or have the father's support at all.

> **D18**: "It was hard because I had to make the decision on my own. I contacted their dad and tried to talk to him about it, but he wasn't much help.

**Table 3.** Resources helpful for caregivers during the tracheostomy decision-making process: illustrative quotes of caregiver and clinician perspectives

| Domain | Caregiver Quote | Clinician Quote |
|---|---|---|
| 1. Social network (e.g., spouses, other family members, friends, and clergy) | **D03**: At first I didn't want to talk to nobody about it, really … I talked to Mom and that was the main one that I have always talked to on decisions … but that was the hardest thing for me to do, was to make any decision. | **Nurse B05/ FG1**: Another thing you can suggest is they can bring a family member that is in the medical field or that is not emotionally so distorted that can help them, that can listen with them. That's what some of our families did … |
| 2. Healthcare providers | **D01**: He was [child]'s primary nurse because he always had her. And he was always good about answering questions for us as well. He helped me get what I needed, like the confirmation of could she be extubated. He was the one that kind of pushed that. Confirmation for me to know, "Okay, she does need a trach." | **Physician B28/ FG4**: There's a lot that they [palliative care] provide because they develop a relationship … we're talking about that relationship of advocacy, the palliative care team really does that well. So when the patients come into the ICU and the palliative care team comes in, it almost creates — I mean it's a security blanket for them. |
| 3. Other parents/caregivers of children with tracheostomy | **D11**: She [parent of a child with tracheostomy] took me to her room and she showed me her little boy … she talked to me. I believe we did talk a little bit about the trach. She helped me out a lot with everything … with the trach and the nursing, she could tell me about that stuff, because she'd been there … She was helpful. | **Physician B19/ FG3:** We actually had a situation from the PICU where the family was completely terrified of a trach … We were able to say, "Hey, why don't you come talk to this mom in our trach/vent clinic," and they could see the child. That really seemed to be the tipping point for them … other parents getting involved, from my experience, has been very helpful for that parent trying to make that decision … |
| 4. Tangible (e.g., print materials, videos, tracheostomy tubes, mannequins, simulation lab) | **D35S**: When we came to a decision to agree to have it and then we learned about it … .They gave us some papers and books and some specialists from that area came and give us some conversation and lay out all the information about it. That's when we learn about it. | **Nurse B09/ FG1:** … maybe having a visual or a video, something that they can take the time and watch and absorb all the information about the technical parts of the trach and what it looks like and how it works. Not just the emotional part of it but the actual education of technical parts of it so they can understand what we're talking about. |
| 5. Internet (e.g., website, social media, online health community) | **D21:** we have talked to other moms. There is a community of us, there is a <diagnosis> Moms community on Facebook, so we all talk to each other about the kids. | **Physician B20/ FG3**: I think there's a Facebook page — saw something today … something about "moms with babies with trachs." It's private so you have to ask to be let in. This mom had found that very helpful. |

> He walked out when I was three months pregnant with her and he's not around a whole lot … I asked him to come down there and be with us through it, and he wouldn't, so I had to make the decision on my own … "

Caregivers especially appreciated emotional support from their social network, which they described as "*comforting*," "*reassuring*," "*encouraging*," "*uplifting*," and "*positive*." Caregivers frequently mentioned their mothers as a resource for decision-making and emotional support. In some cases, caregivers chose not to discuss with family or friends about their child's condition or tracheostomy decision. Some were frustrated with questions from their social network about their child's health. Family support systems were considered important, but were not available for some.

> **D20:** "Because my family — it was like when I found out something was wrong with my baby, everybody was like cryin' all the time, my brother, askin' me stuff all the time. [Child's] daddy was breaking down …. I cried to myself. I didn't want nobody seeing me. It was like I had to be strong for **everybody**, which people should have been kinda there for me…"

2) *Healthcare Providers (HCP):* Many different HCPs — doctors (intensivists, otorhinolaryngologists, pulmonologists), nurses, social workers, supportive care teams (e.g., palliative care) in the hospital, and community providers including home health nurses helped by providing information and resources. Some caregivers specifically mentioned the advocacy of their primary-care physicians during TDM. Support from clinicians was helpful for reassurance, confidence, and learning especially when familial support was lacking. Hospital nurses helped prepare parents for home care of children.

> **D24:** "The nurses did a really good job training me how to suction, how to clean, how to change the trach. I felt really comfortable just within the first three or four days."

3) *Other parents of children with tracheostomy*: Caregivers found interaction with other parents of children with tracheostomy to be valuable. Seeing another child with a tracheostomy was helpful, as many caregivers had no prior experience with tracheostomy. Connection with other parents occurred in the hospital, community (e.g., school, church, Ronald McDonald House), or on the internet; some of these connections were initiated by HCP in the hospital or home, and others by caregivers themselves. Some families maintained long-term relationships as a result of this interaction. In hindsight, many caregivers said they would like to advise parents considering tracheostomy for their children to seek counsel from other parents who already experienced the TDM process. Many already served as a resource or mentor to other parents; some were willing to be a support and share what they learnt during the TDM process.

> **D34:** "I became a NICU Mommy Mentor … I never realized how much support you could literally get just when you got a bunch of women in the same situation."

Not all caregivers received support from other parents — some were not connected with or did not have the opportunity to meet other parents; some chose not to meet other parents, especially if their children did not have the same diagnoses. These caregivers found it hard to compare situations because diagnoses and disease progression were different for each child regardless of tracheostomy status.

> **D15:** " … not everyone's situation is the same, so, I could have gotten an idea from them, like 'Oh this and that,' but I wanted to kind of do it myself since I was going to be the main one. And I wanted to focus on what her needs would be specifically and not be distracted by maybe someone else's condition, how good it was, their setup, their nurses, their home, and you know, mine might not have compared … "

4) *Tangible materials*: Caregivers named print materials, videos, actual tracheostomy tubes, mannequins, and training in simulation labs as helpful. However, use of these materials was not reported by all caregivers. Materials were favored when they were provided in caregivers' first language (English or Spanish). It was often unclear whether these tangible materials were assisting with decision-making, learning about diseases/diagnoses, or tracheostomy care.
5) *Internet*: All English-speaking caregivers mentioned the internet as a resource. General internet research ("Googling") to understand medical terms, diagnosis or child's health condition, tracheostomy, and to seek resources available to care for their children were helpful in the TDM process. Caregivers also named specific websites (e.g., WebMD, Aaron's Tracheostomy) and YouTube to learn about tracheostomy care. Caregivers connected with other parents through membership in social media groups (especially Facebook) related to certain diagnoses or for children with tracheostomy ("Moms with Trach Babies" group), and found these connections valuable. Some received information and other resources (e.g., "care packages") from these online groups maintained by disease-specific foundations. Facebook was also used by caregivers to communicate with their social network about their child's condition, and to help fundraise for their child's care. None of the Spanish-speaking caregivers discussed researching via the internet; one said that a friend did the research and another said they started a GoFundMe webpage to raise money for their child's care. Some caregivers said that HCP recommended specific websites, but this was not consistent. For the most part, they did the research by themselves. Even if HCP gave them all the information, many reported doing their own research. Caregivers acknowledged that information on the internet might be scary, overwhelming, or inaccurate: "it's not been my friend the entire time, but … it helped a lot." Some did not have the time to get information from the internet during TDM.

### *Theme 2: Caregivers reflected that while they used their resources to receive enough overall support in several areas surrounding TDM, there were gaps in that support*

Overall, caregivers described resources to be helpful. These five resource domains were inter-related. For example, HCP provided tangible materials, internet resources and connected caregivers to other parents. Another example was caregivers finding other parents as a resource through their research on the internet.

> **D06:** "They [HCPs] showed me a child [with a tracheostomy] and they gave me a print-out on some information and showed me some pictures and asked me to go look at some pictures. But I actually got to see a child … It wasn't what I expected or wasn't as bad as I thought it would have been."

> **D04:** " … since she's been born, my life has been involved in finding what I can do to help her, so I spent a long time on the internet talking to other families that have what she has."

In general, caregivers used these resources and received the support they needed surrounding decision-making. However, caregivers mentioned gaps in the resources and offered suggestions for improving the quality of support:

> **D18**: "I think maybe just a pamphlet that would give you websites like that you could specifically go to that would give you more information about it, or maybe like a website that you could go on and read other people's stories that have went through it. Or even if they could set up a meeting with another family that did go through it that could talk to you. You would hear their perspective and how it's been on them."

> **D38:** "It was good advice, although I think it could be better with other materials that can give a better idea of how all this works. Perhaps videos or if there are people who are willing to share their experiences perhaps in a video that one could have access to that information."

### *Theme 3: Clinicians were knowledgeable about available resources to support parents, and facilitated their utilization by parents before tracheostomy and in preparation for home care post-tracheostomy*

During clinician focus groups, participants expressed similar support needs of parents, and spoke knowledgably about the resources available to address those needs (Table 3). Clinicians discussed HCP, tangible resources, and parent-to-parent connections more frequently than social networks and internet as resources. In all focus groups, the helpfulness of connecting parents with more experienced parents was discussed. Often, parent-to-parent connections were initiated by hospital-based nurses, or family support programs embedded in the hospital, but clinicians acknowledged that this did not happen consistently. Some clinicians discussed the negative effect on the doctor–patient relationship because of caregivers connecting with other parents via social media, and considered this as a barrier to TDM.

> **Physician B25/ FG4**: "There are social media groups … where people share their experiences and so people enter these relationships with huge chips on their shoulders that may not even be their own chips, but just being warned. 'The doctor's gonna try and talk you into this and you don't have to do that. We were able to get this and if you can't get it, call this hospital or come have your baby born at this hospital because they'll resuscitate. They'll do X, Y, and Z.'"

Clinicians stressed the importance of preparing families for home care, but identified many gaps including lack of consistency in preparation. A standardized curriculum for training parents was recommended by nonphysician groups. They also mentioned that resources provided to parents should be individualized to the needs of the families.

> **Nurse B14/FG2:** "I would like to see more education of these babies going home. Like go in a sim lab, what if this happens? I think we don't do enough …."

> **Nurse B32/ FG5**: "I think we have to find out what their learning style is. Not everyone absorbs information just by talking to them. Do we need to

> show them a video? Do we need to show them a mannequin? Do we need to get books? We need to figure out what their individual style is for understanding what we're saying."

## Discussion

Our study shows that the need for support for caregivers of CMC surrounding tracheostomy placement for their children extends beyond decision-making, and includes support for becoming knowledgeable and skillful about the child's diagnosis, tracheostomy and home care, and emotional and spiritual well-being. During TDM conversations, HCPs should attempt to learn about parents' particular preferences, in order to tailor the offer of a comprehensive set of resources and supports to each family's needs. The five domains of resources — social network, HCP, other parents, tangible materials, and internet — identified in our study, could serve as a framework for HCPs in offering individualized resources to parents during TDM.

Caregivers and clinicians alike considered connecting caregivers with other parents of children who have had tracheostomy to be valuable. Structured parent-to-parent peer support programs helped reduce stress in children with disability (Shilling et al., 2013; Bray et al., 2017). In a survey of parents whose children had tracheostomy, a large proportion of those who had the opportunity to meet another family found that experience helpful (McCormick et al., 2015). Yuen et al. (2021) successfully used trained parents as peer supporters to prepare parents before discharging children with tracheostomy from the hospital. However, in our study, not all caregivers reported being connected to other parents; even if they were connected to other parents, this connection was not always mediated by HCPs. In the McCormick study, nearly half of the respondents desired to meet another family, and yet, did not have the opportunity to do so (McCormick et al., 2015). The challenges associated with HCPs connecting parents to other parents are not known. Some caregivers in our study mentioned that HCPs could not find a parent mentor for them. However, similar to a prior study (Callans et al., 2016), caregivers in our study were interested in mentoring other parents with tracheostomy. If face-to-face parent connections are not possible, online health communities might be an alternative approach for parent-to-parent support (Nicholl et al., 2017), as parents find these connections helpful (Meyer-Macaulay et al., 2021). Hospital leaders may need to create policies to foster a culture where other parents are considered an important resource for parents in the pediatric tracheostomy decision-making process.

Caregivers liked training in preparing for home care of their children with tracheostomy. This is consistent with prior studies wherein parents appreciated extensive hands-on training (Mai et al., 2020). Several clinicians in our study, especially nurses, mentioned the potential benefit of a standardized curriculum to prepare parents for home care. In one study, simulation-based training of parents of children with tracheostomy improved their knowledge and tracheostomy care skills (Yuen et al., 2021). Another study showed that the use of standardized processes when transitioning children with tracheostomy from hospital to home reduced subsequent emergency room visits and hospitalizations (Baker et al., 2016). Such a standardized curriculum for parent training could save HCP time and resources in supporting parents.

The internet was an important resource for caregivers surrounding TDM in our study. Prior studies show the ubiquitous use of internet by parents of children with rare disorders and those with tracheostomy to gain knowledge about their child's condition and for parent-to-parent support (Nicholl et al., 2017; Meyer-Macaulay et al., 2021). Bryan et al. (2020) reported that 93% of parents surveyed used internet for health information for their children. Interestingly, in our study, while all the English-speaking caregivers mentioned internet as a resource, none of the Spanish-speaking caregivers did. This could be because of lack of health information available in Spanish, inadequate access to internet for this population, or cultural factors. However, our study included only six Spanish-speaking caregivers and may not have captured true differences in internet used based on caregiver's language. Disparities in internet use based on health literacy have been reported before (Meyers et al., 2020). Parents' language as a factor in using internet as a resource is worth further exploration.

In our study, clinicians did not discuss internet as an important resource for parents during TDM. On the contrary, clinicians mentioned the negative effects of internet resource on the doctor–patient relationship. HCPs may not be confident about the quality or applicability of information online (Edwards et al., 2017). In the Bryan et al. study, only one-third of parents surveyed reported that their child's physician was interested in the health information that they obtained online (Bryan et al., 2020). When parents of children with rare diseases were surveyed, 78% shared information about what they learnt from the internet with their HCPs, but only 22% stated that their HCP was "very interested" in that information (Nicholl et al., 2017). HCPs may be reluctant to engage with parents through internet/social media for fear of violating professional boundaries (De Clercq et al., 2020). Parents of children with tracheostomy use social media for gaining knowledge and for getting medical advice (Huestis et al., 2020). Therefore, HCPs guiding parents during TDM should explore parents' use of the internet as a resource. Especially since the coronavirus pandemic, the internet has become an indispensable resource, but the amount of misinformation and disinformation it provides has skyrocketed (Topf and Williams, 2021). HCPs can support parents' use of this resource, perhaps by offering internet resources known to be reliable, offering to vet resources a parent has identified, or providing some basic accurate information sources against which parents can check online and social media information.

Our study has limitations. Data were collected about 6 years ago. Certain resources, especially those on the internet, would now be a more prominent resource. Caregivers' memory may have affected their ability to recall specific resources used during TDM several years prior to the interview. This is a single-institution study; experiences about resources, especially HCP and tangible materials, may be different in other institutions. Since this is a qualitative study, the frequency of support needs and resources used could not be quantified. Since resource use was not the primary focus of the study, we did not explore all the themes related to this topic. For example, we could not explore the differences between English- and Spanish-speaking caregivers about internet use. These differences warrant further exploration. Finally, our study does not include information from caregivers who chose not to pursue tracheostomy or directly from children.

## Conclusion

Our study shows that caregivers have many support needs surrounding decision-making about tracheostomy for their children. We identified five different types of resources to be beneficial to caregivers during TDM. HCPs should assess caregivers' need for support during TDM conversations and identify resources to meet these needs.

**Supplementary material.** The supplementary material for this article can be found at https://doi.org/10.1017/S1478951522001122.

**Acknowledgments.** We thank Ms. Aura Rosado MSW, Care Coordinator, Pediatric Enhanced Care Program, Wake Forest School of Medicine (WFSM) for recruiting and interviewing Spanish-speaking caregivers in this study, and for reviewing the summaries of coded text; Ms. Vanessa Ortiz, Patient Navigator, Pediatric Enhanced Care Program, WFSM for reviewing the summaries of coded text; Dr. Quincy Banks for help with literature review.

**Funding.** This project was conducted with support from the National Institute of Nursing Research R21NR013272 (PI: Nageswaran). The sponsor played no role in study design, collection, analysis, or interpretation of the data; in the writing of this manuscript or in the decision to submit the manuscript for publication.

**Conflict of interest.** The authors have no relevant conflicts of interest to disclose.

## References

**ATLAS.ti** (2013) *Qualitative Data Analysis*. Berlin, Germany: Atlas.ti Scientific Software Development GmbH.

**Baker CD, Martin S, Thrasher J, *et al.*** (2016) A standardized discharge process decreases length of stay for ventilator-dependent children. *Pediatrics* **137**, 4.

**Berry JG, Graham DA, Graham RJ, *et al.*** (2009) Predictors of clinical outcomes and hospital resource use of children after tracheotomy. *Pediatrics* **124**(2), 563–572.

**Berry JG, Hall DE, Kuo DZ, *et al.*** (2011) Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals. *JAMA* **305**(7), 682–690.

**Bray L, Carter B, Sanders C, *et al.*** (2017) Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling* **100**(8), 1537–1543.

**Bryan MA, Evans Y, Morishita C, *et al.*** (2020) Parental perceptions of the internet and social media as a source of pediatric health information. *Academic Pediatrics* **20**(1), 31–38.

**Callans KM, Bleiler C, Flanagan J, *et al.*** (2016) The transitional experience of family caring for their child with a tracheostomy. *Journal of Pediatric Nursing* **31**(4), 397–403.

**Campisi P and Forte V** (2016) Pediatric tracheostomy. *Seminars in Pediatric Surgery* **25**(3), 191–195.

**Cohen E, Kuo DZ, Agrawal R, *et al.*** (2011) Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics* **127**(3), 529–538.

**De Clercq E, Rost M, von der Weid N, *et al.*** (2020) To be or not to be in the social media arena? The perspective of healthcare providers working within adolescent and young adult oncology in Switzerland. *International Journal of Adolescent Medicine and Health*. https://doi.org/10.1515/ijamh-2020-0137.

**Edwards JD, Kun SS and Keens TG** (2010) Outcomes and causes of death in children on home mechanical ventilation via tracheostomy: An institutional and literature review. *Journal of Pediatrics* **157**(6), 955–959 e952.

**Edwards JD, Morris MC, Nelson JE, *et al.*** (2017) Decisions around long-term ventilation for children. Perspectives of directors of pediatric home ventilation programs. *Annals of the American Thoracic Society* **14**(10), 1539–1547.

**Feudtner C, Hays RM, Haynes G, *et al.*** (2001) Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics* **107**(6), E99.

**Gower WA, Golden SL, King NMP, *et al.*** (2020) Decision-making about tracheostomy for children with medical complexity: Caregiver and health care provider perspectives. *Academic Pediatrics* **20**(8), 1094–1100.

**Green J and Thorogood N** (2018) *Qualitative Methods for Health Research*. Los Angeles: SAGE.

**Huestis MJ, Kahn CI, Tracy LF, *et al.*** (2020) Facebook group use among parents of children with tracheostomy. *Otolaryngology Head and Neck Surgery* **162**(3), 359–361.

**Jonas D, Scanlon C and Bogetz JF** (2021) Parental decision-making for children with medical complexity: An integrated literature review. *Journal of Pain and Symptom Management*. doi:10.1016/j.jpainsymman.2021.07.029

**Mai K, Davis RK, Hamilton S, *et al.*** (2020) Identifying caregiver needs for children with a tracheostomy living at home. *Clinical Pediatricss (Phila)* **59**(13), 1169–1181.

**McCormick ME, Ward E, Roberson DW, *et al.*** (2015) Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngology Head and Neck Surgery* **153**(6), 914–920.

**McPherson ML, Shekerdemian L, Goldsworthy M, *et al.*** (2017) A decade of pediatric tracheostomies: Indications, outcomes, and long-term prognosis. *Pediatric Pulmonology* **52**(7), 946–953.

**Meyer-Macaulay CB, Graham RJ, Williams D, *et al.*** (2021) "New Trach Mom Here…": A qualitative study of internet-based resources by caregivers of children with tracheostomy. *Pediatric Pulmonology* **56**(7), 2274–2283.

**Meyers N, Glick AF, Mendelsohn AL, *et al.*** (2020) Parents' use of technologies for health management: A health literacy perspective. *Academic Pediatrics* **20**(1), 23–30.

**Muller RG, Mamidala MP, Smith SH, *et al.*** (2019) Incidence, epidemiology, and outcomes of pediatric tracheostomy in the United States from 2000 to 2012. *Otolaryngology Head and Neck Surgery* **160**(2), 332–338.

**Nageswaran S, Golden SL, Gower WA, *et al.*** (2018) Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *Journal of Pediatrics* **203**, 354–360.

**Nageswaran S, Banks Q, Golden SL, *et al.*** (2022) The role of religion and spirituality in caregiver decision-making about tracheostomy for children with medical complexity. *Journal of Health Care Chaplaincy* **28**(1), 95–107.

**Nicholl H, Tracey C, Begley T, *et al.*** (2017) Internet use by parents of children with rare conditions: Findings from a study on parents' web information needs. *Journal of Medical Internet Research* **19**(2), e51.

**Shilling V, Morris C, Thompson-Coon J, *et al.*** (2013) Peer support for parents of children with chronic disabling conditions: A systematic review of quantitative and qualitative studies. *Developmental Medicine and Child Neurology* **55**(7), 602–609.

**Simon TD, Berry J, Feudtner C, *et al.*** (2010) Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics* **126**(4), 647–655.

**Tong A, Sainsbury P and Craig J** (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal of Quality in Health Care* **19**(6), 349–357.

**Topf JM and Williams PN** (2021) COVID-19, social media, and the role of the public physician. *Blood Purification* **50**(4–5), 595–601.

**Yuen A, Rodriguez N, Osorio SN, *et al.*** (2021) Simulation-based discharge education program for caregivers of children with tracheostomies. *Hospital Pediatrics* **11**(6), 571–578.