

# Collaborative decision-making: A framework for decision-making about life-sustaining treatments in children with medical complexity

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## Funding information

National Institutes of Health

## Abstract

**Objective:** Caregivers of children with medical complexity (CMC) face decisions about life-sustaining treatments (LST) like tracheostomy. We sought to develop a clinically relevant and realistic model for decision-making about tracheostomy placement that might apply to other LST in CMC.

**Design:** This qualitative study, conducted between 2013 and 2015, consisted of 41 interviews with 56 caregivers of CMC who had received tracheostomies and 5 focus groups of 33 healthcare providers (HCPs) at a tertiary-care children's hospital in North Carolina. Participants were asked about their perspectives on the tracheostomy decision-making process. Data were transcribed, and coded. Using thematic content analysis, we inductively developed a tracheostomy decision-making framework and process.

**Results:** Many factors influenced caregivers' decisions, including children's well-being and caregivers' values, faith, knowledge, experience, emotional state, and social factors; preserving the child's life was the most important. HCPs consider many clinical and nonclinical factors; recommending tracheostomy for children with limited survival, perceived poor functioning and quality of life, and progressive conditions is ethically difficult. The framework of tracheostomy decision-making has inter-related caregiver- and HCP-level factors that influence the process. The framework contains elements not captured in a shared decision-making model, but better fits a collaborative decision-making (CDM) model. The tracheostomy CDM process that emerged from the data has two nonsequential components that HCPs could use: (1) gaining understanding and (2) holding decision-making conversations.

**Conclusions:** CDM could be a useful model for clinicians guiding families about tracheostomy for CMC. The applicability of CDM for decision-making about other LSTs needs further exploration.

## KEYWORDS

decision-making, framework, pediatric tracheostomy

**Abbreviations:** CDM, collaborative decision-making; CMC, children with medical complexity; HCP, healthcare providers; LST, life-sustaining treatment; SDM, shared decision-making.

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## 1 | INTRODUCTION

Children with medical complexity (CMC) are living longer because of advances in technology.<sup>1</sup> With increasing survival of CMC and expanding treatment options, parents/caregivers (hereinafter “caregivers”) of CMC face decisions about pursuing life-sustaining treatments (LSTs) such as tracheostomy, gastrostomy, chronic mechanical ventilation, scoliosis surgery, etc. These decisions have profound consequences for children and their families in terms of caregiver burdens<sup>2</sup> and children's quality of life.<sup>3</sup> Caregivers find decision-making about LSTs for CMC complex and difficult.<sup>4,5</sup> Supporting caregiver decision-making about CMC is an integral part of pediatric palliative care.<sup>6</sup>

Shared decision-making (SDM) is defined as decision-making in which the patient/parent and the healthcare provider (HCP) share information about treatment options, take steps to arrive at a consensus about preferred option, and agree on the treatment to implement.<sup>7</sup> SDM is associated with increased decisional satisfaction, decreased decisional uncertainty, and lower healthcare utilization and expenditures.<sup>8,9</sup> Although the benefits of SDM are clear, its applicability to decision-making about LST for CMC has not been established.

Current clinical practice is limited by lack of evidence supporting optimal decision-making about LST for CMC. Using tracheostomy as a prototype for LST, we sought to develop a clinically relevant and realistic decision-making model about LST in CMC. We chose tracheostomy because it has tremendous caregiver burden and profound effects on the child's quality of life, with death as the probable alternative. We used qualitative methodology in a research project to understand the pediatric tracheostomy decision-making process from the perspectives of caregivers and HCPs. In four previously published<sup>10-13</sup> papers from this project, we described different aspects of the pediatric tracheostomy decision-making process. Building on these, in this paper, we describe a model of pediatric tracheostomy decision-making.

## 2 | METHODS

This study was conducted at Brenner Children's Hospital (BCH), the tertiary-care children's hospital of Wake Forest Health Sciences (WFHS) in North Carolina. WFHS Institutional Review Board approved the study. Informed consent was obtained from participants.

### 2.1 | Study design

This qualitative study used an *interpretivist* research paradigm<sup>14</sup> and involved interviews with caregivers of CMC and focus groups of HCPs to understand the tracheostomy decision-making process. A qualitative approach is the most rigorous methodology to understand the perspectives of participants, explore the meanings of phenomena, or observe a process in depth,<sup>15</sup> all of which apply to this study. Methodological details are provided in the Standards for Reporting Qualitative Research<sup>16</sup> checklist (Appendix SA) and described previously.<sup>10-13</sup>

## 2.2 | Participants, recruitment, and data collection

### 2.2.1 | Interviews

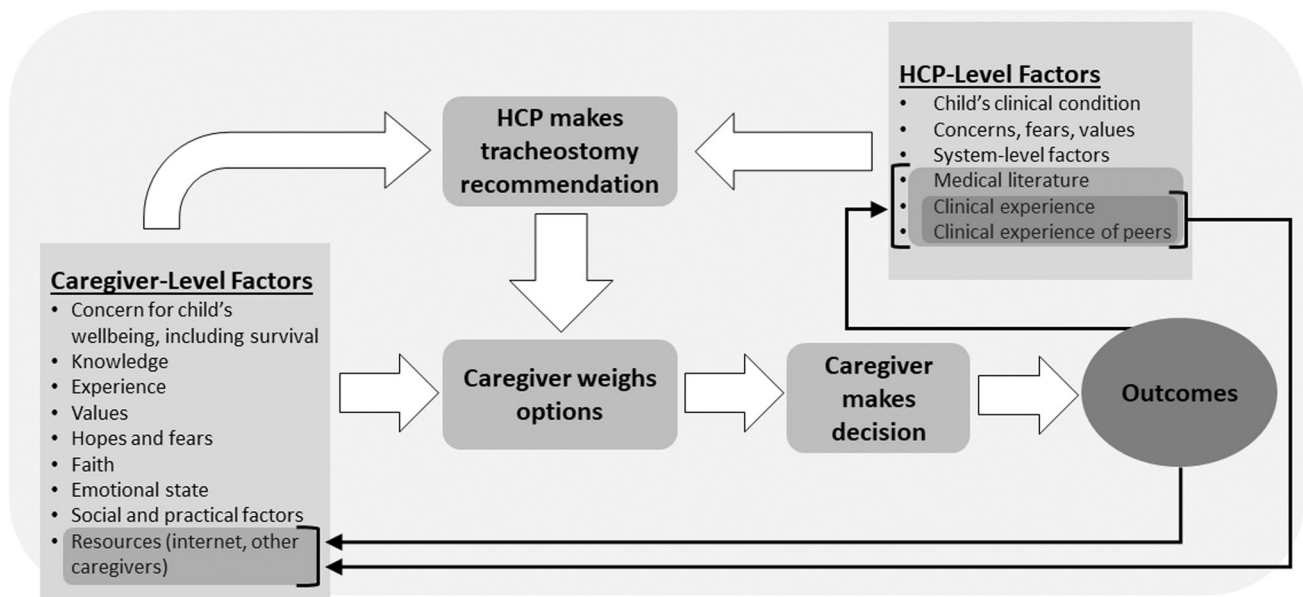
Caregivers were eligible if their children were <18 years old, had a chronic condition that lasted or was expected to last  $\geq 12$  months, had the tracheostomy performed  $\leq 5$  years prior, and were current patients at BCH. Caregivers had to be  $\geq 18$  years old, English- or Spanish-speaking, and the primary caregiver. Bereaved caregivers were included except within 6 months of the child's death. A preliminary list of 140 children was generated from the hospital's administrative database using procedure codes for tracheostomy, a list maintained by the otorhinolaryngology department, and children referred to the pediatric palliative/complex care program. Of these children, 49 were eligible; 73 ineligible; and 18 deferred. Of those eligible, 41 (84%) agreed to participate. From 12/2013 to 11/2014, 41 in-depth, semi-structured interviews (35 English; 6 Spanish) of 56 caregivers were conducted by trained interviewers at locations and times of caregivers' choosing. In 27 interviews, one caregiver participated. In 13 interviews, 2 caregivers participated; in 1 interview, 3 caregivers participated. An interview guide to elicit information about the decision-making process was developed and revised as interviews progressed (Appendix SB). For each interview, a \$30 gift card was provided to participants as an incentive.

### 2.2.2 | Focus groups

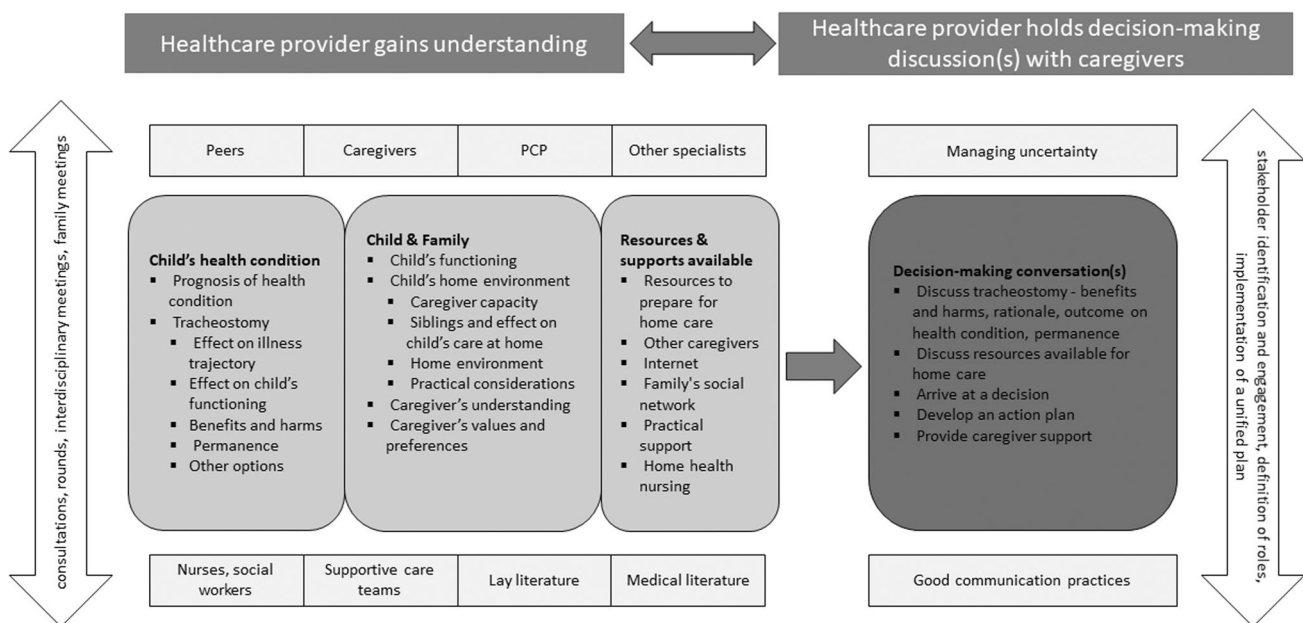
HCPs were eligible if they worked in the neonatal or pediatric intensive care units, or the step-down unit, and were involved in the tracheostomy decision-making process. Five focus groups were conducted with 33 clinicians between September and October 2015; two groups included physicians only; and three groups included nurses, social workers, a care coordinator, and a respiratory, speech and physical therapist. Focus groups were moderated using guides (Appendices SC and SD) designed to elicit clinician perspectives on tracheostomy decision-making. Participants received lunch and a \$25 gift card as an incentive.

## 2.3 | Qualitative data management and analysis

Interviews and focus groups were audio-recorded and transcribed verbatim by a professional transcriptionist. Spanish transcripts were translated into English by a professional translator and transcriptionist. Separate interview and focus group codebooks (Appendices SE and SF) were developed inductively and revised for accuracy as coding progressed. We used ATLAS.ti (v.7) software<sup>17</sup> for data management and analysis. All four investigators coded the first two transcripts as a group to ensure the consistent application of codes. For the remaining transcripts, two investigators independently coded each and reconciled coding differences to arrive at consensus. Coded textual data were



**FIGURE 1** Framework for tracheostomy decision-making for children with medical complexity based on caregiver and healthcare provider (HCP) perspectives



**FIGURE 2** Process for collaborative decision-making about tracheostomy for children with medical complexity

summarized by an investigator and verified by a second investigator. Using thematic content analysis,<sup>15</sup> we examined code summaries and identified all the caregiver and HCP-level factors in the tracheostomy decision-making process. Next, through iterative examination of data, one of the authors mapped the relationships between these factors and developed a framework for decision-making (Figure 1). The framework was reviewed and revised by the other authors. Finally, using a similar

approach, we created a clinically relevant decision-making process for HCPs to use in their clinical practice (Figure 2) based on participants' experiences of and their advice for improving the decision-making process. Although we reached data saturation on themes before the final few interviews, we completed those interviews for the sake of exhausting the entire list. For HCP-level data, our goal was not to saturate data, but to triangulate caregiver experience using clinical perspectives.

## 2.4 | Quantitative data

Child-level data were abstracted from medical records. Brief surveys were administered to participants before their participation in interviews or focus groups.

## 3 | RESULTS

Child, caregiver and HCP characteristics are presented in Table 1. Qualitative results are presented below. Some subthemes presented below have been previously published and are referenced.

**TABLE 1** Characteristics of children, caregivers, and healthcare providers<sup>a</sup>

Characteristic	Median (range) or number (%)
<b>Children (n = 41)</b>	
Age	2.5 years (5 months to 18 years)
Boys	21 (51%)
White	29 (71%)
Black	10 (24%)
Multiracial	2 (5%)
Hispanic ethnicity (any race)	7 (17%)
Health insurance type	
Medicaid	31 (76%)
Private	7 (17%)
Both	3 (7%)
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 to 17 years)
Duration of tracheostomy	1.5 years (2 months to 5 years)
Tracheostomy only	25 (61%)
Tracheostomy and chronic mechanical ventilation	16 (39%)
Decanulated before interview	8 (20%)

**TABLE 1** (Continued)

Characteristic	Median (range) or number (%)
Decanulated and 2nd tracheostomy	1 (2%)
Died before interview	3 (7%)
<b>Caregivers who participated in 41 interviews (n = 56)</b>	
Age	36 years (19–53 years)
Relationship to the child	
Mother	38 (68%)
Father	13 (23%)
Other	5 (9%)
Education level	
<High school	9 (16%)
High school	16 (29%)
Some college	11 (20%)
College	17 (30%)
Missing	3 (5%)
<b>Clinicians who participated in 5 focus groups (n = 33)</b>	
Nurse	11 (33%)
Social worker	3 (9%)
Respiratory therapist	1 (3%)
Physical therapist	1 (3%)
Speech therapist	1 (3%)
Care coordinator	1 (3%)
Otorhinolaryngologist	2 (6%)
Pediatric pulmonologist	2 (6%)
Pediatric intensivist	4 (12%)
Neonatologist	3 (9%)
Pediatric hospitalist	4 (3%)
Female	26 (79%)
Age category	
≤36 years	5 (15%)
36–45 years	15 (45%)
≥46 years	12 (36%)
Missing	1 (3%)
Years of service	
<10 years	10 (31%)
10–20 years	11 (33%)
>20 years	11 (33%)
Missing	1 (3%)

<sup>a</sup>Data presented here were previously published in other papers from this project.<sup>10–13</sup>

(Continues)

### 3.1 | Caregiver-level factors in pursuing tracheostomy

Many factors influenced caregivers' decision to pursue tracheostomy, including their child's well-being and their own values, hopes, fears, faith,<sup>11</sup> knowledge, experience, emotional state,<sup>12</sup> as well as social and practical factors. Information from other parents—either obtained through connections facilitated by clinicians or through the internet—was also a factor.<sup>13</sup> Preserving their children's lives was the most important factor for caregivers.<sup>12</sup> Many caregivers had no prior knowledge of or experience with tracheostomy. Some said they had limited understanding of medical terms and systems, or their child's illness. Caregivers wanted to know the clinical rationale for and risks and benefits of tracheostomy. They had many concerns and fears, and sought information about the procedure, its effects on their child, and its impact on their own ability to care for the child. Information about permanency and duration of tracheostomy was important. Participants said that some caregivers might not fully understand the implications of tracheostomy when they made their decision. Illustrative quotes are presented in Table 2.

### 3.2 | HCP-level factors in recommending tracheostomy

HCP considered many clinical and nonclinical factors when recommending tracheostomy (Table 2). Generally, physicians made recommendations about whether or not to undergo tracheostomy based on CMCs' clinical conditions. Failed extubation, prolonged intubation, and airway obstruction were the clinical reasons for recommending tracheostomy. Physicians also considered the effect of tracheostomy on growth and developmental outcomes, permanency of tracheostomy, repeated hospitalizations, inability to discharge the child from the hospital, availability of services in the community, and caregiver knowledge and capacity (e.g., need for life-long commitment to caregiving and risk of institutionalization). HCPs found it harder to recommend tracheostomy for CMC than for children with acute and reversible conditions. Recommending tracheostomy for children with poor perceived quality of life or functioning or with conditions that are progressive or have limited or unknown survival was ethically difficult for some HCPs.

### 3.3 | Framework for tracheostomy decision-making for CMC

A framework of tracheostomy decision-making for CMC emerged from the data (Figure 1). We found that the many caregiver- and HCP-level factors described above and in prior publications from this project<sup>10-12</sup> were inter-related. Caregivers said that they were/should be the ones to make the decision about

**TABLE 2** Illustrative quotes for caregiver- and healthcare provider-level factors in tracheostomy decision-making<sup>a</sup>

#### Caregiver-Level Factors

##### Child's well-being (survival)

I didn't say that I was *against* it, but I was wanting to make sure that it was what she had to do to survive. If it was something that she needed for survival, then without a doubt, yes...It was a matter of life or death...if it's a matter of life and death, we take life every time. (Caregiver D19)

##### Child's well-being (quality of life)

Nobody should have to fight to live. You shouldn't have to fight that hard just to take a breath and live. I mean he couldn't even enjoy himself, get up and sit down in his chair and watch his cartoons without breathing so hard. (Caregiver D12)

##### Knowledge

...when I say I'm not comfortable making this decision, it's mostly just 'cause I don't have enough facts and I'm just not comfortable makin' a choice on something I don't really know about. (Caregiver D24)

##### Values

What would we advise? That if they are facing a situation like the one we were in, it will depend on what your beliefs are and what respect you have for life and how much you love your children... If it's a person who respects life and believes in God, I think the best decision is to put the trach in. If you have two options of letting her go or putting the trach in, I think the best decision is putting the trach in. (Caregiver D39)

##### Hopes and Fears

I felt like it was something that would affect her, you know, possibly the rest of her life, hopefully not. But you don't want that for your child, you want them to be able to breathe normally, so I was hopeful that with time she would learn to do that on her own...I was very hopeful at that time that we wouldn't need it. (Caregiver D08)

##### Faith<sup>b</sup>

My beliefs played a major role because I have faith in God and I felt confident with pretty much giving the situation to the Lord and feeling okay with it... Jesus Christ is my savior. That's who I lean on and trust for my guidance, and so I just left it in the hands of the Lord and said, "Let His will be done." (Caregiver D33)

##### Emotional State<sup>b</sup>

So we had to make a decision quick. I remember whenever they first brought up a trach, I was terrified. I didn't know what to think because I've seen other children with trachs and I just thought it was like the scariest thing possible. (Caregiver D13)

##### Social and Practical

I think the number one thing that I would tell doctors, is don't make light of the fact that you're asking me to make a decision that's going to change the entire dynamic of my family. And they did, they tried to just 'Oh, well, it's just a really easy procedure.' Well, it's an easy *procedure* in the hospital. It is a *life changing decision* for your family. And that just didn't seem to click to them. They are thinking about it very short term...And that's not your

TABLE 2 (Continued)

Caregiver-Level Factors
<p>decision. As a family that's not the way it works for you. (Caregiver D16)</p> <p>Resources (internet and other caregivers)</p> <p>To the question, "What resources did you use to help make the decision?" The internet, WebMD, and a couple of Facebook pages like Moms with Trach Babies and talking to other parents on Facebook that kids that have &lt;diagnosis&gt;, a few of them that do have the trachs. (Caregiver D04)</p>
HCP-Level Factors
<p><u>Child's clinical condition</u></p> <p>It's usually a category of events that keep happening; cannot keep the airway open or coding or multiple codes and arrests and quality of life. Will this child grow better with a trach? (Nurse B14/FG2)</p> <p>I think the determination of when a child is ready or could benefit from a trach changes based on that child and where they are in their development. (Physician B20/FG3)</p>
<p><u>Caregiver-level (knowledge)</u></p> <p>It's also a lack of knowledge. We know what these things look like. They [caregivers] don't know what it looks like. They don't even know what you're talking about until you start teaching them and showing them what it is. So it's hard for them to even imagine how their life is gonna be outside of here with this. (Nurse B32/FG5)</p>
<p><u>Caregiver-level (capacity)</u></p> <p>I remember a case recently where it [tracheostomy] was gonna mean that the baby wasn't gonna be able to go home with the family because the family couldn't handle ...caring for a trach and so the baby was gonna have to go to like, [long term facility], or somewhere far away if he had a trach. But that's another thing to weigh in, you know? Institutionalization. (Physician B21/FG3)</p>
<p><u>Clinical experience</u></p> <p>...But they do say, "Look at the way she's developing. Look at the way she's done things she's never done before. She's so happy now. We've gone on this trip, we've gone on that trip." Whereas before they would spend all winter in an ICU. There are certain things that make us happy and that is one of them. (Physician B28/FG4)</p>
<p><u>Medical literature and clinical experience of peers</u></p> <p>... years ago, we thought we could ventilate kids in the NICU for as long as they were there without a tracheostomy. The newer literature has come out that you don't need it but it's a judgment call as to exactly when you do it. And you talk to the ENT folks and they say we ought to be traching them earlier because of the airway damage they see, and we sit there and say, probably it's not there. We're all looking at the same elephant but from different angles, and that's what has been the complication in pediatrics developing firm guidelines as they have in the adult world. (Physician B18/FG3)</p>
<p><u>Values</u></p> <p>...medically we know that their child is not gonna have a functional life. They [child] might not even know that they're living. And the parents still want everything done. So a lot of times, there's ethical and moral issues that we have as a team when families disagree...It's difficult when we feel like the trach is just</p>

TABLE 2 (Continued)

Caregiver-Level Factors
<p>prolonging their suffering.... So I feel like we have a lot of complicated discussions within ourselves when it comes to those patients, because we may not agree with doing a trach on a patient we feel has no quality of life. (Nurse B09/FG1)</p>
<p><u>System-level</u></p> <p>I'm not sure how much of a service I'm doing for a family to put a risky device on a child who's chronically ventilated and can't call for help and then them not even be able to get an EMT who can help them when they come, and then maybe even the whole situation gets worse along the way. I think that's been more frightening to me more recently. (Physician B29/FG4)</p>
<p>Abbreviation: HCP, healthcare provider.</p> <p><sup>a</sup>Letter and number following the quotes indicate participant identifier.</p> <p><sup>b</sup>Caregiver and HCP-level factors described in previous papers from this project.</p>
<p>tracheostomy.<sup>12</sup> They considered all the factors (above) and weighed their options, but valued HCPs' guidance in the process (paper in review).</p> <p><i>But it was me and him [child's father] that made the decision... And then whenever we made the decision, he [doctor] come in that next night and he sit down with us, and he said, "well what was y'all's decision?" And we told him, and he said, "Y'all made the right decision..." (Caregiver D07)</i></p> <p>Since there is a lack of medical literature about the prognosis of many rare conditions, and the effects of tracheostomy on these conditions, HCPs rely on their clinical experience and that of colleagues when recommending tracheostomy.</p> <p><i>We struggle in our field of knowing when is the right time for a fairly acutely ill child to move toward chronic ventilation and obtaining an airway. There's not good literature to guide us. We all may have feelings one way or the other, but it's pretty subjective often, and makes it difficult for us to even know what to advocate for in that patient. (Physician B23/FG4)</i></p> <p>Caregivers' decisions to pursue tracheostomy affect their child's health outcomes. These outcomes inform the experiences of HCPs and caregivers. HCPs use their prior experience to identify resources for caregivers, including connection with other caregivers. Caregivers share their experience with other caregivers, especially via social media.</p> <p><i>We go on Facebook, and we have a lot of friends with trachs and SMA. I just wish we could (say), "Hey, get this trach! It will make your kids live a whole lot longer, you</i></p>

(Continues)

**TABLE 3** Shared decision-making versus collaborative decision-making

	SDM	CDM
<b>CONTEXT</b>		
Clear information exists about the health condition (e.g., prognosis)	Yes	No
Adequate evidence exists about the effect of LST on the health condition	Yes	No
Available clinical options are clear	Yes	No
<b>MODEL</b>		
Takes into account caregiver values, preferences, expectations and resources	Yes	Yes
Uses caregiver knowledge about the child	Yes	Yes
Considers caregiver as a subject matter expert on the child's health condition	No	Yes
Takes into account HCP factors in recommending LST including concerns, fears and values	No	Yes
<b>PROCESS</b>		
HCPs conduct intra and interdisciplinary discussions before making recommendation of LST	No	Yes
HCPs use lay literature to inform decision-making	No	Yes
HCPs solicit caregiver input as a subject matter expert on the health condition and use caregiver as a resource in the DM process	No	Yes
HCPs discuss benefits, harms of, and rationale for LST	Yes	Yes
HCPs discuss lack of knowledge, uncertainty about condition and LST	No	Yes

Abbreviations: CDM, collaborative decision-making; HCP, healthcare provider; LST, life-sustaining treatment; SDM, shared decision-making.

*won't have to worry about all this sickness and stuff!*  
(Caregiver D11)

In the tracheostomy decision-making framework, we identify several elements influencing the decision-making process that are not captured in SDM, but by the collaborative decision-making (CDM) model proposed by Politi and Street<sup>18</sup> (Table 3). These include caregivers' knowledge of and experiences with their child's health, HCP-level factors (concerns, fears, values), and HCPs' reliance on clinical experience in the absence of clear evidence about rare conditions and effects of LST on CMC.

### 3.4 | CDM process for tracheostomy decision-making

Informed by data, we developed a process for CDM for HCPs to use in clinical practice (Figure 2). The process has two nonsequential components for HCPs to follow—gaining understanding and holding decision-making conversations. In preparation for decision-making conversations with caregivers, HCPs garner understanding about the: (1) child's health condition, (2) child and family, and (3) resources and supports available for home care. HCPs can obtain this knowledge from various sources including caregivers, nurses, social workers, other clinicians (i.e., primary care and specialist providers, supportive care teams), and medical and lay literature. Gaining understanding from these sources can occur as part of consultations, rounds, and interdisciplinary and family meetings.

*Everybody say, 'Be your child's advocate.' But then so many times I would try to be the advocate, and then they would just kind of shoo it off like it's nothing and just go on. But I guess just try to listen is the best thing I can say. And if they don't understand, ask more questions about it.* (Caregiver D09)

*...if doctors aren't talking to the nurses on 'what else do you know about this family,' then that would be a shame because that's the best key to knowing what's really going on with these families.* (Physical Therapist, B06/FG1)

*We did have to do a lot of education on our doctors to let them realize that just because you go home with a trach and a vent doesn't mean you get 24 a day, 7 day a week nursing care. And that the nurse's care you get is sometimes very suboptimal, and that they don't always show... So when we're in CBES (weekly interdisciplinary meetings) now, we talk about the baby's need for a trach, but then will the family be able to deal with the trach?* (Care Coordinator, B10/FG2)

HCPs can then hold decision-making conversations in which they share information about tracheostomy (benefits, harms, rationale, effect on health condition, expected permanence etc.) and resources for home care, arrive at a decision, develop an action plan, and support caregivers. The process involves managing uncertainty and

using good communication practices (previously reported in a paper from this project).<sup>12</sup> Managing uncertainty involves explicitly discussing with caregivers about the lack of evidence about outcomes of tracheostomy. Many caregivers mentioned that physicians were incorrect in prognostication; one caregiver remarked: “*We are not going to sit here and listen to you prognosticate, and listen to you make predictions, when you've been proven to be wrong several times already*” (**Caregiver D19**). Physicians acknowledged the difficulty of making decisions when there is lack of evidence about outcomes. The decision-making process can be optimized by engaging stakeholders, defining roles and providing a unified plan to the caregiver.

*It would have been better if they would have said, ‘this is what is going to make your child progress in the future’ instead of giving us the option to get rid of her, or letting her go. (Caregiver D07)*

*...when you go in and say, “We think this child needs a trach,” well two other specialties have come in and said something totally different...So if there was some way for us to get to the point where we could stop that kind of thing before it happens so we're all communicating the same thing, that would probably have a greater impact. (Social Worker, FG1/B04)*

*Yeah, they [family] have to be presented with a unified plan from the group. I can't imagine how confusing it could get with multiple people telling you multiple different things. (Physician, FG3/B16)*

## 4 | DISCUSSION

Using tracheostomy as a prototype, we developed a framework for decision-making about LST for CMC (Figure 1). The model that emerged from our data is more complex than and includes elements not found in SDM (Table 3).

SDM involves choosing among two or more options deemed medically reasonable and supported by data.<sup>7</sup> Although SDM has been recommended for pediatric tracheostomy decision-making,<sup>19</sup> it is not sufficient for several reasons. There are no reasonable options besides tracheostomy that enable a child to live. In addition, CMC have rare health conditions that often lack data about prognosis, and evidence for the effects of LST on the trajectory of these health conditions is limited. Moreover, system-level factors, such as availability of home health nursing, are important for HCPs' recommendations and caregivers' preferences for/against tracheostomy. We found the CDM model<sup>18</sup> to better capture these nuances of tracheostomy decision-making for CMC.

The alternate process we propose, is an advancement of the SDM model and accounts for caregiver expertise and HCP-level factors in the decision-making process. Most caregivers in our study felt that the tracheostomy decision was theirs to make.<sup>12</sup> With the

changing healthcare system and ready availability of health information on the internet (especially social media), caregivers now have greater knowledge to make health decisions than ever before. HCPs are no longer the sole source of information. Caregivers also have equal or greater knowledge than HCPs about their child's health and quality of life.<sup>20</sup> By systematically incorporating caregivers' knowledge, our model allows for the creation of a “shared mind” between caregivers and HCPs.<sup>18</sup> Our process also accounts for HCP factors in decision-making, and helps address challenges described previously such as managing uncertainty<sup>18</sup> and need for teamwork between the many HCPs involved in the decision-making process.<sup>19</sup>

We outline a clinically relevant CDM process (Figure 2) for HCPs to use when guiding families about tracheostomy for CMC. The CDM process starts with HCP obtaining greater understanding about the child's health condition, effect of tracheostomy, and about the child and family from a variety of sources (including caregivers). One of the gaps in the decision-making process is the lack of consideration and preparation by HCP about home care of children with tracheostomy.<sup>10,21</sup> CDM addresses this gap by soliciting information about child's home environment and the resources available to support caregivers. CDM also engages caregivers as an expert in the child's care. Caregivers see decision-making to be their role, but often feel unheard and undervalued<sup>20</sup>; CDM could potentially address this gap. CDM could also reduce the discordance seen between caregivers and HCP regarding decisions about LST,<sup>22</sup> and enhance caregivers' understanding and decision-making participation.

Similar to SDM, good communication by HCPs is integral to CDM. Many studies have described the importance of honest, compassionate, accurate and timely HCP communication with caregivers.<sup>12,23</sup> CDM also includes deliberate collaboration between HCPs. Many different HCPs with varied roles are involved in the decision-making process for CMC.<sup>12,19,23</sup> Our study showed that HCPs had difficulty recommending tracheostomy for children with poor perceived functioning or quality of life. This is similar to that of the perspective of clinicians reported in prior studies.<sup>22,24</sup> In another paper from this project, we reported variability among HCPs about tracheostomy recommendation to be a barrier to the decision-making process.<sup>12</sup> HCPs attribute this variability to the lack of medical literature about outcomes of pediatric tracheostomy.<sup>12,24</sup> Caregivers and physicians alike value collaboration between HCPs as a way to reduce variability in care.<sup>12,23,24</sup> Collaboration in CDM is achieved by systematically engaging all stakeholders and implementing a unified action plan. Because CDM accounts for HCP-level factors (i.e., fears, concerns, values etc.), it is possible that this model could reduce moral distress experienced by HCPs when making recommendations about tracheostomy without having a strong evidence-base for its benefits.

Our study has limitations. This is a single-institution study; caregiver and HCP experiences may be different elsewhere. Data collection was completed 6 years ago. Certain caregiver- and HCP-level factors might be different now. However, caregiver and HCP perspectives described in our study are consistent with studies conducted more recently and in other geographic areas.<sup>23,24</sup> Hence,



we believe that the CDM process described can be used elsewhere. Although our study does not include information from caregivers who chose not to pursue tracheostomy or directly from children, the themes discussed here were also seen in a study that included caregivers who did not pursue long-term ventilation for their children.<sup>23</sup> The CDM model and process should be studied further, focusing on these subgroups and the perspectives of children. These limitations notwithstanding, CDM could be a useful model for clinicians guiding families about tracheostomy for CMC. The applicability of CDM for decision-making about other LSTs needs further exploration.

## AUTHOR CONTRIBUTIONS

**Savithri Nageswaran:** conceptualization/design, methodology, investigation, supervision/oversight, funding acquisition, data curation, formal analysis, resources, and drafting the initial manuscript. **William Gower:** methodology, investigation, formal analysis, and review or editing of the manuscript. **Shannon Golden:** methodology, investigation, data curation, formal analysis, and review or editing of the manuscript. **Nancy King:** conceptualization/design, methodology, investigation, formal analysis, and review or editing of the manuscript.

## ACKNOWLEDGMENTS

We thank Ms. Aura Rosado MSW, Care Coordinator, Pediatric Enhanced Care Program for recruiting and interviewing Spanish-speaking caregivers in the study. This work is supported by National Institute of Nursing Research (R21NR013272, PI: Nageswaran).

## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

Summarized qualitative data supporting results of this study are available from the corresponding author upon reasonable request.

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pediatric home ventilation programs. *Ann Am Thorac Soc*. 2017;14(10):1539-1547.

#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Nageswaran S, Gower WA, Golden SL, King NMP. Collaborative decision-making: A framework for decision-making about life-sustaining treatments in children with medical complexity. *Pediatric Pulmonology*. 2022;57:3094-3103. doi:[10.1002/ppul.26140](https://doi.org/10.1002/ppul.26140)