**Appendix A. Consolidated Reporting of Qualitative Studies (COREQ) Checklist1**

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| **Domain 1: Research team and reflexivity** |
| Personal Characteristics |
| 1. Interviewer/facilitator
 | Shannon Golden, MA conducted the English interviews and focus groups. Aura Rosado, MSW conducted the Spanish interviews. |
| 1. Credentials
 | Savithri Nageswaran and W. Adam Gower are physicians; Shannon Golden is a medical anthropologist; Nancy King is a bioethicist; and Aura Rosado is a social worker. |
| 1. Occupation
 | Savithri Nageswaran, W. Adam Gower, and Nancy King are faculty in academic medical schools. Shannon Golden is a senior research associate. Aura Rosado is the care coordinator of the palliative care/complex care program. |
| 1. Gender
 | Savithri Nageswaran, Nancy King, Shannon Golden, and Aura Rosado are cis-females. W. Adam Gower is cis-male. |
| 1. Experience and training
 | Savithri Nageswaran has experience conducting qualitative studies. Shannon Golden has extensive experience in qualitative data collection, analysis, and reporting. W. Adam Gower and Nancy King have subject matter expertise. Aura Rosado has prior experience interviewing Spanish-speaking caregivers of children with medical complexity. |
| Relationship with participants |
| 1. Relationship established
 | Shannon Golden has conducted interviews of 3 caregivers of 3 children for a previous qualitative study. Aura Rosado provided care coordination services for 3 of the 6 children whose caregivers she interviewed. Shannon Golden did not have relationships with participants of the focus groups. |
| 1. Participant knowledge of the interviewer and focus group facilitator
 | The research was explained to the participants prior to the interview and focus group as part of the informed consent process.  |
| 1. Interviewer and focus group facilitator characteristic
 | Interviewer and focus group facilitator characteristics are described above. |
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| **Domain 2: Study Design** |
| Theoretical Framework |
| 1. Methodological orientation and Theory
 | The paper has a phenomenological orientation and an analysis process consistent with thematic content analysis.2 |
| Participant selection |
| 1. Sampling
 | All children were identified as having had a tracheostomy from 3 sources: 1) i2b2 query of hospital administrative database, 2) a list maintained by the otorhinolaryngology department, and 3) children referred to the palliative care/ complex care program. Only children meeting the inclusion criteria were included in the final sample.Healthcare providers were identified by their specialties within the pediatric hospital.  |
| 1. Method of approach
 | Potential participants for interviews were recruited by telephone contact. Focus group participants were recruited by email or in-person.  |
| 1. Sample size
 | 56 caregivers of 41 children participated in the interviews. 33 healthcare providers participated in 5 focus groups. |
| 1. Non-participation
 | 8 caregivers of 8 children with medical complexity did not participate. Of these, 6 refused to be interviewed for various reasons, and 2 cancelled scheduled interviews.We did not calculate non-participation for focus groups. |
| Setting |  |
| 1. Setting of data collection
 | Of the 41 interviews, 33 were conducted in the homes of children, 5 in the hospital; 1 in parent’s office and 2 in restaurants.All focus groups were held at conference rooms in the children’s hospital. |
| 1. Presence of non-participants
 | Children were present in most interviews, but did not participate in the interviews.A notetaker assisted with all focus groups. |
| 1. Description of sample
 | Sample characteristics are described in Table 1. |
| Data Collection |  |
| 1. Interview/ focus group guide
 | An interview guide for caregivers (see Appendix B) was developed based on a conceptual framework of clinician-provider interaction in the tracheostomy decision-making process. The guide was revised as interviews progressed. The guide was not pilot tested. Focus group guides for clinicians (Appendices C and D) were developed based on a conceptual framework drawn from caregiver interviews as it relates to clinical interaction during the tracheostomy decision-making process.  |
| 1. Repeat interviews
 | Repeat interviews were not carried out. |
| 1. Audio/visual recording
 | Interviews and focus groups were audio-recorded |
| 1. Field notes
 | Field notes were completed by the interviewers/ focus group facilitator after the interviews/ focus groups. |
| 1. Duration
 | The median length of interviews was 66 minutes (range: 35 to 175 minutes). The median length of focus groups was 68 minutes (range 59 to 92 minutes). |
| 1. Data saturation
 | For interviews, the list of potential eligible participants was exhausted, resulting in 41 completed interviews. Because there was variability in children’s’ diagnoses, ages, survival, decannulation, and socioeconomic status, we wanted to be sure to get the most comprehensive picture of the pediatric tracheostomy experience possible. We reached data saturation on most themes prior to the final few interviews, but completed those interviews for the sake of exhausting our list. For Spanish-speaking subjects, their data was very similar to English-speakers, and very few in number. We feel they align thematically with the English-speaking data, contributing to data saturation. For clinicians, our goal was not to saturate focus group data, however to help us better understand the caregiver experience using clinical perspectives – triangulation. We achieved this. |
| 1. Transcripts returned
 | Transcripts were not returned to participants for comment and/or correction |
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| **Domain 3: Analysis and findings** |
| Data analysis |
| 1. Number of data coders
 | Four data coders coded the data independently (2 per transcript) and reconciled differences in coding through discussion.  |
| 1. Description of the coding tree
 | A codebook was developed inductively and revised for accuracy as coding progressed. The final interview codebook had 19 codes; one code had 3 sub-codes and another had 4 sub-codes. For focus groups, a separate codebook was developed. It had 12 codes. |
| 1. Derivation of themes
 | All themes were derived from the data.  |
| 1. Software
 | ATLAS.ti v.7 was used for data management and analysis |
| 1. Participant checking
 | Participants did not provide feedback on the ﬁndings |
| Reporting |  |
| 1. Quotations presented
 | Participant quotations are presented throughout the manuscript text. Each quotation is identified by participant number. |
| 1. Data and findings consistent
 | Data that emerged related to this topic are summarized as themes.  |
| 1. Clarity of major themes
 | Three major themes related to this support needs and resources used by parents/caregivers are presented in the Results. |
| 1. Clarity of minor themes
 | Subthemes are described within the major themes. |

1. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.

2. Green J, Thorogood N. *Qualitative methods for health research.* 4th ed. Los Angeles: SAGE; 2018.

**Appendix B. Caregiver Interview Questions**

1. Thinking back, tell me about the first time someone talked to you about having this procedure for your child.
2. Who was involved in the initial discussion, and where did the discussion take place?

*Probe:* How did you feel about the physical setting?

1. What was your reaction to this discussion?

*Probe:* What were your initial concerns about having this procedure for your child (what was important to you at that time)?

 *Probe:* How did the doctors address these concerns?

 *Probe:* How was the subject matter communicated to you?

 *Probe:* What could have gone better?

1. What other options were you presented? By whom?

 *Probe:* What did you think of those options?

1. Throughout the decision-making experience, who played a key role? Why?

 *Probe*: Who referred you to them?

1. At the time, who, if anyone, did you avoid discussing this with? Why?

 *Probe*: Who were the people who did not support your decision?

1. The people who advised you – how did they impact your decision?
2. What other resources did you use to help you make the decision? (By resources, I mean things like the internet, books or reading material, other parents)

 *Probe*: How did you find them? (did you seek them or did they come to you?)

*Probe:* Who recommended them?

1. What was the most helpful thing or who was the most helpful person to you in making this decision? Why?
2. What was the least helpful thing or who was the least helpful person to you in making this decision? Why?
3. Now that you know what you do about tracheostomies, how do you feel about the information and advice you received at the time of the decision?

 *Probe*: Did you receive enough information & support? If not, why?

1. How do you feel now about your decision to give your child a tracheostomy?
2. What are your hopes for your child since the trach was placed?

 *Probe:* What does the future look like for him/her?

1. In your opinion, how can doctors and healthcare professionals best serve families in situations like yours? Please explain.

 *Probe*: communication style

1. What do you know now that nobody told you at the time of the decision?

 *Probe:* What did they tell you to prepare you – what did they say would happen?

1. How did any of your beliefs – your view of the world – play a role in making this decision?

 *Probe:* In other words, how did your beliefs help you decide?

 *Probe:* What – if any – were the spiritual beliefs you considered?

1. If you have a pastor, in what ways did he/she help you with the decision making process?
2. Did you talk about your spiritual beliefs with your child’s doctors or nurses when you made this decision – why or why not?
3. Baptist sometimes offers families the services of a chaplain, or pastoral care. Did you use this service? Why/why not?

 If yes, tell me how that came about and how it worked out.

1. How can pastors best serve families in situations like yours?
2. How would you advise a family who was faced with a decision to give their child a tracheostomy?
3. Is there anything else you would like to tell me about your decision to give your child a tracheostomy?

**Appendix C. Non-Physician Focus Group Guide**

The goal of today’s discussion is to improve the decision-making process related to tracheostomies in children. We would like to discuss the barriers and facilitators to communication and decision-making for both families and providers.

First please help me understand the process:

1. When a patient needs a tracheostomy, how do discussions begin?

*Probe:* Who do you engage?

 *Probe:* When do you approach families?

 *Probe:* How do you resolve disagreements among the team?

1. What is your role when it comes to discussing tracheostomy-related decisions with parents?
2. What difficulties do you/others face in discussing trach options with families?

*Probe:* What gets in the way of good decision-making?

*Probe*: What gets in the way of good communication?

1. How are your discussions different for children with reversible conditions and those with neurological impairment?

**Scenario #1.** Now I am going to share with you a parent experience. Then I will ask for your reaction*. Doctors may not like to present things prematurely, but it does help. If I would have known that she would be on a ventilator, I would have been able to prepare myself. They should have told me, “Ok, babies with pulmonary hypertension may need a ventilator.” I didn’t get that, I just got “She has pulmonary hypertension,” and that’s it. I should have had more information (D06)*

1. What comments do you have about those statements?
2. Sometimes parents tell us the volume of information they receive about their children’s conditions is overwhelming. How can information be presented without overwhelming parents?

*Probe:* What are some strategies to help parents handle or process new information?

*Probe:* How much information to provide?

**Scenario #2.** Here is another parent experience. *When we decided to place the trach, the doctor told us, “It’s not the best decision. It’s better that you let her go because she is not going to live long regardless.” They had already talked to us about five times throughout the week. And I said, “It’s not an easy decision, it’s very difficult. You don’t know how we feel.” I was angry because they were pressuring us. I am very grateful to doctors and the job they do, but I think they should be more sensitive when it comes to speaking with the family, and find better ways to say things. (D39)*

1. What is your response to that parent’s comments?
2. What are ways providers can best communicate the benefits and harms of a tracheostomy?

 *Probe:* Is it more helpful to prepare a family for the best outcome or prepare them for the worst? Why?

1. How often do doctors listen to families’ concerns?

*Probe:* How do we improve this?

**Scenario #3.** One parent made a suggestion. She says: *Sometimes doctors don’t understand where the parents are coming from. The nurses are the ones who know these parents, and they’re there all the time so maybe doctors should ask the nurses stuff like, “How do they like their information?” and “What have you noticed about them?” (D06)*

1. What do you think about her comments?

*Probe:* Is this possible or practical? Why or why not?

1. How should nurses and other providers be engaged by doctors to help families with decision making

**Scenario #4.** I have one more parent experience to share. *Dr. Jones wasn’t trying to be insensitive, but to him, this was a very simple thing. I remember his comment was, “Well, it’s only a 15 minute procedure and it’s not a big deal." And then we were like, “No, no, no. It’s a fifteen minute procedure, but then we are going to have to change our entire lifestyle.” And it was like that concept went completely over his head. I mean he just had absolutely no understanding of how that might affect a family. (D16)*

1. How do you feel about what this parent said?
2. How can doctors better understand what life is like for a family with a child with a tracheostomy?

That’s all I have today. Are there any final comments you would like to share before we conclude?

We have discussed a lot today. Thank you so much for your time and your willingness to be part of this group. Before you leave, please be sure to sign for your gift cards.

**Appendix D. Physician Focus Group Guide**

The goal of today’s discussion is to improve the decision-making process related to tracheostomies in children. We would like to discuss the barriers and facilitators to communication and decision-making for both families and providers.

First please help me understand the process:

1. When a patient needs a tracheostomy, how do discussions begin?

*Probe:* When do you approach families?

*Probe:* Who (healthcare providers) do you engage?

*Probe:* How do you resolve disagreements among the team?

1. What difficulties do you face in discussing trach options with families?

*Probe*: What gets in the way of good decision-making?

*Probe*: What gets in the way of good communication?

1. How are your discussions different for children with reversible conditions and those with neurological impairment?

**Scenario #1.** Now I am going to share with you a parent experience. Then I will ask for your reaction. *Doctors may not like to present things prematurely, but it does help. If I would have known that she would be on a ventilator, I would have been able to prepare myself. They should have told me, “Ok, babies with pulmonary hypertension may need a ventilator.” I didn’t get that, I just got “She has pulmonary hypertension,” and that’s it. I should have had more information. (D06)*

1. What comments do you have about those statements?

*Probe:* What are some strategies to help parents handle or process new information?

*Probe:* How much information to provide?

 *Probe:* How can information be presented without overwhelming parents?

**Scenario #2.** Here is what another parent reported: *When we decided to place the trach, the doctor told us, “It’s not the best decision. It’s better that you let her go because she is not going to live long regardless.” They had already talked to us about five times throughout the week. And I said, “It’s not an easy decision, it’s very difficult. You don’t know how we feel.” I was angry because they were pressuring us. I am very grateful to doctors and the job they do, but I think they should be more sensitive when it comes to speaking with the family, and find better ways to say things. (D39)*

1. What is your response to that parent’s comments?
2. Is it more helpful to prepare a family for the best outcome or prepare them for the worst? Why?
3. What are the ethical and moral questions you wrestle with when discussing tracheostomies for children with neurological impairment?

**Scenario #3.** Here are some more comments from parents: *All of the doctors were good. They each had their own perspective and how they wanted to do things. Day shift doctors may be thinking one direction of what to do, and then night shift comes on and has a whole different view. That’s why it’s frustrating. Because you’ve got one doctor who wants to do it this way, and one wanting it that way. Some of them wouldn’t listen, some of them did. (D18)*

1. How to you feel about what this parent said?
2. How do we reduce variability among doctors?
3. What are the roles, primary team versus specialists?

We had 2 focus groups with non-physician PICU/NICU staff. They told us that the NICU has weekly meetings to discuss long term patients, called CBES. They reported that these CBES are helpful to create a good plan of care and reduce variability.

1. Why or why isn’t this something you think would be helpful in other places such as PICU?

[OK TO SKIP Q12] One nurse also explained that in adult care, there are strict guidelines about when and how long to trach a patient. She said for pediatric care, there aren’t any guidelines.

1. Why is that?

*Probe:* What is needed or what would be helpful in terms of guidelines?

**Scenario #4.**  I have one more parent experience to share. *Sometimes doctors don’t understand where the parents are coming from. The nurses are the ones who know these parents, and they’re there all the time so maybe doctors should ask the nurses stuff like, “How do they like their information?” and “What have you noticed about them?” (D06)*

1. How do you feel about what this parent said?
2. How can nurses and other providers be engaged by physicians to help families with decision making?

Nurses told us that providers sometimes meet as a group to resolve their differences before meeting with the family about tracheostomy decision to avoid giving conflicting viewpoints.

1. What are your thoughts about such meetings?
2. That’s all I have today. Are there any final comments you would like to share before we conclude?

We have discussed a lot today. Thank you so much for your time and your willingness to be part of this group. Before you leave, please be sure to sign for your gift cards.