Data Supplement

Decisions for long-term ventilation for children: perspectives of family members

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Interview Questions for Key Informants
Families Presently Facing Decision

Hi, my name is ____________________ of Columbia University, and I am involved . . . [if applicable] . . . with Dr. Jeff Edwards in a study to learn more about the needs of people when they are making decisions about <u>putting their child on an artificial breathing machine (or ventilator) for a long period of time in order to help them live longer</u> . . . [if applicable] <u>and having their child attached to the ventilator through a tube inserted through the neck (or a “trach” / tracheostomy)</u>.

I asked to talk to you because your child is in the Pediatric ICU on a breathing machine.

The information you share will help us to create better educational materials for families facing this decision. I would like to record our conversation today and make some notes. The recording will be typed out. We will also get some medical information about your child from their medical record. All of the names and anything that can identify you or your child will be removed from the recordings and notes. Also, I am not part of the medical team (ie, the doctors, nurses, and other professionals who are helping to care for your child and give you advice or information). I will not share what you say with the team. Only researchers on the project will be able to review the recordings or any notes. The recordings and notes will be destroyed at the end of the study.

Please take a moment and look over the consent form. It states that:
--everything you say and all information we gather about your child will be confidential;
--your participation is voluntary, you may refuse to answer any question, and you may stop the interview at any time.

Please sign the form to indicate you agree to participate. [Have participant(s) sign consent form or obtain verbal assent to participate if form already signed]

Thank you.

I will now start recording. [Start recording. Questions are in **bold.**]

This interview should last no more than 90 minutes. I have several questions to ask, but I would like you to do most of the talking and give as much detail as you can with your answers.

What has the medical team told you about your child’s medical condition?

How long has your child been on a breathing machine/ventilator?

How long do you or the medical team think your child might need to be on the breathing machine/ventilator?

Have you been discussing what happens if your child continues to need the breathing machine/ventilator for a long time with the medical team?

[If invasive ventilation via tracheostomy is being considered:]
Sometimes when a child needs to be on the breathing machine for a long time, the only way to safely do this and allow the child to leave the ICU is to put a breathing tube into the child's neck (ie, a "trach" or tracheostomy) and attaching the ventilator to the child using this tube. This is an operation that can only be done with your permission because it can be a burden to the child and family because having a child with a trach attached to a ventilator can require a lot of specialized care and attention.

[If noninvasive ventilation (ie, no trach) is being considered:]
Sometimes when a child needs to be on the breathing machine for a long time but otherwise does not need the ICU, the child leaves the hospital on the BiPAP or CPAP ventilator. This can be a burden to the child and family because a child on a ventilator can require a lot of specialized care and attention.

Thinking about children who need the ventilator for a long time . . . [if applicable] and a tracheostomy . . ., **what do you see as the options for children and families in this situation?**

Have you been asked to make / told you may have to make a decision about your child getting a "trach" and staying on the ventilator for a long time?
[If just noninvasive ventilation (ie, no trach) is being considered:] **Have you been asked to make / told you may have to make a decision about your child staying on the ventilator for a long time?**

Before this hospitalization, did any one ever tell you that your child might need to be on a ventilator for a long time in the future and/or you might have to make a decision about the ventilator for your child?

What do you think will happen if your child / a child is kept on the ventilator and leaves the hospital on a ventilator?

From your perspective, what are the pros and cons for your child / a child of being on the ventilator for a long time?

What are the pros and cons for your family of your child / a family of a child being on the ventilator for a long time?

While it is not an easy choice, when a child has a very serious condition or a condition that will shorten his/her life, families, together with their doctors, sometimes decide

[*Choose applicable one*]
[if only invasive ventilation is being considered:]

- ☐ not to have a "trach" / breathing tube put in their neck and not to keep them on a breathing machine

[if both noninvasive and invasive ventilation are being considered:]
  ☐ not to have a "trach" / breathing tube put in their neck
[if only noninvasive ventilation is being considered:]
  ☐ not to keep them on a breathing machine

In these cases, families and doctors choose to
[*Choose any applicable*]
☐ try to support the child's breathing as best they can without a "trach"
☐ focus more on the child's comfort
☐ not try to extend the child's life

Can you understand why some families might consider or make this choice?
[Possible probes of reasons why]

If no, why not?
[Possible probes of reasons why not]

Has the medical team discussed the option of not keeping your child on the breathing machine/ventilator for a long time?

What do you think would happen if your child / a child was not kept on the ventilator . . . [if applicable] **and/or does not get a "trach"?**

This situation would be difficult for any child and family, and can be a difficult decision and options to talk about.

How does it feel to have to (possibly) make decisions about the ventilator . . . [if applicable] **and "trach" . . . for your child?**

What do you think families facing these decisions and options might be concerned about?

What are you concerned about?

What are your hopes?

Children are so important in a parent's life, and parents always want to do the best for them. **How do you go about doing the best you can for your child when he/she is sick?**

People often have a process or way of making a big decision, what is yours?

What information would you like to have to make decisions about your child being on a ventilator for a long time . . . [if applicable] **and having a "trach"?**
What questions do you need answered?

Is there anything you might like to know from families who already have gone through this decision?

What sorts of helpful things have the medical team done or said as you think about your child needing the ventilator . . . [if applicable] **and "trach"?**

What sorts of <u>un</u>helpful things have the medical team done or said as you think about your child needing the ventilator . . . [if applicable] **and "trach"?**

Is there anyone else who you look to for information, guidance, or support in facing these decisions?
[*Probe if there is anyone actively involved in making the decision--eg, child (depending on age/capacity), spouse/significant other, family member, friend, other health care provider(s)*]

Is there anything getting in the way of making a decision?

If so, what would help you to overcome these things?

Can you think of anything else that would be helpful to you or other families who are in this situation?

I have no more planned questions. **But is there anything else you would like to add?**

Lastly, there are two very short questionnaires about you and your family demographics and about making this decision that we would ask you to complete. You may do them now or I can leave them with you and pick them up later.

Thank you very much for allowing me to interview you. We are very hopeful that the information that you and others share can be used to help future families faced with this decision.

Interview Questions for Key Informants
Families Who Previously Faced Decision

Hi, my name is _____________________ of Columbia University, and I am involved . . . [if applicable] with Dr. Jeff Edwards . . . in a study to learn more about the needs of people when they are making decisions about putting their child on an artificial breathing machine (or ventilator) for a long period of time in order to help them live longer . . . [if applicable] and having their child attached to the ventilator through a tube inserted through the neck (or a “trach” / tracheostomy).

I asked to talk to you because your child is on a breathing machine.

The information you share will help us to create better educational materials for families facing this decision. I would like to record our conversation today and make some notes. The recording will be typed out. We will also get some medical information about your child from their medical record. All of the names and anything that can identify you or your child will be removed from the recordings and notes. Also, I am not part of the medical team. I will not share what you say with others. Only researchers on the project will be able to review the recordings or any notes. The recordings and notes will be destroyed at the end of the study.

Please take a moment and look over the consent form. It states that:
--everything you say and all information we gather about your child will be confidential;
--your participation is voluntary, you may refuse to answer any question, and you may stop the interview at any time.

Please sign the form to indicate you agree to participate. [Have participant(s) sign consent form or obtain verbal assent to participate if form already signed]

Thank you.

I will now start recording. [Start recording. Questions are in **bold.**]

This interview should last no more than 90 minutes. I have several questions to ask, but I would like you to do most of the talking and give as much detail as you can with your answers.

Tell me about your child’s medical condition.

How long was your child been on a breathing machine/ventilator?

Tell me about what led to your child needing the ventilator.

Before that hospitalization (ie, the one when your child left the hospital on a ventilator), did anyone ever tell you that your child might need to be on a ventilator for a long time in the future and/or you might have to make a decision about the ventilator for your child?

Did the medical team present putting your child on a ventilator for a long time as a decision for you to make?

What were the options presented to you?

[If interviewee does not say anything about not putting on vent as option, ask:]
Did the medical team discuss the option of not keeping your child on the breathing machine/ventilator for a long time?

What did you think would have happen if your child was not kept on the ventilator . . . [if applicable] **and did not get a "trach"?**

While it is not an easy choice, when a child has a very serious condition or a condition that will shorten his/her life, families, together with their doctors, sometimes decide <u>not</u> to keep them on a breathing machine. In these cases, families and doctors choose to focus more on the child's comfort and not try to extend the child's life with these machines.

Can you understand why some families might consider or make this choice?
[Possible probes of reasons why]

If no, why not?
[Possible probes of reasons why]

How did it feel to have to make decisions about the ventilator . . . [if applicable] **and "tracheostomy" . . . for your child?**

What were you concerned about?

What were your hopes?

Thinking back to when your child first left the hospital on a ventilator, what did you expect to happen to your child?
To your family?

From your perspective now, what are the pros and cons for your child using the ventilator?

What are the pros and cons of your child having been on the ventilator for your family?

People often have a process or way of making a big decision, what was yours for this decision?

When you were making your decision, what questions did you have about a child being on a ventilator for a long time . . . [if applicable] **and having a "trach"?**

What information did you receive from the medical team?

What information would you have liked to have had to make a decision about your child being on a ventilator for a long time . . . [if applicable] **and having a "trach"?**

If you had this information beforehand, how would it have helped?

What sorts of helpful things did the medical team do or say as you made your decision about your child needing the ventilator . . . [if applicable] **and "trach"?**

What sorts of <u>un</u>helpful things did the medical team do or say as you made your decision your child needing the ventilator . . . [if applicable] **and "trach"?**

What supports or guidance did you have when making your decision?
[May need to explain "supports"--family, friends, psychological, spiritual, etc.]

What sort of supports or guidance would you have liked to have had to make your decision?

Was there anything that got in the way of you making a decision?

If so, what would have helped you to overcome these things?

Is there anything you would like to share with families who are facing this decision?

Can you think of anything else that would be helpful to families who are in this situation?

I have no more planned questions. **But is there anything else you would like to add?**

Lastly, there is a short questionnaire about you and your family demographics that we would ask you to complete.

Thank you very much for allowing me to interview you. We are very hopeful that the information that you and others share can be used to help future families faced with this decision.