

Online Data Supplement

Decisions around Long-term Ventilation for Children: Perspectives of Directors of Pediatric Home Ventilation Programs

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Online Supplement 1: Interview guide

Interview Questions for Key Informants
Directors of H MV Programs (Group 3 Version)

Hello, my name is Jeff Edwards of Columbia University, and I am conducting a study to learn more about the needs of people when they are making decisions about putting their child with chronic respiratory failure and a life-limiting condition on invasive or noninvasive chronic ventilation in order to help them live longer.

I asked to talk to you because you are a director of a Pediatric Home Mechanical Ventilation Program.

The information you share will help us to create materials to augment shared decision-making for families and clinicians. I would like to record our conversation today and make some notes. The recording will be typed out. All of the names and anything that can identify you will be removed from the recordings and notes. Only researchers on the project will be able to review the recordings or any notes, which will be destroyed at the end of the study.

You have already read and signed the consent form. But I will restate that:

--everything you say and all information we gather about you will be confidential;

--your participation is voluntary, you may refuse to answer any question, and you may stop the interview at any time.

Thank you for your willingness to participate.

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

This interview should last no more than 60 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.

Could you please state your professional roles?

How are you involved in the care of children on chronic ventilation?

How many years have you been involved in the care of children on chronic ventilation?

How are you involved in families' decision-making around initiating their child on chronic ventilation?

What information do you believe families need to make informed decisions about tracheostomy and chronic invasive ventilation for their child with chronic respiratory failure and a life-limiting condition?

What information do you believe families need to make informed decisions about chronic noninvasive ventilation for their child with chronic respiratory failure and a life-limiting condition?

From your perspective, what are the pros and cons of being on chronic ventilation for the child?

[Probe for benefits of chronic ventilation]

[Probe for burdens of chronic ventilation]

What are the pros and cons of a child being on chronic ventilation for the family?

[Probe for benefits of chronic ventilation]

[Probe for burdens of chronic ventilation]

Have you ever had the experience of a family member saying they wish they knew “X” before they made their decision around chronic ventilation?

If so, what were the things they wished they knew and how do you think it would have helped?

If you believe sensitive topics concerning the potential consequences of the complex care associated with chronic ventilation (eg, emotional/psychological/familial/financial stress, social isolation, occasional need to place child in a chronic care facility) should be discussed with families, how do you suggest broaching them?

What do you think are the major hopes of families in these situations?

What do you think families are most concerned about when considering the option of initiating chronic invasive ventilation?

What do you think families are most concerned about when considering the option of initiating chronic noninvasive ventilation?

What do you think families are most concerned about when considering the option of NOT initiating chronic ventilation?

How do you encourage families to participate in shared decision-making around chronic ventilation?
By “shared decision-making, I means a collaborative process between patient, family, and clinician that seeks consensus on the option that is most consistent with patient/family values.

What are some things that help families in their decision making around chronic ventilation?

What are some things that hinder families in their decision making around chronic ventilation?

What do you believe could be done to lessen these hindrances?

What are some things that help professional caregivers inform and counsel families facing decisions around chronic ventilation?

What are some things that hinder professional caregivers inform and counsel families facing decisions around chronic ventilation?

What do you believe could be done to lessen these hindrances?

When should discussions around chronic ventilation be started for children at risk for chronic respiratory failure?

Do you believe that there are scenarios that initiating chronic invasive or noninvasive ventilation is an obligatory choice for a child's decision-makers?

In your opinion, are there any types of patients or family scenarios who are not good candidates for chronic ventilation?

If so, what do you do when these situations arise?

What do you do if/when you have an opinion about what is the best option for a child?

Can you think of anything else that would be helpful to families or clinicians who are facing this decision?

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

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.

Online Supplement 2: Code definitions

Information	
Information	What information is/should be conveyed. Does not include items coded elsewhere (eg, burdens) that would be discussed with families
Burdens on families	Eg, Caregiving, Psychosocial Can include adaptations of to these burdens
Upsides	Eg, Minimizes recurring hospitalizations
Downsides for child	Of being on vent (not death), esp for the child. Eg, risks of technology and dependence
Worries NOS	Eg, fear of making a mistake
Process of decision making	
Medical candidacy	Whether child is good candidate LTV. How do other medical problems interact with decision of whether to initiate do LTV
Psychosocial candidacy	Non-medical determinants of whether child and family are good candidates
Setting stage for good decisions/Delivery style	What healthcare providers should do in all situations to facilitate shared decision-making Includes: How should decision making be approached. How it should happen. Importance of having the right people involved in the decision. How should information be conveyed
Family hopes	Includes unrealistic hopes (“Miracles”); Medical research.
Barriers to informed decision making	Includes: Psychological context in which the parent is making the decision, like they do not accept the underlying diagnosis/prognosis/risks involved. Misinformation
What experts wish for	What interviewees said would help patients, families and/or the decision making process
Decision NOT to trach/vent or use NIV	How is/should the option of forgoing LTV be addressed Includes “lines drawn in the sand” (“we are going to do NIV but not going to trach even if child worsens”)
Shared DM Paternalism/disagreement	What do about personal opinion that might differ from families Also issues of dissent between or among families/providers; Reservations of providers
Supports - Information Resources	Websites, support groups, other families Includes down-sides of information available through the internet, etc.
Supports - Psychosocial, emotional	Emotional supports - Family, health care providers, community, support groups
Supports - Physical, home care	Supports with medical/physical care of the child. Includes nursing, options for chronic care/respite/rehab facilities
Special populations	
Profoundly impaired child	How does the decision-making process differ if the child is profoundly cognitively impaired. Issues pertinent to them
Cognitively intact child	How does the decision-making process differ if the child/adolescent is cognitively intact Issues pertinent to cognitively intact child or young adult.
Children on NIV	Issues pertinent to children on NIV, esp those using it 24/7