THE JOURNAL OF PEDIATRICS • www.jpeds.com

Family Experiences Deciding For and Against Pediatric Home Ventilation

Renee D. Boss, MD, MHS[1,2], Carrie M. Henderson, MD[3,4], Jessica C. Raisanen, MSPH[2], Nicholas A. Jabre, MD, MS[1,2], Kelly Shipman, MS[5], and Benjamin S. Wilfond, MD[5,6]

Objective To understand what considerations drive family decisions for, and against, pediatric home ventilation.

Study design Qualitative interviews with parents of children who faced a decision about home ventilation in the previous 5 years at 3 geographically dispersed institutions.

Results In total, 38 families (42 parents) were interviewed; 20 families opted for pediatric home ventilation, and 18 families opted against. Approximately one-quarter of children had isolated chronic lung disease; the remainder had medical complexity that was expected to remain static or decline. Parent perspectives about home ventilation generally reflected whether the child was early, or later, in their disease trajectory. Early on, parents often interpreted prognostic uncertainty as hope and saw home ventilation as a tool permitting time for improvement. For families of children later in their disease course, often already with home technology and home nursing, home ventilation held less possibility for meaningful improvement. Nearly all families experienced the decision as very emotionally distressing. Reflecting back, most families described feeling satisfied with whatever decision they made.

Conclusions The 2 principal groups of families in our cohort—those with children whose respiratory insufficiency might improve, and those with children facing chronic decline—warrant targeted counseling approaches about initiating home ventilation. The distressing nature of this decision should be anticipated and family supports reinforced. *(J Pediatr 2021;229:223-31)*.

More than 1 million children in the US rely on home medical equipment, with a growing number of children using home ventilation; this population will increase related to greater availability of home medical technology and more inclusive views of disability.[1-5] Children who are candidates for home medical technology have often faced life-threatening conditions with sequelae that preclude independent eating or breathing.[6,7] Home ventilation is a particularly intensive technology for a child and family, requiring around-the-clock monitoring and robust home health services. Data suggest that home ventilation can have wide-ranging impact on the entire family, including siblings,[8] in the form of parent job loss,[9] financial struggles,[10] depression,[11] and burnout.[12,13] Variable access to and quality of pediatric home healthcare often compounds these burdens.[14]

Decisions to initiate pediatric home ventilation often occur during a prolonged hospitalization. Lengthy hospitalizations are mentally, physically, and emotionally exhausting and can undermine family understanding about achievable goals of care.[15] In addition, because home ventilation is uncommon, few families have relevant previous life experiences. These potential gaps in family understanding elevate the need for high-quality clinician counseling.

Clinicians who guide these decisions should have an understanding of what other families have needed in similar scenarios. Yet few studies have explored how families make decisions about pediatric home ventilation.[16-18] Extant reports are largely single center and focused primarily, if not exclusively, on families who opted for tracheostomy/home ventilation for their child.[16,17,19] These data begin our understanding of how choices about pediatric home ventilation are approached, particularly for parents who do choose tracheostomy/home ventilation.[20] Important questions remain about what drives decisions among families whose children have chronic respiratory insufficiency, including families who choose not to pursue tracheostomy/home mechanical ventilation and families from diverse institutional and geographic contexts.

The goal of this multicenter study of families who chose for, or against, tracheostomy and home mechanical ventilation was to broaden the understanding of how families experience choices about home ventilation. This information is key to determining how clinician counseling can improve decision-making for families.

Methods

This qualitative interview study recruited English-speaking families whose children had received care from academic medical centers in Maryland, Washington, and Mississippi, states chosen for their geographic diversity. Eligible parents had faced decisions about home ventilation within the previous 5 years;

From the [1]Johns Hopkins School of Medicine, Baltimore, MD; [2]Johns Hopkins Berman Institute of Bioethics, Baltimore, MD; [3]University of Mississippi Medical Center, Jackson, MS; [4]Center for Bioethics and Medical Humanities, Jackson, MS; [5]Treuman Katz Center for Pediatric Bioethics, Seattle Children's Hospital and Research Institute, Seattle, WA; and [6]Department of Pediatrics, University of Washington School of Medicine, Seattle, WA

Supported by the National Palliative Care Research Center (Principal Investigator: R.B.). The authors declare no conflicts of interest.

0022-3476/$ - see front matter. © 2020 Elsevier Inc. All rights reserved.

https://doi.org/10.1016/j.jpeds.2020.10.014

adoptive, foster, and grandparents were eligible if they were primary caretakers and decision-makers for the child. Purposive sampling was used to balance inclusion of families from across the regions who had made different decisions about home ventilation; for the purposes of this study, home ventilation was defined as invasive mechanical ventilation delivered via tracheostomy. Identification of eligible families was determined via discussions between the site principal investigator and local intensive care, palliative care, and pulmonary clinicians. Sites required slightly different methods for contacting eligible families: 2 sites required phone/in-person contact by treating clinicians; 1 site approved contact via letter from the research team. Recruitment stopped once thematic saturation was reached.[21] We did not explicitly recruit >1 parent per child, but if both parents wished to be interviewed together, their data were analyzed as a "family." We followed the guidelines of Meert et al in recruiting bereaved families.[22]

A semi-structured interview guide was devised to include domains suggested by previous work of the authors and others, including context and course of child's respiratory insufficiency, treatment options, communication with clinicians, parent concerns, goals and values, and child/family experience after the decision about home ventilation (**Appendix**; available at www.jpeds.com).[18,23,24] The rationale for these domains was to capture parent's longitudinal experience of learning about, making decisions about, and coming to terms with choices about home ventilation. To account for content limitations or question bias that might derive from our research team's perspectives, the interview guide was critically reviewed by our study advisory council (parents of children who had faced decisions about home ventilation; clinicians in pulmonology, palliative care, complex care, intensive care; case managers; home healthcare providers; decision-aid researchers). Audio-recorded telephone interviews with families lasted 30-120 minutes; at each site, interviews were conducted by 1 or 2 of the authors, who were all trained/experienced in qualitative interviewing. Transcriptions were returned to participants for member-checking. Institutional review board approval was obtained at all sites and consent obtained. Participants received a $50 gift card.

Content analysis was initially performed on transcripts using Dedoose software (developed by academics from UCLA, Los Angeles, California) for data management and coding.[21,25] Content related to the family experience of their child's respiratory insufficiency, the treatment options considered, the family's recall of decision-making, and their current feelings about the decision were extracted. Two authors individually assigned codes to a subset of the targeted transcripts, then jointly reviewed codes with the larger group to create a final codebook. One author with experience in complex medical decision-making coded remaining transcripts; questions or uncertainties about specific pieces of content were resolved iteratively with the larger group at weekly meetings. Related codes were grouped into thematic categories, which were then sorted and organized through repeated discussion with the larger group and via consultation with our study advisory council. These were then consolidated into overarching themes that summarize and represent the data.

Results

Between December 2018 and October 2019, 38 families (42 parents) were interviewed (**Table I**). Four families actively declined to participate, and 4 passively declined (eg, voiced willingness to hear more about study, then did not respond to our calls/messages). Just less than one-quarter of participants' children had lung disease of prematurity. The remaining children had multisystem medical complexity, about one-half with rare conditions (both named and unnamed syndromes); some of these conditions were expected to remain static and others expected to decline. Seven of 38 children had died before the interview.

Family characteristics varied across the 3 regions: nearly all non-white, non-married, and rural parents came from 2 sites; nearly all parents with a high school education or less came from one site, although income and employment ranges were similar across sites. Because of small subgroup size, we did not analyze by region. Families came from diverse racial, ethnic, educational, and economic backgrounds. Those who opted for home ventilation more commonly had high school education or less and ≤$50 000 annual household income.

Three themes evolved from family interviews: (1) hearing the option of home ventilation; (2) family experience of decision-making process; and (3) reflecting back on the decision.

Hearing the Option of Home Ventilation

Families typically first heard about potential home ventilation during their child's intensive care unit stay, from intensivist, or subspecialist physicians (**Table II**). Several children had been transferred to a larger hospital for respiratory insufficiency, but tracheostomy and/or home ventilation was inconsistently discussed before transfer. Among children with rare diagnoses, families commonly learned about home ventilation via condition-specific social media connections.

About one-half of all parents reported discussing >1 treatment option for their child (eg, home ventilation with tracheostomy, noninvasive home ventilation, airway surgery, indefinite hospitalization). Few parents (n = 5) recall being offered the option of compassionate extubation. Among families who remember hearing treatment options, one-half chose home ventilation.

Among parents who remember home ventilation as the "only option" for their child, a few felt that doctors had presented it as simply "the next step." Most, however, described home ventilation as the only option because they never considered death to be an option and/or because no clinician

Table I. Participant characteristics at time of decision about home ventilation

Characteristics	All families N = 38	Families who opted for home ventilation N = 21	Families who opted against home ventilation N = 17
Geography			
Maryland	13	8	5
Mississippi	12	6	6
Washington	13	7	6
Community			
Urban	9	3	6
Suburban	16	11	5
Rural	13	7	6
Education			
Some high school	2	2	0
High school	5	5	0
Associates/undergraduate	9	5	4
degree	16	7	9
Graduate degree	6	2	4
Annual household income			
<$20 000	5	5	0
$20 000-50 000	8	5	3
$50 000-100 000	8	5	3
$100 000-140 000	7	5	2
>$140 000	8	1	7
Unknown	2	0	2
Employment			
Work full-time	21	10	11
Work part-time	4	2	2
Do not work outside home	11	8	3
Other	2	1	1
Race/ethnicity			
White/European American	27	16	11
Black/African American	6	2	4
Native American	1	1	0
Asian	3	1	2
Other	1	1	0
Marital status			
Married/living with partner	31	16	15
Divorced/separated	3	3	0
Single	2	0	2
Other	2	2	0
Sex*			
Male	7	4	3
Female	35	20	15
Number of other children in home			
None	7	3	4
1	12	8	4
2+	19	10	9
Housing status			
Own	29	16	13
Rent	7	4	3
Other	2	1	1
Religious/spiritual			
Yes	32	17	15
No	6	4	2

Children	All children N = 38	Children who received home ventilation	Children who did not receive home ventilation
Timing of initial respiratory failure			
At birth	15	10	5
In first year of life	10	6	4
1-5 y	8	2	6
>5 y	5	3	2
Number of hospitalizations before onset of respiratory failure			
None, occurred during birth admission	16	11	5
None	2	2	0
≤3	8	2	6
≥4	12	6	6
Reason for potential home ventilation			
Lung disease of prematurity alone	8	6	2
Medical complexity	30	17	14
Vital status at time of interview			
Alive	31	20	11
Deceased	7	1	6
Health insurance			
Medicaid	14	7	7
Private	9	4	5
Combination	15	10	5

(*continued*)

Table I. Continued

*Parent sex n = 42 reflects all individual participating parents from the 38 families.

raised the possibility. Some of these children had chronic lung disease, with potential for eventual clinical improvement. Among families who understood home ventilation as the only option, three-quarters chose home ventilation.

Most parents felt they had received too little information about the long-term experience of home ventilation for their child and family. The information they received was generally focused on parent training and home nursing. Parents wanted to know more about what day-to-day life would be like for their family, including impact on siblings, jobs, travel, school. About one-half of parents understood their child would need home ventilation indefinitely; about one-quarter believed it would be for a few years, and the remainder reported the timing was "uncertain" or don't remember discussing it. Some parents (n = 4) reported no conversations about long-term outcomes before making the decision.

Parent Experience of Decision-Making Process

Nearly all parents experienced intense, distressing emotions surrounding the home ventilation decision, often because it signaled a loss of hope that the child's respiratory insufficiency would be "fixed" (Table III). This required families to revisit their values regarding quality of life. Grief (about their child's prognosis, their family's upheaval, etc) and fear (of being responsible for a potentially fatal home ventilator malfunction, of reducing their child's ability to communicate, etc) were common. "Getting home" was a passion for many; families commonly were in the hospital for months, and their lives were in chaos. The immediate possibility of going home often drove decisions; some (n = 6) recall never thinking about the particulars of future life at home while making the decision.

Table II. Hearing the option of tracheostomy/home ventilation

Subthemes	Illustrative quotations
Introduction to possibility of tracheostomy/HV	When introduced *"I feel like nobody at [the referring hospital] wanted to be 100% honest with me about what was really going on…Nobody told me a tracheostomy may be what he really needs.…on day 2 of being at [university hospital]the [neonatologist] mentioned in passing, "We're trying to avoid the trach."…I didn't even realize this was an option on the table at this point."* (family 1, site 1, yes HV) *"The trach was brought up before this last hospital visit, by his pediatrician a few months ago."* (family 1, site 2, no HV*)* *"Palliative and her [ICU] team decided that she needed a trach, which wasn't discussed with me. I was just told to meet with the ENT.…I immediately refused [the trach]. I was caught off guard."* (family 4, site 3, no HV)
	Source of info *"Nurses would have whisperings about [tracheostomy]…they would come to me…"* (parent 2, site 2, no HV) *"She's had home nursing all these years. I've always heard them say negative things about trachs. That they were dirty and nasty. They didn't want to deal with trachs."* (family 3, site 1, yes HV) "*We had to push for everything. I was part of the Facebook group. The moms there were giving me suggestions of what to ask for."* (family 7, site 3, yes HV)
The treatment options that families remember	Multiple options *"The other option would be he would have to stay on the ventilator or stay on high flow longer for extended hospitalization…We wanted to see how far he could go, how far he could step down before doing the trach."* (family 5, site 1, no HV) *"We discussed the trach and we discussed the noninvasive ventilator, which is what we decided to go with…because we didn't think [the trach] would help her lifeline…because of her neurologic conditions."* (family 3, site 2, no HV) *"There have been different interventions mentioned…nebulizer…cough assist…BiPAP…then we've talked some about the trach."* (family 6, site 2, no HV)
	Only option *"The doctor came in and said, "We want to do a tracheostomy on your child.""* (family 10, site 1, yes HV) *"I remember not having a lot of options and getting very upset about that."* "(family 1, site 3, yes HV) *"It was kind of like either she went on the ventilator or we would have lost her. Basically wasn't much option"* (family 2, site 1, yes HV)
Focus of information about tracheostomy/HV	Short term *"I was very excited at the idea of just getting home. I just wanted to do whatever it took to get home." (SYa04)* *"…learning all the emergency steps that need to happen, in case something happens [with the ventilator]…"* (family 2, site 1, yes HV)
	Long term *"I wasn't too worried about the day-to-day considerations of bringing her home on the ventilator. I didn't have much concept of what it would be like."* (family 7, site 3, yes HV) *"There wasn't a lot of discussions. It was just, 'You can do this, and you will have nurses,…Nobody really explained to us that when she was given a trach and put on a ventilator, that this would not change the outcome of her life."* (family 4, site 2, yes HV)

BiPAP, bilevel positive airway pressure; *ENT*, ear, nose, throat; *HV*, home ventilation; *ICU*, intensive care unit.

Families had different reactions to discussions with clinicians about the decision. Some valued early and recurrent discussions; others avoided detailed discussions until necessary. Some were overwhelmed by conferences with multiple clinicians; others relished hearing the range of clinician perspectives. Most wanted more information; some struggled with information overload, especially when delivered over just 1 or 2 conversations.

Families also sought perspectives from outside the core medical team (palliative care, social work, child life specialists, etc). More than one-half of children had palliative care involvement, equally distributed between families who opted for or against home ventilation. Palliative care supports were overwhelmingly appreciated. Among families whose child already had home nursing, parents reported that homecare nurses typically expressed negative views about initiating home ventilation. Although most parents identified as religious/spiritual, just one conferred with their religious leader. Some communicated via social media with other parents experienced with home ventilation; few met other families in person. Talking with other families was of great value; those who had were always appreciative, and most wished they'd had the opportunity.

A minority of parents recalled painful conflicts with their partners or family members about whether it was "right" to extend the child's life with home ventilation. A few reported separating from their spouse/partner because of conflict related to the decision. Some described conflict with clinicians or awareness of explicit or implicit conflict between clinicians about whether to proceed with home ventilation.

Just as parents recall variable treatment options, they also recall variable participation in the decision-making process. About one-half remember home ventilation presented as a decision that clinicians and parents would make together. Among remaining families, most felt like it was a decision that the parents made alone; several felt like it was chosen by the medical team.

Table III. Family experience of decision-making process

Subthemes	Illustrative quotations
Intense emotions accompanied the decision	Lost hope *"Each decision is another permanent piece, it's like you are climbing a ladder and it's just one step closer...to death...like I'm admitting that she's regressed to the point where she needs another intervention"* (family 6, site 2, no HV)
	Grief *"Do you know when somebody goes through the 7 stages when someone dies? I probably went through all of those with the decision to get a trach."* (family 2, site 2, yes HV)
	Fear *"How do you make a decision like that for somebody's life? What if I'm making the wrong decision? What if something happens in the OR?...I have severe anxiety now because of everything that we've gone through."* (family 1, site 1, yes HV)
Discussions with core medical team	Few vs many clinicians *"It was really good to have a continuity doctor to go through it all. Every step of the way, she was with us. It made talking about it, it made accepting things, easier."* (family 1, site 3, yes HV) *"We had a couple of care conferences with different doctors from the ICU team. There was at least one doctor there from the bioethics team. She was such a great advocate for doing what was best for [our child]."* (family 2, site 3, yes HV)
	Minimal vs extensive information *"It was a lot of information…the brain dump was overwhelming."* (family 4, site 3, yes HV) *"We don't like to be told what to do. We like to be given reasons why and weigh the evidence. We liked hearing from both sides about the pros and cons and in the end coming to a decision based on that evidence"* (family 5, site 1, no HV)
Discussions with others	Other team members *"[The palliative care team] really helped in facilitating a different way of thinking about [my child]and helping the doctors see that [my child] is more of a hospice situation, not that we think he is going to die anytime soon. But a hospice situation because our values are different. It's not just a straight-up safety first."* (family 5, site 1, no HV)
Conflict about the decision	With partner *"I tried to turn [the trach] down, but his mother would not let me turn it down…I just started crying every time I heard it."* (family 8, site 1, yes HV)
	With close family/friends *"We had a few comments about how cruel it would be to keep someone alive on the ventilator…it was a disagreement because…I wanted her at home, and I saw her still in there, and still interacting with us."* (family 4, site 2, yes HV)
	With/within medical team *"We took [the trach/home ventilation] option off the table for [the doctors], because if you leave it up to them…everybody has a solution for a temporary fix…Why would we put this nonverbal child with this deadly diagnosis through this…?"* (family 2, site 1, no HV)
Weighing the options	Child quality of life *"Knowing that she had a life-limiting diagnosis, we did not want the bulk of her life to be in the hospital…That was part of our motivation to move ahead with the trach and vent.…It was going to require a lot of extra work but it was going to be able to be at home and make memories with her, which was more important to us than living without mechanical ventilation."* (family 2, site 3, yes HV) *"We could have gotten the trach a couple of years ago, and his quality of life would have diminished even more. It would just be prolonging the obvious…"* (family 2, site 1, no HV)
	Child experience of treatment option "*It became more of us advocating to get her off of intubation orally…we were very much ready to get her onto something that would allow her to be a child."* (family 1, site 3, yes HV) *"The biggest thing I asked doctors about was his vocalization. He's not verbal, but he sure does vocalize what he wants and needs and feels. That was one of the biggest conversations we had, how does [tracheostomy/home ventilation] look like from a vocalization perspective?"* (family 4, site 1, no HV)

ICU, intensive care unit; *OR*, operating room.

When asked how they weighed the decision, parent experiences largely differed depending on how long their child had been ill. Families whose children were early in their disease trajectory were often hopeful about improvement or recovery, and saw home ventilation as permitting time to wait for improvement. For families of children who had been living with their condition for a longer period, often already with home technology and home nursing, home ventilation held less hope for meaningful improvement. Families of older children more often declined home ventilation.

Reflecting Back on the Decision

At the time of the interview, most parents reported feeling satisfied with their decision, whether for or against home ventilation (Table IV). When asked directly, few families reported regret; regrets were spontaneously raised in other points of the interviews by about one-quarter of families, usually that the home ventilation decision was made too hastily or too slowly.

The most common support that parents wished they'd had when making the decision was access to other families experienced with home ventilation. Parents also wanted more

Table IV. Reflecting back on the decision about tracheostomy/HV

Subthemes	Illustrative quotations
Satisfaction with decision	*"Even if I had to do it again today, no matter how hard it was, no matter the heart aching, no matter how bad I missed my child, I can honest to God say I wouldn't change a thing about the choices I made for him…"* (family 1, site 3, no HV) *"It was the greatest decision I could have made for my son. Because of the vent, my son is still here."* (family 9, site 1, yes HV*)*
Regret about decision	*"Only that I didn't push…to get her trach sooner…she spent more time living in the hospital than at home."* (family 1, site 3, yes HV) *"I think I'd have not tried to rush it… he was 6 months old and I just wanted him home."* (family 1, site 3, No HV) *"Had I known that [the tracheostomy/HV] would just prolong her life, not actually help her live…"* (family 4, site 2, yes HV)
Supports we wish we'd had	Connection with other families *"No offense to any medical team whatsoever, you all are the experts, but you all don't have the home experience. Just being able to talk to the families about something as simple as bath time and going through a grocery store. 'How do you do it? Give me tips and pointers." Having the family experience is the greatest tool you can have."* (family 5, site 2, yes HV) *"We can hear from doctors and nurses all day long, but if you hear from someone who's actually gone through it and experiencing the same things as you, it means a lot more."* (family 6, site 3, yes HV) Emotional support during decision *"Emotional support…when you are in a meeting and it is pretty much just you and the doctor…you need someone there for your emotion."* (family 1, site 2, yes HV) More information about life with tracheostomy/HV *"All of the medical stuff, insurance stuff, DME stuff, the everyday stuff you are not aware of. It's that everyday living that wasn't explained."* (family 2, site 2, yes HV) *"The financial part…the loss of income…I wish we had known how long it would take for social security to kick in. It's taken a very long time."* (family 4, site 3, yes HV) *"I wish I would have known that nursing is not reliable…"* (family 8, site 1, yes HV)
Advice for other families facing the decision	Take time to make the decision *"There's a shock that happens, that takes some time for the layers to peel off for the parent to understand what [trach] would do to not only their child's life, but their own lives and relatives, family friends, everything, It's not easy"* (family 3, site 1, no HV) *"If you are not ready, don't make the decision."* (family 9, site 1, yes HV) Explore all available options *"Make sure you go through all the possibilities before you decide."* (family 4, site 1, yes HV*)* Talk with other families *"Have a conversation with somebody who's going through it. I expect everybody who's facing the decision is having the medical conversation. I think that, 'What is my life going to look like?' conversation with somebody who's actually living it would be helpful."* (family 4, site 1, no HV) Make decision out of love *"I think parents really need to be that force that discern the whole wellbeing of their child. Doctors are going to mostly look at signs and symptoms and numbers. You know your kid best."* (family 5, site 3, no HV) *"Make your decision that is best for your family and do not feel guilty about it. Come to a decision and be at peace with it…Most importantly make a decision out of love and thoughtfulness."* (family 2, site 1, no HV)

DME, durable medical equipment.

emotional support and more information about what they and their child would experience with home ventilation, eg, related to travel, finances, and daily routines.

The most consistent advice that parents wanted to offer other parents was to take time to consider all available treatment choices, and to talk with other families who have been through this. Most who had opted for home ventilation wanted parents to know they could learn to manage home ventilation, even if it seemed scary. Both families who chose for, and against, home ventilation offered, "Make the decision out of love" (family 4, site 3, no home ventilation).

Discussion

In this cohort of families who have faced decisions about pediatric home ventilation at multiple different institutions, we identified a range of individual family experiences. Nevertheless, there were several common experiences with decision-making that suggest how to reinforce clinician counseling: parent priorities often track with where a child is in their illness trajectory, palliative care engagement was welcome regardless of the family's decision, and parent emotions surrounding the decision can be overwhelming without explicit supports (**Table V**).

Family experiences often differed depending on the degree of certainty about the child's overall prognosis. Early in a child's disease trajectory there was often prognostic uncertainty, and parents tended to be hopeful about the potential for decannulation, neurodevelopment, and survival. In our cohort, such children were typically infants with rare diagnoses, and their parent's choices to pursue home ventilation were commonly motivated by strong desire to bring a very long hospitalization to a close and allow the child, and parents, to come home. That urgency had a tendency to eclipse parents' worries about what life after discharge would be like. In contrast, even though many older children in our cohort also had rare diseases, their families had already experienced

Table V. Communication strategies to guide family decisions about HV

Communication strategies	Example language
For all families	
Repeatedly reassess when, how, how much parents want to know about home ventilation	"Is it still helpful to discuss this with the larger team once a week, or do you prefer to talk with one of us every day?"
Consider involving palliative care, regardless of child prognosis or parent perspective	"I'd like to have the palliative care team meet with you, because they have a lot of experience helping families think through challenging decisions…."
Encourage family to take time to gather and process information	"It might be tempting to decide quickly, because you want to get home soon. But parents who have also faced these decisions recommend taking the time to fully explore what home ventilation might mean for your whole family."
Tailored to early vs later in child's medical course	
Share the range of treatment options, including compassionate extubation if relevant	Early: "Some families in this situation choose tracheostomy and home ventilation, hoping their child will grow out of their breathing problems. Other families want their child to go to a long-term care facility until they are big enough for home BiPAP. Still other families feel that their child is suffering too much, and make a choice to remove the breathing tube and allow the child to pass away." Later: "Some families in this situation choose tracheostomy and home ventilation, because their child has already been doing okay with technology and home nursing. Other families decline home ventilation, because they feel that medications and technology have not improved their child's disease or helped their child to live a better life."
Share predictions about how child may/may not be liberated from home ventilation	Early: "No one knows for sure if he will come off the home ventilator, but there is reason to hope that he will within a few years." Later: "Once we begin home ventilation, he is likely to need it for the rest of his life."
Offer practical information about life with home ventilation	Early: "I'd like to help you hear from families who have also faced this decision. It might help for you to learn more about what it is like for babies to learn to move around, eat, and communicate with home ventilation. And also how this might affect your other children, your job, and your day-to-day life." Later: "I'd like to help you hear from families who have also faced this decision. It might help for you to learn more about what it is like for children to learn to communicate, go to school, and socialize with home ventilation. And also how this might affect your other children, your job, and your day-to-day life."
Anticipate parent emotions—grief, fear, desperation to end hospitalization	Early: "Most families in this situation are still shocked that their baby has never been able to leave the hospital. It is really scary to imagine that your baby is so sick that they cannot even breathe on their own. It is normal to have these feelings. Tell me more about what you have been feeling." Later: "Most families in this situation are sad to have reached a point that they have feared, where their child cannot breathe on their own. And are scared that their child's disease is only going to get worse. It is normal to have these feelings. Tell me more about what you are feeling."

recurrent hospitalizations, other home medical technologies, and home nursing. These children's chronic or declining trajectories were central to their families' decisions against home ventilation; families weighed this new technology against their existing experiences, and assessed that it would neither be temporary nor would improve their child's quality of life.

The 2 principal groups of families—those with children whose respiratory insufficiency might improve, and those with children facing chronic decline—warrant targeted counseling approaches. As demonstrated in the Kids Inpatient Database, infants are the most likely of all children to receive tracheostomies.[26] We found that families of infants were largely naïve to the impact that chronic illness and home technology could have on the entire family—yet these elements were central to decisions made by families of older, medically complex children who already lived that life. When counseling families of infants/children early in their disease course, therefore, discussions should be enriched with information about what day-to-day home life will be like and what parenting a child with chronic illness will be like. We should encourage these parents that a yearning to bring a prolonged hospitalization to an end should not undermine the time necessary to explore what home ventilation could mean for them and their child after discharge. Families of older children who already have medical technology also need time to consider how home ventilation can change their experiences. Importantly, they need clinicians to share the difficult news that home ventilation is not likely to reverse their child's clinical decline.

The decisions about home ventilation made by individual families within these 2 groups were not uniform. Some parents of infants were clear from the time of diagnosis that home ventilation did not offer an acceptable quality of life, and some parents of older children sought every possibility to extend their child's life and believed home ventilation could improve their child's current quality of life. A desire for the child to be home with the family was a common motivation for both groups: for some, home ventilation was the best way to achieve that goal, for others the goal was achieved by declining home ventilation.

Children in this cohort had variable etiologies for their respiratory insufficiency. We do not know which treatment options were relevant for each child, eg, indefinite hospitalization in an acute or long-term care setting vs noninvasive ventilation vs compassionate extubation, nor do we know which options were actually presented, only what parents remember hearing. A substantial number of families recall no option besides home ventilation, and believing that there were no other options was associated with greater likelihood of moving forward with home ventilation. Given that many children in the cohort had life-limiting conditions, it is unclear why more families do not remember discussing compassionate extubation. Perhaps clinicians raised the option, but it was too painful for parents to process. Perhaps the option was not offered. That some families in our cohort regretted choosing home ventilation highlights the importance of creating space for parents to consider alternatives. This requires clinicians to be clear about which options are/are not relevant for a child—including compassionate extubation—perhaps with help from ethics consultants or frameworks.[20,27] It also requires clinician skill in talking about the possibility of a child's death. Palliative care involvement should be engaged to support clinicians and families in these conversations.[19,28,29] Palliative care was appreciated by many families in our cohort, equally among those who opted for, and against, home ventilation.

Nearly every parent recalled intense emotional distress around the home ventilation decision. Despite their child's underlying condition, many parents had hoped that they would improve; discussing home ventilation directly threatened that hope. Explicitly or implicitly, discussions about home ventilation required families to (re)define their goals and values and to consider the threshold beyond which they might decline life-sustaining therapies. In their work on "regoaling," Hill et al highlight how several parent vulnerabilities can impede re-evaluation of goals as a child's illness evolves.[30] Williams et al suggest that having to consider home ventilation is associated with adverse inpatient family outcomes.[31] To make decisions about home ventilation, parents need more robust emotional support, perhaps via incorporation of screening tools to triage predictable parent needs or incorporation of cognitive-behavioral or problem-solving therapies.[32] Shaw et al have demonstrated that a 6-session cognitive–behavioral intervention for mothers of hospitalized premature infants substantially reduced depression, anxiety, and trauma both in the short term and at 6-month follow up.[33,34] Similar approaches could be studied among parents of children with chronic respiratory insufficiency.

Illuminating the variable yet distinct experiences of families was possible in our study due to intentional recruitment of those who had made diverse choices about home ventilation. Most existing studies of pediatric home ventilation have been limited to families who opted for that technology; this information only partially prepares clinicians to counsel families who may or may not chose home ventilation. The analysis by Hebert et al of recorded family meetings demonstrated that, although both risks and benefits of tracheostomy are presented to families, physicians spent more time discussing the benefits than the burdens of the intervention.[35] This unbalanced approach to counseling may reflect the unbalanced evidence base that currently characterizes relevant literature. Parents in our cohort who chose home ventilation, like similar parents in other studies,[16] were nearly all satisfied with their decision and perceived many benefits of home ventilation. But importantly, nearly all parents in our cohort who chose against home ventilation were also satisfied with their decision. This suggest the need for broader inclusion criteria to build the evidence base about family experience.

We recognize several limitations to our study. Our data regarding home ventilation decisions are based on parent report: we do not know what was actually said or done. Clearly, however, parent experience is central to successful decision-making. Although our overall cohort size was robust for qualitative analysis, subgroup size precludes more than hypothesis generation. For example, we found that families who opted for home ventilation were of lower income and education. Should this association be replicated, it aligns with other data suggesting that patients with socioeconomic vulnerability may choose more aggressive medical interventions.[36] Limited subgroup size also prevented analysis by family factors such as race; minority race is associated with greater mortality related to home ventilation, and work is needed to understand if, or how, this impacts parent counseling.[37] Sample size also precluded subgroup analysis of those families who opted against home ventilation, comparing children who did or did not receive a period of noninvasive ventilation at home; these choices deserve further exploration. Finally, due to study resources we were unable to include non–English-speaking families, and the potential impact of language barriers on decision-making is an obvious target for future study design.

The number of children facing decisions about home ventilation is expected to increase. Families find these decisions very distressing, and these data offer suggestions to help: allow parents to direct how difficult information is discussed, be clear about how home ventilation will or will not impact prognosis, present all available options—including compassionate extubation, when appropriate—and permit time for parents to really process the decision. All parents wanted to hear from other parents about what life might look like if the family chose for or against home ventilation. To support this goal, our study group has created the Family Reflections Web site (www.family-reflections.com) to offer balanced information from different families who made different choices about home ventilation. We continue to evaluate how to better help families facing the option of home ventilation. ■

We have tremendous gratitude to the parents who were interviewed for this study and shared generously of their personal experiences. We also thank the following individuals who strengthened study design, participant recruitment, data analysis, or manuscript review: Dr Laura Sterni, Dr Alison Miles, Ms Karen Babcock, Dr Sharon McGrath-Morrow, Dr Michael Collaco, Dr Angelle Klar, Dr Andrew Hayslett, Dr Christian Paine, Dr Oscar Rodriguez, Dr Abigail Rosenberg, Dr Aaron Wightman, Dr Jori Bogetz, Ms Meg Barracato, Dr Pamela Donohue, Dr Gretchen Schwarze, Prof Karen Rothenberg, Ms Ann Schrooten, and Ms Jenny Shaffer.

Submitted for publication Jun 30, 2020; last revision received Oct 6, 2020; accepted Oct 9, 2020.

Data Statement

Data sharing statement available at www.jpeds.com.

References

1. Feudtner C, Villareale NL, Morray B, Sharp V, Hays RM, Neff JM. Technology-dependency among patients discharged from a children's hospital: a retrospective cohort study. BMC Pediatr 2005;5:8.
2. Cox CE, Carson SS, Holmes GM, Howard A, Carey TS. Increase in tracheostomy for prolonged mechanical ventilation in North Carolina, 1993-2002. Crit Care Med 2004;32:2219-26.
3. Amin R, Sayal P, Syed F, Chaves A, Moraes TJ, MacLusky I. Pediatric long-term home mechanical ventilation: twenty years of follow-up from one Canadian center. Pediatr Pulmonol 2014;49:816-24.
4. Fine-Goulden MR, Ray S, Brierley J. Decision making in long-term ventilation for children. Lancet Respir Med 2015;3:745-6.
5. Graham RJ, Fleegler EW, Robinson WM. Chronic ventilator need in the community: a 2005 pediatric census of Massachusetts. Pediatrics 2007;119:e1280-7.
6. Wilson-Costello D, Friedman H, Minich N, Fanaroff AA, Hack M. Improved survival rates with increased neurodevelopmental disability for extremely low birth weight infants in the 1990s. Pediatrics 2005;115:997-1003.
7. Burns SM, Earven S, Fisher C, Lewis R, Merrell P, Schubart JR, et al. Implementation of an institutional program to improve clinical and financial outcomes of mechanically ventilated patients: one-year outcomes and lessons learned. Crit Care Med 2003;31:2752-63.
8. Heaton J, Noyes J, Sloper P, Shah R. Families' experiences of caring for technology-dependent children: a temporal perspective. Health Soc Care Community 2005;13:441-50.
9. Thomson J, Shah SS, Simmons JM, Sauers-Ford HS, Brunswick S, Hall D, et al. Financial and social hardships in families of children with medical complexity. J Pediatr 2016;172:187-93.e1.
10. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. Arch Pediatr Adolesc Med 2011;165:1020-6.
11. Kuster PA, Badr LK. Mental health of mothers caring for ventilator-assisted children at home. Issues Ment Health Nurs 2006;27:817-35.
12. Peckham A, Spalding K, Watkins J, Bruce-Barrett C, Grasic M, Williams AP. Caring for caregivers of high-needs children. Healthc Q 2014;17:30-5.
13. Donohue PK, Williams EP, Wright-Sexton L, Boss RD. "It's relentless": providers' experience of pediatric chronic critical illness. J Palliat Med 2018;21:940-6.
14. Edwards JD, Houtrow AJ, Lucas AR, Miller RL, Keens TG, Panitch HB, et al. Children and young adults who received tracheostomies or were initiated on long-term ventilation in PICUs. Pediatr Crit Care Med 2016;17:e324-34.
15. Nelson JE, Mercado AF, Camhi SL, Tandon N, Wallenstein S, August GI, et al. Communication about chronic critical illness. Arch Intern Med 2007;167:2509-15.
16. Nageswaran S, Golden SL, Gower WA, King NMP. Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. J Pediatr 2018;203:354-60.e1.
17. October TW, Jones AH, Greenlick Michals H, Hebert LM, Jiang J, Wang J. Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. Pediatr Crit Care Med 2020;21:136-42.
18. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. Pediatrics 2006;117:e48-60.
19. Edwards JD, Panitch HB, Nelson JE, Miller RL, Morris MC. Decisions for long-term ventilation for children. perspectives of family members. Ann Am Thorac Soc 2020;17:72-80.
20. Glass KC, Carnevale FA. Decisional challenges for children requiring assisted ventilation at home. HEC Forum 2006;18:207-21.
21. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15:1277-88.
22. Meert KL, Eggly S, Dean JM, Pollack M, Zimmerman J, Anand KJ, et al. Ethical and logistical considerations of multicenter parental bereavement research. J Palliat Med 2008;11:444-50.
23. Callans KM, Bleiler C, Flanagan J, Carroll DL. The transitional experience of family caring for their child with a tracheostomy. J Pediatr Nurs 2016;31:397-403.
24. Boss RD, Hutton N, Sulpar LJ, West AM, Donohue PK. Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns. Pediatrics 2008;122:583-9.
25. Dedoose Version 8.3.17, web application for managing, analyzing, and presenting qualitative and mixed method research data (2020). Los Angeles (CA): SocioCultural Research Consultants, LLC. www.dedoose.com. Accessed September 30, 2020.
26. Muller RG, Mamidala MP, Smith SH, Smith A, Sheyn A. Incidence, epidemiology, and outcomes of pediatric tracheostomy in the United States from 2000 to 2012. Otolaryngol Head Neck Surg 2019;160:332-8.
27. Ray S, Brierley J, Bush A, Fraser J, Halley G, Harrop EJ, et al. Towards developing an ethical framework for decision making in long-term ventilation in children. Arch Dis Child 2018;103:1080-4.
28. Porta NFM. Palliative care approaches to neonates with chronic respiratory failure. Semin Perinatol 2017;41:124-7.
29. Henderson CM, Wilfond BS, Boss RD. Bringing social context into the conversation about pediatric long-term ventilation. Hosp Pediatr 2018, hpeds.2016-0168.
30. Hill DL, Miller V, Walter JK, Carroll KW, Morrison WE, Munson DA, et al. Regoaling: a conceptual model of how parents of children with serious illness change medical care goals. BMC Palliat Care 2014;13:9.
31. Williams CSP, Grossoehme DH, Forbes ML, Friebert S. Provider consensus on candidate protective and risk factors for adverse psychosocial outcomes following discharge from a PICU: a modified Delphi study. Pediatr Crit Care Med 2020;21:e1-7.
32. Benscoter D, Borschuk A, Hart C, Voos K. Preparing families to care for ventilated infants at home. Semin Fetal Neonatal Med 2019;24:101042.
33. Shaw RJ, St John N, Lilo EA, Jo B, Benitz W, Stevenson DK, et al. Prevention of traumatic stress in mothers with preterm infants: a randomized controlled trial. Pediatrics 2013;132:e886-94.
34. Shaw RJ, St John N, Lilo E, Jo B, Benitz W, Stevenson DK, et al. Prevention of traumatic stress in mothers of preterms: 6-month outcomes. Pediatrics 2014;134:e481-8.
35. Hebert LM, Watson AC, Madrigal V, October TW. Discussing benefits and risks of tracheostomy: what physicians actually say. Pediatr Crit Care Med 2017;18:e592-7.
36. Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, et al. Socioeconomic position and use of healthcare in the last year of life: a systematic review and meta-analysis. PLoS Med 2019;16:e1002782.
37. Cramer JD, Graboyes EM, Brenner MJ. Mortality associated with tracheostomy complications in the United States: 2007-2016. Laryngoscope 2019;129:619-26.