

# Decisions around Long-term Ventilation for Children

## Perspectives of Directors of Pediatric Home Ventilation Programs

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### Abstract

**Rationale:** The decision of whether to initiate or forgo long-term ventilation (LTV) for children with life-limiting conditions can be complex and impactful. Providers are responsible for helping families to understand the consequences of their options and guiding them through shared decision-making, but little has been published on how to do this.

**Objectives:** To assess how directors of pediatric home ventilation programs facilitate shared decision-making with families facing decisions of whether to initiate or forgo LTV for their children with life-limiting conditions. In addition, to assess directors' perspectives on these families' decisional needs.

**Methods:** Purposeful recruiting of directors/codirectors of pediatric home ventilation programs at children's hospitals was used. We performed semistructured interviews using an open-ended interview guide developed *de novo* to assess their approach to informed, shared decision-making around LTV and their perspectives on these decisions. Qualitative data analysis was conducted using a thematic approach based on framework analysis in which thematic saturation was achieved.

**Results:** A sample of 15 experienced physician directors across North America was interviewed. All (15/15) inform families of the potential benefits and burdens/risks of LTV for the child and of the option to forgo LTV. All stress to families the physical, emotional, and social impact of caring for a child using LTV on the family; 12 directors also highlight the financial impact. All recommend that decision-making around LTV should be interdisciplinary, initiated early, and not rushed; nine described their approach as guided by the family's goals for the child and their family. All recommend that providers be transparent, candid, active listeners, and supportive. All directors believe that the family's decision should be respected, but vary in the extent to which they recommend an option to families. They described barriers to decision-making that stem from families, providers, and other sources.

**Conclusions:** As providers who follow children using LTV, directors of pediatric home ventilation programs have perspectives regarding the decisional needs of these families and how to meet them that can help inform and shape the practices of other providers who assist families facing this decision.

**Keywords:** respiration; artificial; child; decision-making

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Each year, hundreds of infants and children develop chronic respiratory failure (CRF) with on-going dependence on mechanical ventilation, either invasive, via a tracheostomy, or noninvasive (1, 2). Many of these children have other severe conditions that result in functional limitations, medical fragility, and shortened life expectancies (3–5). Although long-term ventilation (LTV) can support respiratory function, it does not mitigate these other conditions. LTV does, however, demand constant, complex domiciliary care. For children with life-limiting conditions, families may ethically forgo LTV if it is considered ineffective or overly burdensome, even when the child is not overtly dying (6). Consequently, the decision of whether LTV is the best option for children with CRF and their families can be difficult and impactful.

As part of shared decision-making, providers (e.g., physicians, nurses, respiratory therapists, social workers, etc.) should help families understand the complex consequences of initiating or forgoing LTV and align the families' decision with their goals and values. However, providers inconsistently present relevant information (7, 8). Families of children with conditions known to progress to CRF report wanting more and earlier information about LTV from providers (7). In addition, CRF can often develop unexpectedly after acute or acute-on-chronic critical illness, forcing families to make decisions around LTV in times of stress with little forethought.

Despite the gravity and often exigency of this decision, little has been published on how best to inform and guide families facing it. To aid providers who assist families in this decision-making, we conducted interviews with directors of pediatric home ventilation programs to assess how they facilitate informed, shared decision-making around LTV for children with life-limiting conditions, and their perspectives on these complex decisions.

## Methods

### Participants and Data Collection

Eligible participants were directors/codirectors of pediatric home ventilation programs at children's hospitals in the United States and Canada. Identification of potential participants occurred in two steps.

First, investigators (J.D.E. and H.B.P.) with the most knowledge of pediatric home mechanical ventilation programs generated a list of 10 directors. Second, this list was supplemented with seven more names after a review of recently published literature on PubMed and a Web-based search. Two other participants were volunteered by two directors already participating. Directors of programs affiliated with rehabilitation or chronic care facilities were excluded because they may not be involved in decision-making around LTV.

A total of 19 directors were identified and invited to participate via e-mail; those who did not initially respond were re-emailed up to two times. Documentation of informed consent was e-mailed to participants, who returned a scanned copy before interviews.

A total of 15 participants completed an in-depth, semistructured interview over the phone with one investigator (J.D.E.). An open-ended interview guide was developed *de novo* to elicit participants' experience and opinions regarding the following topics: what information families need to make informed decisions around LTV; the pros/benefits and cons/risks of LTV for the child and family; the hopes and worries of families facing these decisions; and how to facilitate shared decision-making and broach sensitive topics. The interview guide is available in the online supplement. Unscripted probes were used to further elucidate or clarify participants' responses when appropriate. Interviewees were encouraged to delineate differences between invasive ventilation and noninvasive ventilation (NIV) in their responses.

Interviews were audio-recorded and transcribed *verbatim* by a professional medical transcriptionist. Personal identifiers were removed, and transcripts were reviewed by an investigator (J.D.E.) for accuracy. Although we initially estimated that thematic saturation would be reached after completion of 10 interviews, we elected to conduct interviews with all invited directors who were willing to be interviewed.

### Data Analyses

Qualitative data analysis was conducted using a thematic approach based on framework analysis (9, 10). The thematic framework was developed based on *a priori* hypotheses of the importance of informed, shared decision-making, and included the

following key domains: information parents need to enable informed decision-making; the process of decision-making; and special populations. Themes were identified within each key domain, based on analysis of interview texts. Definitions of the codes related to each domain are available in the online supplement. Two investigators (J.D.E. and M.C.M.) independently coded each transcript. All coding discrepancies were resolved through discussion and consensus.

NVivo 11 (QSR International, Melbourne, VIC, Australia) was used for coding. The Columbia University Medical Center (New York, NY) Institutional Review Board approved this study.

## Results

All 19 directors (or their assistants) responded to solicitation e-mails. Four initially showed interest in participating, but could not ultimately be scheduled for an interview. A total of 15 directors (79% of invited participants) were ultimately interviewed between October 2015 and March 2016. Eleven were pediatric pulmonologists, two were pediatric intensivists, and two specialized in both pediatric pulmonology and critical care. These directors had a median 19 years of experience caring for children using LTV (interquartile range = 12–27; range = 2–38). After analysis of the 15 completed interviews, the investigators confirmed that thematic saturation had been achieved. Themes were categorized into three broad domains—information, decision-making process, and special populations (Table 1).

### Information

Beyond explaining the child's condition and (when possible) prognosis with and without LTV, all directors highlighted the need to inform families of potential benefits, risks, and burdens of LTV for the child and family. There was universal agreement among directors that families should be told explicitly that forgoing LTV is an option, and that this could ultimately lead to the child's natural death.

**Benefits for child/family.** As the principal benefit, directors highlighted that LTV allows the child to live and remain at home. A total of 10 out of 15 directors added that it was important to explore if LTV would improve a child's quality-of-life and

**Table 1.** Thematic framework and selected quotes

Domains	Themes	Selected Quotes
Information	Benefits for child	<p>“Also, the kid can have a life. I have kids who are on 24/7 and still go to school. You can have some semblance of a normal life, though it’s not normal, <i>per se</i>.”</p> <p>“I think it does, for many kids, help them stay out of the hospital or out of the ICU or out of a chronic care facility, if it’s working. I think it does make kids feel better, again if they’re tolerating it...I think if the child feels better, then that is happier for the family, and the parents are happy with that and they like that if it manages to help keep the child out of the hospital, that’s a pro for the family.”</p> <p>“The benefits of the family I think really come down to, for the most part, them feeling that they love their children, want them alive, and are doing everything they can to make that happen.”</p> <p>“They look at life in a completely different perspective because they are doing something that is very tangible to improve the quality of life of their child. For some, it actually brings some positive rewards in a way, because there is a task, there are some results, and in a way, they need their child’s presence to have a meaning in life.”</p> <p>“I do think some of the worst ones are the stigma associated with it.”</p> <p><i>Invasive ventilation</i>: “The con is there’s all the issues associated with a tracheostomy.”</p> <p><i>NIV</i>: “We’ve seen kids who have had very significant skin problems and midface hypoplasia.”</p> <p>“I think one of the things is actually impressing upon the family the responsibilities and level of invasiveness and responsibility that comes with caring for a child with both invasive and noninvasive ventilation at home. And I think if families are appropriately counseled about that, we help to better support them and make sure this is really something that they want for their child and for themselves and for their family.”</p> <p>“It’s an extraordinary difficult and burdensome thing for families, they don’t complain about it, but it is an extraordinary experience that is unlike almost any other situation.”</p> <p>“We do portray a significant part of what they’re going to have to deal with as significant burdens on the family, potential for family disruption, certainly altering lifestyles. And we want make sure that they understand that this is not easy, not simple, and they’re making a decision that’s probably gonna affect their family for the rest of everybody’s lives.”</p> <p><i>NIV</i>: “I think we view noninvasive ventilatory support as not as big a step, or as resource consumptive, or as emotionally draining as vent and trachs. We tend to treat it that way.”</p> <p>“I do caution them to if they have questions, and if they have concerns about what they read on the internet, let’s talk about it. And I can explain how that does apply to them, or doesn’t apply to them. And so that we can at least talk about they’re reading.”</p> <p>“I think always the most invaluable thing is actually letting the family talk to another family who already live with a child with similar technology and maybe has a similar medical condition, because I find they get sort of that real life perspective from another family that we can’t provide as a clinician to them.”</p> <p>“I think just letting the family talk and addressing their questions always brings up these larger issues to help make sure they’re really getting what they need when they’re making these decisions.”</p> <p>“I think it’s very important to have the Vent Team involved, because many times a primary team, if they don’t do this on a regular basis or as an outpatient, they may not know all the aspects of care and what this means at home.”</p> <p>“But I’ve come to the conclusion that to try and use euphemisms and try and avoid discussing topics really isn’t helpful. And while families may be upset at the moment, in general, they’re thankful that we were as honest as we could be with them.”</p> <p>“I think every family wants their child to be as healthy as possible for as long as possible. And some families are quite realistic about it, and others are incredibly unrealistic about it.”</p> <p>“I think that the prospects for research now are greatly altering people’s decision-making, because they have a lot more hope for things that are on the horizon.”</p> <p>“I think the biggest hindrance is lack of information”</p>
	Risks/burdens for child	
	Burdens for family	
Decision-making process	External sources of information/support	
	Setting the stage for decision-making	
Barriers to decision-making	Hopes and worries of families	
	Providers’ opinions on best choice	
	Barriers to decision-making	

(Continued)

Table 1. (Continued)

Domains	Themes	Selected Quotes
Special populations	Cognitively intact older children Children who are profoundly cognitively impaired or have very poor prognosis Young children on NIV Children fully dependent on NIV	<p>"I always felt that well, we shouldn't ventilate everyone because we could. And I think that the mindset has changed now that I'm seeing that, from an administrative standpoint, that if a family wants to do this, that you were obligated to do this no matter what you think is ethically appropriate. And so I'm struggling with this too, because I've been evolving over the past 30 yr on what is appropriate, and what is not appropriate."</p> <p>"Doing everything we can to not put unrealistic burdens on families, such as saying, 'Do you want us to do this or not or just let your child die?'" You can word it in a way to really make families have a heavy burden to carry regardless of the choice made, and so I think shared decision-making sometimes involves a degree of paternalism that we are slow to make in our current medical culture, but that paternalism can remove a burden of guilt from a family, and yet, how to do that while respecting their autonomy is not always black and white."</p> <p>"We tend to provide our opinion by just conveying what's the likelihood of success or failure, or improvement or no improvement."</p> <p>"If the child has the capacity to be part of this [decision-making]...then I'd say that [their participation is] an absolute"</p> <p>"I have a lot of profoundly neurologically devastated children with tracheostomies, and it's always for the family, it's not for the child. The family feels that they're not ready for their child to die, and I'm not ready to take that away from them. So I have a lot of patients who are neurologically devastated with tracheostomies and ventilators, and they go along for years like that, and it brings their family joy, so that's what we do."</p> <p>"Some [young children] just never seem to get to the point where they seemed comfortable or rested with [NIV]."</p> <p>"To some extent, if you've got a progressive disorder, if they said they only wanted to do noninvasive ventilation, you're really talking about some degree of 'accept natural death' or 'do not resuscitate' stance."</p> <p>"I often try to suggest to them that, actually, those on noninvasive support who are truly dependent may be less safe than those with a tracheostomy. Although it's noninvasive, as a result it's also probably less stable."</p>

Definition of abbreviations: ICU = intensive care unit; NIV = noninvasive ventilation.

not just prolong life. All commented that LTV can improve dyspnea, hypercapnia, and/or hypoxemia, resulting in greater comfort and stability. A total of 12 directors said that LTV can help improve pulmonary reserve and clearance, potentially preventing hospitalizations; one questioned if increased infection risks from tracheostomies might negate this benefit. Five said that LTV can promote growth and development in young children and strength/energy in older children by minimizing the caloric demands of breathing.

Having the child home also was stressed as a benefit for families; five directors added that this applied even when the child had profound neurodevelopmental deficits. Two mentioned that families sometimes gain psychosocial/spiritual benefits, such as new perspectives and sense of purpose.

**Risks/burdens for child/family.** All directors believed that families need to be informed of the risks and burdens of LTV for their child (Table 2). Although directors stressed different risks/burdens, all mentioned potential emergency/life-threatening complications of LTV. Although few patients who use NIV are at risk for sudden death when not connected to NIV, some directors cautioned against underappreciating its life-supporting importance. A total of 14 directors said that they inform families of the possibility that NIV may be insufficient for children with severe conditions in the long term during initial decision-making, and how this could lead to future decisions around invasive ventilation.

All directors underscored that families should be informed of the commitment required to care for a child needing LTV—"24/7" attention from an "awake, alert caregiver." Directors try to convey what this level of responsibility will be like for the whole family (e.g., emotional stress, social isolation and stigmatization, physical strain, lack of sleep), suggesting that it will have an inevitable "life changing" impact. A total of 12 directors also inform families of the likely financial impact (i.e., out-of-pocket expenses). Eight directors spoke of NIV having less of an overall impact than invasive ventilation. If the child cannot be safely cared for at home, directors broach the topic of the child residing in a chronic care facility or

**Table 2.** Risks and burdens of long-term ventilation for the child as described by directors of pediatric home ventilation programs

Modality	Risk/Burden	No. Who Mentioned (Out of 15)
Invasive and noninvasive	Positive-pressure ventilation may be needed for the remainder of the child's life*	14
	Disconnection from interface/ventilator	12
	Ventilator malfunction	10
	Loss of privacy <sup>†</sup>	7
	Stigmatization and prejudice <sup>†</sup>	6
	Community resources for adults on LTV may be considerably less than for children <sup>‡</sup>	3
Invasive	Airway obstruction (e.g., mucus plugging)	14
	Tracheostomy decannulation	14
	Even after tracheotomy, hospitalization may be protracted	10
	Tracheal bleeding	8
	Surgical risks of tracheotomy	7
	Tracheal granulomas	6
	Infection (e.g., tracheitis and pneumonia)	5
	Impaired speech development in infants and toddlers	3
	Limitations in community/school participation <sup>†</sup>	2
	Periodic airway bronchoscopy to evaluate for granulomas and tracheostomy sizing <sup>‡</sup>	1
Noninvasive	May not meet their ventilatory needs long term*	14
	Potentially less safe method to ventilate in some patients with airway compromise	7
	Improper mask fit	6
	Pressure-related facial skin/bone issues (e.g., irritation, breakdown, craniofacial deformity/midfacial hypoplasia)	6
	Inability to tolerate, especially toddlers	3
	Aerophagia and abdominal distention resulting in discomfort and increased risk of aspiration	2
Nonadherence, consequences of which can be difficult to appreciate <sup>†</sup>	2	

Definition of abbreviation: LTV = long-term ventilation.

\*Depending on child's diagnosis/prognosis.

<sup>†</sup>Especially relevant for older children and young adults.

<sup>‡</sup>Depending on hospital or community.

medical foster care, temporarily or permanently.

Directors also discuss the pros and cons of professional home health providers (e.g., home nurses and aides) with families. A total of 13 emphasized that families often do not qualify for as many paid hours of professional home care as desired and, more commonly, that families cannot find home health providers to fill the hours allowed. A total of 10 stressed that the competence of home health providers can be variable, and that there is a degree of privacy lost by having providers in the home.

**External sources of information/support.** Directors were asked about the internet and other resources to help families facing these decisions. A total of 13 conceded that using the internet (e.g., social network/parent/association sites) was

inevitable, and that it was a helpful source of information/support.

However, they added that it could be obstructive, recommending caution, and that families talk to them about what they find.

A total of 13 directors try to facilitate a meeting in person or by phone with another family with a child using LTV at home to provide a real-life perspective. This accommodation is usually only made for families considering invasive ventilation. Other resources mentioned include institutionally developed LTV training videos or pamphlets/booklets. One director mentioned a tracheostomy decision guide as a potential resource (11). Most said that there is little or nothing published specifically to help and inform families or providers facing these decisions.

## Decision-making Process

**Setting the stage for decision-making.** Directors emphasized that the decision-making process around LTV should be interdisciplinary and unhurried and that it should start as soon as CRF is anticipated or diagnosed—either early during the hospitalization or, ideally, during a period of relative wellness before acute illness pushes the susceptible child into CRF. They stressed that the pulmonary/home ventilator team, as the service that longitudinally manages CRF, should be involved before a decision is made. A total of 13 directors volunteered that they had experienced being consulted after the decision was made, raising concern that families were not being fully informed about all the options and their consequences or were being pressured/rushed to make decisions. Other examples of services that could/should be involved included intensive care, otolaryngology, neurology, primary care, palliative care, social work, and chaplaincy.

When asked about how information should be conveyed to families and how to address barriers and worries, directors stressed that providers should be transparent, candid, and consistent. They encouraged lay-appropriate language without euphemisms. All emphasized that providers should be compassionate and supportive (e.g., not only talking about burdens; reassuring families that they will have supports and will become proficient in LTV care), which means being receptive to what families are saying/not saying.

Espousing the spirit of shared decision-making, nine described their approach in terms of inquiring what the families' goals and values are, and then addressing if/how LTV can help meet those goals. When families consider forgoing LTV, all directors recommended supporting the child and family and, when possible, providing palliative care. Six recommended palliative care regardless of the options considered or chosen, though these directors shared that palliative care services are readily available at their institutions.

**Hopes and worries of families.** Directors reported a variety of hopes and worries that they perceive impact families' decision-making (Table 3). Two directors reported that some families are making choices

**Table 3.** Hopes and worries of families facing decisions around long-term ventilation for their child as described by directors of pediatric home ventilation programs

	Hope/Worry	No. Who Mentioned (Out of 15)
Hopes	Their child will have the best quality of life possible for as long as possible	10
	Their child will have as normal a life as possible (e.g., live at home, go to school)	8
	Their child will be liberated from LTV	6
	Their child will be cured (i.e., a miracle)	6
	Medical research will find a cure/therapy	6
	Their child will be free from suffering	6
	Their child can maximize his or her potential	4
	Their child will stay out of the hospital	2
	Providers, family, and friends will agree with and support their decision	2
Worries	Will the child be comfortable on and tolerate LTV?	10
	Will they be able to learn everything necessary to care for the child on LTV?	6
	Will they make a mistake that leads to the child's death?	4
	Is LTV going to work?	3
	How are they going to talk and eat with a tracheostomy?	3
	The child will not be able to leave the home and go out in the community	3
	Stigmatization	2
	Other people will judge them and their decision	2
	The resulting grief if they decline LTV or limit LTV to NIV	2
	Are they "giving up" on the child if they decline LTV or limit LTV to NIV?	2
	Providers will stop treating other things (e.g., discomfort, infections) if they decline LTV or limit LTV to NIV	1
	What will death be like for the child if they decline LTV or limit LTV to NIV?	
	How is going to affect their families' lives?	1
	What is their child going to do when he/she is older and the parents have passed away?	1
	Are they doing the "right" thing?	1
	Are they being selfish?	1

Definition of abbreviations: LTV = long-term ventilation; NIV = noninvasive ventilation.

based on hopes that new medical research will ameliorate their child's condition. Although cautiously sharing hope in medical progress, they recommended families recognize that it might not occur, and that they should make decisions based on the current situation.

**Barriers to decision-making.** Potential barriers to decision-making around LTV stemmed from families, providers, and other sources (Table 4). When asked what would be helpful to address these barriers and aid families, responses included multi-institutional outcome data, earlier referrals/consultation, institutional pathways to facilitate early involvement of all services and expedite discharge, and education for providers to mitigate negative bias around children with severe disabilities.

**Providers' opinions on best choice.** All directors felt that families should be the final decision-makers. However, 12 expressed that they sometimes feel that forgoing invasive ventilation is the best choice for particular children who have very poor prognoses, are profoundly cognitively impaired, and/or will be institutionalized with no family contact. In these cases, five directors are comfortable giving their recommendations to not initiate invasive LTV; one director advocated for a degree of paternalism to mitigate families' potential burden of guilt. Two directors try to be as nondirective as possible. Others try to be very clear about the ramifications/expectations of LTV when they have strong opinions. Some tell families that they can withdraw LTV later, even if the child is not actively dying. When true disagreements

arise between families and providers about what is the best choice for the child, directors suggested ethics and legal services involvement.

### Special Populations

Directors discussed considerations pertinent to decision-making for four specific groups: cognitively intact older children, children who have very poor prognoses or are profoundly cognitively impaired, young children using NIV, and those fully dependent on NIV support.

All directors insist that cognitively capable older children be involved in discussions and even decision-making around LTV. One director highlighted how she explicitly addresses patients' autonomy and right to not initiate or stop LTV when they become 18, sometimes to parents' vexation. Directors also spoke about the stigmatization that these adolescents endure and their struggles with NIV adherence.

Directors' reservations about initiating invasive LTV revolved around children who had advanced multisystem disease, intractable pain, or a variety of profound and progressive conditions (e.g., brain death, anencephaly, minimally conscious state, trisomy 18, spinal muscular atrophy type 1). In these types of situations, most directors (13 of 15) worried that they might be prolonging life "beyond the level of a good quality of life," and several expressed more comfort offering NIV and/or that LTV was more for the family than the child. A few directors offered anecdotes of how these patients or families ultimately taught them valuable lessons (e.g., prognostication is difficult; having these children at home can improve some families' quality of life, even if LTV does not seem to improve the child's).

Three directors emphasized how it can be particularly difficult to get young children/toddlers to tolerate NIV, leading to amplified stress for the family. When initiating children on NIV as outpatients, one director has the child and family try NIV in the clinic so that all can experience it.

A total of 14 directors do not support children using round-the-clock NIV, as the risks/burdens outweigh the benefits. Exceptions included older patients who can do mouthpiece ventilation while awake, or families who choose NIV primarily to provide comfort and agree to forgo invasive ventilation, intubation, and

**Table 4.** Barriers to informed decision-making around long-term ventilation as described by directors of pediatric home ventilation programs

Source	Barrier	No. Who Mentioned (Out of 15)	Comment/Example
Family	Inability to really grasp the information provided or the “big picture”	7	
	Unrealistic expectations	5	For example, in miracles; about what LTV can do; about amount of help they will receive in the home; in medical progress/ innovations
	Focusing on the here and now to the detriment of the long term	3	
	Stress/fear of making any decision	3	
	Denial or lack of readiness/willingness to hear information	3	
	Theological fatalism	1	The viewpoint that a higher power controls everything so there is no decision for them to make
	Unrelated family stressors	1	
Provider	Fear that they are being discriminated against because of their socioeconomic status	1	
	Not fully informing families	14	Includes: <ul style="list-style-type: none"> <li>● Information about LTV and that not initiating LTV is an option</li> <li>● Not involving the appropriate teams in decision-making (e.g., pulmonology/home ventilator team)</li> <li>● Using euphemisms or nonlay language</li> </ul>
	Mixed or inconsistent messages	4	
	Inability to provide prognosis (and sometimes diagnosis)	4	Although genetic testing is getting better, it is not perfect
	Negative biases regarding the quality of life and abilities of many children on LTV	3	Lack of nuanced outcome data for children on LTV Accurate impressions can be hindered because many providers only interact with such children when they are hospitalized.
	Rushing families to make decisions	3	
	Not willing to broach difficult topics	2	For example, that condition will be static or progressive; the impact of LTV on the family
	Focusing on the here and now to the detriment of the long term	2	
	Changing inpatient providers	2	Providers rotate on and off clinical service
	Not engendering a sense of trust in families	1	
Other	Inability to surmount cultural or language differences	1	
	Setting unrealistic expectations	1	
	Influence from outside sources/people	6	For example, other family members or religious/cultural community
	Misinformation from outside sources/people	5	For example, from the internet, television/media, support groups. Includes overly negative and positive impressions of people dependent on medical technology
	Insufficient home care, emergency care, or palliative care resources in the family’s area (e.g., rural area)	2	
Disagreement/discord between family and providers	1		

Definition of abbreviation: LTV = long-term ventilation.

cardiopulmonary resuscitation. Eight directors talked about how converting children using round-the-clock NIV to invasive ventilation can improve stability, mobility, ability to vocalize, oral-motor development, and social interactions in some children/infants. Four directors shared

how the “stability” of invasive ventilation can give families with a very fragile child a sense of security compared with NIV.

Two directors talked about “technology creep,” where NIV is started with the intention of just night-time use, but is

increasingly used to the point where the child becomes fully dependent on it. Families can become acclimated to this dependence, which influences subsequent decisions about invasive ventilation in a way that families perhaps would not have initially predicted/chosen.

## Discussion

LTV remains the most common option to support most children with CRF. When children with CRF have other life-limiting conditions, families must decide between LTV and allowing the child's underlying conditions to take their natural, often terminal, course. Although providers are obliged to inform families of all options and their consequences, providers may not present information regarding LTV consistently, in enough depth, or early enough (7, 8). When shared decision-making is suboptimal, families may be making less-informed decisions and are at risk for unrealistic expectations, decisional distress/regret, and complicated grief.

Seeking to aid providers in informing families, this study is the first to assess how directors of pediatric home ventilation programs, whose role is to longitudinally care for these children and to be routinely involved in these decisions, facilitate decision-making around LTV. The program directors who participated in this study emphasized the importance of going beyond telling families why their child needs LTV, the basic details of LTV, and, if applicable, steps toward discharge from the hospital. They recommended informing families of the potential benefits and risks/burdens of LTV for their child and burdens of caring for a child using LTV on the family, as well as the option to forgo LTV. Directors recommended that decision-making around LTV should be interdisciplinary (especially with involvement of providers experienced in the care of children using LTV), initiated early, and guided by the family's goals for the child and themselves. Knowing what/how "experts" tell families can help other providers inform/guide families in decision-making, especially other providers who do not have this longitudinal experience and/or practice, where there is

no home ventilator program or knowledgeable provider available for consultation. Knowing families' worries and potential barriers to decision-making can help providers address/avoid them and possibly prevent divisiveness with and within families. Although it may not be possible to go into detail about all benefits, risks, burdens, or worries, all should be topics for consideration and discussion, and particularly relevant or distressing topics should be delved into more deeply.

Although directors agreed that families' decisions should be respected, they varied in their approach to providing families with their own opinions or recommendations. Numerous studies have shown that providers have varying practices/opinions regarding providing LTV to children with life-limiting conditions and/or severe neurodevelopmental disabilities (12–18). Our data can also aid providers in seeing where there is overlap and dissimilarity in what/how they counsel families. The variation in practices and perspectives among providers regarding LTV for some children suggests a need for additional evidence-based LTV educational studies/materials that supplement provider counseling and help ensure that fundamental information relevant to decision-making is available to all. To accommodate as many families as possible, such materials should be available in other languages besides English (e.g., Spanish).

This study has several limitations. In the absence of a comprehensive list of home ventilator programs, identification of potential participants was based on the investigators' knowledge of such programs supplemented by a review of recent literature and a Web-based search. Thus, recruitment was not (nor was it meant to be) random nor exhaustive. A small number of other directors were invited to participate, but did not ultimately do so. We did not query families to learn if what and how directors tell them is hearkened or

appreciated. Similarly, we did not interview other providers who play integral roles in helping families facing these decisions (e.g., intensivists, otolaryngologists, ventilator program managers, respiratory therapists, nurses). Only North American directors were interviewed, so our findings may not be generalizable to other regions. Although two investigators did perform coding independently, we did not assess interrater reliability, as discrepancies were rare and neither coder emerged as dominant. Some of the burdens of LTV mentioned may be just as, or more, attributable to other chronic conditions (severe neurodevelopmental disabilities) than LTV; others may be irrelevant to families who decide to place their children in chronic care facilities.

Decision-making around LTV for children with life-limiting conditions can be complex for families and providers. As providers who follow these patients longitudinally and regularly participate in decision-making around LTV, directors of pediatric home ventilation programs have perspectives regarding the decisional needs of these families and how to meet them that can help inform and shape the practices of other providers charged with guiding families facing these decisions. Further efforts, including investigation of the perspectives of families themselves, are needed to understand and meet their decisional needs. ■

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