

Tracheostomies and Assisted Ventilation in Children With Profound Disabilities: Navigating Family and Professional Values

abstract

Parental requests for gastrostomies, tracheostomies, or assisted ventilation in children with profound disabilities raise ethical concerns about children's interests, parental decision-making, and health care costs. The underlying concern for many relates to the perceived value of these children. Clinicians should make efforts to appreciate the family's perspective regarding children with profound disabilities who require respiratory and nutritional medical support. Finding opportunities to learn about the family members' lives outside of the health care setting may facilitate a deeper understanding of what it means to live with a child who has profound disabilities. In conversations with families, referring to interventions as futile and conditions as lethal will obscure the value-based nature of these decisions. Respiratory and nutritional interventions are not clearly against the interests of most children. Even for children with a limited life span, life-sustaining interventions may be important for the child and family. Health care costs are a serious societal issue; however, the costs associated with profound disabilities are not the most significant contributor. Societal decisions not to provide life-sustaining health care to children with profound disabilities would require a public process. Clinicians may have personal views regarding decisions for their own family or for their vision for society. However, clinicians have professional obligations to families who have different values. It is important to present balanced information and support parental decision-making so parents may decide to forgo or use life-sustaining interventions according to their values and goals. *Pediatrics* 2014;133: S44–S49

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Prologue

About 20 years ago, I was taking over our clinical pulmonary service, and my colleague began his sign-out report by saying, "We have a challenging ethical issue: Raphael is a 2-week-old with campomelic dysplasia who is in the NICU on a ventilator, and the parents are not willing to withdraw support." I learned that Raphael's family was originally from Mexico, primarily Spanish speaking, Catholic, and were "waiting for a miracle." There was a care conference in 2 days, and I was expected to help this family understand that Raphael had a lethal form of dwarfism.

I had no experience with this condition; reading the literature confirmed what my colleague had told me. These children have severe respiratory insufficiency, profound developmental delay, ambiguous genitalia, and usually die during infancy. But the final sentence in the standard textbook noted a 17-year-old with an IQ of 45.¹ This prompted me to call several skeletal dysplasia experts who described a range of outcomes. Most infants died after decisions to withdraw life-sustaining care. Each knew of a few children who were treated (requiring mechanical ventilation for years) but eventually were able to spend time off the ventilator. Some of these children had only moderate developmental delay but typically required multiple spine surgeries.

At the care conference, I explained that even if Raphael survived infancy, he could expect to experience years on the ventilator and repeated surgeries. His father asked, "Will he suffer?" I described my clinical experience with families whose children needed long-term assisted ventilation at home. For some, this had extraordinarily adverse physical, emotional, social, and financial impacts; in other cases, the children and family seemed to thrive despite the challenges.² Raphael's mother then said, "We have been praying for a miracle, and today we have one." I realized then that concepts such as "suffering" and "miracles" are social constructions: we each use these terms to mean different things.

As a clinical ethicist and pediatric pulmonologist, one of the most distressing challenges for clinicians that I hear about is when parents request gastrostomy tubes, tracheostomy tubes, or long-term assisted ventilation for children with profound disabilities.³ Over the years, my views have been trans-

formed by talking with families about how they value their child and by meeting with families outside of the clinical context. I offer some reflections here in the hope of assisting clinicians who are asked to provide life-sustaining care for children who have profound disabilities or to discuss palliative care options with the families.

The core underlying concern is whether a life with profound disabilities is a life worth living. A secondary concern is whether providing life-sustaining measures for this life is worth the costs such measures require. These concerns occur in the context of myriad causes of profound developmental disability: chromosomal anomalies such as trisomy 18, perinatal complications such as intraventricular hemorrhage, metabolic conditions such as Leigh's disease, or from trauma such as near-drowning. The conditions sometimes are described as a poor prognosis, referring to the predicted neurologic outcome.⁴ Many clinicians seem to place a high value on cognitive functioning and independent living, a value that not all parents of children with profound disabilities share.⁵ Clinicians' impressions of what life is like with profound disabilities typically are based on experiences limited to providing medical care and, for some, only inpatient care. Parents, in their efforts to present their family's viewpoint and beliefs, often call into question, rightfully, the values and perspectives that clinicians hold that may be influencing the clinical recommendations.

MAKING CLINICAL RECOMMENDATIONS IN THE CONTEXT OF A VALUE-BASED DECISION

Clinicians must decide, in these situations, whether to make specific recommendations. A clinician could

recommend withdrawing the ventilator, offering comfort care, or proceeding with the tracheostomy; or they could provide information and let the family decide.

In most clinical situations, clinicians make recommendations.^{6,7} When the decision is about withholding life-sustaining treatment, however, the decision is weighted with values; we therefore often try to remain neutral.⁸ This approach reflects important concepts such as respect, family-centered care, and nondirectiveness.

Although well intended, a fact-based, value-neutral approach is not achievable. Whenever we talk to families, we create a narrative that we convey to them,⁹ and attempts at balance will nevertheless reveal implicit biases.¹⁰ A spectrum of approaches can be taken to direct behavior in any medical context, related to the content of the information, the explicitness of a recommendation, and efforts to control behavior (Fig 1). The particular approach taken will vary on the basis of the clinician's assessment of the benefits and risks of the decision and the clinician's view that an alternative decision is also reasonable. How clinicians approach newborn screening, infant sleeping position, or vaccination recommendations are based on such considerations.

Clinician recommendations are not only appropriate for general pediatric advice but are reasonable also for life-and-death decisions. Even though the values at stake are more intense, offering guidance and recommendations in life-and-death situations is appropriate.¹¹ A recent commentary about cardiopulmonary resuscitation distinguished between contexts in which resuscitation should be mentioned as a plausible option to be considered versus when it is appropriate to not recommend this option.¹² In fact, a recommendation can be a direct way for clinicians to communicate their underlying values,

rather than these values emerging more subtly in the chosen descriptive narrative.¹³

In the meeting with Raphael's family, the neonatologists made an explicit recommendation to withdraw the ventilator. In this regard, the clinicians' transparency may have been helpful to the family because it allowed the family to be very clear that they wanted life-sustaining interventions for Raphael. The team reluctantly agreed to the tracheostomy and gastrostomy placement. Raphael was transferred to a chronic ventilator setting. When I would see Raphael in this setting, 3 questions were repeatedly raised by the pediatric residents: (1) Is this in the child's interest? (2) Are there limits to parental requests for lethal conditions? (3) What about the costs? The rest of the present article addresses these questions.

IS LONG-TERM MECHANICAL VENTILATION IN THE INTERESTS OF A CHILD WITH PROFOUND DISABILITIES?

An apparently clear and ethically pertinent question (whether long-term mechanical ventilation is in the interests of a child with profound disabilities) is, in fact, a "trick question" because it may be the wrong question, and the best answer may not be a simple yes or no. A better question is whether mechanical ventilation is against his or her interests. This

question has 2 distinct aspects. The first aspect is whether any life with assisted ventilation is against a child's interests. There is a range of respiratory conditions that might require long-term mechanical ventilation. Assisted ventilation is used for intrinsic lung diseases, which can range from chronic lung disease of prematurity that has the potential for improvement with time to lung disease associated with heart disease and progressive pulmonary hypertension. Assisted ventilation also can be used for problems with central control of breathing which can occur with global brain damage (eg, from massive traumatic brain injury) or as an isolated problem (eg, congenital hypoventilation syndrome). Assisted ventilation for hypotonia may be related to isolated muscle weakness (eg, spinal muscular atrophy) or associated with cognitive problems (eg, Leigh's disease). Specific individuals may view the benefits and harms of extending life by using long-term assisted ventilation differently, depending on the underlying clinical context.¹⁴

The second aspect involves the question of whether any assisted ventilation is against a child's interests. Noninvasive ventilation may have different effects than assisted ventilation through a tracheostomy tube. Ventilation via a tracheostomy tube will have different burdens when required 24 hours a day

compared with instances of children who may be able to spend time off the ventilator. Is life with assisted ventilation unpleasant or painful? We have to be careful with this judgment, as most people reading this do not live with assisted ventilation or have a close friend who does so. Even though some adults decide that life on a ventilator is not worth living, other adults have expressed the belief that continued life with ventilator assistance is meaningful.¹⁵⁻¹⁷ These perspectives make it difficult to argue that ongoing life with a ventilator is clearly against a child's interests.⁵

We must also consider the question of interests related to the underlying developmental disability. Although most children with developmental disabilities have clear interests, some have argued that those with the most profound disabilities do not have interests in the same sense as others. Arras¹⁸ argues that it is not necessary or even appropriate to claim that these children have interests, but that, instead, we should consider "relational potential": Does the child have the capacity to form relationships with other people, and are there people who value their relationship with the child? Particularly, when the family can express the value of the relationship, the child will have exceeded the relational potential. The relational potential threshold, although dependent on those with whom relationships are formed, supplies a basis for parental claims for providing life-sustaining interventions in the absence of evidence that such interventions are clearly against the child's interests. Using this framework, Raphael's family's commitment to him can help to resolve this concern regarding ongoing life with ventilator assistance.

When I share this perspective with skeptical colleagues, they are not easily persuaded. A persistent concern is that

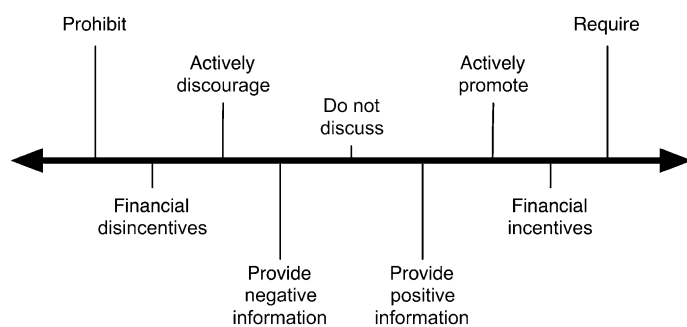


FIGURE 1
Spectrum of approaches to influencing health-related behavior.

parents want life-sustaining interventions for their own needs and interests. These colleagues find it hard to imagine that life, from both the family's and the child's perspective, could be meaningful. Many articles also reflect this view. Duff,¹⁹ a neonatologist, argued in the 1980s against requiring parents to treat children with Down syndrome and other conditions: "... using modern medical technology, the profession of medicine and the public will become trapped increasingly in a kind of 'Medical Vietnam,' rightly claiming some gains which sometimes will be dramatic, but wrongly inflicting great harm, wastefully consuming enormous resources sorely needed elsewhere, and immorally covering up the results."

McGraw and Pearlman,²⁰ also neonatologists, writing about clinicians who were willing to resuscitate infants with trisomy 18, stated: "Some neonatologists are abandoning the best-interest standard, which would require that clinicians agree only to treatment strategies that are consistent with furthering the good of the infant, and instead are adopting an 'ethic of abdication' in their approach to difficult treatment/nontreatment decisions." These concerns suggest a view different from that of parents about what is in the child's interests.²¹

SHOULD PARENTAL REQUESTS FOR LONG-TERM MECHANICAL VENTILATION BE LIMITED IF THE CONDITION IS LETHAL?

There is no simple solution to disagreements about values, but sometimes the concern is expressed as a clinical concern. Consider the following example. Born in 2010 in Ontario, Canada, Joseph Maraachli was diagnosed with Leigh's disease when he was ~5 months old. He had had a sister, born in 2002, who also had Leigh's disease; she had lived for 18 months,

and for the last 6 months of her life, had a tracheostomy. After Joseph experienced a respiratory arrest when he was ~9 months old, his parents requested a tracheostomy. The London Health Sciences Center issued a press release declaring that their "plan of care did not involve performing a tracheostomy, which is not a palliative procedure." They described a tracheostomy as "an invasive procedure in which a device is installed in a hole cut in the throat. It is frequently indicated for patients who require a long-term breathing machine." They noted that this indication of long-term mechanical ventilation was "not, unfortunately, the case with Baby Joseph, because he has a progressive neurodegenerative disease that is fatal."²² Although the press release suggested that the decision not to perform a tracheostomy was a clinical decision, it was a decision based on contested values.

The clinicians for Raphael and Joseph described the conditions as "lethal" and "fatal." "Lethality," however, is not a simple factual term about death. Some children with asthma die. Most people with type 1 diabetes have a shortened life span. One does not usually talk about asthma and diabetes, however, as lethal conditions. In pediatrics, lethality typically is used to describe conditions with shortened life spans and developmental disability for which there is normative judgment by those using the term that interventions are not appropriate.⁴ Lethality is the pediatric equivalent to "futility," and the concerns expressed about futility^{23–25} can be applied to lethality. It can be an effort to turn a normative decision about benefits/harms and the value of life into a factual claim. As such, it can close off further conversation with a family who has a different assessment, as occurred

with Raphael and Joseph. Regardless of their views about the value of life with disabilities, most clinicians are not comfortable directly expressing to parents that they think a child's life (eg, a life with campomelic dysplasia or Leigh's disease) is a life not worth living. In addition to lethality, terms that might be used include "quality of life," "suffering," and "family burden"; these terms may be more subtle but still reflect the underlying view.

I am not suggesting that clinicians change their views about the value of life for children with disabilities. I would respect their choice not to provide life-sustaining interventions for their own child with a similar condition. However, I would also accept parental choices to provide those treatments. There are 3 reasons that I would encourage skeptical clinicians to be more willing to provide such care. First, parents cannot force clinicians to provide this care, and families cannot perform and care for tracheostomies and gastrostomies on their own. This scenario is what Joseph's parents experienced. As clinicians, we have a special responsibility to provide services that are available only with the active participation of health care providers. This scenario is what occurred with Raphael. The clinicians were not enthusiastic, but they appreciated what they ought to do based on his parents' wishes. Second, the families of these children lived with the experience of these decisions for many years. Despite initial challenges, Raphael's family felt welcomed by the health care team over time. Third, when there is genuine disagreement regarding a child's interests, clinicians should let parents make the decision. For such families, the health care team can be a supportive force or a confrontational force.

SHOULD COST AND RESOURCE USE INFLUENCE WILLINGNESS TO PROVIDE LONG-TERM ASSISTED VENTILATION?

Rising health care costs are the most challenging social issue our health care system faces.^{26,27} Resources must be considered in relation to outcome achieved. The balance between outcomes and resources will look different depending on the perspective (Fig 2). There are many causes and contributions to rising health care costs. Children with profound disabilities who need assisted ventilation are a very small population, and the cost of care for them does not compare with expenditures for adults in the last months of life.²⁸

The primary concern about these children may not be costs per se but the value of the outcome, regardless of cost. Costs sometime are invoked because the child will have a short life even with interventions, as with Joseph, or because the child may have a much longer life because of interventions, as with Raphael.

There are several considerations that should mitigate the cost concerns of clinicians who are asked to manage life-sustaining interventions. The first consideration is the current system for collective decision-making about health care resources. In the United States, a decision not to provide a tracheostomy for a child will not translate explicitly to a saving that can be allocated to other unmet needs. We sorely need

a better system for collectively prioritizing our health care needs and developing systems to share costs across the public. The public process is the forum in which those who do not agree with the costs expended on children with profound disabilities should press their case.

The second consideration is the issue of justice. Children with profound disabilities can clinically benefit from life-sustaining interventions. Parents of children with profound disabilities might be as interested in these services as any other parent. If we provide these interventions for others, we need to articulate a principled reason to treat profoundly disabled children and their families differently.

One perspective that would argue further against excluding such services for these children and their families is that they are one of the most vulnerable groups. As a political issue, it is conceivable that popular sentiment would allow for the exclusion of such children from these health care services. It will save some money, and these children cannot vote or make political contributions. However, society has morally progressed by protecting the rights and welfare of disenfranchised groups. There will be a societal cost to all of us if we were to collectively adopt a stance of not providing these interventions to children with profound disabilities. Although cost constraints and resource limitations are important considerations,

focusing on costs also deflects the conversation from the value of children with disabilities.

CONCLUSIONS

Raphael remained in the ventilator facility for 9 months. He was discharged to home and used assisted ventilation for 4 years, at which point he could breathe without assistance. His tracheostomy was removed after several more years but eventually was replaced when it became clear he did better with intermittent assisted ventilation.

Joseph's family arranged a transfer to Cardinal Glennon Children's Hospital in St Louis, where a tracheostomy was performed. His family returned home 1 month later, and Joseph lived for 6 more months.

I learned several lessons from Raphael and Joseph (Table 1). It is important to reflect on our own values about life with a profound disability. This

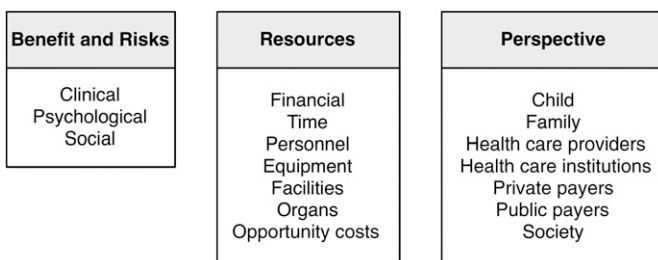


FIGURE 2
Balancing outcomes and resources.

TABLE 1 Engaging With Families of Children With Profound Disabilities Who Request Gastrostomies, Tracheostomies, or Assisted Ventilation

Understand parents' values and goals for their family
Consider when a parental request should be opposed because it is clearly against the child's interest rather than because it is a disagreement related to values
Avoid describing disagreements about values by using concepts such as futility and lethality regarding children who could live months to years with these interventions
Providing "balanced" information (both positive and negative dimensions) can be difficult; therefore, the following should be considered: (1) input from clinicians involved in long-term medical care; and (2) offering access to families who have had both positive and negative experiences in similar contexts
Directive recommendations are appropriate, if done sensitively and if based on the family's goals and the feasibility of reaching those goals
Supporting parents' goals with life-sustaining intervention for children with profound disabilities treats both the child and the parents with respect and expresses the value of their child

reflection may help us be more aware of the narratives we convey to families and our choice of words to describe situations. Providing balanced information may be difficult, particularly if clinicians have limited experience with children with profound disabilities outside of the inpatient setting. Involving clinicians who care for such individuals over years in the outpatient setting may be helpful. Facilitating families' access to other families who

have had positive as well as challenging experiences may help families make decisions for themselves. Finally, understanding the values and goals of each family is critical.

Offering directive recommendations to withdraw life-sustaining interventions may be appropriate, particularly if based on the family's goals and the medical feasibility of reaching those goals. But when families request life-sustaining interventions,

we have an opportunity to support a family facing a journey that few of us will ever embark on ourselves.

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