



Mini-symposium: Ethics and Palliative Care

To trach or not to trach, that is the question

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Educational aims

The reader will come to appreciate how to:

- Review the ethical issues which need to be considered before implementing additional respiratory support, including tracheostomy.
- Distinguish between tracheostomy used as a bridge and as a destination therapy.
- Highlights the importance of advance care planning and goal setting in decisions related to tracheostomy.
- Better assist patients and families in reaching informed decisions related to various modes of respiratory support.

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ABSTRACT

Progressive neuromuscular disease requires increasing degrees of respiratory support to sustain life. Each step from intermittent to continuous—and noninvasive to invasive—ventilation requires thoughtful consideration based on the goals of the patient and family, and the inherent benefits and burdens of the treatment. Tracheostomy, in particular, should not be viewed as an inevitable next step when less permanent or invasive methods prove insufficient. Like other modes of respiratory support, tracheostomy may represent a bridge to recovery of pulmonary function, or a stabilizing action in the hope that novel therapies may prove beneficial. In other situations, tracheostomy represents a destination therapy, necessitating consideration of the implications of chronic mechanical ventilation. Institutional, social, and financial considerations may affect decisions related to tracheostomy, as may implicit bias regarding quality of life. The complexity of such care and decisions highlight the need for optimal palliative care throughout the patient's life.

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INTRODUCTION

Progressive respiratory deterioration is a hallmark of many pediatric neuromuscular diseases. Whereas in decades past this necessarily led to a child's death, now there are multiple modalities of support that can sustain life [1], beginning with suctioning and cough assist, progressing to intermittent and then chronic non-invasive positive pressure ventilation, and ultimately invasive ventilation. To provide the latter on anything other than a very temporary basis, a tracheostomy is required to ensure comfort and reduce the risk of complications.

Unreflective progression from one modality to the next may illustrate what has been called the “technological imperative”: the impulse to do everything one is trained to do, regardless of the cost/benefit or the burden/benefit ratio [2]. But just because it is possible to do something doesn't mean that one should do it. Clinical ethics focuses on what *ought* to be done in light of the relative burdens and benefits of a specific treatment, evaluated in the context of the patient and family's goals. The question of whether to provide additional respiratory support is largely a matter of personal values which may come into conflict, thus creating an ethical dilemma. Escalating intervention would likely sustain life, but it might also increase suffering, both in terms of the intervention itself as well as the life it prolongs.

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Non-invasive positive pressure ventilation (NIPPV)

The first step in addressing an ethical dilemma is to prevent it from occurring. In the context of increasing need for respiratory support, this means maximizing current treatment to postpone that need. This might involve optimizing nutritional status, engaging in physical therapy, and taking active steps (such as immunizations and hand hygiene) to prevent respiratory infections. Managing secretions with suctioning and cough assist are also helpful.

While respiratory decline can be postponed through such interventions, it cannot be prevented. The next step is NIPPV, which may at first seem like a logical response. It is not permanent in the way that a tracheostomy seems to be, and can stabilize a patient who has experienced an acute decompensation without the need for invasive ventilation (and the sedation and constant monitoring that generally accompany it). The burden of NIPPV is not insignificant, however, often requiring restraints and clearly being uncomfortable for the patient.

In some situations—such as a viral infection which tipped a patient “over the edge”—the need for NIPPV may be likely time-limited, with the benefits clearly seeming to outweigh the burdens. However, in situations that represent an incremental decline in respiratory function rather than an acute decompensation, NIPPV may herald the need for ever-increasing respiratory support, if life is to be sustained. This necessarily raises the question of whether invasive ventilation will be provided when NIPPV becomes either intolerable or ineffective. If there is doubt as to whether the patient will eventually require invasive ventilation—or when a patient has consented to invasive ventilation should NIPPV prove insufficient—it generally makes sense to proceed.

But if the need for invasive ventilation appears inevitable and this escalation is either unacceptable to the patient or deemed inappropriate by the team, consideration should be given to whether NIPPV should be initiated at all. Certainly, NIPPV may “buy time” for loved ones to visit and say goodbye, but in these situations it will not prevent the patient's death.

The decision to forgo NIPPV—or any other treatment necessary to sustain life—is obviously intensely difficult for patients and families, especially when the patient is a child. A natural inclination is to defer or avoid the decision, so as not to feel responsible in some way for the patient's death. (Indeed, recent literature highlights the emotional challenges that surrogates face after refusing life-sustaining treatment [3]). Patients and families must recognize, however, that the default response of modern medicine is to do everything possible to sustain life. Thus, not deciding to limit treatment is essentially equivalent to deciding *not to limit* treatment.

To be sure, instituting NIPPV does not commit the patient to continuing respiratory support, for there is no ethical distinction between withdrawing and withholding [4]. (From a clinical standpoint, it could even be argued that withdrawing is *superior* because at least it gives the intervention a chance to work.) From an emotional standpoint, however, withdrawing may be more difficult on a patient and family. Rather than withholding a hypothetical intervention that may or may not benefit the patient, withdrawal usually involves a palpable decision to remove a modality that is keeping the patient alive (at least for the time being). This highlights the importance of optimal communication and advance care planning (discussed below), to potentially spare patients and families from the most agonizing of decisions.

Invasive ventilation

Should NIPPV either be ineffective or intolerable for a patient, the next step on the path to life prolongation is *invasive* ventilation (generally through an endotracheal tube, at least initially). As in

the case with NIPPV, invasive ventilation can stabilize a patient in acute respiratory distress, offering the possibility of improvement while other steps (such as antibiotics and pulmonary toilet) are taken to maximize respiratory status.

Invasive ventilation is definitely an escalation over NIPPV, however, and thus requires thoughtful consideration. Sedation is usually required in light of the discomfort of an indwelling endotracheal tube, thus diminishing the ability for meaningful interaction. Endotracheal intubation also requires hospitalization, which impacts the patient's quality of life as well as affecting family relationships and responsibilities.

In the context of progressive neuromuscular disease, the need for invasive ventilation may herald a “new chapter” in the patient's condition. Even if the patient is able to wean from the ventilator, it is quite likely that he will require such support again in the near future. Patients may have prior experience of mechanical ventilation, either directly in their own lives from previous decompensations or indirectly by watching other patients with their condition undergo it. Such prior experience of mechanical ventilation may be extremely illuminating in terms of future decisions about this and similar modalities. For all these reasons, the decision about whether to escalate to invasive ventilation should not be assumed and should ideally be addressed in advance.

Recognizing the complications and complexity of invasive ventilation, some clinicians may be reluctant to proceed with intubation. They may harbor concerns that “once the tube is in, it's impossible to remove.” Not only should physicians be reassured that withdrawing and withholding are ethically equivalent, families must be made aware of this, as well. Otherwise families might be unduly reluctant to consent to intubation out of fear of “losing control.” The end result is the patient being deprived of a potentially beneficial intervention.

Hopefully endotracheal intubation is successful in bridging the patient to independent respiratory function. If not, one option is to proceed to tracheostomy (which is discussed in the next section). The other alternative is compassionate extubation, which can be a harrowing decision for patients and families. In order to avoid proceeding to tracheostomy “by default,” it may be helpful to frame decisions about invasive (or any form of) ventilation as a time-limited trial, after which its efficacy (in terms of achieving the patient's goals) can be reassessed [5]. This explicitly acknowledges the uncertainty of the desired outcome, and provides a clear time frame for a decision to be made.

Absent such a time frame, it is easy to understand why a family might continually defer a decision to withdraw mechanical ventilation, so as not to feel responsible for their loved one's death. This can also lead to the undesirable situation of tracheostomy being performed not based on a thoughtful decision weighing the benefits and burdens of chronic invasive ventilation, but as the only remaining recourse when no active decision has been made at all.

Tracheostomy

The natural dividing line between short- and long-term invasive ventilation—and thus a logical conclusion of a time-limited trial—is tracheostomy, which makes possible chronic invasive ventilation. Tracheostomy offers practical benefit in terms of comfort, stability, and reduced risk of certain complications (such as ventilator-associated pneumonia). By the same token, it heralds an increase in the patient's level of dependence on medical technology (especially if the patient is completely dependent on the ventilator). It may impact the patient's ability to communicate, and has profound practical implications for the level of care required.

For all these reasons, the question of tracheostomy has been termed a “threshold moment” [6] that demands thoughtful consideration before proceeding. A crucial distinction is whether

tracheostomy represents a bridge to something else, or a destination unto itself. In the case of the former, tracheostomy may provide the opportunity to treat intercurrent illness, address comorbidities, and pursue pulmonary rehabilitation, with the hope of eventually weaning from the ventilator.

In assessing whether to pursue tracheostomy as a “bridge” therapy, several factors must be taken into consideration. The first is the extent of invasive ventilation required, as nighttime ventilation carries fewer monitoring requirements and entails less infringement on daily life than does continuous ventilation. The second is the likely duration that such a “bridge” will be needed, based on a realistic expectation of clinical improvement. The third is the impact on quality of life while the “bridge” is in place, because whether a tracheostomy is required for weeks or for years, the same basic challenges of care and monitoring exist, as do practical limitations on what a patient is able to do.

Another factor is the likelihood that tracheostomy does, indeed, represent only a bridge. For even when there is good reason to believe that the patient will at some point no longer require mechanical ventilation, lack of expected clinical improvement may ultimately render tracheostomy more of a destination. This is particularly true in the case of degenerative neuromuscular diseases, where patients are less likely to recover the ability to breathe independently.

In some cases—such as where ventilator-dependence represents the culmination of a steady clinical decline in the context of progressive neuromuscular illness—tracheostomy clearly represents a destination therapy. Even acknowledging this, some patients may opt for tracheostomy given the alternative of not surviving. Admittedly, they may also not be able to fully appreciate what life with a tracheostomy will be like, in terms of self-assessed quality as well as care needs. No matter how well the procedure and its implications are explained, patients and families often need to experience an intervention for themselves to fully grasp its implication for their lives.

Connecting prospective families with those who have personal experience with tracheostomies can be helpful in deciding whether to proceed. It can also be reassuring for patients and families to be reminded that just because a tracheostomy is performed does not mean that there is an ethical obligation to continue mechanical ventilation through it. This is precisely the reason why it is so important to regularly review the patient's goals and values, to determine whether the tracheostomy is achieving its intended purpose.

The motivation for proceeding to tracheostomy should also be thoughtfully considered. Often to be transferred out of the ICU, ventilated patients need to undergo this procedure. One might reasonably question whether a desire to free up an ICU bed for a more critically ill patient might be influencing a decision regarding tracheostomy, or at least the timing of it. In a similar vein, could insurance coverage and cost considerations be factors in a facility's decision to recommend tracheostomy? And on a more human level, some have wondered whether physicians' laudable desire to “cure” patients might lead them to try to stabilize and transfer patients who remain ventilator-dependent—thus requiring a tracheostomy—despite every effort to wean them [1].

From a practical standpoint, it is important to explore the logistics of tracheostomy care. For a ventilator-dependent patient, constant monitoring and support will be necessary in order to attend to any acute complications or malfunctions. Families often bear the primary responsibility, but depending on how large the family is and what other commitments they might have, additional assistance is often required. While state funding is often available for children with such “high tech” needs, in many areas trained staff are not available to fill the funded positions. Thus while the actual tracheostomy procedure is rather straightforward, the practical

implications of the procedure—on the patient as well as the family—are far-reaching.

It should also be noted that recent discoveries in the treatment of neuromuscular diseases may impact patient decision-making. Tracheostomy is certainly a destination therapy for untreatable conditions, but given documented initial successes with both antisense oligonucleotides [7] as well as gene therapy [8] for treatment of Spinal Muscular Atrophy (SMA), a family might proceed with tracheostomy hoping that it will be a bridge to improved function as a result of novel therapies. Such therapies, however, come with many unknowns—especially with regard to long-term efficacy and side effects—and often with burdens of administration (such as requiring intrathecal injections). So just because a treatment could possibly prolong a patient's life does not mean it is the right choice for that patient and family.

Amid all these important considerations, the most fundamental question—and one that is often not explicitly addressed—pertains to the patient's current and anticipated quality of life. As a “threshold moment,” the tracheostomy decision point allows for thoughtful reflection as to the relative benefits and burdens of the patient's life that mechanical ventilation would help sustain. The fact that tracheostomy is being considered reflects a clinical deterioration not only of the patient's respiratory status, but likely also his ability to care for himself, interact with the world, and participate in valued activities. Viewed in this light, it becomes clear that deciding about tracheostomy must take into account many factors beyond pulmonary function.

Here caution is necessary, given physicians' documented tendency to underestimate quality of life [9]. In situations where a patient also has cognitive disability, physicians—who tend to value cognitive intactness more than families [10]—might not consider the patient's life as one worth being sustained via tracheostomy. For patients who are cognitively intact, other limitations may lead physicians to underestimate quality of life, not recognizing that patients with disabilities often report a higher quality of life than do those without (the so-called “disability paradox” [11]). Rather than professional assessment—which can be quite biased—the appropriate arbiter of what constitutes a “life worth sustaining” is the patient, or the family if the patient is not able to.

There may come a time—whether prior to initiation of NIPPV, invasive ventilation, or tracheostomy, or upon reconsideration of their relative burdens and benefits—that the decision is made to focus entirely on the patient's comfort. Here symptom control is imperative. Appropriately titrated opioids have shown great efficacy in treating dyspnea [12], and multidisciplinary palliative care should be provided (as for any patient considering forgoing life-sustaining medical treatment). Patients and their families should be assured that a decision to forgo such treatment need not involve suffering, as failure to explicitly address this may lead families to assume that not escalating the level of respiratory support is the equivalent of “doing nothing.”

Rather than framing such decisions solely in terms of what respiratory support will and will not be provided, a broader-ranging discussion of the patient and family's goals of care is crucial. Certainly if the overriding goal is life prolongation, then escalation makes sense. But patients and families generally have other goals, such as returning home and engaging in valued activities. They also have specific fears (such as dying in pain, alone, or dependent on machines) which need to be identified in order to be addressed. It is also crucial to clarify what steps the patient and family are willing to take in order to achieve their goals, and what level of functioning is acceptable to them [13].

By ascertaining these intensely personal considerations, clinicians are better able to understand what the patient and family are most concerned about, and whether an escalation of treatment—or even simply maintaining the current level of

intervention—is consistent with the patient and family's goals. This empowers the physician to make a clinical recommendation, whether about NIPPV, intubation, or tracheostomy. This recommendation is admittedly value-laden—for the decision is both ethical as well as clinical in nature—but it is based on the *patient's and family's* values, not the clinician's.

It is difficult to imagine a more emotionally-wrenching decision than a parent opting to redirect care of their child toward comfort. By making an informed and thoughtful recommendation, the medical team can remove some of this immensely heavy weight from the parents' shoulders [14]. The recommendation should be framed in terms of the goals that have been identified and avoid undue emphasis on what is not going to be done (e.g., continued mechanical ventilation) in favor of what *is* (e.g., maximizing the quality of the patient's remaining life). Far from “doing nothing,” a decision to forgo further life-prolonging treatment may represent a parent's heartfelt desire to protect their child from future suffering, and enable that child to live—and die—on his own terms, according to his deeply-held values.

Who, how, and when to decide

For early-onset neuromuscular diseases—such as SMA Type 1—parents are tasked with making decisions because patients lack sufficient decision-making capacity (DMC). While the accepted standard is the patient's “best interests,” this is often not a helpful construct because “best” is a superlative and risks being reduced to the parents doing what the medical team believes is the most desirable option. A more helpful construct is the “harm principle,” whereby parents are permitted greater discretion as long as their decision is not overtly harmful to the child [15].

Whereas the harm principle is usually applied to parental refusal of intervention that the medical team recommends, in the context of neuromuscular disease—especially in relation to chronic invasive ventilation—clinicians may feel that an additional intervention itself represents harm, and thus be reluctant to provide it. While such a conclusion may betray implicit quality-of-life bias on the part of clinicians, it may also reflect a deeper appreciation (and understanding) of the burden associated with that treatment.

Here it is important to identify what specific “harm” may be incurred by escalating respiratory support. NIPPV is clearly uncomfortable, as is endotracheal intubation. Tracheostomy necessitates monitoring, restricts freedom, and generally coincides with increased dependency in other areas of life. For clinicians these developments may appear to represent sub-optimal quality of life, but this feeling may not be shared by patients and their families [10]. Subconsciously, clinicians may be comparing the patient's life to their own quality of life, which presumably includes far fewer burdens and restrictions. But the operative question—given the ramifications of the decision—is whether the hypothetical patient's life is better than *no life* at all.

Recognizing potential bias against providing escalating respiratory support—especially in the context of cognitive disability—Wilfond suggests inverting the question [16]. Rather than asking whether such support is in the child's best interests, clinicians should ask whether ventilation is *against* those interests. Such an inversion frequently leads to deferring to the family's request for additional intervention, recognizing that they have wrestled with that decision (often over a prolonged period of time) and can only achieve what they believe to be in their child's best interests with the support of the health care system.

Here it is crucial to explain not only the current situation but also the likely outcomes of various interventions in clearly understandable terms. Care should be taken not to assume diminished quality of life (even with greater dependence on technology), which is often disproven by the “disability paradox.” Reassurance

must also be provided that deciding not to escalate treatment will not entail suffering. Viewed in this light, it becomes clear that such decisions involve a great deal more than a specific procedure (such as tracheostomy), highlighting the need for broad-ranging palliative care patients suffering from progressive illness [17].

In addition to the “who” and the “how” of deciding regarding escalating respiratory support, there is also the question of “when.” Precisely because neuromuscular disease often has a predictable progression, discussions about what treatments are consonant with the patient and family's goals can occur in advance. This has several advantages, including preempting emotionally charged in-the-moment decisions which often lead to maximal treatment in the absence of a concrete decision to forgo specific interventions. In addition, early intervention can provide significant clinical benefit, in terms of nutrition as well as respiratory support. For instance, if a patient and family have decided that tracheostomy is acceptable, then initiating this procedure earlier in the disease course (i.e., before it becomes absolutely necessary) may help prevent deleterious chest wall remodeling [12].

Discussions should therefore be initiated early on in the disease course, to prepare patients and families for what the future holds. Both the clinical as well as practical implications of various treatment decisions should be reviewed. Patients and families should be assured that opting to initiate a treatment does not necessitate continuing it. Applying the framework of a time-limited trial may reduce the weight of responsibility that parents carry with them, by acknowledging the possibility the treatment may not achieve the patient's goals and establishing waypoints where overall benefits and burdens can be reconsidered. It also paves the way for substantive conversation at “threshold moments” such as potential tracheostomy. Given the clinical and emotional complexity of those conversations—and recognizing the need to appropriately present a comfort-directed plan of care as an option—ongoing pediatric palliative care involvement is essential.

As noted, decisions regarding early-onset neuromuscular diseases are made by the patient's parents. For some other conditions—such as Duchenne's muscular dystrophy (DMD)—patients may be able to participate both in real-time decision making as well as advance care planning, which is what professional statements recommend [18,19] and adolescents have requested [20]. This logically raises the question of the degree to which an adolescent's decisions should be respected, especially related to refusal of treatment [21].

This is a very complex question, and in the context of advance care planning it is important not to make any promises that one isn't able to keep. But even if one cannot promise to honor an adolescent's precise treatment requests, this does not mean that the values and goals such a patient expresses are not meaningful or influential. One might say that an adolescent's advance statements carry “moral weight,” [22] even if they are not absolutely binding.

Unfortunately, advance care planning conversations aren't often taking place with minors. Nurses [23], doctors [24], and parents [25] all report difficulty in engaging in such discussions, for profound emotional reasons. In one study, nearly half of the adolescent subjects with serious illness (in this case, metastatic cancer or HIV infection) hadn't discussed issues such as their goals of care or preferred surrogate with anyone in the previous month [26].

Hopefully additional emphasis on advance care planning and age-specific tools will improve the situation. One such tool is an adaptation of the well-known Five Wishes document called My Thoughts, My Wishes, My Voice [27], which allows adolescents and young adults to answer the following questions.

- Who should make decisions if I can't?
- What kind of treatment do I want?
- How comfortable do I want to be?

- How should people treat me?
- What do I want my loved ones to know?
- Spiritual wishes
- How do I want to be remembered?

CONCLUSION

The title of this article is “To trach or not to trach, that is the question,” but it should be apparent by now that tracheostomy is not the only question, or even the most important one. The overriding question—which is frequently unspoken—is what a patient and family’s goals are, and what they are willing to endure in order to achieve those goals. Identifying those goals takes considerable time and nuance, but once accomplished leads to an informed and relevant discussion of what steps are appropriate to help the patient and family achieve their goals. So rather than being the starting point of a discussion, tracheostomy should be the conclusion, naturally following from the goals that have been identified and influence every other question (and answer) that follows.

DIRECTIONS FOR FUTURE RESEARCH

- Continued exploration of antisense oligonucleotides, gene therapy, and other modalities which may fundamentally change the course of previously untreatable conditions such as SMA.
- Optimization of communication regarding prognosis and treatment options, both with patients and their families.

Practice points

Tracheostomy

- Permits chronic invasive ventilation with greater stability and reduced discomfort and complications.
- Represents a threshold moment, distinguishing short-term from long-term mechanical ventilation.
- May function as a bridge to improved function, or as a destination without anticipation of improved function.
- Should ideally follow from previously-identified patient goals.

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