

# Can Parents Restrict Access to Their Adolescent's Voice?: Deciding About a Tracheostomy

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Parents are the default decision-makers for their infants and children. Their decisions should be based on the best interests of their children. Differing interpretations of children's best interests may be a source of conflict. Providers' biased evaluations of patients' quality of life may undermine medicine's trustworthiness. As children mature, they should participate in medical decision-making to the extent that is developmentally appropriate. In this month's Ethics Rounds, physicians, a philosopher, and a lawyer consider parents' demand, supported by the hospital's legal department, that their 17-year-old son be excluded from a potentially life-and-death medical decision.

## abstract

### THE CASE

TK is a 17-year-old (almost 18-year-old) boy with cerebral palsy, arthrogyriposis, Pierre Robin sequence, scoliosis, and restrictive lung disease, who was admitted to the PICU with postoperative respiratory failure after elective mandibular advancement. His providers believe that his respiratory failure is due to poor airway tone, secretions, and postoperative edema and treated him with high-dose dexamethasone. A third trial of extubation was unsuccessful. It is uncertain whether TK will benefit from additional time and steroid therapy or whether this is his new baseline.

A tracheostomy might be required for successful extubation. It is unlikely that TK will also require mechanical ventilation. When the medical team introduced the possibility of a tracheostomy to TK's parents, they responded "absolutely not." They believe TK had a good quality of life

before surgery. He, for example, was taking college-level classes, was an active Eagle Scout, and wanted a girlfriend. His parents believe a tracheostomy will cause too much suffering. TK's parents state that a tracheostomy would prevent TK from doing things that he enjoys such as swimming. They also do not want TK to know about the possibility of tracheostomy and asked the team not to use the word tracheostomy in his presence. They feel it would be best to "let him go" if the next trial of extubation is unsuccessful.

Most of TK's providers are uncomfortable not involving him in this decision given his age and development. When his sedation is lightened, TK can respond with thumbs up or thumbs down to questions like "Does anything hurt?" and "Are you doing OK?" His parents contend that they have made medical decisions for TK his whole life. They assert that, for 17 years, providers have wanted them

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Drs Lanocha, Tate, and Antommarrina conceptualized the article and drafted the initial manuscript; Drs Salter and Elster drafted the initial manuscript; and all authors reviewed and revised the manuscript, approved the final version as submitted, and agree to be accountable for all aspects of the work.

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to “let TK go” because they only saw a disabled person who did not deserve the same medical care as “normal” kids. His mother asked why, suddenly, do doctors want to keep TK alive? They assert that those recommending the tracheostomy will not be in their house, helping them care for him. His parents argue that because he is 17, they are still his legal guardians and that the providers cannot perform the tracheostomy, or even discuss it with TK, without their consent.

The hospital’s legal department agrees that TK’s parents can control what information is shared with him. If the providers discuss the tracheostomy with TK over his parents’ objection, they could sue for intentional infliction of emotional distress. If you were TK’s attending, what would you do?

#### **NATALIE LANOCHA, MD, AND TYLER TATE, MD, MA, COMMENTS**

Individual or collective experiences of dehumanization or mistreatment serve to destabilize or even dissolve bonds of trust with medical providers and systems. Black, indigenous, and people of color, transgender persons, and people with disabilities have suffered systematic discrimination contributing to perceptions of medical systems as lacking trustworthiness. The case of TK exemplifies mistrust in those living with or caring for others with disability, a phenomenon that unfortunately is not unique to TK.

Several hypotheses exist as to why individuals living with disability have historically not benefited from the health care system. Many of these can be traced to the “medical model of disability.” The medical model maintains that “a person’s functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure.”<sup>1</sup> In putting the

focus on the individual body as problematic, the medical model contrasts with the “social model of disability,” which accounts for the role that social barriers (anything from building design to engrained biases) play in disenfranchising people with disabilities.<sup>2</sup> The medical model underwrites the idea that people living with disability have “special” needs requiring extraordinary efforts to be met, rather than ordinary needs, overlooked because society has been constructed specifically to accommodate able bodies.

A drive to fix or cure bodies pervades modern medicine<sup>3</sup> and influences the clinical approach to caring for those with disability. Although some individuals undoubtedly benefit from the goal of cure, this aim presumes that every person with disability seeks to conform to society’s definition of normal.<sup>4</sup> For adolescents in particular, “well-child” care, research, and social norms presuppose a developmental goal of an able-bodied high school athlete.<sup>5</sup> For those living with disabilities, and, arguably, for many other adolescents, this model is deficient. In contrast to cure, a focus on care seeks to enhance well-being holistically and in a way that is tailored to each individual patient but without endorsing ableism (the belief that people with disabilities are inherently inferior) or suggesting that disability is a fault that demands repair.<sup>6</sup> Emphasizing care can engender personal empowerment and shift attention to social determinants of health rather than foreground perceived shortcomings of the disabled body.

With layered experiences of outright or implied dehumanization, both personal and communal, it is not surprising that many individuals living with disability, and families caring for those with disability, such as TK’s, have found the health care system to lack trustworthiness. Renewal of trust may, however, be possible.

Sullivan<sup>7</sup> argues that for clinicians to establish trustworthiness they must display three ideals: competence (medical expertise and reliability), caring (demonstration of a beneficent motivation in attending to that with which they are entrusted), and comprehension (the ability to understand and communicate why a patient or family expresses certain attitudes, including mistrust). Despite what many clinicians believe, competence and caring are often insufficient for overcoming mistrust; comprehension is also essential. Although, admittedly, it may feel risky to attempt to recognize and label mistrust, comprehension can communicate honesty and the capacity to accurately judge a situation. In so doing, comprehension effects bonds of trust in formerly fraught situations.

Effective comprehension also requires the virtue of humility. Elbaum<sup>8</sup> notes how, “a provider’s humility in seeking to comprehend mistrust may be just as significant to the patient as the ultimate comprehension itself.” It is not enough to learn the history of ableism or racism in medicine in an attempt to meet each patient where we think they are. Instead, providers must meet each patient where they actually are, with fresh and empathetic inquisitiveness. To do this well, we must appreciate that each patient’s experience intersects with communal histories of discrimination but is also entirely unique.

For TK’s parents, years of medical interactions signaled that their son’s condition did not merit treatment because he would never be a “normal” able-bodied adolescent. Over time, his parents subverted the medical system and found their own ways to promote his flourishing. They may be fearful that this will be taken away from him through the tracheostomy by the same system that dismissed their initial pleas for care. They may have heard about

similar experiences from other families with disabled children, but their experience is unique and marred by specific encounters with indifferent providers.

In approaching mistrust, we can use the Sullivan<sup>7</sup> model. We must also humble ourselves, curiously listen, and acknowledge that families are the experts of their own lives. This approach seeks to humanize those who have long experienced dehumanization and dismissal, thereby rehabilitating the role of the clinician. Only when appropriate attention has been given to their experience, may we then signal comprehension, call out mistrust where it exists, kindle any embers of trust, and work to repair the systems. As we see it, this is the work that is required before ethical deliberation can even get off the ground.

#### **ERICA K. SALTER, PHD, COMMENTS**

TK's case presents an uncomfortable situation for clinicians: an almost-adult patient (mere months away from legal decision-making authority), whose well-intentioned but perhaps overbearing parents request a treatment plan that might result in his death and preclude discussion with the patient about his wishes. When legal decision-making authority is on the imminent horizon and the stakes are high, what decision-making role should we give a chronically ill adolescent?

The years of adolescence are typically characterized by burgeoning capacity and autonomy, as teenagers and their parents begin preparing for the approaching reality of legal decision-making authority. Although legal decision-making authority lies generally with the parents until the child turns 18, parents and clinicians should and typically do look for opportunities for a teenager to be involved in their medical care, both to demonstrate respect for that growing capacity and to provide opportunities

for practicing the skills that adulthood requires.<sup>9</sup> Ideally, we would hear directly from TK about this important decision, but his parents have requested that we not discuss it with him at all, perhaps in part because TK has experienced a different sort of adolescence. TK does not appear to have been given many (or any) opportunities to practice medical decision-making. In fact, his parents report that they have been making decisions for TK his whole life; thus, this decision should be no different.

Although uncomfortable for the clinical team, I think this situation should be viewed not as a problematic deviation from the norm but instead as an example of loving parents flexibly adjusting roles within the context of an intimate family to accommodate an immensely challenging clinical reality. And in so many respects, these parents have risen to that challenge: they have cared diligently for TK's medical needs and have attended carefully to his psychological and social needs as well via opportunities like Eagle Scouts, college-level classes, and the possibility of a girlfriend. They have been devoted advocates of their son and his interests, and TK has thrived in their care. Indeed, he would likely not be alive today if it were not for the dogged advocacy of TK's parents.

Currently, TK's parents are the de facto decision-makers, both concerning the tracheostomy and concerning what to disclose to TK, and TK's parents have clearly articulated a decisional preference. However, given the stakes of this particular decision, it is prudent to explore the preference further, through conversation with the parents. Starting with conversation with the parents (and not with TK) demonstrates a willingness to work within the requested boundaries. Conversations should be conducted by a small group of trusted team members (rather than a large crowd),

and the team should approach the parents with humility, curiosity, and compassion rather than judgment or suspicion. Under the right conditions, these conversations could build trust and understanding between TK's family and his health care team.

Conversations with his parents should address at least the following three topics. First, health care representatives should invite TK's parents to share more about their experiences with caring for TK, their hopes and fears, and specifically their rationale for this particular decision, which appears to be a departure from their norm. What is it, specifically, about the tracheostomy that they imagine will be prohibitive? Second, the clinical team should attempt a "substituted judgment" line of inquiry with the parents, inviting explicit input about TK's beliefs, experiences, and wishes: what would he say is essential to an acceptable quality of life? This strategy respects the parents' wish of not discussing the decision directly with TK while also attempts to put TK and his interests at the center of the conversation. Finally, on the basis of the parents' answers to the previous questions, the clinical team should ensure that they have offered and discussed all information about and available resources for supporting caregivers of patients with a tracheostomy (eg, home nursing assistance, respite care, medically intensive group homes, the possibility of swimming with a tracheostomy by using specialized equipment). These parents are already experiencing a profound and sacrificial caregiving burden, and the prospect of additional responsibilities may (understandably) be unfathomable. Providing information and resources may help them better imagine life with a tracheostomy as a possibility, both practically and emotionally.

The goals of these exploratory conversations are threefold. First, they help the health care team to

better understand the parents' decisional rationale, which, when put in a more robust context, may become more reasonable. Second, they explicitly attend to TK, as the central stakeholder, without violating the parents' boundaries. In this way, TK has a voice (albeit mediated) at the table, which may encourage his parents to see the situation from a fresh perspective. Finally, they invite the parents to explicitly acknowledge their own experiences and struggles as important and deserving of attention and resources. If achieved, these aims may naturally produce some movement in the parents' perspectives.

However, these conversations may not shift perspectives (either the clinical team or the parents), and the impasse may remain. If this is the case, these parents should be trusted to make an informed decision for their son and family. As the primary decision-makers and bearers of responsibility for TK's care, TK's parents are in the best position to be aware of and evaluate the risks and benefits of a tracheostomy for TK and their family.<sup>10</sup> In addition, this honors and protects the most fundamentally stabilizing and secure relationship in TK's life (that between him and his parents). Going against TK's parents' wishes for this decision risks harming not only the important therapeutic alliance clinicians have with TK's parents but also risks disrupting the relational roles within this intimate family.<sup>11</sup> These roles have developed over a lifetime of serious illness and have served this family well. Thus, although questions about an adolescent's ability and desire to make medical decisions might, in other families, be a more central question, we have sufficient reason (not only legal but relational as well) to continue honoring TK's parents' decision-making authority for this decision.

Taking this position might result in TK's death. This is a tragedy for

everyone and certainly for TK's parents. If not for the dedication and advocacy of TK's parents, TK would likely have died many years ago. They have admirably delayed this tragedy for 17 years. Indeed, his parents have reminded us that, for most of TK's life, medical professionals have encouraged them to let him go and allow him to succumb to his conditions.

Regardless of the parents' ultimate decision, the clinical team should work with TK's parents to create more opportunities to hear from and interact with TK. Because TK is intubated and usually sedated, his ability to communicate is significantly limited, but the team might explore options for reducing sedation and using assisted communication technology. Either way, physical interaction (sitting at the bedside, holding his hand) and, when TK is able and comfortable, brief conversations about how he is feeling can be had. Not only does this improve TK's current quality of life, but it provides more opportunities for TK's voice to be heard and helps make the most of his family's time together, however long that may be.

#### **NANETTE ELSTER, JD, MPH, COMMENTS**

In clinical care, knowledge of the law is necessary but not sufficient, as is illustrated by TK's situation. The legal department's assessment that TK's parents can control the information provided to TK is accurate but does not address the ethical issues. Also, exceptions often exist in the law. Medical decision-making for minor patients is one of those areas.

The law supports parental rights in decision-making for children on the basis of the assumption that parents understand their child's needs and level of comprehension and the family's needs and means. Thus, parents are presumed to be in the best position to make a decision for their child, acting in their best

interest. Parents' rights, however, are not absolute. Diekema<sup>12</sup> has argued in favor of the Harm Principle, which "provides a foundation for interfering with parental freedom that more accurately describes an appropriate standard for interfering with parents who refuse to consent to medical treatment on behalf of a child. State intervention is justified not when a parental refusal is contrary to a child's best interest, but when the parental refusal places the child at significant risk of serious preventable harm."<sup>12</sup>

In most states, 18 is the legal age of majority.<sup>13</sup> With majority comes rights and responsibilities, including, but not limited to, the ability to enter into binding contracts, the right to vote, and the right to make medical decisions. The demarcation of 18, however, is arbitrary and raises the question of whether the decision-making ability of an 18-year-old individual differs significantly from the decision-making ability of a 17-year-old individual. Exceptions to the legal bright line from childhood to adulthood exist but may not necessarily be based on capacity. Most states, for example, allow minors to consent independently for certain types of mental health, substance abuse, and reproductive health treatment.<sup>13</sup> Some of these laws consider the potential benefits and risk of parental decision-making. Minors may also petition the court to become emancipated if they can prove they are able to support themselves.<sup>13</sup>

The law reflects that the determination of who makes decisions for adolescents is not based solely on capacity. It is also based on the need for uniform application and to respect the constitutionally recognized right of parents to the care, control, and custody of their minor children.<sup>14</sup> Ethics, however, necessitates a more nuanced approach to patient decision-making, which as seen in this case, may

potentially conflict with the law. Former Supreme Court Justice Potter Stewart said, "Ethics is knowing the difference between what you have the right to do and what is right to do."<sup>15</sup>

The potential conflict between law and ethics in the case presented requires examination of both TK's and his parents' interests. Given TK's proximity to adulthood, his goals and values should be considered, especially given that if the tracheostomy is performed, this will impact him as an adult. Feinberg<sup>16</sup> argued that children have a right to an open future. "[The child's right] while... still a child is to have future options kept open until [the child] is a fully formed, self-determining adult capable of deciding among them."<sup>16</sup> If TK's interests are not considered and death is imminent without the procedure, this begs the question of whether his right to an open future is being protected if his views about the procedure are not considered.

TK lacks physical capacity and will continue to require involvement of his parents and/or other care providers to address his activities of daily living if the tracheostomy is performed. He does not, however, seem to lack decisional capacity. Up until this hospitalization, he has been taking college-level courses and participating as an Eagle Scout, and when sedation is lifted, he is able to respond to yes or no questions. Because he will soon be an adult, excluding him from learning of the treatment options raises ethical concerns. His parents do have the legal right to make decisions for him, but given the gravity, if not finality, of the decision being made, TK should be informed of his prognosis and treatment options. He should have the opportunity to express his wishes even if they are not the sole determining factor in the decision. Given his extensive experience with illness, disability, and the health care system, he is likely to have a deeper

understanding of the issues than would many adolescents his age. TK's heightened understanding may lead to a greater maturity to be able to balance the risks and benefits of what is being proposed. He may, in some jurisdictions, be considered a mature minor, enabled to make this medical decision but not emancipated.<sup>17</sup>

Clearly, TK's parents are involved and devoted parents and likely want to ensure that their son does not suffer any more. They also are aware of the family's emotional, financial, and physical means, a vantage point that puts them in the best position to determine if the tracheostomy is not only in TK's best interest but also the family's best interest. Respecting the commitment and knowledge of TK's parents is critical to resolving not only the ethical issues raised but also in reducing the likelihood of a legal challenge. Rather than escalating this complex decision to an adversarial one, ensuring that the voices of the health care team and the family are heard by one another is critical. An ethics consult is one way to address this. Through a facilitated dialogue, TK's parents and health care providers might come to understand each other's interest in caring for TK. Involving social work and/or pastoral care may be another way to allay some of the concerns raised. Social workers may identify options of which his parents are unaware to assist with TK's care if he receives a tracheostomy. Addressing concerns such as financing, respite care, and counseling might address some of the parents' concerns.

TK's interests should be paramount. To protect TK's emerging autonomy as well of the family's autonomy and to avoid causing moral distress for the health care team, reaching a mutually agreed on solution is ideal. Although seeking court intervention to override the parents' decision is possible, this should be the last resort. Court intervention creates an

adversarial relationship between the health care team and the parents and may also create an adversarial relationship between TK and his family and/or between TK and the health care team. Additionally, a legal solution does not resolve the ethical concerns of all the stakeholders. Seeking an ethics consultation and/or family meeting to discuss these issues and ensure that parental concerns are heard and TK's interests are represented would better address the ethical concerns raised. "Pediatric health care providers have legal and ethical duties to provide a standard of care that meets the pediatric patient's needs and not necessarily what the parents desire or request."<sup>18</sup> A solution that addresses the ethical issues in a satisfactory manner may be able to preserve these important interests and relationships and avoid litigation.

#### OUTCOME OF THE CASE

The day before TK's fourth extubation attempt, three conversations shifted TK's parents' position on tracheostomy. First, the one person in the hospital the family described as "trustworthy," a child life specialist who had listened closely and compassionately to TK's parents' description of his life, joined a meeting with TK's parents. This conversation served to align the PICU with perceptions of trust and provided TK's parents a safe space within the chaotic environment of the PICU. The second conversation occurred between a palliative care attending and TK's oromaxillofacial surgeon who worked primarily at a different hospital. After hearing of the conflict, the surgeon called TK's parents. He too took time to listen and provided reassurance about the tracheostomy. Ultimately, both of TK's parents agreed that, should the extubation be unsuccessful, they would consent to the tracheostomy. After extubation, TK breathed on his own, and a tracheostomy was not

needed. In the end, no one elicited TK's preferences regarding the tracheostomy.

**ARMAND H. MATHENY AN TOMM MARIA, MD, PHD, COMMENTS**

This case poses a quandary. Why do TK's parents, who have consistently sought treatment for him (at times, over providers' objections), object to the tracheostomy? Although it

would prevent him from activities such as swimming, this seems like a reasonable trade-off with the things that it would permit him to do. Supportively pursuing this potential discrepancy may lead to significant new information about his parents' interests that can be satisfied.

In addition to his parents' preferences, TK's preferences are

fundamentally important. These preferences may include how the decision is made in addition to what decision is reached. TK may prefer to defer to his parents. If he, however, wishes to be involved in the decision, there is a tension between doing what is right and avoiding civil liability. Hopefully, institutions are willing to support their providers in incurring risk to do what is right.

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