

Are We Allowed to Discontinue Medical Treatment in This Child?

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One of the most difficult ethical dilemmas in pediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. The question is: How can medical treatment be discontinued when the child is not dependent on mechanical ventilation or ICU treatment? What is the appropriate palliative care and does it justify the use of sedatives or analgesics if this also might shorten life?

One of the most difficult ethical dilemmas in pediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. The question is: How can medical treatment be discontinued when the patient is not dependent on mechanical ventilation or ICU treatment? What is considered proper palliative care and does it justify the use of sedatives or analgesics if this also might shorten life?

We present such a case and seek commentary from experts with experience in such difficult cases. Laura Miller-Smith is a pediatric intensivist at Children's Mercy Hospital in Kansas City, Missouri. Vicki Forman is a nurse at Verdugo Hills Hospital in Glendale, California, and the author of *This Lovely Life: A Memoir of Premature Motherhood* (2009). Wendela Leeuwenburgh-Pronk is a pediatrician, currently working at Emma Children's Hospital in Amsterdam. Dick Tibboel and Corinne Buysse are pediatric intensivists at the Sophia Children's Hospital in Rotterdam, Netherlands. They were the physicians involved in

the case. The parents consented to publication of the case.

THE CASE

Anna was born at term after an uneventful pregnancy. At birth she was diagnosed with Down syndrome, a small atrial septal defect type II, and respiratory distress due to stenosis of the choanae. Anna's parents welcomed her into their life, never questioning the quality of life for and with a disabled child. During infancy, Anna developed multiple mysterious problems that seemed unrelated to the Down syndrome. She had feeding problems with the constant urge to vomit. The cause of these problems was unknown.

At the age of 7 months, a gastrostomy and jejunostomy were placed, which alleviated her symptoms only mildly. She had intermittent severe respiratory distress, thought to be due to a combination of laryngotracheomalacia and severe obstructive sleep apnea due to stenosis of the choanae and hypotonia.

At age 9 months, she remained dependent on oxygen supplementation and noninvasive positive-pressure respiratory support. A tracheotomy alleviated the symptoms of obstructive sleep apnea syndrome, but Anna

abstract

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suffered from sputum/saliva retention for which endotracheal suction several times every hour is necessary. An EEG revealed subclinical seizure activity.

A skin culture grew methicillin-resistant *Staphylococcus aureus*. Isolation further compromised her development because she could not go to the playroom or outside for a walk. Isolation, masks, robes, and hats limited normal human interaction.

At the age of 11 months, she was able to focus only briefly and occasionally grasp a finger. She no longer showed any signs of recognition in response to her parents and did not smile. She was diagnosed with cerebral visual impairment and a mild conductive hearing loss.

She exhibited constant movement, facial grimacing, choking, coughing, and vomiting. The medical team and parents together agreed to a do not resuscitate (DNR) order. The parents also requested withdrawal of positive-pressure respiratory support.

The PICU team was divided on the decision to withdraw medical treatment. The PICU team members consulted with specialists in developmental and genetic disorders, discuss the case with Anna's family physician, and consult the university clinical ethics committee. In their opinion, the treatment so far had not established any improvement and considered no additional treatments available that would result in improvement of quality of life. Continuing medical treatment was unanimously regarded as futile. The medical team agreed to accede to the parents' request to discontinue medical treatment.

The parents then requested that, when medical treatment is discontinued, Anna will receive sufficient narcotics and benzodiazepines to sedate her. How would you respond?

LAURA MILLER-SMITH, MD, COMMENTS:

The transition from pursuing cure to accepting death and providing palliative care can be difficult for

health care providers. As highlighted in this case, that transition can be accompanied by moral distress and ethical uncertainty. Often, such distress and uncertainty are the result of less than optimal education for health care providers on the ethical and legal aspects of end-of-life care. The case illustrates a concern that often arises, spoken or unspoken, in situations of withdrawal of medical support.

My first response in this scenario would be to ask the family to tell me more about the reasons why they are making this request. There is some ambiguity in what the parents might mean by "sedate." I would want to hear them explain their concerns about their child. I would take the request as an opportunity to explain to them, in some detail, the process that we go through when we withdraw life support. I always try to clarify with the family what events will transpire when such therapies are withdrawn. I give them specifics about what support will be discontinued, and what will remain, what medication will be given and in what situations, the expected duration until the child will expire, and the clinical changes that will occur during that time period. I will frequently ask the parents what their concerns are surrounding these events. For most, the prevention of suffering, rather than hastening of death, is paramount.

In the given scenario, the parents may be asking that their daughter not be allowed to suffer during removal of life-sustaining support. If that is the case, and their goals are now to minimize pain, agitation, and dyspnea, then narcotics and benzodiazepines are appropriate medications to accomplish these goals. I will always inform the family that the side effects of these medications can be respiratory suppression, but that we accept that risk of this complication because our priority is relief of pain and agitation.

Most parents are able to understand this concept of "double effect," although their comfort with the secondary consequence is variable. I have had families request lower doses of medication (and, in some cases, even no sedation or anxiolytics), because they do not want, in any way, to hasten their child's death. Others have requested more of such medication to ensure that suffering is minimized, knowing that this may give them less time with their child.

The process of treating end-of-life pain and distress, even knowing that such treatment might hasten death, has been labeled with many names. Some call it "terminal sedation" or "palliative sedation."¹⁻³ Regardless of the semantic nuances, the central ethical feature of such end-of-life care is that it requires that pain and suffering are refractory to standard medication doses. These attempts should be made before the escalation of sedation to the point of unconsciousness. In cases in which a patient is sedated to a level of unconsciousness, however, it is usually difficult to truly know whether the patient is suffering. Thus, the moral nuance comes down to the care providers' intention. Is it to provide comfort and minimize pain, even if doing so requires higher doses of medication? Or is it to hasten death? If support is truly titrated to meet the patient's need, and attempts have been made to use more routine dosing, then, ethically, terminal sedation or palliative sedation can be justified by the concept of "double effect." Thus, I will increase the doses of medication I use to achieve my goal of pain relief.

What, then, is the difference between such practices and active euthanasia? In the United States and many other countries, there is clearly a legal difference. Physicians may not legally give a patient medication with the explicit goal of hastening his or her death. However, the gray zone between prevention of pain and

facilitating a faster death comes down to the physician's intention. With providing palliative medications, our intention must be to treat pain and discomfort.

There have certainly been documented cases⁴⁻⁶ in which the physician's intentions have been questioned by either other health care providers or even family members, and what may have otherwise been viewed as routine palliative care comes under scrutiny by either internal or external review. It is difficult to verify the physician's intentions after an event. Because of the concern of legal ramifications, some physicians may feel uncomfortable giving the dose of medication that is needed to prevent suffering. This is true even though the legal risk is very low.⁴ Such liability-driven restraint also raises ethical concerns. My obligation is to treat my patient through the time of their death, and do my best to prevent the suffering that may accompany it. I should not hesitate to provide treatments that achieve these goals. I am transparent with both families and nursing staff about the goals of care, the medications and doses needed to achieve those goals, and my intentions. I carefully document such discussions in the medical record. This process should prevent subsequent second-guessing about intention. Institutional adoption of palliative care guidelines can also support the health care team in ensuring that adequate pain control is achieved, without fear of reprisal.

Recently, after having the conversation with a parent about how I could use medications to treat pain and discomfort, but not to hasten death, the mother told me "No one would do this to my pet. Why are we doing it to my daughter?" For this mother, her daughter's fate had been determined during her prolonged cardiac arrest. When the child was found to have severe neurologic insult that would not progress to

brain death, the family chose to withdraw support. Although they legally understood my limitations, they ethically had significant trouble with the fact that I could not use the tools at my disposal to "free" their daughter from her suffering. In their minds, her death was a *fait accompli*. We were only delaying the inevitable. Such cases are occasions to struggle with what it truly means to have a "good death." Our dying patients' families will never forget their final hours with their child. Those memories should not be tainted by fears that they, or we, did not do everything we could to ensure that their child died with dignity and minimal suffering.

VICKI FORMAN, RN, COMMENTS:

For health care providers, Anna's case is ethically complex. For Anna's parents, it is heartbreaking. It may be difficult for health professionals to understand just how confusing, exhausting, and emotionally devastating it can be to go through a long and difficult course of medical treatment of a chronically ill child who is unresponsive to therapy.

It is clear that Anna's medical course was characterized by unpredictable complications that were not necessarily connected to her diagnosis of Down syndrome. We don't know how her parents dealt with these surprises.

Most parents fear having a disabled child. Yet, they also know that there are no guarantees that a child will be free of impairments that may have lifelong implications. Despite their fears of what it might be like to raise a child with developmental delays or impairments, they would never have chosen the alternative of a life without that child. Most parents want their children to have the best treatment no matter how disabled those children are or how poor the prognosis.

Given all that, I would guess that these parents would not have come to their request for a DNR order lightly.

Anna, of course, has rights of her own. It is not surprising that the intensivists would question whether a DNR order was appropriate. Given the burdens of ongoing treatment and the uncertainty of the prognosis, however, such a parental request is logical and understandable. It is time to have a conversation regarding Anna's long-term care and prognosis.

For a child such as Anna, one complication can beget another. The absence of neurologic development, her significant complications, and the likelihood that further interventions will not improve her outcome should lead any provider to the ultimate questions: To what end are we continuing treatment? Would a DNR order and the withdrawal of medical treatment be the more humane choice?

The PICU team members clearly have an ethical obligation to care for Anna. Parental requests to withhold or withdraw life-sustaining treatment of profoundly disabled children who are not otherwise terminally ill may seem to be requests to violate this obligation and thus are often greeted with horror. Some team members think they could never make similar requests or decisions. But Anna's parents have the same obligation. No parent desires to make the request Anna's parents made.

In this case, however, I would assume that Anna's parents were also considering Anna's future. I would assume that their requests come from their consideration of what is in Anna's best interest. After all, they had already consented to other interventions (tracheostomy, gastrostomy), indicating that they wanted life-preserving measures when those were likely to benefit Anna. I would see their request as coming from a desire to protect Anna from further suffering in the event of a catastrophe.

Once the parents request to withdraw treatment, a more profound ethical dilemma arises. A DNR is one thing. Interventions that may hasten death

at the time of withdrawal of therapy are something else entirely. Again, a caregiver could assume in this instance that the parents were looking for an “easy” end to Anna’s complicated life. Examined from the parents’ perspective, however, the request for pain relief and sedation may actually be a way to ensure that Anna’s transition from life to death would be pain-free.

In cases in which a child is to be removed from life support, family members often focus, appropriately, on concerns about pain and suffering. If these concerns underlie the request for narcotics and sedation, the PICU team has a duty to explain as best as possible the dying process, what the parents can expect, what Anna may experience, and what interventions are best suited to ease her suffering, with the caveat that nothing can truly be predicted. It is reasonable to provide morphine to ease the work of breathing, or benzodiazepines to relieve visible agitation. It is not reasonable to medicate Anna in the absence of these symptoms, and the team is ethically bound to explain these conditions to Anna’s parents.

Finally, what are the parents’ expectations about Anna’s death, now that they have made the decision to terminate treatment? Are they looking to the medication to ease Anna’s suffering or do they believe pain relief and sedation will make death somehow easier? The choice to implement a DNR and then withhold care is very abstract, whereas the death of a child is unbearably concrete. Despite their apparent belief that medications might ease Anna’s suffering, the team is duty-bound to prepare the parents for the physiologic (and psychological) realities of Anna’s last hours. With honest communication about this process, perhaps Anna’s parents would feel more assured that pain relief and sedation may not be necessary, or that if they are, they will be administered appropriately.

WENDELA G. LEEUWENBURGH-PRONK, MD, DICK TIBBOEL, MD, AND CORINNE BUYSSE, MD, COMMENT:

The individual members of the PICU team had different opinions on the decision to withdraw medical treatment in this case because the diagnosis of Down syndrome is not generally associated with a poor quality of life. In this case, however, further treatment seemed futile to some because of the severe complications that Anna had developed in addition to the Down syndrome. Others, however, thought that her problems might still be successfully treated. In particular, they pointed out that Anna was able to breathe on her own. Thus, it seemed likely that she could be discharged from the PICU. After discharge, doctors could focus on the amelioration of the feeding problems and treatment of her seizures.

The PICU team attempted to define Anna’s well-being in terms of both her current condition and her prospects for the future. They appropriately requested a second opinion from specialists in developmental pediatrics and in genetics. The PICU team also consulted the university clinical ethics committee.

The process of evaluation was comprehensive. Over the course of several weeks these experts visited Anna multiple times. They interviewed her parents and the nurses caring for her. They also requested the opinion of Anna’s general practitioner. The general practitioner visited Anna in the hospital and discussed the situation with the parents and PICU doctor.

The team then held a multidisciplinary meeting. The doctors, nurses, and social worker caring for Anna discussed her prognosis and quality of life. They concluded that the treatment so far had not led to any improvement and that it was unlikely that continued

treatment would lead to improvement. The medical team judged Anna’s current quality of life to be very bad with ongoing pain and suffering that was difficult to treat. Thus, continuing medical treatment was unanimously regarded as only prolonging suffering and disability and could therefore be considered harmful. Therefore, the medical team agreed that the parents’ request for discontinuation of medical treatment was appropriate.

According to Dutch law, the active termination of a child’s life is illegal. It is legally justified, however, to withdraw treatment in case of medical futility and treat signs of discomfort with sedatives or analgesics. The question arising here is whether such treatment is proper palliative care or whether, instead, it is a prohibited hastening of death. The main purpose of this treatment must be to alleviate discomfort and not to shorten or end life. We explained that to the parents and provided treatment according to those principles.

JOHN D. LANTOS, MD, COMMENTS:

In cases such as this, doctors and parents have been working together against tremendous odds in the hope that they can save the precious life of a child. The months of hard work have been an emotional roller coaster, with parents and professionals buffeted between hope and despair. In such cases, it is often difficult for everybody to simultaneously come to the realization that continued treatment is not in the child’s best interest. Hope springs eternal. But if, after consultation with experts, discussion among the professionals, input from the ethics committee, and heart-wrenching discussions with parents, it is everyone’s considered judgment that further life-prolonging treatment is not beneficial, then the withdrawal of such medical treatment is appropriate. At that point, the focus of medical therapy must be on the

treatment of the patient's symptoms and efforts to make sure that the patient does not suffer during the dying process.

OUTCOME OF THE CASE

Over the course of many days before Anna's death, the responsible doctor talked with the parents openheartedly. The doctor's goal was to maintain an atmosphere of transparency and mutual respect.

This doctor placed Anna on her mother's lap in preparation for withdrawing the supplemental oxygen. The doctor had propofol at hand to be used if Anna showed any signs of discomfort. After discontinuation of the oxygen supplementation, some signs of

discomfort were noted. Propofol relieved Anna's discomfort. She died within a few minutes.

In the course of weeks and months thereafter, the medical team met with Anna's parents several times to reflect on the course of events. The parents repeatedly said that they appreciated the humane care given by the PICU team.

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