When Life-Sustaining Treatment Is Withdrawn and the Patient Doesn’t Die

One of the most difficult decisions that doctors and parents must make is the decision to withdraw life-sustaining treatment. Doctors find it easier to withdraw treatments in situations where withdrawal will be rapidly fatal rather than in situations in which treatment withdrawal will lead to a prolonged dying process. Mechanical ventilation is usually such a treatment. Withdrawal of ventilation generally leads to the patient’s rapid demise. Doctors may tell parents that death will occur quickly after a ventilator is withdrawn. But what happens when the doctors are wrong and a patient survives without life support? What should doctors do next? We present a case in which that happened and asked 3 experts to comment on the case.

Stefan Kutzsche is a senior consultant in neonatology at Oslo University Hospital Ulleval in Norway. John Colin Partridge is a neonatologist and professor of pediatrics at University of California, San Francisco. Steven R. Leuthner is a neonatologist and professor of pediatrics and bioethics at the Medical College of Wisconsin. They each recommend slightly different approaches to this dilemma.

ETHICS ROUNDS

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ABBREVIATION
IUGR—intrauterine growth retardation

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One of the most difficult decisions that doctors and parents must make is the decision to withdraw life-sustaining treatment. Doctors find it easier to withdraw treatments in situations where withdrawal will be rapidly fatal rather than in situations in which treatment withdrawal will lead to a prolonged dying process. Mechanical ventilation is usually such a treatment. Withdrawal of ventilation generally leads to the patient’s rapid demise. Doctors may tell parents that death will occur quickly after a ventilator is withdrawn. But what happens when the doctors are wrong and a patient survives without life support? What should doctors do next?

We present a case in which that happened and asked 3 experts to comment on the case. Stefan Kutzsche is a senior consultant in neonatology at Oslo University Hospital Ulleval in Norway. John Leuthner is a neonatologist and professor of pediatrics at University of California, San Francisco. Steven R. Leuthner is a neonatologist and professor of pediatrics and bioethics at the Medical College of Wisconsin.

THE CASE

An infant with severe intrauterine growth retardation (IUGR) was born at 26 weeks of gestation with a birth weight of 280 g. Extreme IUGR, oligohydramnios, and pathologic feto-placental circulation were recognized at weeks 13 and 18 respectively. The parents decided not to terminate pregnancy even when the mother developed severe preeclampsia. Elective cesarean delivery was performed after treatment with antenatal steroids; Apgar scores were 5 at 1 minute and 6 at 5 minutes. The child was intubated and transferred to the NICU. The parents were counseled about the probable poor outcome but wished to continue with intensive therapy.

The neonatal course was complicated by the development of bronchopulmonary dysplasia, moderate retinopathy of prematurity, and a subependymal intraventricular bleed. At 3 weeks of age, the little boy was weaned to external continuous positive airway pressure.

Respiratory failure developed at 3 months, secondary to persistent pulmonary hypertension and a right–left shunt. High-frequency oscillating ventilation and treatment with nitric oxide, sildenafil, and bosentan were started. However, frequent episodes of low oxygen saturation continued. About 2 months later, doctors and parents discussed the options of continuing or discontinuing ventilatory support. After the family meeting, the parents agreed to discontinue mechanical ventilation. Off the ventilator, the patient remained stable on 1 L/min of 40% oxygen by nasal cannula. Nasogastric feeds were continued. Morphine was given as required for discomfort. There was moderate respiratory distress but the child appeared not to be in pain. The parents were disconcerted because they had been led to believe that their son would soon die.

WHAT SHOULD THE DOCTORS DO NOW?

Steve Leuthner writes:

When we make the difficult decision to stop life-sustaining treatment of an infant, there is always some uncertainty about when, and whether, the infant will die. Every doctor knows cases in which the child survived longer than we had expected. Some survived for years.

In this case, some clarifications might help guide further discussion with the family on the next steps.

How much time has passed since the ventilator was stopped? If we are only an hour out, then I might discuss with the family how it could take hours to days for an infant to die. Ideally, this should have been discussed before the withdrawal. I would assure them that this is not unexpected, that we will do what we can to control pain and discomfort, and that the most important thing now is to share this precious time with their infant. The parents should be encouraged to hold, bathe, and feed their infant. I would assure them that we will do what we can to control pain and discomfort. I would acknowledge how difficult yet normal it is for a parent to struggle with the wish for a quick, comfortable death. If, on the other hand, the infant were now stable for a few days or weeks, I might acknowledge that we made an error in our prediction and I would reevaluate the infant’s medical condition. I would reconvene the family, apologizing to them if they felt we had misled them, and again explain why we can’t always predict timing of death. I would then suggest that we need to talk about goals of care for the infant.

What do we already know about the family values in this case? Clearly the mother put her own health and life at risk when she developed preeclampsia, yet she chose not to terminate at a time the clinical situation appeared grave. We know that, despite counseling about poor outcome early in the NICU course, the family chose to continue intensive therapy. So I would ask, what is now different 5 months later? What are the reasons why the withdrawal of the ventilator was recommended and agreed to by the family? Perhaps the family wanted everything done as long as there was any hope of survival but, at the 5-month juncture, became convinced that aggressive support was futile.

Alternatively, perhaps some level of “quality-of-life” threshold has been finally crossed for this family. Given the previous predictions/intuitions of death, the extreme premature gestation, the severe growth restriction and microcephaly, with an (admittedly small) intraventricular hemorrhage, and now
with severe bronchopulmonary dysplasia, pulmonary hypertension, and many episodes of hypoxia, some neurodevelopmental impairment is guaranteed. They may have agreed to withdraw the ventilator because they realized that the infant would either die or would survive with significant neurodevelopmental impairments.

Understanding their values will help us understand how to help them. If the only reason they agreed to withdraw life support was because they believed that survival was impossible, then it may be appropriate to reintegrate intensive life-saving treatment. If, on the other hand, they agreed to withdraw based on a benefit-burden proportionality and quality-of-life assessment, then things are not really different now. The infant still needs good palliative care. A palliative care service could have and now can help develop a new palliative care plan.

So what are the current options to consider and offer this family? I see 3 possibilities.

We could reintubate the infant and reinstitute an aggressive path of tracheostomy and ventilator support. This approach will likely only prolong the course of this terminal illness and increase suffering for the infant and the family during the dying process.

A second option would be to continue the current care of oxygen, gavage feeds, and morphine. We would need to think about where to draw the line on life support as opposed to symptom control. Should we use continuous positive airway pressure? Antibiotics? All these possibilities need to be considered. Depending on these choices, we need to consider where this all can take place. One potential problem with this type of plan is that sometimes it seems we set the infant, the family, and ourselves up for a situation in which we are waiting and hoping for something to happen. That could lead to a bad psychological dynamic for family and staff alike.

A final option would be to continue down a comfort care—only path. This might entail weaning the oxygen completely and giving morphine as needed if more hypoxia and distress develop. We could consider withdrawing the artificial nutrition and hydration.

With any of these choices, the overwhelming likelihood is that the infant will die. The different approaches will not change that outcome, they only alter when he will die and under what circumstances. Those choices should be determined by the family’s values and preferences for how they’d like to take care of an infant in the last days or weeks of his life.

John Colin Partridge writes:

Unexpected outcomes of medical care decisions inevitably complicate interactions with families of critically ill infants, leading to ethical dilemmas and unexpected changes in treatment plans. In the case of this markedly IUGR 290-g ex-26-week infant with pulmonary hypertension, providers and parents agreed to discontinue, and not reintroduce, mechanical ventilation. We must assume that the intent of extubating the infant was to prevent a later death despite therapy or to preclude survival with a very poor neurodevelopmental outcome. Both providers and parents presumably viewed death as a reasonable option and an expected, and imminent, outcome. The case does not relate important aspects of the earlier informed-consent process: (1) to what extent the counseling physicians prospectively discussed the possibility of a lingering death with the family, and (2) whether they attempted to ascertain the parents’ understanding of what would occur if the infant did not die soon after extubation. Now at 5 months of age and extubated, the infant is “stable,” with moderate respiratory distress on cannula oxygen. He is receiving morphine for discomfort, but shows no apparent signs of pain. The infant’s current treatment regimen is not particularly onerous, but the prognosis is either a poor neurodevelopmental outcome on the chance that he survives or a delayed death from pulmonary hypertension if he cannot survive extubated.

At this point, the medical team needs to readdress survival estimates, expected neurodevelopmental outcome, and the balance of burdens and benefits for longer-term survival of whatever duration. Reasonable treatment options appear to be: (1) to discontinue oxygen and medications and redirect the medical goals to comfort care, (2) to discontinue medications while continuing oxygen as a comfort measure, or (3) to continue all treatments in hopes that the persistent pulmonary hypertension will gradually improve. Restarting mechanical ventilation would likely not be efficacious and thus does not seem a reasonable option. If only short-term survival is foreseen, comfort care seems the most reasonable treatment option, and the one most aligned with the parents’ expectations. Oxygen might be considered a comfort measure, but the chance that it would prolong the infant’s death must be carefully weighed against the possible benefit of easing air-hunger. Analgesics should be prescribed to minimize pain, and sedatives used to treat agitation. A Do-Not-Resuscitate/Do-Not-Intubate order should be written and explained to the parents. Support for the parents and providers is critical to helping parents cope emotionally and to helping manage providers’ moral distress during what is likely to be a prolonged dying.

In contrast in this case, it appears that the infant might survive for an uncertain period of time with treatments that are neither invasive nor particularly burdensome. Overall, the infant’s expected prognosis remains poor but not hopeless. Continuing, but not escalating, the treatment regimen seems a reasonable option, allowing time to determine the
Medical care is not usually beneficial for children with extreme IUGR. This infant defied those odds and survived for several months, although with life-threatening complications that continued to require frequent interventions. It became increasingly unlikely that the infant would ever be able to leave the hospital. As clinicians told the parents that they felt that their interventions were not of any benefit, the parents agreed to discontinue artificial ventilation. Doctors and parents both expected that the infant would die quickly. The plan, then, seemed to be as follows: 1. The infant would be extubated and doctors would see how the infant did. 2. The doctors and parents could both hope that the infant may make it. 3. If not, doctors would not reintubate.

In my opinion, all members of the team should respect the infant’s unspoken right to live and the parents’ wishes to have their infant survive. The clinician’s role, at this point, is to strengthen the parents’ relationships with the child and prepare them in the practicalities of the withdrawal of life support. Parents must be told that even though the doctors did not expect their infant to live after withdrawal of ventilation, it would be possible that their son could live for days or even weeks. The parents hoped that their infant would survive. They are prepared for the worst. But when the infant confounded expectations and seemed to “want to live,” the parents also wanted their infant to live.

The parents asked doctors for acting to benefit their child by sustaining their child’s life in a hope that his peaceful death could occur later. They expected clinicians to treat symptoms of discomfort, independently of whether their child received life-sustaining care or only palliative care. Their wishes were based on the principles to benefit and avoiding harm. This created a considerable dilemma. The parents may have lost confidence in the doctors’ ability to predict the child’s outcome. The doctors may have felt that they let the parents down by not accurately predicting what would happen after the ventilator was discontinued. What should the doctors do now?

The only achievable goal now was to build a stable therapeutic and empathic relationship between the parents and medical team. The latter needed to help the parents to understand what medical and nonmedical end points and goals might be achievable. In particular, they must support the parents coming to terms with the uncertainty of the infant’s life span, and in finding some meaning in their infant’s slow deterioration. Above all, the parents needed to know that the team had not abandoned them. The doctors and nurses should be careful to use neutral or positive language and not to suggest that the infant’s continued survival was a problem.

John D. Lantos comments:

In the United States, it is legal to withdraw life-sustaining medical treatment under a variety of circumstances. But it is not legal to give a lethal injection to a dying patient. The ethical difference between the 2 sorts of interventions may seem philosophically precious. After all, some say, the goal in both is to bring about the death of the patient in a situation where the prognosis is dismal. But one of the justifications for permitting the withdrawal of treatment but prohibiting active euthanasia is that we are sometimes incorrect in our prognosis. We may think that the withdrawal of life support will lead to a patient’s death. But it doesn’t. The most famous instance of this phenomenon is the case of Karen Ann Quinlan. Ms Quinlan survived for 9 years after her ventilator was withdrawn.
We should always explain to parents that this outcome is possible and that it is not the withdrawal of the ventilator that causes death, it is the underlying disease. This may comfort parents by absolving them of responsibility for authorizing the death of a loved one. Cases like this one show that the distinction between treatment withdrawal and active euthanasia can be valid and morally important. Such cases should make us humble.

OUTCOME OF THE CASE

The medical team and the parents assessed the infant daily. The parents were helped to understand that the choice of palliative care did not mean they were failing their child. Opportunities were created for them to express emotions, and to review and honor their son’s life; they slowly prepared to bring their child home and were offered a step-down family room outside the neonatal unit. The infant was discharged at the age of 6 months on nasal oxygen insufflation, oral morphine, and nasogastric feeding. The community health service supported both the patient and the family. Nurses were engaged for 7 night shifts a week and the hospital team visited daily. Although becoming increasingly difficult to sedate and needing more morphine, the infant remained responsive and interactive. After 3 weeks with palliative home care and a memorable time for the family, the boy died peacefully at home with his parents.

REFERENCES


FROM FIBER TO FULLNESS, FRUIT FILLS: With frequently changing views on what foods are most nutritious, the value of fruit, because of its high natural sugar content, is often debated. As discussed in the New York Times (Well: July 31, 2013), researchers have been investigating fruit and fruit intake in order to better guide national nutrition recommendations. When examining the value of nutrient consumption, considering the type of sugar and how it is packaged is essential. Fructose, a monosaccharide found in whole fruit, is often avoided by dieters. A simple web search of the term “fructose” brings up a barrage of articles linking fructose to weight gain, high blood pressure, and even death. However, research suggests that avoiding fruit to minimize fructose intake is inappropriate. Previous feeding studies linking fructose consumption with elevations in body fat, blood pressure, and insulin resistance provided unrealistically high amounts of fructose. Feeding studies showed no adverse effects with isocaloric substitution of fructose for glucose at average consumption levels for body weight. Additionally, many studies have linked whole fruit consumption to protective effects against obesity and weight-related morbidity, possibly due to their high fiber content or the delayed release of the sugars from the fruits in the gut. Even those investigators most critical of sugar in diets recommend continued consumption of whole fruits. With the effects of obesity on the minds of many researchers and citizens, continued investigation of the value of fruit is essential in ensuring we make healthy food choices.

Noted by Leah H. Carr, BS, MS-IV
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