Providing Comfort or Prolonging Death for a Baby with "Dead Gut Syndrome"?

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Case Summary

The patient was born at 29 weeks gestation. There was a prenatal diagnosis that the child's small intestine had developed outside of the abdominal cavity. The length of gestation had made the initial prognosis good. But after birth, surgery to place the intestine back into the abdominal cavity found that the baby actually had very little small intestine and a diagnosis of "dead gut syndrome" was made. The amount of small intestine was not compatible with survival. The transplant service saw the baby twice and each time said the baby's profile did not meet the transplant protocol.

The attending physician discussed the case with the family. The parents both insisted they did not want the baby to suffer more than necessary. Thus it was decided that the baby would be made DNR, total perenteral nutrition (TPN) would be discontinued, and infections would not be aggressively treated. Mechanical ventilation would be continued, but if the baby extubated himself, he would not be reintubated. However, the baby was successfully weaned from the ventilator over the course of several days.

The patient continued to live for almost two weeks, causing dismay among all parties. At that time, the attending physician called the ethics consultant and asked if he was "doing the wrong thing" by depriving the baby of TPN for so long. He was concerned about the length of this process and the fact that it might be causing the family to doubt their decisions. The consultant argued that the actual length of this process did not affect the ethical dimension as long as the patient is kept comfortable. Since the patient's potential for progress was nonexistent and the patient's length of life would be only a few weeks to a few months with aggressive treatment, the declining of nutrition and hydration by the family was within contemporary ethical standards.

Although the TPN was withdrawn, IV fluids continued to be given and this likely kept the patient alive substantially longer than if the fluids had been discontinued. The ethics consultant stressed to the attending physician that fluids need not be administered as long as the baby is kept comfortable by alternate means. The attending physician discussed this with the family and the IV fluids continued. In general, the parents were comfortable with continuing the current level of treatment but not in withdrawing anything further. The patient finally died three weeks after the TPN was discontinued. The length of the dying process caused serious distress among the nursing staff, who felt they had helped to "kill" this baby. The attending physician was not so sure he would be quick to offer discontinuation of TPN in the future. The ethics committee members heard about this case from the consultant's report and were concerned.

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Commentary

Robin Lynne Pierucci

The patient in this case does not have enough small bowel to be compatible with life. Given this prognosis the decisions to establish a DNR status and discontinue TPN are both appropriate. However, by not attempting an earlier extubation or withdrawing the hydration as well as the TPN, the attending physician set the stage for the ensuing disaster.

From a medical standpoint, there was no obvious reason for this child not to recover respiratory function. We do not know if the infant would have spontaneously breathed well enough to survive without the ventilator's assistance, but in slowly weaning it off over "several days," a life that could not be saved was undoubtedly prolonged. Regarding the hydration, though we are not told exactly what intravenous fluid was running, it is usually a combination of sugar, water, and some electrolytes. Roughly speaking, in stopping the TPN, the balanced nutrition for growth and development was removed, but by continuing hydration, enough sugar and water were continued to sustain life. Again, because a treatment was not withdrawn, life was sustained. Because there was no hope of survival without this medical intervention, the infant's life was prolonged.

From an ethical standpoint both of the above actions, extubating the infant earlier and stopping the hydration, are perhaps even more emphatically appropriate. As stated by the AAP committee on bioethics, "Although many health care professionals feel reluctant to discontinue life-sustaining treatments, most philosophical and legal commentators find no important ethical or legal distinction between not instituting a treatment and discontinuing treatment already initiated. . . . Continuing nonbeneficial treatment harms many patients and may constitute a legal, as well as moral, wrong."[1]

It is impossible to know if with earlier extubation this child would have died due to respiratory insufficiency, but the point is that treatment was continued in a fashion consistent with life preservation as opposed to letting go of one we could not fix. The IV fluid in this case is a nonbeneficial treatment. It is not sustaining the patient until a cure becomes possible, nor is it treating the disease process itself. The intravenous fluid is prolonging a life whose "potential for progress was nonexistent." This is not ethically responsible medicine.

Perhaps in not withdrawing all support, the attending physician was attempting to be gentle with a family who had just received admittedly heartbreaking news. Even if this were the case, medically, the attending should have been cognizant of the scenario he had set up in mixing and matching a little withdrawing with a little withholding, and let the family know of the possible outcome (i.e., it might take a long time to die this way, meaning weeks). Perhaps if the parents had been made aware of this, they would not have been "comfortable with continuing . . . treatment but not in withdrawing." That the attending physician "was not so sure he would be quick to offer discontinuation of TPN in the future" means he still does not fully understand the ethical or medical ramifications of his decisions. Further education of this attending is necessary, and continuing to recommend discontinuing IV fluids remains ethically and medically appropriate.

Note

1. Kohrman A. American Academy of Pediatrics: Guidelines on forgoing life-sustaining medical treatment. *Pediatrics* 1994;93:532–6, at 532.

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Commentary

Jacqueline J. Glover

The case of a dying baby with "dead gut syndrome" is one of the most difficult in pediatric ethics. I have been involved in several such cases and they are extremely challenging for all parties, especially the parents. With the luxury of being an "armchair quarterback," I will comment on this case from the perspective of when it first began and at the end point described in the narrative.

What makes this case uniquely difficult is that we have a baby with a normal brain who has full potential to feel the discomfort of dehydration and who has no comorbidities such as sepsis that can readily lead to death if treatment is forgone. We must squarely face the difficulties associated with the fact that this baby will die because he cannot eat.

In the cases in which I was involved, the ethics consultant(s) first met with the team to give them an opportunity to think things through together and to sort out the full range of clinical choices and possible sequelae and their own values and feelings about these choices. Basically, there are three options. The first is full aggressive support with the plan of eventual transplant. TPN would be used as a bridge to transplant. An intermediate plan would use TPN to promote the longest possible survival with no plans for transplant. The third choice would be a comfort care plan.

The first choice was ruled out by the transplant service. The second choice would involve maintaining the baby on TPN with the goal of having him survive as long as possible, understanding that it might not be long considering the multiple side effects of prolonged TPN use, including infections and liver failure. Would that choice really be in the baby's best interests? Are the burdens associated with TPN outweighed by the prolonged survival? Many professionals, including, presumably, the team in this case and the physicians and nurses with whom I worked, consider the burdens disproportionate to the benefits and would not recommend this option. The team would need to consider if and how they would go along with this choice by the family. What services are available to support this family and this level of care?

The third option of a comfort care plan would be the best. Every intervention would need to be assessed according to the goal of not prolonging the baby's dying and keeping him as comfortable as possible. The team would need to work through what was involved in a comfort care plan—from the ventilator to TPN, antibiotics, IV hydration, morphine—and where the baby will stay and how the parents can be present as much as possible. Hopefully, it would become obvious to the team that withdrawing TPN and maintaining IV hydration is not a good choice. It merely prolongs the dying and is not necessary for comfort. The baby can be kept comfortable with morphine.

What about the ventilator? Some babies with "dead gut syndrome" are very premature and septic and they need the ventilator to survive. Withdrawing the ventilator in these circumstances is totally appropriate and spares the family the slow death from dehydration. It seems the baby in this case was not septic and not very premature and was only on the ventilator following the surgery. Would it be morally acceptable to remove the ventilator rather than wean the baby as was done in the case? I think so. This is a baby with a condition that is not compatible with life and we wouldn't put him on a ventilator to treat emerging respiratory problems. It is true that we

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"caused" the respiratory problems with the surgery. But—applying the same sort of reasoning involved in a decision not to suspend a DNR order in the operating room—patients need not be sustained even through iatrogenic respiratory problems. Depending on the baby's current status, it would be important to prepare the parents for what they could expect, either immediate death or death within a short time from respiratory failure. If the baby were already on extubatable settings, then a respiratory death is not likely.

The next step is to coordinate a meeting between the team and the family. The family should be invited to bring a support person along with them (a chaplain, minister, or trusted relative or friend). The team should provide the family with the current status of the baby. The family should be asked about their values. What's most important to them in the care of their baby? What are they hoping for? What do they fear the most? Are there particular spiritual or religious views that inform their views? What support mechanisms are available to them?

The team then explains the range of options in the care of the baby. A discussion follows, matching the families' values with the options. I am assuming from the case that the family would choose a comfort care plan. Rather than focusing on individual interventions (like the ventilator, IV fluids, antibiotics), they choose the goal and then discuss the means to support this goal. A comprehensive plan of care is developed and the parents are fully informed about what to expect. The discussion is framed in terms of what will be done to meet the family's goals and values, rather than in terms of only what will not be done or what will be taken away. Hopefully, the family will see the rationale for forgoing IV hydration as well as TPN. Disagreements will need to be negotiated.

If an ethics consultation were called at the end point in the case, I would try to reconstruct the rationale and values behind the current choices. A plan to "not escalate care" is attractive as a potential compromise, but it trades one type of discomfort for another—the discomfort associated with withdrawing everything up front as part of a cohesive plan of care with the discomfort of unnecessarily prolonging the dying process. I would strive to reconstruct, in so far as possible, the steps that I would take in the first place with a special emphasis on trying to secure appropriate spiritual and emotional support for this family. I would try to be available to the staff (especially nursing staff) to discuss their questions and concerns. After it is over, I would be sure to schedule some follow-up educational opportunities with the staff to discuss this difficult case.

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Commentary

Carson Strong

In this case, one should expect that providing hydration sufficient to maintain fluid balance would tend to prolong the dying process. In a well-known case at Johns Hopkins University, fluids (and feedings) were withheld from a newborn with anomalies, and the infant died after 15 days,[1] compared to three weeks in the present case, in which fluids were given. In the famous Baby Doe case, fluids and nutrition were withheld and the infant lived only six days.[2] In the case at hand, prolonging the dying process risks causing suffering for the infant from various complications that can arise, and it adds to the emotional burden on the family. We learned from the Johns Hopkins case that prolonged dy-

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ing is also emotionally difficult for the nurses and other health professionals caring for the infant.[3]

An important feature of the present case is uncertainty concerning what the infant is experiencing. In particular, we do not know the degree of discomfort, if any, caused by withholding nutrition or reducing fluid input. The caretaker's task is to keep the infant comfortable in the face of this uncertainty. If there is concern that thirst would be caused by withholding sufficient hydration to maintain fluid balance, then any discomfort associated with thirst could be addressed by sedating the infant to the point of unconsciousness. In fact, one could argue for sedation in this case on independent grounds: nutrition was being withheld, and sedation would be a reasonable palliative measure in case withholding nutrition caused hunger. Maintaining an IV line could be justified as a route for sedation. One possible approach would be a continuous IV infusion of morphine. This implies, of course, that some IV fluids would be given.

These considerations support the view that in the case at hand, it would not be necessary to infuse sufficient fluids to maintain fluid balance. Doing so could prolong the dying process but would not provide added comfort for the infant. Withholding nutrition and "adequate" hydration is justifiable because the infant's condition is incompatible with long-term survival. Sedation would be justifiable as a comfort-providing measure,[4,5] and an IV route would seem to be more consistent with comfort care than injections. This case illustrates the fact that American healthcare often does not do well at providing comfort to the dying. It speaks volumes that the neonatologist in this case looked back and concluded, not that maintaining fluid balance was unnecessary, but that nutrition should perhaps have been provided. Currently, there are no established clinical guidelines for comfort care of dying neonates. Further investigation of the use of sedation and analgesia for dying infants is needed.

In counseling the parents, the physician should advocate a dying process that is as comfortable for the infant as possible and free of interventions that prolong dying. The physician should try to reach an agreement with the parents that this is an appropriate goal. Once this goal has been agreed upon, the physician should propose a plan for implementing this goal that includes stopping nutrition, giving sedation for comfort, and giving only the amount of fluids necessary to provide sedation. If concern later arises that the infant is taking "too long" to die, the parents (and nurses) can be reassured that the infant is being kept comfortable.

Some neonatologists or neonatal nurses might be reluctant to withhold nutrition or reduce fluids because they think this would constitute killing the infant. However, this would be an inappropriate way to characterize such care in this case because the cause of death is the infant's inability to digest food. There is a need for further discussion of this issue among neonatologists and neonatal nurses, so that they can come to terms with the idea that withholding nutrition and reducing fluids sometimes is the ethically preferable approach.

Notes

1. *Who Should Survive? One of the Choices on Our Conscience*. Videotape. Joseph P. Kennedy Jr. Foundation.
2. Fost N. Putting hospitals on notice. *Hastings Center Report* 1982;12(4):5–8.
3. See note 1, *Who Should Survive?*
4. Partridge JC, Wall SN. Analgesia for dying infants whose life support is withdrawn or withheld. *Pediatrics* 1997;99:76–9.
5. Kenny NP, Frager G. Refractory symptoms and terminal sedation of children: ethical issues and practical management. *Journal of Palliative Care* 1996;12:40–5.

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What Actually Happened

The ethics consultant attended two of the weekly nursing conferences on this unit to process the feelings that the nurses expressed about the case, to explain the kind of ethical reasoning that has evolved regarding the forgoing of life-sustaining treatment, and to acknowledge some things he could have done better. In particular, this consultant came to believe that he had made a mistake in inferring that his job was only to provide the information to the attending physician that was requested. This physician had suggested that he would prefer to deal directly with the family and only needed information from the consultant. Although the physician continually held open the possibility that at some time in the near future he might ask the consultant to meet with the family, that request never came despite repeated offers of assistance.

In general, the consultant now thinks that either one should carry out all the steps that comprise a normal consultation process, including meeting with the family and then facilitating a meeting of the healthcare team with the family, or one should sign off the case. He wonders if being present in the background but unable to help may simply give ethics a bad name.

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