When Parents Refuse a Septic Workup for a Newborn
Elizabeth Simpson, Margaret Moon and John D. Lantos

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When Parents Refuse a Septic Workup for a Newborn

Sometimes, parents refuse medical intervention for philosophical reasons. Pediatricians have an obligation to protect children from medical neglect on the part of their parents. Often, it is not clear where exactly to draw the line between parental rights and the best interest of the child. The law is clear, however. If the doctor suspects medical neglect, he or she has an obligation to notify child protective services (CPS). CPS, and eventually a judge, will then determine if the parental behavior is or is not legally acceptable. For doctors, however, there is often a trade-off between protecting the child and preserving a therapeutic alliance with the parents. We present here a case of a newborn at risk for sepsis whose parents do not want standard medical evaluation and treatment. Two general pediatricians, Elizabeth Simpson, MD, director of the general care nursery at Truman Medical Center, and Margaret Moon, MD, MPH, a bioethicist and pediatrician at Johns Hopkins School of Medicine, offer their responses to the case.

CLINICAL ETHICS CASE REPORT: PART I

A 30-year-old woman presented to labor/delivery at term gestation after a failed home delivery with a lay midwife. Her membranes had ruptured 38 hours before delivery. One hour before presentation, she had developed a temperature to 102°F. The pregnancy had been uncomplicated. She had early prenatal care and a negative screen result for group B streptococcal infection 1 week before delivery. Her white blood cell count was 49,000/μL with 18% bands.

The woman and her husband refused fetal monitoring. They insisted on carrying out their plan for a natural birth and said that, right after delivery, they wanted to be discharged and take the child home. The obstetrician recommended that the mother receive intravenous antibiotics. She agreed to this treatment.

The pediatric service was consulted 1 hour before delivery. The parents were informed that the infant was at significant risk for a life-threatening infection, and a sepsis workup and intravenous antibiotics were recommended for the infant immediately after birth. The parents and their midwife, who remained at the bedside, continued to insist that no interventions be provided to the infant unless the infant looked clinically ill.

The infant was born via normal spontaneous vaginal delivery with a pediatrician present in the delivery room. His Apgar scores were 7 at 1 minute and 8 at 5 minutes. Examination was normal. Pediatricians continued to recommend a sepsis workup and intravenous antibiotic therapy, and the parents continued to refuse and were packing their bags to go home with the infant. They promised to bring the infant back if he looked sick.

Margaret Moon

This case is about the limits of our duty to respect parental autonomy and, more specifically, how pediatricians might justify and implement
an abridgment of parental authority. It challenges us to frame a plan for caring for children when parents question standard medical knowledge and reject standard practice.

Generally, parents have the right to make medical decisions for their children. This right derives from our beliefs about the parent-child relationship and our social and political notions about the family and family’s rights to privacy. We respect this right, in part, because it reflects a humble awareness of the limits of medicine. We may think that we know what is best, but we can be wrong, because medicine is complicated and health is only 1 aspect of well-being.

We presume that the parents have the child’s best interests at heart, or at least the child’s good-enough interests. As pediatricians, we celebrate family and support the role of parents. We are acutely aware, however, that the presumption of parental goodness is highly rebuttable. We recognize limits, particularly when the parental choice puts a child in imminent danger, when we suspect that the relationship is abusive, or when parents seem to lack decision-making capacity.

So there is the tension: we have a legal and moral tradition that emphasizes the parents’ rights to be left alone and to raise their children as they see fit. We do not want to interfere with families, because we believe that an intact family benefits the child. However, we also have an obligation to make an independent assessment of what is best for the child and to override parents’ decisions if they are too egregious.

This case raises questions about whether parental decisions crossed that threshold. The parents’ rejection of antibiotics for their infant is inconsistent with established medical knowledge but not uncommon in the alternative medicine community. Even if we think that the belief is incorrect, we cannot call it delusional. They are not incompetent. More information regarding the parents’ understanding of the medical issues and their capacity for decision-making in general would be helpful in confirming that they have decisional capacity, but, as presented, there is no reason to doubt that they do.

Regarding abuse, there is no implication that these parents want anything less than the best for their infant. After all, they sought early prenatal care and complied with care throughout gestation.

We are left with the question of whether refusal of standard medical therapy in this case puts the child in imminent danger. The incidence of positive blood culture results in asymptomatic term infants whose mothers received intrapartum antibiotics for clinical chorioamnionitis is 1.5% (13% for symptomatic infants).1 American Academy of Pediatrics guidelines clearly specify admission and intravenous antibiotics in this setting, because untreated early-onset sepsis is often devastating.2 However, 98.5% of asymptomatic infants likely will not develop sepsis. Does this level of risk equal “imminent danger?” Does it warrant forcing hospitalization of the infant over the objection of the parents? Who is allowed to decide? Are there other therapeutic options that offer room for compromise?

Application of the data to this specific case requires a subjective interpretation of the meaning of the risks in this setting. William Osler aptly described medicine as “a science of uncertainty and an art of probability.”

The best option in this case is to recognize the limits of medical knowledge and focus on developing a therapeutic alliance with this family that will protect the infant in the next few days and beyond. We have excellent reason to be concerned about this infant but imperfect data with which to justify aggressive abridgment of parental authority. We have substantial reason to respect this family’s goals and interests. Communicating respect and focusing on the shared goal of promoting the infant’s safety might improve dialogue. Forcing antibiotic therapy might make it functional therapeutic relationship impossible. If the current conflict causes these parents to avoid contact with the medical community in the future, the child will suffer. I would make it clear to these parents that observation of their child at home is against medical advice. I would stress that the risk to their infant, although small, is potentially deadly. I would try to negotiate a compromise—maybe a plan that involves hospitalization with cultures and observation but without presumptive antibiotics. If I could meet these parents halfway, I might be able to protect the child’s interest miles down the road.

Elizabeth Simpson

The first thing that I would do as the attending physician on this case would be to call for a social work consultation. Cases such as this require multidisciplinary input. Together with my social worker, I would contact CPS. This case raises legal issues that are more complex than the medical issues. I would seek expert help.

My overall goal would be to persuade the parents to voluntarily allow a septic workup and the initiation of antibiotic therapy. The benefits of treatment in this case are overwhelming. The risk of asymptomatic sepsis is thought to be between 1% and 2%, and consequences of the untreated illness are extremely dire. For me, this rises above the threshold of acceptable risk for an infant when there is a safe, effective, and relatively nonburdensome treatment.

I understand that the parents disagree, but as a pediatrician my moral obligation is to the infant. Furthermore, I have a legal obligation to report parents who are not acting in the...
The next morning, after the infant had received a dose of antibiotics, the parents told the pediatricians that they had found a different pediatrician—a family practitioner who accepted the care of the infant and who had admission privileges at the hospital. That doctor wrote a discharge order for the baby.

What do you do now?

Elizabeth Simpson

Despite being fired, I have a responsibility for patient-information handoff. This transfer of information and care went poorly. Either insufficient information was exchanged or the receiving physician was unwilling to follow the current standard of care. I would contact the family physician and request a change in his or her plan of care. If the physician’s plan remained unaltered, I would involve the medical director of the nursery, the ethics committee of the hospital, and the executive committee of the hospital. Points of discussion would include the following.

1. What are the medical staff privileges of the family practitioner? Is the physician credentialed to care for infants who require more than routine care? Many hospitals require generalists to have consultation privileges in order to care for ill newborns.

2. Although the infant received a dose of antibiotics already and looked good, it would still be of significant benefit for this infant to continue antibiotics until culture results are available.

3. This infant is not a candidate for early discharge. Discharge is clearly not in line with the standard of care. Because of the high-risk status of this infant, the infant cannot be discharged safely until he is older than 48 hours.

I would notify the hospital ethics committee, legal affairs office, and executive committee. I would recommend that I or another pediatrician on staff

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Simpson et al would need to treat the infant with anti-

we were waiting for the results, we plan to get blood tests now that will give

permanent disability. I would explain our

they develop symptoms can be left with

older children and that it is dangerous to wait until they develop symptoms, be-

cause infants who are not treated until they develop symptoms can be left with permanent disability. I would explain our plan to get blood tests now that will give us results in 2 to 3 days and that, while we were waiting for the results, we would need to treat the infant with anti-

biotics. I would explain that the risks of antibiotic administration are extremely low. Finally, I would stress that the blood tests and treatment with intravenous anti-

biotics are not optional.

I would restate the plan as clearly as possible:

- obtain a complete blood cell count and blood culture now and insert a heparin lock (the parents can choose whether to observe the procedure);
- start the infant on intravenous antibiotics and explain the schedule to the family; and
- ask about feeding plans and voice commitment to support breastfeeding and rooming in as much as possible.

I would then offer the family a few minutes alone to discuss/digest what they have been told and come up with some questions for me. While they were discussing this, I would recontact my social worker, check on the status of CPS involvement, and alert the hospital’s security department to be ready to stop the parents if they tried to take the infant out of the hospital.

**CLINICAL ETHICS CASE REPORT: PART II**

**CPS was contacted. They contacted the police, who came to the hospital. Confronted with the police, the parents agreed to allow the infant to stay in the hospital and to have a diagnostic workup and intravenous antibiotics. They agreed to blood tests and to 1 dose of antibiotics but did not consent to a lumbar puncture. Given the parents’ acquiescence, the police and CPS did not pursue a court order for protective custody. The infant’s initial complete blood cell count revealed a white blood cell count of 14 500/µL without a left shift. The infant’s vital signs remained within normal limits.**

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**Elizabeth Simpson**

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I would notify the hospital ethics committee, legal affairs office, and executive committee. I would recommend that I or another pediatrician on staff
assume care for the infant. I would again contact CPS to obtain custody of the infant. At the time of eventual discharge, I would refer this case for both internal and external peer review.

**Margaret Moon**

Although care has been transferred to a different physician, the risk to the infant has not changed. The medical team’s duty to this infant has changed but has not disappeared. The relationship with the parents has changed dramatically. As this story unfolded, it seemed reasonable to anticipate that an effective therapeutic alliance with this infant’s parents was possible. As noted previously, there are 2 important points of contention in this case: (1) the definitions of harm as imminent; and (2) the view that presumptive antibiotic therapy was the only option for preventing serious harm. Both views relied on subjective interpretation of limited data. Negotiation between doctors and parents about a satisfactory response to these 2 disagreements seemed possible. However, attempted negotiation failed. I would not have done what the doctors did in this case, but now that the state, in its CPS manifestation, has intervened to protect the interests of the child and the parents have tried to initiate an end run around the state, the situation has changed.

At this point, new questions about the parents arise. Is their behavior still consistent with a desire to promote the best interests of this infant? Do they still seem to have adequate decision-making capacity? Do their preferences matter anymore?

There is no specific evidence that the parents wish anything other than well-being for the infant. The persistent problem is a difference in belief about the risks and benefits of antibiotic therapy. The parents’ behavior, particularly the lengths to which they are going to avoid standard therapy, makes one wonder about their ability to properly care for their child. A careful re-consideration of their decision-making capacity, particularly their capacity to make choices that will adequately protect this infant, is warranted.

At this point, I would inform the infant’s new physician of the infant’s history and the potential implications of the decision to discharge the child. I would then notify CPS of the parents’ plans to leave the hospital. I would call security to delay the parent’s departure until CPS could reevaluate the situation.

**EDITOR’S COMMENTS**

The toughest ethics cases arise when fundamental values are in conflict and every choice is bad. This case raises complex questions about the threshold that doctors should use for reporting suspected medical neglect. Such cases are most complicated when the parents are not classically neglectful but, instead, just have different values regarding appropriate medical care. The doctor must then decide whether to allow parental values to determine the course of care or to use their medical authority to override parental rights. Ultimately, doctors are not the ultimate decision-makers about the proper limits of parental authority. Our job is to notify the courts. The judge makes the ultimate decision, and we are bound by it.

Drs Simpson and Moon clearly set the reporting threshold differently. Dr Simpson argues that the threshold should be quite low. After all, parental refusal to allow a relatively risk-free medical intervention endangers the child. Dr Moon sets the threshold a little higher; she is willing to compromise and to alter her treatment plan to preserve a therapeutic alliance with the parents. Neither pediatrician, however, is comfortable with the parents’ own preferences to take the child home. But another doctor is. When doctors disagree, the courts will often defer to parents. In 1 such case, the New York Court of Appeals wrote that parents only had to provide treatment that had been “recommended by their physician and not totally rejected by all responsible medical authority.”

In this case, everyone agreed that the risk of sepsis for an asymptomatic child was low. For the pediatricians, that was outweighed by the fact that the consequences of sepsis would be dire. For the family practitioner, the balance tipped the other way.

As might have been expected, given these odds and that the child did receive a dose of antibiotics, he remained stable. The 1 dose of antibiotics also bought a little time. The initial culture reading would likely be back soon.

Personally, I would have reported the case to CPS initially. However, because the child remained stable and had received a dose of antibiotics, I would not have stood in the way of discharge the next day. I would have tried to talk to the parents and the family practitioner into administering 1 more dose of antibiotics before the infant went home. I would have sought an agreement from the parents to bring the child back if the culture results were positive.

—John Lantos, Section Editor

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3. In re Hofbauer, 393 N.E. 2d 1009 (NY 1979)
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