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# Child Abuse, Incarceration, and Decisions About Life-sustaining Treatment

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abstract

Most critical care interventions for children occur in the framework of a supportive environment with loving parents that are present at the bedside to help to guide medical interventions through shared decision-making. What happens, however, if the parents are precluded from being at the bedside because of legal entanglements? How should clinical decisions progress in those cases? In this Ethics Rounds, we present the case of an infant with severe hypoxic-ischemic encephalopathy at birth whose mother was incarcerated shortly after delivery. We explore clinical and legal challenges that the medical team faces in determining best interests for the infant in this context and difficulties in deciding what therapies to provide and for how long.

Decisions about withdrawing life-sustaining treatment of infants with hypoxic-ischemic encephalopathy are complex. Prognostication can be difficult in infancy. Parents are emotionally stressed. Such decisions become exponentially more difficult when the cause of the encephalopathy may be related to medical neglect and the mother is charged with a crime and imprisoned. In this article, we present such a case and analyze the intertwined legal and ethical issues.

## THE CASE

An infant is precipitously born at term after a pregnancy complicated by no prenatal care, maternal illicit substance abuse, and meconium aspiration syndrome. Apgar scores were 0/0/2, and the infant has profound acidosis, hypoxia, and multiorgan system failure after delivery. Therapeutic hypothermia is initiated, and extracorporeal membrane oxygenation is considered because of unremitting pulmonary hypertension. However, the infant is independently deemed not to be a candidate for extracorporeal membrane oxygenation by 2 separate quaternary medical centers because of the concern for severe hypoxic-ischemic encephalopathy with potential devastating neurodevelopmental impacts.

As a warrant had previously been issued for her arrest, the infant's mother is incarcerated after her hospital discharge. She faces new charges for felony drug possession. She is also charged with child endangerment because she had had a rupture of membranes 2 days before seeking medical treatment and an illicit substance in her possession on arrival to the labor and delivery unit. She has been informed if the infant dies she will face additional, more serious charges to the extent that the law will allow in the state. Child Protective Services (CPS) has chosen to sever all parental rights with the exception of medical decision-making.

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She is not being allowed to visit the child and can only be reached by prearranged phone calls, but she repeatedly expresses that all life-supportive therapies continue with the exception of chest compressions were the infant to require cardiopulmonary resuscitation. The infant's paternity is in question, and no other family members have attempted to contact the medical team or visit the infant.

The infant is 2 weeks old and remains ventilator dependent with high respiratory support needs, renal dysfunction, and labile vital signs. The infant has regained minimal neurologic function principally limited to basic brainstem reflexes. Neurology consultants have reviewed the progression of results of EEG studies over the past few days and believe that the neurologic outcome will be decidedly poor with no meaningful recovery moving forward. The mother continues to be held in custody, pending the outcome of her infant.

Who should make decisions regarding life support for this infant?

## PAUL C. MANN, MD, COMMENTS

Parents are presumed to be the appropriate surrogate decision makers for their children until doctors suspect and judges agree that they are not acting in the best interest of the child. In this case, the mother's failure to seek medical care after her rupture of membranes, in concert with her presumed illicit substance abuse and the previous warrant for her arrest, led to an incarceration after delivery. In situations of parental arrest, medical decision-making authority is not automatically terminated, but imprisonment precludes their abilities to be present for medical office visits and/or at the bedside during hospitalization. The medical team can reach the mother by phone, but the state is preventing any face-to-face meetings. This could contribute to a lack of understanding of her infant's grim neurodevelopmental and clinical prognosis.

The criminal charges of medical neglect for her behavior during pregnancy are ethically troubling. Many groups, including the Association of Women's Health, Obstetric and Neonatal Nurses; the American College of Obstetricians and Gynecologists; and the American Academy of Pediatrics (AAP) oppose laws that criminalize maternal behaviors during pregnancy.[1] Expectant mothers are typically given wide latitude to make decisions, even when obstetricians and pediatricians disagree with those decisions. Courts rarely intervene in such cases, even when the birth outcome could be jeopardized. Pregnant women have the same rights as other adults to make medical decisions. A court-ordered cesarean delivery would be coercive. Doctors who perform one without a court order could be committing battery. So, the first important point in this case is that mothers should not end up in jail as a result of birth outcomes.

In addition, the mother in this case wants what many reasonable parents want in similar circumstances. In cases of severe hypoxic-ischemic encephalopathy at birth, parents frequently require weeks of supportive clinical counseling to cope with the sudden tragedy of an unexpected birth outcome and accept the profound neurodevelopmental impairments that may result. Some parents make the difficult choice to withhold or withdraw life-supportive therapies. Others ultimately pursue more aggressive medical interventions.[2] Diekema and Wilfond[3] support a compassionate approach to parental decision-making in these contexts, allowing for significant latitude in decisions the medical team might not agree with even when neurodevelopmental impairments may be profound. Wilkinson[4] suggests a thoughtful assessment of the benefits and burdens of continued medical intervention before considering whether it may be appropriate to withhold or withdraw life-sustaining therapies. In this case, continued mechanical ventilatory support risks a future with profound neurologic impairments and potential suffering lived separate from the loving support of a birth family. This is a future that many reasonable people would consider to be not in the child's interests.

Such deference to parents is based on the recognition that parents bear the impacts of their choices. But that is not true in this case. The state has (at least temporarily) severed all maternal rights to her infant with the exception of medical decision-making. Although she may grieve a life with substantial disability for her child, she will not be responsible for caring for her infant at home in the foreseeable future, if ever.

Her choice to continue life-sustaining treatment of her child, then, could be based on 1 of 3 hopes. She could wish to continue life-sustaining treatment because (1) she hopes and believes that her infant might have a meaningful neurologic recovery, (2) she believes that her infant's quality of life will be good enough even with profound disability, or (3) she fears the criminal implications for herself if the infant dies.

Unfortunately, the medical team is precluded from assessing the mother. With no other surrogate decision makers available to guide therapy, providers are left to weigh the burden of continued medical intervention against the significant possibility of ongoing suffering with uncertain benefit. In the end, taking no legal action to remove maternal medical decision-making will result in a medically complex infant with profound neurologic impairments

being cared for in the state foster care system.

The medical team has an obligation to advocate for the child. In this case, that means that they should petition the court to appoint a guardian ad litem (GAL) whose task will be to independently consider what is in the child's best interest and then on the basis of that assessment make recommendations to the court about whether to discontinue life-supportive interventions.

## ELLIOTT M. WEISS, MD, MSME, COMMENTS

To start, it may be helpful to have some background on both the criminalization of actions by pregnant women against their fetus and terminology related to parental rights. I will then make 2 recommendations for clinicians confronted by such situations.

A few states criminalize drug use by pregnant women.[5] An amendment to the Tennessee fetal assault law made it a crime to give birth to a child with neonatal abstinence syndrome. Alabama's chemical endangerment laws have been interpreted to include drug use during pregnancy. Proponents of such laws suggest that they deter drug use, punish criminals, and protect fetuses and the children that they will become. Opponents believe that such laws deter women seeking prenatal care. Opponents also point out that the laws are implemented in ways that exacerbate social, economic, and racial disparities. As noted above, most professional medical organizations (including the American Medical Association and the American College of Obstetricians and Gynecologists) are against the criminal prosecution of pregnant women who use illegal drugs.[6–8] But some legislators take a different view.[9]

In the United States, there is a constitutional right to parent one's children.[10] Parental rights include the right to make medical decisions. Parents are assumed to be in a better position than anybody else to know and decide what is best for their children. But such a prioritization makes sense only if we assume (as is generally the case) that parents have an ongoing relationship with their children.

In the current case, that is unlikely. The medical team has been told this mother can have no contact with her infant, presumably forever. Yet she still maintains control of medical decision-making. The law, in this case, is a mess. But it is the law.

So what can the medical team do? First, the medical team should request a CPS appointment of a GAL as soon as possible. This action ought to be seen as much-needed advocacy for the infant. The mother has a clear conflict of interest because of legal ramifications to her that might result from the child's outcome. This action also reflects a recognition that the medical team may also not be the best advocate for the child. Clinician theorizing about potential (bad) futures for this infant (the unloved and abandoned bedbound child, the taxpayer burden, or the adopted child who ruins a marriage) can risk skewed judgment.

Although a GAL may decrease some decisional burden on the clinicians, he or she does not eliminate it. Difficult decisions must still be made. The medical team must help the GAL by determining what not to offer. This may include ≥3 classes of interventions: acute lifesaving interventions (extracorporeal life support and/or dialysis), treatment of unremitting disease with no potential path forward (inhaled nitric oxide for pulmonary hypertension), and life-extending treatments in the setting of a devastating outcome (surgical feeding tube, ventriculoperitoneal shunt, and/or tracheostomy).

This case should also be brought to the hospital ethics committee. Difficult decisions are better when made jointly. The benefits of decisions by committee include reaching a better decision (potentially) and limiting decisional burden from overwhelming a single individual. A committee could offer a range of opinions about whether the benefits of different treatments outweigh the risks and burdens. In this case, the treating neonatologist, the rest of the medical team, and the infant would all benefit from seeking guidance from others whether through a formal ethics consultation or ethics committee referral or through informal discussion with trusted colleagues.

Individuals in the United States who use illicit substances face massive social, legal, and economic consequences. For pregnant women, the risks are high. As medical providers, we must do our best to support the mother-child dyad within the confines of local law and current societal realities. The GAL can be a tool to assist us. We should not hesitate to use this resource. We must not hesitate to ask for help even when we feel confident that we are making a reasonable choice.

## REBECCA R. SELTZER, MD, RACHEL A.B. DODGE, MD, MPH, AND RENEE D. BOSS, MD, MHS, COMMENT

We find 3 important questions in the case: (1) Did the mother's actions constitute child abuse and warrant severing of her parental rights? (2) If so, why are her medical decision-making rights retained? (3) How should decision-making proceed to represent this infant's best interests?

First, the Child Abuse Prevention and Treatment Act mandates reports to CPS when a substance-exposed infant is born.[11] There is substantial state by state variability in how this mandate is interpreted and implemented. As of 2018, 24 states and the District

of Columbia consider prenatal substance use to be child abuse and allow for its use as grounds for termination of parental rights.[12] The termination of parental rights is a civil, not criminal, proceeding. Only 2 states, Alabama and South Carolina, have upheld criminal charges against women related to substance use during pregnancy.[13]

In this case, prenatal substance use seems to be one of the grounds used as justification to sever parental rights. The second question that arises then is as follows: If a state feels a parent is so unfit that he or she should lose his or her parental rights (even the right to visit his or her infant in the hospital), why should that parent be allowed to make high-stakes medical decisions? This practice has little variability among states. When a state initially determines by clear and convincing evidence that a parent is unfit, it usually terminates physical custody. The child is removed from the parent's home and placed in an environment that promotes safety and well-being. But parents often retain legal authority to make medical decisions until a decision is made in the judicial process about the termination of all parental rights. That can take months or years. The mother in this case will rarely or never see her infant or interact with clinicians, but she will still direct preference-sensitive decisions such as the use of chronic ventilation or surgical feeding tubes.

The AAP supports this approach and states the process for decision-making about life-sustaining medical therapies (LSMTs) for victims of severe child abuse should be similar to that of all other critically ill children.[6] This includes treating the parents with respect and compassion and including them in serious medical decisions. Sometimes, this approach leads to questions about whether such parents are making decisions that protect the child.

So we reach our third question: How should decision-making proceed to incorporate the child's medical status, prognosis, and the family's values?[14] Parents are given authority to direct serious decisions under the assumption that they love their child and will make decisions on the basis of the child's best interests. A parent's ability to do this may be compromised by an inadequate understanding of the child's condition or by conflicting interests.[15] Both factors are relevant to this case. Because the mother cannot visit her infant, it seems unlikely that she has a meaningful understanding of her infant's complex medical status or prognosis. And, because her criminal charges are contingent on whether her infant lives or dies, she has an inherent conflict of interest in making medical decisions that could end the infant's life. In cases in which LSMT decisions must be made and the parent has a conflict of interest, the AAP recommends that a GAL be appointed as an objective voice and advocate for the child's best interests.

A mediator, such as an ethics consultant, should facilitate communication among the involved parties about this infant's best interests. If the mother is deemed a competent decision maker, then state laws require her involvement regardless of concerns about her ability to act as a meaningful parent. If the medical team and ethics committee believe that she is acting against her infant's best interest even after they have taken time to educate her and explore her motivations, they should communicate that to the GAL. The GAL may recommend continued treatment. Or, even without the recommendation, the judge may be reluctant to withdraw LSMTs from a child without parental consent.

With this case, we highlight several laws, policies, and practices that do not take the infant's best interests into account and should be reconsidered.

1. Punitive laws may have actually caused this infant's poor outcome by deterring prenatal care. Efforts should be focused on encouraging high-quality prenatal care and treatment resources and support for pregnant mothers who use illicit substances rather than instilling fear of legal ramifications.[16]
2. Despite the inherent conflict of interest, it is standard of care to allow parents to retain medical decision-making rights after charges of harm and/or abuse. If a parent is deemed unfit to have physical custody of a child because of concerns for safety and well-being, then allowing that parent to make medical decisions may be detrimental to the child's well-being.
3. If decision-making authority is retained, as it was in this case, then preventing the parent from visiting the child's bedside or openly communicating with the medical team undermines the decision maker's ability to make an informed decision that represents the child's best interests. Perhaps there would be no conflict between the mother and team if these barriers were removed. If conflicts still persist, then using a GAL is likely the best option.

## CASE RESOLUTION

At 3 weeks of life, the infant remained ventilator dependent with no purposeful responses to serial neurologic examinations and worsening renal failure. Repeated attempts were made to communicate the grave nature of the clinical progress to the mother and CPS. Despite these conversations, no additional code limitations were set

in place. After a lengthy discussion with the ethics committee and legal counsel, the institution elected to petition the local court to completely terminate maternal rights and appoint a legal guardian. The courts were in the process of appointing that guardian when the infant had a sudden clinical deterioration. The infant died without receiving cardiopulmonary resuscitation.

## JOHN D. LANTOS, MD, COMMENTS

There is a legal maxim that "bad cases create bad law." This case reveals ways in which bad law can lead to bad cases. Many of the problems in this case were legally iatrogenic. This mother clearly had serious substance abuse problems. Laws criminalizing her behavior likely led her to avoid necessary prenatal care. With better prenatal care, the infant might not have suffered the perinatal insult. Then, the laws made it difficult to include the mother in decision-making and created a legal conflict of interest (when there need not have been any) that further undermined her perceived reliability. Such laws have enormous costs and no benefits. They reflect the attitude that substance abuse makes pregnant women less than human. They disparage pregnant women and harm infants. Given this toxic legal environment, the doctors in this case did the best that they could.

*All of the cases in Ethics Rounds are based on real events. Some incorporate elements of a number of different cases in order to better highlight a specific ethical dilemma.*

## ABBREVIATIONS

AAP: American Academy of Pediatrics
CPS: Child Protective Services
GAL: guardian ad litem
LSMT: life-sustaining medical therapy

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