

End-of-Life Decision Making for Unborn and Newborn Infants

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Introduction

Most expecting parents anticipate that having a baby will be one of the happiest moments of their lives, but some families are required to make difficult, heartbreaking decisions early on, sometimes even before the child is born. As medicine and technology continue to advance, physicians are better able to diagnose disorders early in the pregnancy. And while some families opt to terminate the pregnancy, many others oppose termination, or the disease is discovered too late in the pregnancy for termination to be an option. Some families do not have time to plan ahead when their babies are born prematurely, either before the point of viability or at the cusp. These families are thus required to make difficult health care decisions as they simultaneously cope with the potential loss of their unborn or newborn child. A variety of legal and ethical questions surround this issue. Are parents entitled to decline aggressive life support, based on an understanding of the poor chance or quality of their child's survival? When is it appropriate for parents to decline resuscitation or intensive intervention in a neonate? Does the child's condition need to be incompatible with life? What if the physician disagrees with the parents' wishes? And can the parents' decision be made during pregnancy? **Decision Making During Pregnancy and After Birth**

The law generally favors a woman's right to make decisions regarding her body before and at the beginning of a pregnancy. The woman's right to make these decisions diminishes at the point the fetus is deemed viable at approximately 23 to 25 weeks of gestation.¹ At this time, the concept of what is in the best interest of the fetus or the infant comes into play with the parents as the primary surrogate decision makers; however, the parental right to make health care decisions for their fetus or infant is not absolute. Under long-standing U.S. Supreme Court precedent, the state has an interest in protecting the life, health, and wellness of a child, or even of a viable fetus. In *Roe v. Wade*, the U.S. Supreme Court held that a woman has the right to terminate a pregnancy prior to the time of viability without interference from the state.² According to the Court's three-tiered approach, the state: (1) cannot regulate abortion during the first trimester; (2) can regulate abortion between the first trimester and the time of fetal viability only to protect the health and safety of the mother; and (3) can regulate abortion to protect its compelling interest in the fetus only after viability because at that time, "the fetus is then presumably capable of meaningful life outside the mother's womb."³ The Court modified this approach in *Planned Parenthood v. Casey*, but still held that the point of fetal

viability is the time when the state's interests are: strong enough to support a prohibition of abortion or the imposition of a substantial obstacle to the woman's effective right to elect the procedure. . . . [At the time of viability,] there is a realistic possibility of maintaining and nourishing a life outside the womb, so that the independent existence of the second life can in reason and all fairness be the object of state protection that now overrides the rights of the woman.⁴ The concept of state interest in the welfare of a fetus also applies to parents who wish to make decisions regarding end-of-life care for their newborn child. While parents generally are the primary surrogates for their children (even prior to birth), sometimes a physician or state official believes that the parents' wishes or desires are not in the child's best interest. During these difficult disagreements, the parents' ultimate right to make decisions about their child's care can be overruled. The state's overriding interest in the health and wellbeing of children can supersede parental decisions.⁵ In some jurisdictions, physicians are permitted to override a parent's decision, while in other jurisdictions judicial intervention may be required before a physician can go against a parent's wishes.⁶

Ethical Considerations

Physicians have an ethical duty to inform their minor patients' parents or guardians about resuscitative and other intensive lifesaving procedures and potential outcomes.⁷ There are significant challenges with this process as it relates to an unborn child because of the uncertain nature of the outcomes. And while these discussions may occur prior to birth, they generally are not binding because the child's condition can never be truly known prior to birth.⁸ Parents and providers can plan as best they can with the information they have, but health care decisions must be reevaluated upon the infant's birth, and as the infant progresses or fails to progress. The plan may be ever-changing based on whether the child's condition is discovered to be different than previously anticipated. Specific requirements for the decision not to resuscitate and associated documentation differ by state. In many jurisdictions, a physician may terminate treatment as medically futile because in the physician's opinion additional procedures or tests will yield no net benefit to the patient.⁹ However, the definition of "futile" is imprecise, and currently, there are few statutory guidelines on making futility decisions other than state-level "do not resuscitate order[s]" or "advance medical directive" legislation. There is little to no guidance on allowing a physician to withdraw care based on the physician's belief that such care is futile. The American Medical Association's Code of Ethics states that a decision on what care is medically futile requires "necessary value judgments" that must "give consideration to patient or proxy assessments of worthwhile outcome" and "take into account the physician or other provider's perception of intent in treatment, which should not be to prolong the dying process without benefit to the patient or to others with legitimate interests."¹⁰ The providers "may also take into account community and institutional standards, which in turn may have used physiological or functional outcome measures."¹¹ While this guidance is useful, the lack of a generally accepted definition leaves the determination in the judgment of the individual provider. What should the appropriate standard be to decline resuscitation of an infant? Must the child have a terminal illness that is incompatible with life? What if the child would simply live a very unpleasant, painful life? And what if the child had a small chance of one day living a relatively normal life, but certain basic requirements of life, such as feeding, were excruciatingly difficult? Would treatment in these situations be "futile"? The answers

to these questions are not entirely clear. **United States Child Abuse Protection and Treatment Act**¹² The United States Child Abuse Prevention and Treatment Act (CAPTA) requires that states that wish to receive federal CAPTA funding establish procedures to ensure that health care providers do not withhold or withdraw lifesaving medical treatment from infants, except in certain exceptional circumstances.¹³ CAPTA provides federal funding to states for child abuse prevention, assessment, treatment, investigation, and prosecution activities.¹⁴ The program also provides grants to public agencies and nonprofit organizations for demonstration programs and projects. The implementing regulations state that non-treatment may not be based on “subjective opinions about future ‘quality of life’ of a . . . disabled person.”¹⁵ The three circumstances under which treatment would not be “medically indicated” for a neonate include: (1) the infant is chronically and irreversibly comatose; (2) the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (3) the provision of such treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.¹⁶ The standard of judgment espoused in the regulations is the treating physician’s “reasonable medical judgment.”¹⁷ Although CAPTA’s language is fairly clear-cut, it has no effective enforcement method. The law places the condition on states, not individual providers or health care institutions. It does not create a private right of action, nor criminal penalties. Therefore, while a blatant disregard of the law is not advisable, the law is infrequently enforced. **Case Law**

Few cases have addressed a parent’s right to choose nonresuscitation for an infant, or a physician’s right to go against a parent’s wishes. In 1994, a Michigan jury acquitted dermatologist Gregory Messenger on manslaughter charges after he removed his infant child from life support.¹⁸ In that case, Messenger’s wife went into labor at 25 weeks gestation and gave birth to a one pound, 11 ounce baby. After meeting with the neonatologist prior to delivery and learning that an infant at this age had a 30-50% chance of surviving and a 90% chance of developing intracranial bleeding, the Messengers indicated that they did not want the baby resuscitated or placed on life support after birth. The physician assistant in the delivery room resuscitated and ventilated the baby upon birth. When he learned that his son had been placed on intensive life support against his and his wife’s wishes, Messenger requested that they have time alone with their baby. He unhooked the ventilator, and the baby died later that morning. While the *Messenger* case supported the right of a parent to refuse intensive treatment for a neonate, more-recent cases in Texas, Wisconsin, and Washington have contradicted that holding. In *Miller v. HCA*,¹⁹ *Montalvo v. Borkovec*,²⁰ and *Stewart-Graves v. Vaughn*,²¹ the courts found that physicians are not required to comply with parents’ wishes to not resuscitate an extremely low birth weight infant. In *Miller*, a physician resuscitated a 23-week-gestation infant against the parents’ previous statement that they did not want any intensive treatment to resuscitate their baby. At birth, the infant had a heartbeat and cried spontaneously, so the neonatologist intubated her and placed her on a ventilator.²² Several days later, the infant suffered a brain hemorrhage resulting in significant cognitive and physical impairment.²³ The Millers sued the hospital for battery and negligence for treating the infant without parental consent. The Texas Court of Appeals overturned a \$60 million jury verdict, holding that parents could withhold

treatment only if their child's medical condition was terminal.²⁴ The Texas Supreme Court affirmed, holding that parental consent is not mandated during the "emergent circumstances" of pre-term birth and that the baby "could only be properly evaluated when she was born."²⁵ The court even went so far as to say that "any decision . . . made before [the infant's] birth . . . would necessarily be based on speculation."²⁶ In *Montalvo*, the parents did not explicitly state pre-birth that they did not want their child to be resuscitated, but alleged that they were not offered the option of non-resuscitation and had only given informed consent for the mother's cesarean section, not the infant's resuscitation. The *Montalvo* court held that "in Wisconsin, in the absence of a persistent vegetative state, the right of a parent to withhold life-sustaining treatment from a child does not exist."²⁷ Furthermore, the court cited CAPTA as authorizing the provider to treat.²⁸ Finally, in *Stewart-Graves*, an infant was born without a heartbeat or spontaneous breathing and was resuscitated for 24 minutes.²⁹ The infant survived, but suffered from severe physical and cognitive impairment.³⁰ The parents brought a cause of action on behalf of themselves and their child for failure to obtain informed consent, wrongful birth/life, and breach of the standard of care, alleging that the physician denied them the opportunity to decide whether resuscitation should continue beyond ten minutes and that the physician should have discontinued resuscitation efforts when it was no longer reasonably possible for the infant to survive without severe brain damage.³¹ The Washington Supreme Court held that informed consent was not required, even though the infant's father was in the nearby waiting room, because the infant would have died if resuscitation were delayed to obtain consent.³² While the court did not decide whether a parent may refuse lifesaving treatment on behalf of a child, it held that "such a decision cannot be truly 'informed' . . . when the circumstances permit no more than a hasty explanation of probable outcomes by a physician whose attention must primarily focus on lifesaving efforts."³³ In addressing the wrongful birth/life causes of action, the court held that it will not uphold a claim for wrongful birth or life if the alleged negligence occurred post-birth. A wrongful birth action is predicated on a duty owed to the parents that arises before the child is born based on the parents' constitutional right to reproductive autonomy. The court cited *Planned Parenthood* in holding that: [b]efore birth, a fetus has no cognizable constitutional interests to balance against the mother's liberty interest. At the point of viability, however, the State's interest in the preservation of potential life intervenes. Once an infant is born, of course, the parents' right to reproductive autonomy is fully displaced by the infant's constitutionally protected right to life.³⁴ According to the court, countervailing state interests may override whatever right a person may have to refuse life-sustaining treatment, including: (1) the preservation of life; (2) the protection of innocent third parties; (3) the prevention of suicide; and (4) maintaining the ethical integrity of the medical profession.³⁵ The court found that in the case of a viable newborn requiring emergency resuscitation, the state's interest in preserving life is significant, and whether the infant's condition is "hopeless" can only be assessed accurately once the infant is stabilized.³⁶

Practical Advice

As it relates to end-of-life decision making for infants, the law is rarely black and white. It is essential to assess the facts of the particular case and consider the state's case law. The earlier the conversation begins, the longer both the family and providers have to prepare. If the child is expected to have a severe condition or anomaly, prenatal consultation should provide the expectant

parents with factual information about survival and outcomes. The medical team should inquire about and understand the parents' beliefs and attitudes about quality of life, and respect for their wishes must form the basis for these conversations. However, it is essential that the providers make clear that any decision made prior to birth may be reevaluated and modified spontaneously based on the child's condition after birth. After birth, the physician's primary duty is to the newborn infant.

Conclusion

Under CAPTA and the sparse case law addressing end-of-life decision making for infants, a physician can override parental refusal to resuscitate or parental insistence to treat. Ultimately, a consultation with the institution's ethics committee is an excellent opportunity to develop a full discussion with a variety of perspectives from the individuals who deal with these issues most frequently. Many conflicts can be avoided through clear, candid, and compassionate discussions with the infant's parents, but ultimately, the physician must exercise medical judgment in the best interest of the infant. *Originally published by In-House Counselor (September 2014).*

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1 See Gerri R. Baer & Robert M. Nelson, *C. A Review of Ethical Issues Involved in Premature Birth,*" in *Preterm Birth: Causes, Consequences, and Prevention*, Institute of Medicine Committee on Understanding Premature Birth and Assuring Healthy Outcomes (Richard E. Behrman & Adrienne Stith Butler eds., 2007).

2 *Roe v. Wade*, 410 U.S. 113, 163 (1973).

3 *Id.*

4 *Planned Parenthood v. Casey*, 505 U.S. 833, 870 (1992).

5 See e.g., *Stewart-Graves v. Vaughn*, 170 P.3d 1151 (Wash. 2007).

6 See generally, *Miller v. HCA*, 118 S.W.3d 758 (Texas 2003); *Montalvo v. Borkovec*, 2002 Wis. App. 147 (Ct. App. Wis. 2002); and *Stewart-Graves*, 170 P.3d 1151.

7 Baer & Nelson, *supra* note 1.

8 *Id.*

9 Robert M. Veatch & Carol Mason Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 Am. J.L. & Med. 15, 16 (1992) (describing the concept of medically futile care).

10 American Medical Association, *Opinion 2.037—Medical Futility in End-of-Life Care*, available at: www.ama-assn.org//ama/pub/physicianresources/medical-ethics/code-medical-ethics/opinion2037.page.

11 *Id.*

12 Pub. L. No. 104-235, 110 Stat. 3063 (1996) (codified at 42 U.S.C. § 5101 et seq.).

13 42 U.S.C. § 5106a(b)(2)(C).

14 Child Welfare Information Gateway, *About CAPTA: A Legislative History 1* (2011).

15 45 C.F.R. pt. 1340 app.

16 42 U.S.C. § 5106g(5) (1988).

17 *Id.*

18 *People v. Messenger*, 221 Mich. App. 171 (Mich. Ct. App. 1997).

19 *Miller*, 118 S.W.3d 758.

20 *Montalvo*, 2002 Wis. App. 147.

21 *Stewart-Graves*, 170 P.3d 1151.

22 *Miller*, 118 S.W.3d at 764.

23 *Id.* at 763.

24 *Id.* at 764-65.

25 *Id.* at 767-68.

26 *Id.* at 769.

27 *Montalvo*, 2002 Wis. App. at P17.

28 *Id.* at P18-P19.

29 *Stewart-Graves*, 170 P.3d at 1154.

30 *Id.*

31 *Id.*

32 *Id.* at 1157.

33 *Id.* at 1158.

34 *Id.* at 1159.

35 *See generally, Stewart-Graves*, 170 P.3d 1151.

36 *Id.* at 1161-62.

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