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## Parents vs. Physicians: Treatment Decisions for Compromised and Severely Ill Newborns

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Parents vs. Physicians: Treatment Decisions for Compromised and Severely Ill Newborns

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## **Introduction**

The birth of a newborn with a life-threatening disease or a congenital defect who requires life-sustaining treatment poses a myriad of medical, legal, ethical, religious, and social concerns. These newborns require significant resources and sophisticated technology; spending months in incubators surrounded by technical equipment, parents, and health professionals. The care of these newborns can be extremely burdensome for both the parents and the physicians; and when decisions about the appropriate medical treatment or limitations of treatment for these newborns, questions and disagreements arise.

Because of changes in medical technology, the birth of a baby born with severe disability now signals a moment of decision. This research paper posits that the decision about the medical care of severely compromised newborns should solely rest with the parents, and not the physicians or the state. Parents should have the affirmative right to withhold or withdraw treatment from their severely ill newborn because they are the ones who will bear the burden of the outcome, not the physicians.

## **Pre-viable and Neonate babies**

Viability, as the word has been used in United States constitutional law since *Roe v. Wade*, 410 U.S. 113 (1973)<sup>1</sup> is the potential of the fetus to survive outside the uterus after birth, natural or induced, when supported by up-to-date medicine.<sup>2</sup> Viability not only depends on the initial upfront maturity of a fetus at the moment of birth, but also on how well multiple fetal organ systems adapt to a series of targeted therapies directed at sustaining them over days, weeks and months after birth.

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<sup>1</sup> *Roe v. Wade*, 93 S. Ct. 705 (1973).

<sup>2</sup> Reference Medical Report, *Fetal Viability*, <http://www.reference.md/files/D005/mD005328.html> (last visited Dec. 3, 2019).

Periviable birth is currently defined as delivery occurring from 20 0/7 through 25 6/7 weeks' of gestation.<sup>3</sup> These births comprise a particularly high-risk group of patients cared for by obstetricians, neonatologists and other caregivers. Once a fetus has passed into at least 22 weeks of normal gestation, it is statically possible to survive after birth beyond the neonatal period with the assistance of intensive medical care. Infants born at 22 weeks' gestation have reported rates of moderate to severe neurodevelopmental impairment of 85% to 90%; for infants born at 23 weeks' gestation, these rates are not significantly lower.<sup>4</sup> Most infants born at 26 weeks and above have a high likelihood of survival, and virtually none below 22 weeks will survive. The chance of survival thus increases dramatically over these few weeks, and this crucial time window may be considered the period of periviability. In addition to the high risk of death in the immediate newborn period, children born at the limit of viability have a high risk of permanent disability.<sup>5</sup> Disabilities such as, cerebral palsy, blindness, profound hearing loss, developmental quotient and severe neurodevelopmental impairment.

Multiple factors have been found to be associated with short-term and long-term outcomes of periviable births in addition to gestational age at birth. These include, but are not limited to, nonmodifiable factors (eg, fetal sex, weight, plurality), potentially modifiable antepartum and intrapartum factors (eg, location of delivery),<sup>6</sup> intent to intervene by cesarean delivery or induction of labor, administration of antenatal corticosteroids and magnesium sulfate), and life-sustaining interventions and postnatal management (eg, starting or withholding

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<sup>3</sup> Tonse Raju, Brain Mercer, David Burchfield, Gerald Joseph, *Periviable birth: executive summary of a joint workshop*, 123(5), J. OBSTET GYNECOL. 1083-1096 (May 2014).

<sup>4</sup> Kimberly Leslie, Edward Bell, Jeannie Klein, John Dagle, *Improving survival of extremely preterm infants born between 22 and 25 weeks of gestation*, 119(4), J. OBSTET GYNECOL. 795-800 (April 2014).

<sup>5</sup> Tyson Jon, Nehal Parikh, Judith Langer, *Intensive care for extreme prematurity--moving beyond gestational age*. 358(16), NEW ENG. J. MED. 1672-1681 (April 2008).

<sup>6</sup> Wolters Kluwer, *Obstetric Care Consensus No. 4*, 127 J. OBSTET GYNECOL. 157-169 (2016).

and continuing or withdrawing intensive care after birth).<sup>7</sup> Because of the uncertainty of the prognosis, it is important that the parents are provided with accurate information regarding anticipated short-term and long-term outcomes associated with preivable birth.

The goal of pregnancies involving a peri-viable fetus is help the child survive through critical care management. Critical-care management of life-threatening conditions has two goals, first goal is a short term to prevent imminent death and the second goal is long term, survival with minimized morbidity and maximized functional status.<sup>8</sup> Caesarean delivery is the first step in critical care intervention, then resuscitation and admission to the NICU to administer ongoing life-sustaining treatment.

Antenatal Corticosteroids, is one of the most important antenatal therapies available to help improve newborns outcomes. It is administered before preterm birth used to reduce neonatal mortality and multiple morbidities.<sup>9</sup>

Magnesium sulfate is another form of antenatal therapy that use to prevent and treat seizures in women with preeclampsia or eclampsia, fetal neuroprotection, and short-term tocolysis.<sup>10</sup> However, women receiving Magnesium sulfate have an increased risk of developing minor side effects such as, hypotension, tachycardia, respiratory depression, discomfort at the injection site, drowsiness, headache, dizziness, mouth dryness or thirst, and blurred vision.<sup>11</sup>

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<sup>7</sup> *Id.*

<sup>8</sup> ACOG Practice Bulletin, *Clinical management guidelines for obstetrician-gynecologists*: No. 38, 100 OBSTETRICS AND GYNECOLOGY. 617 – 624.(Sept. 2002).

<sup>9</sup> Peter Crowley, *Prophylactic corticosteroids for preterm birth*. THE COCHRANE DATABASE SYSTEMATIC REVIEW. (2000).

<sup>10</sup>Committee Opinion No. 652. American College of Obstetricians and Gynecologists, *Magnesium sulfate use in obstetrics*. Committee Opinion No. 652. American College of Obstetricians and Gynecologists.127 OBSTETRICS AND GYNECOLOGY. 52-53.(Jan. 2016).

<sup>11</sup>Sanman Malapaka, Mamatha Ballal, *Low-dose magnesium sulfate versus Pritchard regimen for the treatment of eclampsia imminent eclampsia*. 115 INT J GYNAECOL OBSTET. 70-72 (Oct. 2011).

Nonetheless, these adverse effects are transient and disappear by decreasing the dose administered.

Another example of antenatal therapy is Tocolytic Therapy which is administered to delay preterm delivery long enough for antenatal corticosteroids to be administered, or for the mother to be transported to a fertility care facility.<sup>12</sup> However, there is no evidence that tocolytic therapy directly benefits neonatal outcomes.

### **The State's Standard of Treatment When Dealing with Compromised Newborns**

When dealing with adults, the law generally requires informed consent from a competent adult before a medical procedure or decision may be made because adults have the fundamental right to refuse and access treatment without interference by the state.<sup>13</sup> Infants on the other hand are incapable of giving consent and as a result their parents decide on their behalf. However, parental authority is not absolute; the state may intervene when the parents act contrary to the best interest of a child. The doctrine of *parens patriae* holds that the state may act as “surrogate parent” when necessary to protect the life and health of those who cannot take care of themselves, including children.<sup>14</sup>

When parents disagree with the physician's medical judgment regarding withholding or withdrawing medical treatment from an infant, a reviewing court appropriately employs the best interest doctrine. This doctrine is the ethical model for medical decision making for the viable infant and all young children and requires the decision maker to use medical information

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<sup>12</sup> American College of Obstetricians and Gynecologists; Committee on Practice Bulletins-Obstetrics practice bulletin, *management of preterm labor*, 127 J. OBSTET GYNECOL (2012).

<sup>13</sup> Jessie Hill, *The Constitutional Right to Make Medical Treatment Decisions: A Tale of Two Doctrines*, 86 TEX. L. REV. 277, 329 (2007).

<sup>14</sup> Yolanda V. Vorys, *The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children*, 42 OH. ST. LAW. J. 815–816 (1981).

(diagnosis, prognosis, and treatment options) in deciding among various modes of treatment.<sup>15</sup>

The best interest standard only focuses on the best interest of the patient, not the parents, the doctors or the state.

Beauchamp and Childress define the best interest standard as one in which “a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs. The standard requires the surrogate to act so as to always make the decision most favorable to the child.<sup>16</sup>

Best interests’ are not purely confined to considerations of best medical or clinical interests, but include other medical, social, emotional and welfare factors.<sup>17</sup> The court will weigh up the overall advantages and disadvantages of treatment, and undertake a balancing exercise to determine what the child's best interests are. In cases involving the withdrawal of treatment, the court will need to conclude ‘to a high degree of probability’ that it is in the best interests of the child for treatment to be withdrawn.<sup>18</sup> When bringing this claim to the court, the individual has to prove the preponderance of evidence that the treatment or withdrawing the treatment is in the best interest of the child.

In the medical setting, courts have frequently placed a high burden on the state to show that medical treatment is necessary before compelling treatment over parental objections, and the state is most likely to interfere with a parent’s decision when the child is suffering from a serious

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<sup>15</sup> Mark Mercurio, *Physicians' refusal to resuscitate at borderline gestational age*, 25(11) J. PERINATOLOGY. 683-684 (Nov. 2005).

<sup>16</sup> Allen E. Buchanan, Dan W. Brock, *The Ethics of Surrogate Decision-Making*, in DECIDING FOR OTHERS: 234–237 (1990).

<sup>17</sup> Paul Muirhead, *When parents and physicians disagree: What is the ethical pathway?*, 9.2 J. PAEDIATR. CHILD HEALTH. 85-86 (2004).

<sup>18</sup> Betty Wolder Levin, *Caring Choices: Decision-making about Treatment for Catastrophically Ill Newborns*, CUNY ACADEMIC WORKS. (1986).

and potentially life-threatening illness or injury that can be readily managed with medical treatment.<sup>19</sup> The state must establish that parental choices endanger the child and thus fall below the acceptable threshold.<sup>20</sup>

### **Health Regulation**

The United States Child Abuse Prevention and Treatment Act (“CAPTA”) is critical landmark legislation originally enacted in 1974. It is the only federal program exclusively dedicated to the prevention, assessment, identification and treatment of child abuse and neglect.

CAPTA which is also known as an amendment of the “Baby Doe Law” was as a result of several widely publicized cases involving the deaths of disabled newborns. The primary baby doe case was in 1982 when Baby Doe was born with down syndrome and an abnormal connection of the trachea and esophagus.<sup>21</sup> The baby required immediate surgery to correct the defect. However, the parents, with the advice of their physician, chose to withhold surgery and medical care because the child would still be cognitively impaired. Officials at the hospital had the Indiana Juvenile Courts appoint a guardian to determine whether or not to perform the surgery. The court finally ruled in favor of the parents and upheld their right to an informed medical decision.<sup>22</sup> The infant, by then known nationally as Baby Doe, died five days later of dehydration and pneumonia. The Indiana Supreme Court refused to hear the case.<sup>23</sup>

The second case was somewhat similar called baby Jane Doe who was born with an open spinal column, hydrocephaly and microcephaly. Baby Jan Doe’s parent who were Roman Catholic Christians declined surgery on the child and decided to choose conservative

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<sup>19</sup> Kathleen Knepper, *Withholding Medical Treatment from Infants: When Is It Child Neglect?*, 33 U. LOUIS. J. FAM. L. 1-2 (1994).

<sup>20</sup> HARRY KRAUSE & DAVID MEYER FAMILY LAW IN A NUTSHELL (2d ed.1986).

<sup>21</sup> Marcia Chambers, *Initiator of 'Baby Doe' Case Unshaken*. N. Y. TIMES, November 13, 1983.

<sup>22</sup> *Id.*

<sup>23</sup> Michael White, *The end at the beginning*. 11(4) THE OCHSNER J. 309-16 (2011).

management with nutrition, and antibiotics. The New York Supreme Court found that baby Jane Doe's life was in imminent danger and appointed a legal guardian who consented to the spinal surgery.<sup>24</sup>

Response to the Baby Doe case was particularly vocal from pro-life and disability rights groups, which decried the death as infanticide. Reagan, who was himself concerned by the case, ordered US Surgeon General C. Everett Koop and Secretary of the US Department Health and Human Services (HHS), Richard Schweiker, to notify all public health care institutions that they could lose federal funding if they did not provide treatment to handicapped infants under Section 504 of the Rehabilitation Act of 1973, the first civil rights statute for handicapped.<sup>25</sup>

The Baby Doe Law, represent the first attempt by the US government to directly intervene in treatment options for neonates born with severe congenital defects.<sup>26</sup> The law mandate that, as a requirement for federal funding, hospitals and physicians must provide maximal care to any impaired infant, unless select exceptions are met. If a physician or parent chooses to withhold full treatment when the exceptions are not met, they are liable for medical neglect. After a prolonged legal battle, President Ronald Reagan signed the law on 9 October 1984 as an amendment to the Child Abuse Prevention and Treatment Act (CAPTA) of 1974. Since then, Baby Doe Law have influenced both the parents' right to make medical decisions for their child and the way laws can affect treatment options in the U.S.<sup>27</sup>

CAPTA requires that states who wish to receive federal CAPTA funding establish procedures to ensure that health care providers do not withhold or withdraw lifesaving medical

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<sup>24</sup> George Annas, *The case of Baby Jane Doe: child abuse or unlawful Federal intervention*, 74 AM. J. PUB. HEALTH. 727-729 (1984).

<sup>25</sup> *Id.*

<sup>26</sup> David Stevenson, Ariagno Ronald, Kutner Jean, Raffin Thomas, and Ernle W.D. Young. *The 'Baby Doe' Rule*. 255 AM. J.L. & MED.1909-1912 (1986).

<sup>27</sup> Jack Resnik, *The Baby Doe Rules (1984)*. EMBRYO PROJECT ENCYCLOPEDIA. (201).

treatment from infants, except in certain exceptional circumstances.<sup>28</sup> Failing to provide appropriate nutrition, hydration, and medication to any infant with a life-threatening condition always constitutes "withholding of medically indicated treatment." The same holds true for failing to provide such an infant with a treatment that, in the physician's reasonable medical judgment, is most likely to ameliorate or correct the condition, unless at least one of the following exceptions applies: The infant is chronically and irreversibly comatose; 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 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.<sup>29</sup>

However, CAPTA does not authorize the Federal Courts to intervene in individual medical decision unless if it constituted as child abuse or neglect. For example, *In the Matter of AMB, Minor*<sup>30</sup> the baby was born prematurely and her heart was missing a septum. Two of her heart valves were deformed, her aorta was small, and the size of her heart had forced her left lung to collapse partially. Physicians used prostaglandin to open the baby's ductus arteriosus to help circulate oxygenated blood through her body and placed her on a ventilator. After going through each steps of CAPTA to determine if the child's condition satisfied any of the medical exceptions to a finding of neglect, the court found that the decision to terminate life support and provide comfort care did not violate CAPTA because the treatment that was being provided to the patient was futile and inhumane. In that case, the infant was born five week prematurely, and was intubated and placed on a ventilator. The neonatologist testified that there was no hope of

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<sup>28</sup> Child Welfare. *About CAPTA: A legislative history*. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, CHILDREN'S BUREAU. (2019) <https://www.childwelfare.gov/pubPDFs/about.pdf> (Last visited Dec. 2, 2019).

<sup>29</sup> *Id.*

<sup>30</sup> *In the Matter of AMB, Minor*, 248 Mich App 144, 640 NW2d 262 (2001).

the infant surviving without life support because her heart lesions were not compatible with long-term survival. Family Court authorized hospital staff to remove life support and provide the infant with palliative care. The infant died soon after.

Therefore, as long as abuse and neglect are not found when dealing with compromised newborns, the decision to provide or withhold medical treatment is made by the parents or legal guardian and not the physician according to CAPTA.

### **Physicians standard of care when dealing with ill newborns**

Treatment and nursing of ill infants has rapidly become more advanced during the last decades. Developments in medicine, technology, and nursing have increased survival rates among premature and severely ill infants. Parents are typically informed by the treating physicians about therapeutic options, the nature of available interventions, and their child's expected prognosis with and without treatment.

Physicians must tell the parents, the chance that the intervention will achieve the intended clinical benefit; the risk involved with treatment and nontreatment; the degree to which treatment can be expected to extend life; the pain and discomfort associated with the intervention; and the quality of life the child can be expected to have with and without treatment. Physicians must also provide access to counseling services or other resources to facilitate decision making and to enable parents opportunity to talk with others who have had to make similar decisions; and seek consultation through an ethics committee or other institutional resource when disagreement about the appropriate course of action persists.<sup>31</sup>

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<sup>31</sup> *Code of Medical Ethics Opinion 2.2.4*, AM. MED. ASS'N, <https://www.ama-assn.org/delivering-care/ethics/code-medical-ethics-consent-communication-decision-making> (2015) (Last visited Dec. 3, 2019).

Nonetheless, parents who wish to withdraw or withhold life-sustaining medical treatment against medical advice will not be accorded a post hoc remedy under informed consent doctrine. Where exigent circumstances create an exception, where there exists no viable treatment alternative and death will result without treatment, and where an accurate prognosis is unknowable even if treatment is administered.

Informed consent doctrine, with its origins rooted in the common law tort of battery, echoes the principle of one's right to be free of bodily invasion consistent with the fundamental notion laid down in *Roe* and *Casey*.<sup>32</sup> Informed consent is predicated on the duty of a physician to disclose to his patient information that will enable him to evaluate knowledgeably the options available and the risks attendant upon each, before subjecting that patient to a course of treatment.<sup>33</sup> Under the doctrine, the patient who consents to an operation is given the opportunity to show that the surgeon withheld information concerning “the inherent and potential hazards of the proposed treatment, the alternatives to that treatment, if any, and the results likely if the patient remains untreated.”<sup>34</sup>

To be clear, these informed consent actions do not allege negligent acts regarding the care provided, rather the nature of the complaint alleges that the physician was under a duty to provide information about the medical condition of the infant, review alternative treatment options, and then obtain parental consent before delivering life-saving resuscitation.

If disagreement regarding treatment persists, the physician must provide the opportunity for a second opinion, and may not withdraw from a patient’s care without providing a referral.<sup>35</sup>

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<sup>32</sup> *In re A.C.*, 573 A.2d 1235, 1243 (D.C. 1990).

<sup>33</sup> *Lafelice v. Zarafu*, 534 A.2d 417, 418 (N.J. Super. 1987).

<sup>34</sup> *Id.*

<sup>35</sup> Judith Erlen, *Child Health Care*, 15 THE CHILD’S CHOICE: AN ESSENTIAL COMPONENT IN TREATMENT DECISIONS. 156–160 (1987).

When the physician and health care team believe that parental decisions are clearly inconsistent with the child or adolescent's best interests, the assistance of an institutional ethics committee or ethics consultant is recommended. If this is not available or the conflict is not resolved at this level, then the involvement of local child protection authorities and the legal system may be unavoidable.<sup>36</sup>

### **Taxonomy of Treatment**

Advancement in neonatology technology and treatment procedures have moved beyond the historic objective of simply providing better care to a modern “pushing the envelope” in extending the survivability of barely viable neonates.<sup>37</sup> Despite medical progress, knowledge and experience of neonatologists in determining the neonates' survival prognosis or likelihood of having severe handicaps remains problematic, and as a result treatment of terminally ill or disabled infants are limited.

#### **1. Terminally Ill: The baby cannot be saved and should receive palliative care**

To palliate means to relieve. Palliative care is care designed to make a baby with a life-limiting condition as comfortable and symptom-free as possible when it is clear that further treatment aimed at cure is neither possible nor effective. Historically, palliative care has been thought of as end-of-life treatment. However, this form of intensive, active care aimed at the relief of physical and emotional discomfort can be beneficial to the baby and family from the time of diagnosis of a life-limiting illness.<sup>38</sup>

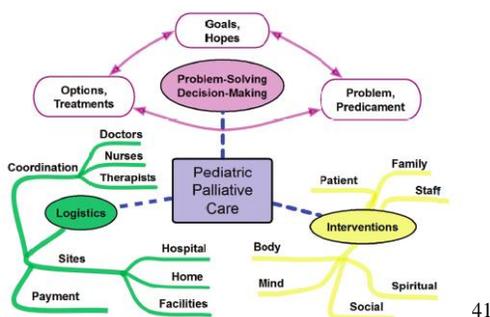
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<sup>36</sup> Kathlyn Hesson, Donald Bakal, Keith Dobson, *Legal and ethical issues concerning children's rights of consent*. 34 CAN. PSYCHOL. 317–328 (1993).

<sup>37</sup> Hugh MacDonald, *Perinatal Care at the Threshold of Viability*, 110 J. PEDIATR.. 1024 (2002).

<sup>38</sup> Brian Carter, *PALLIATIVE CARE IN INFANTS AND NEONATES: PEDIATRIC PALLIATIVE CARE*. (2018).

Palliative care enters into discussion when the goal of treatment is no longer focused on curing a condition but on making your baby as comfortable as possible. Palliative care is recommended for newborns who: are born at extremely low birth weight; are born before 23 weeks of gestation; are born with a lethal abnormality or malformation; will experience more burden than benefit from further treatments for their condition<sup>39</sup>; and whether the condition will result in death during the infant's first few hours of life or after several years.<sup>40</sup>



Once, the terminally illness is identified, meeting between the parents and physicians are scheduled in order to discuss available options and treatments for the infant. This is one of the most important steps when dealing with palliative care because it provides the parents with the opportunity to discuss their goals and hopes they have for the infant. At the meeting, the physician along with the interdisciplinary care team guides the family through the decision-making process, with the goal to avoid conflicts, cultural misunderstandings and deficient clinical care.<sup>42</sup>

Once palliative care (end of life) treatment is decided, the place where death occurs, whether in an intensive care unit, another area of the hospital, another institution, or at home,

<sup>39</sup> Id..

<sup>40</sup> Narendra Aladangady & Leonard De Rooy, *Withholding and withdrawal of life sustaining treatment for newborn infant*, 88(2) *EARLY HUM. DEV.* 65–69 (2012).

<sup>41</sup> Chris Feudtner, *Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making*, 54(5) *PEDIATR. CLIN.* 583-607 (2007).

<sup>42</sup> Id.

may depend on such factors as the wishes of the family. The family must have the opportunity to carry out important family, religious, and/or cultural rituals and to hold the child before and after death.<sup>43</sup>

Palliative care also comes into discussion when there are life sustaining machine and treatment for the terminally ill infant. The main goal is to enhance quality of life in the face of an ultimately terminal condition, while focusing on relief of symptoms and conditions that cause distress and detract from the child's enjoyment of life. It also seeks to ensure that bereaved families are able to remain functional and intact.<sup>44</sup>

Palliative care include education, grief and family counseling, peer support, music therapy, child life intervention or spiritual support for both the patient and siblings, and appropriate respite care. Respite care, the provision of care to an ill child (in his or her usual state of health) by qualified caregivers other than family members, allows the family time to rest and renew, whether for hours or days, on a schedule, or intermittently as needed.<sup>45</sup> Palliative care is best provided using an integrated interdisciplinary approach. The provision of palliative care for children involves a partnership between the child, family, parents' employer(s), teachers, school staff, and health care professionals, including nurses, chaplains, bereavement counselors, social workers, primary care physicians, subspecialty physicians, and consultants.<sup>46</sup>

**2. Baby Doe: The baby can be saved, maybe with disabilities, and needs to receive therapeutic care for the underlying condition, and maybe curative treatment for reversible threats to health**

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<sup>43</sup> Marcia Levettown, *Palliative care in the intensive care unit*. 6 NEW HORIZ TRANSL MED. 383–397 (1998).

<sup>44</sup> Committee on Bioethics, *Guidelines on forgoing life-sustaining medical treatment*, 93 J. PEDIATR. 532–536 (1998)

<sup>45</sup> Committee on Bioethics, *Ethics and the care of critically ill infants and children*, 98 J. PEDIATR. 149–152 (1996).

<sup>46</sup> Committee on Bioethics, *Informed consent, parental permission, and assent in pediatric practice*, 95 J. PEDIATR. 314–317 (1995).

There is often difficulty in medically seeing the marginally-viable newborn through their first thirty days of life that ultimately determines survival and whether the child can be saved with a possible chance of disability. The high adverse outcome rates for these newborns creates a discussion between many physicians as to whether aggressive medical treatment, including resuscitation, should be provided to these newborns.

In a study, neonates born below twenty-three weeks or 500 grams, only 36% of respondents would honor parents' expressed wishes to initiate treatment, 57% would provide "comfort care" alone, and 4% would provide "full resuscitation."<sup>(36)</sup> Respondents were also asked to rank the relative importance of six possible (\*875) concerns-viability, futility, quality of life, resources, litigation, religion-in informing their initial treatment decisions. The study authors expressed reassurance about their findings; informants were "well-motivated" insofar as "patient-oriented outcome variables" (futility, viability, quality of life) were emphasized over "societal or personal."<sup>47</sup>

In *Montalvo v. Borkovec*,<sup>48</sup> the parents claimed negligence by doctors for violating the informed consent law in taking steps to save a premature baby's life without obtaining the parent's informed consent. The baby in this case was 23 weeks old and weighed 679 grams and delivered by cesarean section and then survived after medical personnel resuscitated. The court held that the doctrine of informed consent comes into play only when there is a need to make a choice of available, viable alternatives.<sup>49</sup> In this case, the doctors had no viable alternative to resuscitate the baby because under the case law in *Edna*<sup>50</sup>, withholding or withdrawing life-sustaining medical treatment is not in the best interest of any patient who is not in a persistent

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<sup>47</sup>Jehanna M. Peerzada, *Delivery Room Decision-Making at the Threshold of Viability*, 145 J. PEDIATR. 492 (2004).

<sup>48</sup> *Montalvo v. Borkovec*, 647 N.W.2d 413 (Wis. Ct. App. 2002)

<sup>49</sup> *Montalvo*, 647 N.W.2d at 418.

<sup>50</sup> *Edna M.F. v. Eisenberg*, 210 Wis.2d 557, 568, 563 N.W.2d 485 (1997)

vegetative state. In simpler words, if the newborn is not in a vegetative state, the right of a parent to withhold life-sustaining treatment from a child does not exist.

Similarly, In *Stewart-Graves v. Vaughn*,<sup>51</sup> an emergency caesarean section was performed when a fetal monitor indicated a precipitous drop in the fetal heart rate. The infant, Liam was delivered without a heart rate and as a response, the doctors resuscitated Liam without informing the parents. Liam, currently suffers from multiple disabilities such as cerebral palsy, mental retardation, seizure disorder, microcephaly, respiratory distress requiring frequent suctioning, and must be fed through a feeding tube. The parents claimed negligence by doctors for violating the informed consent law in taking steps to save a premature baby's life without obtaining the parent's informed consent. The court held that in an emergency situation, where immediate action is necessary for the protection of life, consent will be implied when it is impractical to obtain actual consent from a patient or the patient's authorized representative. The duty of health care provider to provide parents with material information to prevent birth of child with deficits did not apply to neonatal physician's resuscitation efforts on child born alive.<sup>52</sup>

When it comes to newborns who can be saved and as a result of them being saved, they end up with disabilities; cases and research have shown that under informed consent and emergency situation doctrine physicians and the hospital have the duty to treat these newborns. Unless there is a viable alternative, or if the newborn is born in a vegetative state.

**3. Disabled: The baby is disabled, and the decision needs to be made as to whether it should be saved with curative treatment and thereafter provided with therapy to live its best life**

Infants born at 27 weeks of gestation or less or weighing less than 100 grams are considered to be extremely premature. These newborns teeter on the cusp of viability and it's only with

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<sup>51</sup> *Stewart-Graves v. Vaughn*, Supreme Court of Washington, En Banc. 162 Wash.2d (2007)

<sup>52</sup> *Vaughn*, 162 Wash.2d at 130.

aggressive medical intervention that increases their chance of survival. If the newborn do survive, they are likely to experience a lifetime of severe physical, mental and emotional handicaps as a direct result of the medical treatment they receive.<sup>53</sup> As a result, the decision of whether the child should be saved with curative treatment and thereafter therapy is a decision between the parent and physicians.

Curative care, is one of the most common form of medicine practiced in the United States. It is defined as care to overcome disease and promote recovery<sup>54</sup>. It is a specific style of medical treatment and therapies to improve or eliminate symptoms that the patient is experiencing and to potentially cure the patient's medical problem.

A form of curative cure is called aggressive care, which aims to eliminate medical issues, rather than minimizing the issue. Infants receiving aggressive care will typically receive medication, undergo surgery, or any other measures that could be considered effective to treat the illness. For example, a child who has cerebral palsy, which is a disorder that affect movement and muscle tone or posture can be recommended by the doctor to see a occupational and physical therapist; focusing on improving the child's strength, coordination and balance. Whereas, if the child who has microcephaly has difficulty speaking, the doctors can recommend the child to visit a speech language pathologist who will teach the child how to improve communication skills by engaging in series of activities to stimulate language development, such as looking at and talking about books or practicing. Nonetheless, curative care is only discussed when cure is attainable, physicians treating terminally ill infants will likely not suggest curative care and rather suggest palliative care.

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<sup>53</sup> Craig A. Conway, *Baby Doe and Beyond: Examining the Practical and Philosophical Influences Impacting Medical Decision- Making on Behalf of Marginally-Viable Newborns*, 25 GA. U. L. REV. 1097 (2009)

<sup>54</sup> Trisha Torrey, *Curative Care Aims to Improve or Eliminate Symptoms* Very well Health (2019), <https://www.verywellhealth.com/curative-care-2615157> (last visited Nov 27, 2019).

## **Parents constitutional right to make medical decision on behalf of their children**

Under United State law, minors are generally considered incompetent to provide legally binding consent regarding their health care. Parents or guardians are generally empowered to make those decisions on their behalf, and the law has respected their decisions.<sup>55</sup> For example, The Free Exercise Clause of the First Amendment, protects parents right to refuse medical treatment for their children because of the parents' religious belief. Constitutional cases such as *Meyer v. Nebraska*<sup>56</sup> and *Pierce v. Society of Sisters*<sup>57</sup>, also made it clear that parents have the fundamental right and authority to make decisions on behalf of their children without undue influence from the state.

In *Meyer v. Nebraska*, Nebraska passed a law prohibiting teaching children any language other than English. Meyer, taught German in a school and was convicted under the law. The Court held that the law was unconstitutional because it violated the liberty protected by Due Process Clause of the Fourteenth Amendment, and the right of parents to control the upbringing of their child as they see fit. In *Pierce v. Society of Sisters*, the compulsory education act required parents or guardians to send children between the ages of eight and sixteen to public school in the district where the children resided. The court held that the state has the power to regulate all schools, but parents and guardians have the right and duty to choose the appropriate preparation for their children.

This fundamental right was further galvanized in *Prince v. Massachusetts*,<sup>58</sup> where the Court articulated “that the custody, care and nurture of the child reside first in the parents, whose

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<sup>55</sup> *Meyer v. Nebraska*, US 262: 390 (1923), *Pierce v. Society of Sisters*, U.S. 268: 510 (1925), *Wisconsin v. Yoder*, US 406: 205 (1972), *Parham v. J.R.*, U.S. 442: 584 (1979), and *In Re Phillip B*, Cal Ct. App 156: Cal Rptr 2d 48 (1979).

<sup>56</sup> *Meyer v. Nebraska*, 262 U.S. at 399–410;

<sup>57</sup> *Pierce v. Soc’y of Sisters*, 268 U.S. 510, 534–35 (1925)

<sup>58</sup> *Prince v. Massachusetts* 321 U.S. 158 (1944)

primary function and freedom include preparation for obligations the state can neither supply nor hinder.” In those cases, the language of parental rights was regularly accompanied by the language of parental duty. Common law since then has legitimized a wide-spectrum of parental rights, such as the right to make decisions surrounding the education of a child, and religious training of a child.

However, in *HCA v. Miller*, the court concluded that where treatment was urgent and life-sustaining, and the child’s condition could not be certified terminal because the need for care arose, the hospital was required to provide treatment regardless of parental consent.<sup>59</sup> In *Miller*, the parents had instructed doctors prior to birth not to resuscitate the infant after receiving news that the premature infant would likely be delivered with severe impairments.<sup>60</sup> The court recognized that parents have no right to refuse urgently- needed life sustaining medical treatment to their non-terminally ill children. The infant was determined viable at birth and was not terminally ill and would likely suffer from severe impairment in which there are advanced technology to help the child.

Nonetheless, parents should continue to have the affirmative right to decide what is best for their infant without the state interference because it is clear that our founding farmers intended to provide parents with the fundamental right to make decisions pertaining to their child. For both legal and moral reasons, parents are given a wide latitude to decide what enhances their child’s well-being in areas ranging from housing, clothing, nutrition, and religion, to health care decisions. This is based on that belief that virtually all parents love their children and wish them to be healthy and happy members of society. As such, parents can identify the

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<sup>59</sup> *HCA, Inc. v. Miller*, 36 SW 3d 187 (2000).

<sup>60</sup> *Id.* at 190

interests of their child and they can and do assess what they believe to be in the best interest of their child.

### **Conflicts between Parents and Physicians in Decision Making**

Infants are incompetent to provide binding decisions regarding their health and as a result parents or guardians are allowed to make those decisions on their behalf. However, the state may intervene when the parent makes a decision contrary to the best interest of the child, if the parent refuses to provide necessary care to a child.<sup>61</sup> Pediatric bioethics presumes that the decisions should be in the child's best interest. But what happens when dealing with newborns? Over the years, there have been a constant disagreement about the nature of a parent's role in regards to medical decision pertaining to compromised or severely ill newborns.

In pediatrics, the duties to protect and promote health-related interests of the child and adolescent by the physician are also grounded in the fiduciary relationship (to act in the best interest of the patient and subordinating one's own interests) between the physician and patient, but these duties may conflict with the parent's or patient's wishes and set up tensions either within the family or between the family and the physician.<sup>62</sup> These disagreements often occur in cases where the prognosis for the severely ill infant or child is that they will survive, but with a poor quality of life. The presumption is that the parent has authority to make treatment decisions for a child when the child does not have the capacity to do so. While this is true, the treatment choices of the parent on behalf of the child must be in the child's best interests.

### **Why Parents should be the only primary medical decision makers for their infant child**

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<sup>61</sup> Christine M. Hanisco, *Acknowledging the Hypocrisy: Granting Minors the Right to Choose Their Medical Treatment*, 16 N. Y. LAW SCH. J. HUM. RIGHTS. 904 (2004).

<sup>62</sup> Michael Woods, *Overriding Parental Decision to Withhold Treatment*, 5(8) AMA J.ETHICS. 247-250 (2003).

The Supreme Court has established that parents have the protected right to bring up their children. This right is derived from the Due Process Clause of the Fourteenth Amendment and Free Exercise Clause of the First Amendment.<sup>63</sup> These same constitutional principles extend to the parents right to make medical treatment decisions for their minor child, excluding abuse or neglect.

However, making decisions to withhold or withdraw treatment for severely ill newborns should be solely decided by the parents or guardian of the infant. The interests of infants are necessarily embedded within the interest of the family. The unique interdependence between the child and the family justifies the family's participation in treatment related decisions. Within the family unit, there is a strong presumption in favor of the parents as primary decision-makers for their children. The argument that no treatment should be given to a compromised or severely ill newborn is predicated on the quality of life of the newborn, mental anguish of the child, the affect it has on the family and the family's economic losses.

### **Statistics**

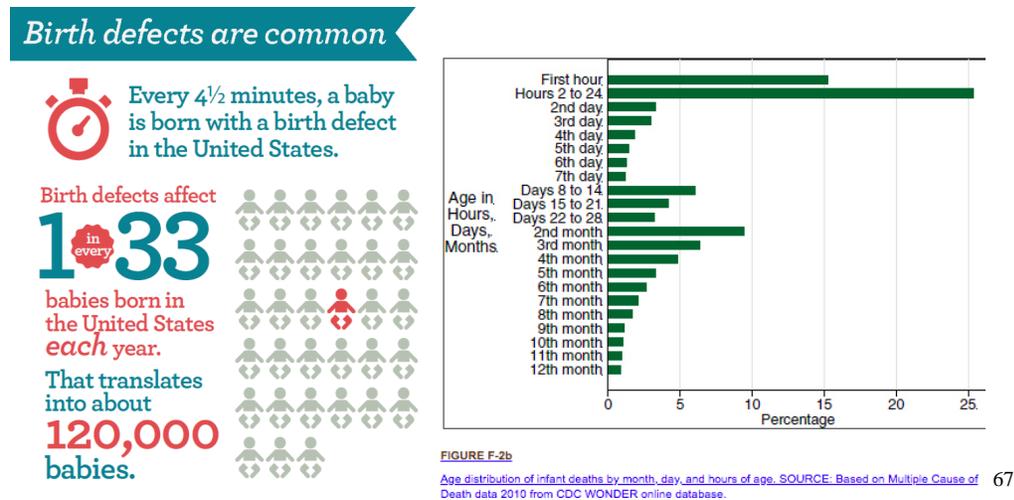
Each year in the United States, More than 29,000 infants under 1 year of age die each year and 66% of these deaths occur during the neonatal period with many in the neonatal intensive care unit (NICU)<sup>64</sup>. Leading causes of death in infants from complex chronic conditions include cardiovascular conditions (32 percent), congenital/genetic conditions (26 percent), respiratory conditions (17 percent) and neuromuscular conditions (14 percent). Birth defects affect 1 in every 33 babies born each year in the U.S, approximately 12 infant deaths related to birth defects occur for every 10,000 babies born. Common birth defects include

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<sup>63</sup> *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925)

<sup>64</sup> Jiaquan Xu, Kenneth Kochanek, Betzaida Tejada- Vera, *Deaths: Preliminary data for 2007*. 58 (1) NATIONAL VITAL STATISTICS REPORT. 1-51 (2009).

congenital heart defects, cleft lip and cleft palate, and spina bifida.<sup>65</sup> Every year, more than 500,000 children live with a life-limiting illness.<sup>66</sup>



### 1. Argument: Quality of life for the infant

Quality of life for the infant, I believe is one of the most important concept that needs to be understood by the family alone in order to make treatment decisions. There are several definitions of what quality of life means when discussing newborns. One definition focuses on the infant’s future health development, well-being, the potential ability to reciprocate in human relationships, and about the human costs to the child and family that will accrue with survival. However, courts have recognized that quality of life determinations should be based on the individual circumstances of the person, taking into account his or her perceptions of life without discrimination.

<sup>65</sup> Lynn Almlı, Rebecca Russel, Caroline Alter, *Association Between Infant Mortality Attributable to Birth Defects and Payment Source for Delivery*, 66 (3) MORTALITY AND MOBILITY REPORT. 84-87 (2017).

<sup>66</sup> Bruce Himmelstein, Joanne Hilden, Ann Boldt, and Steven Weissman, *Pediatric palliative care*. 350 (17) NEW ENG. J. MED. 1752–1762 (2004).

<sup>67</sup> Centers for Disease Control and Prevention. *Update on Overall Prevalence of Major Birth Defects—Atlanta, Georgia, 1978-2005*. 57 (1) MORTALITY AND MOBILITY REPORT.1-5 (2008).

Quality of life that could be considered intolerable to one who is able-bodied may not be intolerable to one who is born with terminal illness or has developed long-term disability.<sup>68</sup> It is not a comparative judgement about the quality of life of different individuals, nor is it a determination that some individuals are of higher value or worth than others. However, as with non-disabled children there should be due consideration of the impact of treatments on the child's ability to communicate, experience awareness of those around them, experience pleasure, attain goals and be independent, and the negative impact of treatment in terms of pain, discomfort and distress.<sup>69</sup>

The quality of life for an infant with illness that will either need life sustaining treatment or machine to live or has less than twenty four months to live should be determined by the parent rather than the court or physicians. In general, once a child is in a womb, parents have an idea or a vision of what they want the child's quality of life to look like. Everyone desires to have a healthy baby, who can play sports, be into arts, music and dance; and once the child has an illness the vision of a healthy baby fades away creating a new definition of quality of life for the baby.

Because each individual has a particular definition of what quality of life means to them, allowing the physician or the court to administer their judgement as to what the quality of life for the infant would be like in the future, would only demonstrate their vision and idea of life for the child, ignoring the parents' visions and ideas of what they wanted their child's life to be like. This will create disparities between the physician, the court and the family of the child. As a result, parents will be left with the burden of the outcome decided by the physician and the court.

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<sup>68</sup> U S Commission on Civil Rights. *Medical discrimination against children with disabilities*. U S Government Printing Office, (1989).

<sup>69</sup> Gary L. Albrecht, Patrick Devlieger, *The disability paradox: high quality of life against all odds*. 48 (8) SOC SCI MED. 977-988 (1982).

Therefore, it is important to look at relevant factors in assessing quality of life for children with severe illness, such as: the nature of future life for that individual, the value that they will derive from it and the relative balance of positives and negatives for them. Looking at these relevant factors, it is best that the sole decision maker should be left to the parents because they are the one taking care of the infant and carrying on the burden of the outcome, not the court nor the physicians.

## **2. Argument: Financial Costs of Care for the Infant**

Following the best interest standard that physicians and courts look at, it is assumed that society acknowledges a duty to save infants who are severely ill. However, society overlooks the need for resources and cost to take care of these infants and as a result, families are then left with the overwhelming pressure of providing care for these infants with the lack of money and resources.<sup>70</sup> In the past, health insurance programs often did not cover the costs of newborn care, in the 1970s, laws required health insurance plans to cover care from the first day of life. The costs of care were not limited to what the family could afford to pay. From 1940 to 1980, the percentage of the medical expenses paid by third-party plans increased from under 20% to over 70% of which more than half came from government sources.<sup>71</sup>

Treatment of a single infant may cost as much as \$250,000 not counting special services or institutional care. The average cost for infants hospitalized in neonatal intensive care units is around \$3,000 per day. While the average cost to an employer of a healthy baby born at full-term, or 40 weeks of gestation, is \$2,830, the average cost for a premature baby is \$41,610. If the

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<sup>70</sup> Arthur Caplan, and Cynthia B. Cohen. *Imperiled Newborns*. 17, No. 6 THE HASTINGS CENTER REPORT. 5–32 (1987).

<sup>71</sup> Robert M. Gibson and Daniel R. Waldo, *National health Expenditures*, 3 (1) HEALTH CARE FINANCE REVIEW. 1-54 (1981).

baby is born at 26 weeks, the cost can quickly rise to \$250,000 or more.<sup>72</sup> On average, hospital charges for infants admitted to a special care nursery totaled \$76,164 for the initial hospital stay following delivery. Infants born <32 weeks had an average hospital charge of \$280,811, more than 9 times as high as charges for infants born at 39-41 weeks. Infants born just a few weeks early (37- 38 weeks) had average charges more than \$7,000 higher than infants born 39- 41 weeks.<sup>73</sup>

**Table 1. Length of Stay and Hospital Charges Among Special Care Nursery Admissions**

<b>Gestational Age</b>	<b>Average Length of Stay (Days)</b>	<b>Average Hospital Charges (Dollars)</b>
All Admissions	13.2	\$76,164
<32 weeks	46.2	\$280,811
32-33 weeks	20.3	\$102,182
34-36 weeks	9.8	\$51,083
37-38 weeks	5.9	\$37,137
39-41 weeks	4.9	\$29,771
42+ weeks	6.5	\$47,282

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Babies who are born premature often qualify for Supplemental Security Income and Medicaid. As long as a family meets the income and asset requirements, a child who weighs less than 2 pounds, 10 ounces, at birth or no more than 4 pounds, 6 ounces, but is small for her gestational age can qualify for SSI benefits. While your baby is in the hospital, the maximum social security SSI benefit is \$30 per month, no matter what your income is. After your baby comes home from the hospital, the amount of benefit you receive will depend on your family income. In many states, a baby who gets SSI automatically is eligible for Medicaid to help pay

<sup>72</sup> Lacey M. Eden, and Lynn Clark Callister, *Parent Involvement in End-of-Life Care and Decision Making in the Newborn Intensive Care Unit: An Integrative Review*. 19 (1) J PERINAT MED. 29-39 (2010).

<sup>73</sup> Kimberly Allen, *Parental decision-making for medically complex infants and children: an integrated literature review*. 51 INT J NURS STUD. 9 (2014).

<sup>74</sup> Anna Catlin, *Extremely long hospitalizations of newborns in the United States: data, descriptions, dilemmas*. 26(12) J PERINAT MED. 742-748 (2006).

for health care costs. However, Medicaid usually covers sixty percent of NICU stays, while the parent has to put up the remaining forty percent.

What if the infant only has a single parent who has a low income and is unable to afford the forty percent? This creates a disparities between low socio economic household with single parents because not everyone can afford the forty percent. Even so, after neonatal period is over and families are able to go back home, they are likely to face more expenses for medical treatment which is often uncovered by health insurance.

Also, the cost of life saving treatments and machines are very high with limited benefits. These treatment and machines, support life but are unable to cure the underlying condition, and may in some cases merely prolong dying. The prolonged care of totally dependent children is very expensive and if life is prolonged in infants who will be unable to engage in meaningful relationships with others, this must encroach on the resources available for the care and support of the much greater number of severely ill children who can form and sustain such relationships.

Despite, the help from the government families are still left with the overwhelming pressure of providing care for these infants with the lack of money and resources. Whereas, if treatment decisions were based solely on the parent, it is likely that cost and resources will be taken into account. Whereas, if treatment decision were based on physicians or the courts, they are likely to ignore that aspect and at the end of the day leave the parents and the family with the overwhelming pressure of providing care for these infants.

### **Conclusion**

Decision making about treatment for compromised or severely ill newborns is very complex. During the past two decades, clinicians, bioethicists and members of our society at large have become more concerned about both the power and the limits of medicine. Ultimately,

decision making for compromised or severely ill infants depends on more awareness and critical evaluation of the factors involved, such as the quality of life, the financial cost, lack of resources and the effect of the outcome on the family.

However, I believe the decision should be left to the parents because they have the affirmative right to decide how to raise their child and therefore should be allowed the right to make medical treatment decision in regarding the child as long as it does not constitute neglect or abuse. Our founding father recognized the importance of family without a state interference and allowing the state to interfere when it comes to making treatment decisions regarding these newborns without a finding of neglect or abuse is taking away the parents constitutional right. Nonetheless, there needs to be more awareness and discussion both about the basis for decision making for severely ill and compromised newborns.