

COMMENT



Baby Doe at 40! Neonatologist legal and ethical opinion changes over time

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This spring marks 40 years since the ethical dilemma surrounding Baby Doe, born with Trisomy 21 and esophageal atresia, gained national attention. Baby Doe's parents, acting on the advice of the delivering obstetrician, refused to consent to surgery and the courts refused to intervene. After his death, President Reagan lamented that the "judge let Baby Doe starve and die," and he ordered the Federal Government to intervene.¹ Ultimately, this led to the Baby Doe regulations (BDR), requiring states that accept federal grant money to investigate and prevent the withholding of "medically indicated treatment" from disabled infants with life-threatening conditions.²

Would the BDR lead to the overtreatment of neonates? At least one pioneer in neonatal ethics, William Silverman, was deeply concerned about such an impact "in our notoriously litigious country."³ Neonatologists seemed to agree. Shortly after the Baby Doe legislation was passed by Congress, in 1988, Kopelman and colleagues sent a survey to 1007 neonatologists who were members of the Perinatal Pediatrics Section of the American Academy of Pediatrics (AAP).⁴ In all, 49% (494) responded, with the vast majority (76%) believing that the BDR were not necessary to protect the rights of handicapped infants. The authors summarized that most neonatologists viewed the regulations as "a mistake—that they sometimes encouraged or required the overtreatment of infants."⁴

Was this view justified and did it stand the test of time over the decades? It is difficult to say. There have been very few court opinions that have addressed the regulations, and none at the Federal Appellate or Supreme Court level necessary to set a widespread legal precedent. It should also be noted that medicine is generally regulated at the State level and may vary widely in different States across the country. Since the late 1980s, there has been significant evolution in the approach to neonatal ethical decision-making. First, the AAP has formally adopted the best interests standard when considering providing or foregoing life-sustaining medical treatment for infants and children.⁵ Second, there has been an increasing emphasis on shared decision-making and a personalized approach in which clinicians and parents collaborate to make decisions surrounding the care of critically ill newborns.

On the legal front, in October 2020 the Executive Office of the President published Executive Order 13952, "Protecting Vulnerable Newborn and Infant Children." (EO-PVNIC)⁶ In the order, the Secretary of Health and Human Services is instructed to ensure

that parents are not unlawfully discouraged "from seeking medical treatment for their infant child solely because of their infant child's disability."⁶ Some pediatric ethicists have expressed concerns that the order may have a negative impact on shared decision-making.⁷

Do neonatologists share this concern in the same way they were concerned about the BDR in 1988? How have their views regarding the care of critically ill infants as well as relevant federal regulations changed over the past three decades? To answer these questions, Polidoro and colleagues had the interesting idea to replicate the 1988 Kopelman survey with the addition of questions surrounding the 2020 Executive Order.⁸

The survey was modified with permission from the original authors and distributed to approximately 4000 members of the AAP Section on Neonatal-Perinatal Medicine. They received 445 responses (11%). Nearly all practiced in tertiary care Level 3 and 4 neonatal intensive care units. The respondents were geographically diverse, predominantly female (60%), Christian (57.3%), and Democratic (63%). Interestingly, nearly one-third (29%) were unaware of the BDR and a similar number (28%) were unaware of the Executive Order.

The initial survey had three case scenarios involving management of:

1. A term infant with Trisomy 21 and congestive heart failure at 3 weeks of age;
2. A 25-week, 550 g preemie with a large cerebral intraparenchymal hemorrhage;
3. A full-term infant with advanced congenital hydrocephalus, blind, and minimally responsive, with shunt infection and life-threatening ventriculitis.

With the new survey, the authors could directly compare the views of the 1988 neonatologists to those practicing in 2021. For case 1, the 2021 group was less likely to believe that the BDR required catheterization (12.8 vs. 22%) and more likely to be influenced by parental wishes (87.1 vs. 77%). For case 2, the 2021 group was more likely to consider withdrawal of support (86.4 vs. 75%) and again more likely to be influenced by parental wishes (95.9 vs. 87%). Note that the gestational age was changed from 25 weeks to 23 weeks, reflecting improved survival at the lowest gestational ages. For case 3, there was a large decrease in the number of neonatologists who felt the BDR compelled them to treat the infant in 2021 (14.1 vs. 47%).

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Neonatologists in 2021 had a more positive view of the BDR than they did in 1988. A greater number felt the law improved care for all infants (15.2 vs. 5%) and was needed to protect the rights of handicapped infants (29.1 vs. 14%). Fewer neonatologists in 2021 felt there was overtreatment of critically ill neonates when their chances for survival are very poor (38.6 vs. 56%). With respect to the EO-PVNIC, the vast majority of neonatologists (77%) did not believe it was needed to protect the rights of handicapped children. Additionally, most disagreed that the order would require treatment in any of the three scenarios, although it should be noted that nearly a quarter of respondents did feel that the order would compel treatment in each of the three cases.

The survey has several limitations. The 11% response rate in 2021 is disappointing, especially compared to the robust 49% in 1988. At the same time, they did get over 400 responses, and there is no way to know what the survey results would be with a higher response rate. Additionally, several respondents answering questions about the BDR and the Executive Order were unaware of them prior to the survey. Finally, not all neonatologists practicing in the United States are members of the AAP and would not have had access to the survey.

Overall, with the passage of time it seems neonatologists are more likely to consider parental wishes, a primary component of shared decision-making, and less concerned that they were forced to make a treatment decision based on federal regulations. This may relate to the passage of time in which there has *not* been the high-profile court case involving the BDR. It may also reflect the increasing involvement of parents in critical decision-making surrounding their babies. Finally, it should be recognized that ethical norms do evolve with time. It is quite certain that, if Baby Doe were born today, he would have the surgery, ideally with parental consent as part of a collaborative, compassionate shared decision-making process.

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COMPETING INTERESTS

The author declares no competing interests.

ADDITIONAL INFORMATION

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