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Jatinder Bhatia

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BABY DOE: DOES IT REALLY APPLY NOW?— PALLIATIVE CARE OF THE ILL NEONATE

Jatinder Bhatia, M.D.*

INTRODUCTION

In December 1984, the Department of Health and Human Services published a proposed rule¹ implementing the Child Abuse Amendments of 1984, the so-called Baby Doe Rules.² These amendments mandate that, in order to qualify for federal funding, states have in place plans for reporting instances of medical neglect, a term which includes withholding of medically indicated treatment from disabled infants with life-threatening conditions.³ “Withholding of medically indicated treatment” is defined by the statute as “the failure to respond to an infant’s life-threatening conditions by providing treatment . . . which, in the treating physician’s or physicians’ *reasonable medical judgment*, will be most likely to be effective in ameliorating or correcting all such conditions,” with exceptions.⁴ The proposed rulemaking explained:

The physician’s ‘reasonable medical judgment’ concerning the medically indicated treatment must be one that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved. It is not to be based on subjective ‘quality of life’ or other abstract concepts.⁵

* Professor and Chief, Section of Neonatology, Medical College of Georgia.

1. Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 48160 (proposed Dec. 10, 1984) (to be codified at 45 C.F.R. pt. 1340).

2. Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101–5106i (2006)). These amendments to the Child Abuse Prevention and Treatment Act (CAPTA), 42 U.S.C. §§ 5101–5107, 5118 (2006), are informally known as the Baby Doe Amendments or Rules in reference to the Indiana child whose death prompted the changes.

3. 42 U.S.C. § 5106(a)(b)(2)(B) (2006).

4. *Id.* at § 5106g (emphasis added).

5. Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. at 48163.

This view was reiterated in the final rule published in April 1985.⁶ The Baby Doe Rules ushered in a new era in the field of neonatal-perinatal medicine by focusing national attention on the dilemma of withholding treatment from defective newborns. The Baby Doe Rules and their exceptions have been reviewed elsewhere. In this review, the issue of palliative care and barriers to the same will be discussed.

I. THE PROMISE OF PALLIATIVE CARE

While the Baby Doe Rules were designed to specifically address withholding of care, their interpretations and ramifications have been quite different. For example, one commentator suggests:

Your baby is born four months premature, weighs one pound and is deaf, blind and missing half its brain—a human thing that previously would have been allowed to die. But now a little known law insists your doctor keep the baby alive. Miraculously, over the next six months, it survives operation after operation, all without painkillers. You love the child. It is yours. The government that willed it alive says its crushing costs are yours as well: hospitalization, day care, special education. Now multiply your little miracle by the quarter of a million critically disabled children brought to life since the law was passed. The title [sic] miracle is yours. The shame is ours.⁷

It is “testimonials” such as this along with numerous others have led to misconceptions regarding true treatment goals, whether it be for an infant with multiple lethal congenital anomalies or a critically ill infant who has reached the point where a reasonable conclusion could be that further treatment is futile.

6. Appendix to pt. 1340 of 45 C.F.R.; Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14889 (Apr. 15, 1985).

7. Mark Hunter, *Preemies: Baby Doe Law Creates Miracles—At a Cost*, Mar 9, 1998, PEDIATRIC SERVS., <http://www.pediatricservices.com/prof/prof-01.htm>.

With the increasing rate of preterm births in the United States and an approximate incidence of congenital anomalies of 20%, the practitioner is going to be faced both by an expected or unexpected fetal or neonatal death.⁸ In the case of an anomaly that may prove to be lethal, palliative care may be an option with the family being able to give an advance directive outlining their goals for perinatal care in conjunction with obstetrics and neonatal caregivers.

The best interest of an infant is generally the one acceptable criterion by which to arrive at a treatment decision. One line of argument is that a newborn cannot be said to have an interest in its own existence.⁹ In the current era of family-centered care, family interests need to be considered. However, family interests are not considered unless it is for the effect that these interests have on the interest of the patient. As stated by Stevenson and Goldworth,¹⁰ there is no past history and the family as surrogates cannot provide a substitute judgment. Further, it is unrealistic to expect that the family can choose for the infant without choosing for themselves.¹¹ Pregnancy demands dual goals to establish care for both the fetus and the mother. This relationship raises complex issues about best interest of fetal and maternal health, especially if it is the mother who has to make decisions about fetal care.

Thus, palliative care, which is defined as the active total approach to care and embraces physical, emotional, and spiritual elements, becomes of great importance in the field of neonatal-perinatal medicine. It focuses on enhancement of the quality of life for the child, support for the family, and the management of respite care through death and bereavement.¹²

8. Joyce A. Martin et al., *Annual Summary of Vital Statistics—2003*, 115 PEDIATRICS 619, 628 (2005).

9. Howard Brody, Commentary, *Contested Terrain: In the Best Interests of . . .*, HASTINGS CENTER REP., Dec. 1988, at 37, 37–38.

10. David K. Stevenson & Amnon Goldworth, *Ethical Dilemmas in the Delivery Room*, 22 SEMINARS IN PERINATOLOGY 198, 202 (1988).

11. Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 406 (1988); J. Chris Hackler & F. Charles Hiller, *Family Consent to Orders Not to Resuscitate: Reconsidering Hospital Policy*, 264 J. AM. MED. ASS'N 1281, 1283 (1990).

12. Steven R. Leuthner, *Fetal Palliative Care*, 31 CLINICS IN PERINATOLOGY 649, 658–61 (2004).

II. IMPLEMENTING PALLIATIVE CARE IN THE NEONATAL CONTEXT

As stated in a previous publication, palliative care should be considered in three general categories:¹³ [1] neonates at the limit of viability, [2] neonates with lethal congenital anomalies, and [3] neonates with serious medical and surgical conditions unresponsive to maximal therapy.¹⁴ The concept of withholding versus withdrawing of care should be understood and communicated both with the caregiving team and the family. Decisions to provide palliative care should revolve around diagnosis, prognosis, and the degree of certainty of both. This should include consultation with all appropriate medical personnel as well as clergy if so involved.

Considerations of diagnostic and prognostic certainty:¹⁵

Diagnosis and prognosis certain	Trisomy 13, 15, 18, anencephaly, complex congenital heart disease, renal agenesis/dysgenesis
Diagnosis and prognosis uncertain	Dwarfism, severe and prolonged oligohydramnios, hydranencephaly, extreme prematurity <22–23 weeks
Prognosis uncertain	Mild oligohydramnios including prolonged rupture of membranes, hypoplastic left heart syndrome, multiple anomalies, diaphragmatic hernia, severe

If the prognosis is poor, indicating death, palliative care can begin in the delivery room and, one hopes, after dialog with parents before the event. Pain, dignity, warmth and privacy should be assured. Even

13. *Id.* at 650–51.

14. Brian S. Carter & Jatinder Bhatia, *Comfort/Palliative Care Guidelines for Neonatal Practice: Development and Implementation in an Academic Medical Center*, 21 J. OF PERINATOLOGY 279, 282–83 (2001); Anita Catlin & Brian Carter, *Creation of a Neonatal End-of-Life Palliative Care Protocol*, 22 J. OF PERINATOLOGY 184, 187 (2002).

15. Jatinder Bhatia, *Palliative Care in the Fetus and Newborn*, 26 J. PERINATOLOGY S24, S25 (2006); *see also* Leuthner, *supra* note 12, at 652.

if the diagnosis is not confirmed (for example, a fetus with oligohydramnios where lung immaturity/hypoplasia is suspected), dialog can continue to include discussion that tests may be conducted to verify the initial diagnosis, and, if confirmed, palliative care can continue. In this case, delivery room assessment followed by an appropriate plan of care needs to be decided. This plan may include admission to the intensive care unit, invasive and non-invasive diagnostic testing, and, if the combined information and clinical judgment deems ongoing care to be futile, discussion with all parties needs to ensue in order to chart a path of care.

Where the problem becomes complicated is when there is an uncertain prognosis: for example, a fetus with hypoplastic left heart syndrome. Couple this with the mother's being a teenager with poor family support. Explaining to this family dyad that the infant may require three major surgical procedures, each with particular survival statistics, becomes a major hurdle in decision-making. Further, if the mother or family has to move to another city or state to receive this care and spend prolonged periods of time there, issues about the initial uncertain prognosis start to arise. The burden of therapy versus its possible benefits needs to be considered, and even though controversial in terms of the Baby Doe Rules, quality of life needs to be considered.

The problem gets even more complicated when decisions have to be made regarding palliative care or intensive care based on delivery room assessment of gestational age. The golden question is: *How small is too small?* Published guidelines provide a loophole to override a parental decision and reverse a decision to provide palliative care, and proceed with resuscitation and intensive care.¹⁶ How certain are we? Gestational age by obstetric dating is more accurate than the estimation of gestational age from physical and

16. Leuthner, *supra* note 12, at 650-55; Carter & Bhatia, *supra* note 14, at 279; Catlin & Carter, *supra* note 14, at 184; Hugh MacDonald, *Perinatal Care at the Threshold of Viability*, 110 PEDIATRICS 1024 (2002). See generally Naveed Hussain & Ted S. Rosenkrantz, *Ethical Considerations in the Management of Infants Born at Extremely Low Gestational Age*, 27 SEMINARS IN PERINATOLOGY 458 (2003).

neurological criteria.¹⁷ Moreover, due to the subjectivity of some of the criteria and the excitement of the delivery room, confusion could lead to more aggressive resuscitation only to have later clinical deterioration warrant a change to palliative care or withdrawal of care. “If based on all clinical evidence it is not in the best interest of the infant to undergo aggressive resuscitation and palliative care has been discussed, one needs to ask the question: Just because I can, should I?”¹⁸ As early as 1984, Dunn and Stirrat¹⁹ proposed the limit of twenty-two weeks gestation or 500 grams for reporting perinatal statistics. Although survival of the extremely low birth weight infant has improved, accompanying morbidities, including blindness and deafness, suggest that survival should be linked to quality of life.²⁰ Additionally, data have demonstrated that the improved technology and advances in treatment have not improved survival at the lower limits of viability, twenty-two weeks.²¹

Regardless of survival rates in different units and countries, there remains significant variability in physicians’ attitudes towards resuscitation at the limits of viability. In one study, at twenty-three weeks, 90% of neonatologists considered treatment to be of uncertain benefit; about half held the same view at twenty-four weeks.²² Before twenty-three weeks, 84% felt that treatment was futile, while at twenty-five weeks, 84% felt that it was beneficial.²³ Of concern is that when benefits of resuscitation were considered uncertain, all of the respondents reported that they would resuscitate at parental request, most if parents were unsure.²⁴ On the other hand, 24% would

17. SONOGRAPHY IN OBSTETRICS AND GYNECOLOGY: PRINCIPLES AND PRACTICE 137–39 (Arthur C. Fleischner et al. eds., Appleton and Lange 5th ed. 1996); see generally Michael A. Kohn, Caroline L. Vosti, Dennis Lezotte, & Richard H. Jones, *Optimal Gestational Age and Birth-Weight Cutoffs to Predict Neonatal Morbidity*, 20 MED. DECISION MAKING 369 (2000).

18. Bhatia, *supra* note 15, at S24, S25.

19. Peter M. Dunn & Gordon M. Stirrat, *Capable of Being Born Alive?* 1 THE LANCET 553 (1984).

20. See generally Janet M. Rennie, *Perinatal Management at the Lower Margin of Viability*, 74 ARCHIVES OF DISEASE IN CHILDHOOD F214 (1996).

21. Hussain & Rosenkrantz, *supra* note 16, at 458.

22. Jehanna M. Peerzada, Douglas K. Richardson & Jeffrey P. Burns, *Delivery Room Decision-Making at the Threshold of Viability*, 145 J. PEDIATRICS 492, 497 (2004).

23. *Id.* at 492.

24. *Id.* at 494.

override parental wishes if they requested no intervention.²⁵ This discrepancy goes against the general consensus that parents should be involved in decision-making. Stevenson and Goldworth go into details about futile treatment that will not be discussed here.²⁶

Even if one were able to make appropriate decisions, one cannot predict long-term sequelae in the delivery room. The decision to proceed with treatment at the border of viability brings with it a high probability of great expense and emotional burden for the parents if the infant survives. Although the survival rate for infants from 22–25 weeks of gestation increases with each additional week,²⁷ the incidence of moderate or severe neurodevelopmental disability in survivors at 18–30 months is high, 30–50%, and does not appear to decrease over the three-week gestation period.²⁸ Further, if we consider withdrawing care when efforts are futile, then what is the difference between making such a decision before birth? Therefore, given that predictions of survival can never be absolute, prenatal consultation allows a certain degree of certainty, and it appears reasonable for physicians and parents to make a decision for palliative care before the birth of the child.

Byrne and Goldsmith have recently published evidence-based suggested practice:²⁹

- Gestation, birth weight or anomalies associated with almost certain death or very high morbidity: resuscitation not indicated
- High rate of survival and acceptable societal risk of morbidity: always resuscitate
- Outcome indeterminate regardless of resources: parental wishes or choice

25. *Id.* at 497.

26. See generally Stevenson & Goldworth, *supra* note 10.

27. James A. Lemons et al., *Very Low Birth Weight Outcomes of the National Institute of Child Health and Human Development Neonatal Research Network, January 1995 through December 1996*, 107 PEDIATRICS e1 (2001).

28. MacDonald, *supra* note 16, at 1024.

29. See generally Steven Byrne & Jay P. Goldsmith, *Non-Resuscitation and Discontinuation of Resuscitation*, 33 CLINICS IN PERINATOLOGY 197 (2006).

Nonetheless, we do not become more certain after a few days of assessment and may actually prolong death and promote suffering. There is always the loophole to override perinatal directive and resuscitate.

Plans for palliative care and neonatal care need to be in place for site of delivery, personnel, family, clergy, and all procedures carried out in the spirit of family-centered care. However, the current barriers are different than when Baby Doe regulations were published. In practice, Baby Doe is no longer an issue. Hospice care for infants in most institutions is poorly developed with notable exceptions. Moreover, physicians are not comfortable with decision-making at the end of life, and these infants are often transported to “tertiary care” centers where the inevitable occurs. In turn, parents want the caregivers to make the decision for them as they do not want to “pull the plug.” Thus, time needs to be taken to prepare the family for these issues and together make the decision to withdraw care if needed while emphasizing that one is not withholding care.

CONCLUSION

These ethical dilemmas, without even discussing legal matters, bring complex issues of ethics, personal values, and spiritual needs together. We know that these processes can begin in the perinatal period. If appropriate education and preparations are made, palliative care—whether expectant or emergent—can be made into reality.