



The offer they can't refuse: parents and perinatal treatment decisions

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Summary Despite a widespread myth of parental autonomy in decision-making for extremely preterm neonates, families in the United States are often not given access to accurate information about the consequences of preterm birth, resuscitation and treatment, or about their ethical options. Professional, philosophical, and financial incentives for hospitals and neonatologists to provide intensive treatment may trump parental wishes in delivery rooms and neonatal units. Parents may also be intimidated by the atmosphere of intensive care and by the behavior of committed staff. Prenatal advance directives allow parents to receive information on outcomes, treatments, and options, including palliative care, 'on their own turf' and as a part of routine prenatal counseling. The use of directives and other techniques for transparency in obstetric and neonatal care could improve the process of informed parental choice. © 2008 Elsevier Ltd. All rights reserved.

Introduction

In delivery room crises, families are at the mercy of an ever-accelerating life-support technology and of their physicians' philosophies and motives concerning its use.¹

Twenty-five years ago I wrote these words in a letter to *The New England Journal of Medicine*. Sadly, they continue to describe the plight of parents of extremely preterm newborns in the United States.

During the past 25 years, the scope of neonatal life support has rapidly expanded, professional and financial motives for its use have become more compelling, and the philosophies of aggressive interventionists have prevailed. At the beginning of this era, routine treatment for infants

of <26 weeks' gestation or birth weights < 750–800 g was controversial.² Today, aggressive treatment is common for infants born at or below 23 weeks' gestation with birth weights ≤ 500 g.³ Despite the widespread myth of parental autonomy, families in the United States have little informed input in decisions regarding resuscitation or treatment.^{4–11}

A 'gray zone' is established

My involvement with neonatology began in 1975 when our son was born very prematurely and endured a complex medical course that involved ethical decision-making. In 1983 I published a book for parents¹² and became involved both with the parent support movement and with the neonatal research community, acting as a liaison between the two. In 1992 I assembled a group of parents to bring their concerns about neonatology to an international conference

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of neonatologists and obstetricians.¹³ Chief among our concerns was the growing disenfranchisement of parents in decisions regarding extremely preterm infants. We offered recommendations¹⁴ to improve the process of informed choice and to recognize a 'gray zone' of treatment in which parents would be allowed to choose palliative care whenever the risk of death and disability outweighed the probability of intact survival.

At that time, communities throughout the United States were convening committees of physicians, ethicists, lawyers, and members of the public to discuss the humane and rational use of our burgeoning life-support technologies. Groups working on neonatal care agreed that births at <26 weeks' gestation constituted a 'gray zone' where outcomes were sufficiently poor and treatment so arduous and uncertain that parents should have the option of palliative care.^{15,16} The American Academy of Pediatrics (AAP) and the American College of Obstetricians and Gynecologists (ACOG) made similar statements acknowledging that most such infants die despite aggressive treatment, or survive with severe impairment.¹⁷ This was true when these groups drafted their statements, and it remains true today.^{18,19}

The suffering of fetal infants during resuscitation and months of treatment continues to be a source of 'moral distress'.²⁰ These are infants whose skin is so gelatinous it pulls off to the touch, infants for whom the most basic maneuvers of care inflict injury.²¹ Provision of analgesia and anesthesia to these infants is difficult and dangerous, leaving a medical and ethical dilemma in which both the pain of treatment^{22,23} and the use of pain-relieving medications²⁴ can be permanently damaging.

Premature birth, in and of itself, derails the process of normal brain development,²⁵ but preterm birth before 26 weeks confers an added vulnerability, leaving survivors with a uniquely 'severe and diffuse pattern of brain abnormality', a pattern of abnormality that worsens as gestational age at birth decreases.²⁶ Such brain abnormalities appear related to autism and other psychiatric disorders frequently reported among extremely preterm children.²⁷ Children born at <26 weeks' gestation appear particularly vulnerable to damage involving the cerebellum and to associated symptoms of autism; exposure of the very immature brain to pain is a suspected cause of this damage.²⁸

The gray zone is ignored

Despite biologic rationales and community and medical support for a gray area <26 weeks, this proposed boundary for parental decision-making has been largely ignored by neonatologists in the United States.⁷⁻¹¹ Resuscitation to 22 weeks has become the default mode in most hospitals, even though most resuscitated infants will endure their treatment only to die or survive with permanent disability. As noted by Singh et al: 'For most other patients (adults or older children) faced with comparable prognoses in other ICUs, their preferences, or those of their surrogates, would be determining factors in decisions about continuing or withholding intensive intervention. That is apparently not the case in the NICU.'⁸

In the 1980s, neonatologists had strongly objected to the government's attempt to mandate such treatment (under the

Baby Doe regulations) on the grounds that these regulations violated the rights of parents and failed to consider the suffering of infants.²⁹ What changed their minds?

The race to treat at ever-lower gestations was, I think, fueled by therapeutic and economic exuberances that animated neonatology in the 1990s. During this period, neonatologists cited the promise of steroids and surfactant as reasons to resist defining any area of neonatal care as 'gray' or open to parental choice. They hoped that the short-term 'improvements' they were seeing from the use of these drugs would translate into better outcomes even in the most immature infants.^{30,31}

By the 1990s, neonatal units had also become major profit centers for hospitals in the United States, generating revenues critical to the economic survival of many medical centers.^{32,33} Neonatology enjoyed an influx of physicians, eager to practice the most lucrative subspecialty in pediatrics.^{33,34} The entire hospital system had, in the words of pediatrician John Lantos, become financially 'hooked on neonatology',³² with clear incentives to expand care to new populations.

Unfortunately, when the studies from the steroid/surfactant era began to come in, they showed no improvements in developmental outcome.^{35,36} Some studies revealed 'deteriorating outcomes'.^{36,37} Moreover, poor outcomes were associated with the use of steroids and surfactant, the very drugs on which neonatologists had pinned their earlier hopes.^{19,35,36}

Life in the gray zone: is this what parents want?

When neonatologists are asked why they pushed the margins of viability below 26 weeks in the 1990s and beyond, they rarely cite therapeutic or financial considerations, but rather insist that treatment at ever-lower gestations is driven by parents.

To the extent that this is true, it can often be explained by parents who come into the delivery room and neonatal unit uninformed, or misinformed, about the consequences of premature birth and neonatal care.^{4-7,9,10} A survey conducted in 2004 of 89 sequentially published media articles on preterm infants revealed that the majority of these writings portrayed premature birth as a positive event. Most failed to mention ongoing health problems or disability. Only one article out of the 89 surveyed gave statistics on the likelihood of disability.³⁸

Hospitals and neonatologists do their part in promoting 'miracle baby' myths. A medical center boasts in its public relations brochure of a 'dedication to excellence' that helps 'babies as small as 12 ounces grow and develop into healthy young men and women'.³⁹ Media doctor Bernadine Healy (quoting neonatologist Billie Lou Short) asserts in *US News and World Report* that 95% of 2-pound babies 'survive to live full and happy lives'.⁴⁰ At best, such statements are misleading; at worst, they are false.^{3,18,19}

Quality of life in the gray zone

The 'full and happy lives' phrase appears to be based on 'quality of life' studies by Saigal et al,^{41,42} research

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