

Virtual Mentor

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POLICY FORUM 2

Jumping to Premature Conclusions

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In the United States, one in eight babies is born prematurely, accounting for more than 500,000 births each year. Before the 1970s, babies that were even mildly premature often died, but recent scientific developments have led to a decrease in their mortality. Contemporary with the birth of the neonatology field was the birth of modern bioethics. Ethical questions posed as a result of improved treatment of prematurity have been numerous—one prominent concern being the tiny baby at the “limits of viability.” To assume that extreme prematurity is the main ethical problem in neonatology, however, is to jump to premature conclusions. The large majority of preterm infants are between 32 and 36 weeks’ gestation, and these “late preterm” births impose the largest emotional and financial burdens on families and society.

This article will discuss prematurity, the recent technological advances that led to increased neonatal survival, and the complexity of decision making for treatment of these infants. I will focus on a neglected ethical issue of great importance: the rising number of premature births. As a consequence of lax governmental investment in the prevention of preterm birth, society, babies, and families continue to pay more every year—financially, physically and emotionally—for avoidable burdens of prematurity.

Neonatology is a recent subspecialty of pediatrics that focuses on the medical care of newborn infants who require intensive monitoring and treatment. The majority of patients in neonatal intensive care units (NICUs) are born prematurely. A normal gestation lasts 40 weeks after the mother’s last menstrual period, and prematurity is defined as a gestation lasting fewer than 37 weeks. In 1963, Patrick Bouvier Kennedy, son of the late President John F. Kennedy, was born at a gestational age of 35 weeks and died 2 days later. At that time, to be born 5 weeks early was a substantial risk. Three recent developments in neonatology—respirators, antenatal corticosteroids, and surfactant replacement therapy—have given babies born at 35 weeks’ gestation mortality rates only slightly higher than those of full-term infants.

Babies born in the last 20 years are more likely to survive and less apt to develop a disability than those at the same gestational age born before 1980. Even so, the number of premature babies with disabilities or significant morbidity as a result of prematurity has remained relatively unchanged because, even though a lower percentage of survivors have impairments, more babies survive. And prematurity rates are continuing to rise. Although all developed countries have rising rates of preterm births, the United States retains the highest rate among industrialized countries with 12.5 percent in 2004 [1], and most of these preterm babies in NICUs are late preterm, with gestational ages

between 32 and 36 weeks. Babies that are extremely preterm, with a gestation of fewer than 28 weeks or a weight of less than 1,000 grams (also called extremely low-birth-weight babies), comprise 0.8 percent of all deliveries and about 10 percent of NICU admissions. Currently, infants weighing 1,000 grams or born at 27 weeks' gestation have an approximately 90 percent chance of survival, with the majority having normal neurological development [2].

The earlier in its gestation that a baby is delivered, the greater the risks of complications, mainly developmental delay, cerebral palsy, chronic pulmonary disease, learning disability, hyperactivity, and, much less frequently, deafness and blindness. Babies of less than 26 weeks' gestation, as noted, form a minority of babies in the NICU. Of the survivors, about half are without disability at 3 years of age, and 25 percent have a major impairment such as cerebral palsy (10 percent), blindness (2 to 5 percent), deafness (2 to 5 percent), and developmental delay. These are the babies that make the headlines in newspapers and receive much attention from bioethicists regarding the decision-making dilemmas they pose.

The questions are of three main types: (1) whether to intervene medically, (2) whether a medical intervention should be stopped once it has started, and (3) who should be primarily responsible for these decisions and how. The decisions are critical; failure to provide the medical care in question often leads to death, whereas intervening often brings a chance of survival, either with or without serious impairments. Dilemmas arise on a case-by-case basis, raising one of the most profound questions regarding human life: which life with disability is worse than death?

Thankfully decision making for the majority of preterm infants is much simpler; more than 80 percent of NICU preterm admissions are babies born after 30 weeks' gestational age. Mortality in these babies is extremely low, and individual outcomes are generally excellent. On a population basis, however, the implications of the large numbers of late preterm infants are more important. About 10 percent of babies are born late preterm in the United States, and the frequency of long-term disabilities such as cerebral palsy, although low, is higher in these babies than in those born at term. More babies with disabilities originate each year from this group of patients than from extremely preterm or full-term infants. Half the patients in cerebral palsy registries were not admitted to a NICU at birth. For the remaining half, most were of a gestation greater than 28 weeks at birth. In general, there would be no ethical question about whether to admit these babies to the NICU. In order to substantially decrease disability rates from late prematurity in the population and the NICU costs, one would have to let patients of 28 to 36 weeks' gestation die, which would of course be morally unacceptable.

Preventing Prematurity

A major issue in neonatal ethics is how to prevent babies from being born preterm in the first place. Because of advances in obstetric surveillance, the number of medically induced preterm births for fetal or maternal reasons has grown,

accompanied by a decrease in the stillbirth rate. About 25 percent of preterm deliveries are medically induced because of risk to the fetus or mother [3]. Limiting this source of prematurity may be neither feasible nor desirable.

Today, multiple pregnancies (twins, triplets, or more) and delayed childbearing account for a significant, and potentially reducible portion in the rate of prematurity. The substantial increase in multiple births over the last 2 decades [1, 4, 5, 6] is attributable, in large part, to artificial reproductive technologies (ART). Multiple gestations can occur following ovarian stimulation or when more than one embryo is transferred during in vitro fertilization (IVF). In the United States, 32 percent of live births following IVF are multiple pregnancies. Multiple births increase the risks of fetal, maternal, and neonatal morbidities. Fifty percent of twins and more than 90 percent of triplets are born preterm and admitted to the NICU.

Also contributing to growing numbers of preterm babies is the fact that the average maternal age is increasing; women who deliver after 40 years of age have a greater than 16 percent risk of delivering preterm [1]. As women age, their fertility declines and more employ ART to get pregnant, which places them at even greater risk for premature delivery because now they may have twins or triplets.

Given these biological realities and their consequences for newborns, our society should inform women about the risks of delayed child bearing and encourage them to have children earlier. On average, women in their early twenties have fewer financial resources than those over 35. When a woman decides to have children in early adulthood, does the government provide generous maternity leave, social and economic support for their education, and subsidized, universal childcare services when the child is young? The answer, unfortunately, is no. Society rewards performance, work, and wealth, creating an incentive to delay childbearing. The same women who would receive very limited financial incentives were they to become pregnant at an earlier age when the risks of prematurity were lower end up paying for expensive ART services years later and increasing their risks.

Conflicts between Goals of ART and Best Interest of Newborns

Infertility is a health problem that ART can help treat. There are some alternatives to ART, mainly adoption (local and international) and surrogacy, but these alternatives can be complicated and costly, and are unacceptable to some. ART services are neither reimbursed nor regulated by the Canadian and U.S. governments, which creates discrimination in access to treatment due to the cost of services. Physicians who provide ART are vulnerable to conflicts of interest. ARTs are effective—the rate of conception for fertile couples trying to conceive a baby naturally is about 25 percent per cycle. Some IVF providers, on the other hand, state a success rate per cycle as high as 60 percent [7]. This efficacy comes with a cost: an epidemic of multiple births created by physicians and governments that oftentimes produces complications for babies, their families, and society.

Infertile couples are emotionally vulnerable, which can mean they are willing to take greater health risks to acquire a baby. Because patients pay per cycle of IVF, a “two- or three-for-one” deal is an appealing alternative. But having twins is a lottery; 50 percent of IVF twins are preterm, some extremely preterm. It is also a gamble for women, inasmuch as every risk associated with pregnancy increases when a woman carries more than one fetus. In one study, despite being adequately informed of the risks, patients in fertility clinics still wanted twins: 85 percent of childless women in one study had the goal of getting pregnant with twins [8]. In fertility literature, success of a cycle of infertility treatment is counted as a live birth after 20 weeks’ gestation. By implanting more than one embryo and impregnating patients with fewer treatment cycles, the success rate of a fertility clinic improves, which attracts more clients and improves financial competitiveness: multiple pregnancies can therefore also be seen as beneficial for the fertility physician. These conflicts of interest are largely responsible for the tremendous increase in multiple pregnancies in the United States and Canada. Hence, in a society where the patient pays for IVF, there is a perverse economic incentive for both patients and physicians to increase the risk of complications for mothers and disabilities in babies.

While the ethics hot topics in the reproductive world are pre-implantation genetic diagnosis, selection of various performance genes, and pregnancy in woman over 60, the numbers involved in those endeavors are very small, or even theoretical. In contrast, we calculated that 17 percent of NICU admissions were multiple gestations following ART [9]. Most of these could have been avoided by rigorously controlling the clinical practices relating to the treatment of infertility. It’s easy to envision a public policy to decrease multiple births. Unlike Canada and the United States, some countries—Sweden, Belgium, Finland, and Denmark, for example—regulate and reimburse ART services. In these countries, single-embryo transfer during IVF is the norm. Where financial conflicts of interest related to ART are avoided, patients and physicians seem far less willing to take the unnecessary risk of multiple births in order to become pregnant as quickly as possible. Having children with the least risk for the mother and infant seems to be the morally responsible position.

The cost of IVF treatment goes beyond fees for the procedure itself; it includes the cost of health care to women and their children born from such techniques. Reimbursement for ART should be contingent upon regulating IVF and ovarian stimulation. Exceptions to single-embryo transfer could be considered only for mothers over 38, where the transfer of two embryos can be acceptable to achieve a singleton pregnancy. Medical societies and health-system regulations in the United States and Canada have a moral responsibility to reduce the frequency of multiple gestations following IVF to a level similar to that found in countries where single-embryo transfer is the norm, for example to 6 percent in Sweden (compared to about 32 percent in the United States). Restricting embryo transfers without including reimbursement will likely lead to “reproductive tourism”—women traveling abroad to find unregulated fertility centers where they can continue to have multiple-embryo transfers and hope for multiple gestations with the attendant risks and costs.

Do U.S. hospitals want to decrease NICU stay? While in most areas of pediatrics, frequency and duration of hospitalization have decreased over several years, NICU admissions have gone up mainly because of the increase in prematurity. According to pediatrician and ethicist John Lantos, “NICUs have become the economic engine that keeps children’s hospitals running [10].” Lantos adds, “It almost seems as if society, by some mechanism, is working against health to produce more and more low-birth-weight babies, and that medicine is then working against society, desperately trying to patch the wounds caused by some nameless thing that is forcing our babies from the womb too soon [11].” Countries that have made single-embryo transfer the norm have drastically reduced the rate of multiple births without affecting the pregnancy rate. These countries have lower prematurity rates. Why do we see the epidemic of multiple births as an immutable social and political phenomenon when so many countries have demonstrated that this epidemic is controllable? Do our institutions also have conflicts of interest?

Canada and the United States are successful in developing specialists who have the skills to make preterm babies survive with a good prognosis. NICUs are the most efficient and cost-effective ICUs in modern medicine, but they should not be seen as the only solution to prematurity. In my NICU, physicians and our government are responsible for a preventable 17 percent of the admissions and for significant avoidable mortality and morbidity, which produce unacceptable financial and emotional costs [9]. Medical developments have changed the way physicians and society respond to diseases of neonates, to their illnesses, and to the pain and suffering of their parents. We have to question whether we are responding adequately to these new challenges. Rising prematurity rates and the continued unchecked epidemic of multiple births are a sign of political and moral failure.

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