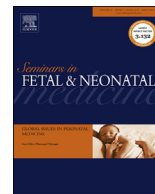




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Review

International and cross-cultural dimensions of treatment decisions for neonates



John D. Lantos*

Children's Mercy Hospital Bioethics Center, and University of Missouri – Kansas City, Kansas City, MO, USA

S U M M A R Y

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Neonatal mortality rates vary widely among countries. According to data from the World Health Organization, neonatal mortality in low- and low–middle-income countries is ~30 per 1000 babies. In upper middle-income countries, that number was just 10 per 1000. In the highest-income countries, it was <5 per 1000. These data may not be accurate. Many countries do not report the tiniest babies as live births. Thus, their reported infant mortality rates are much lower than their actual infant mortality rates. Another big difference between countries is in the rate at which congenital anomalies are diagnosed prenatally and the rate at which pregnancies are terminated by induced abortion. International comparisons therefore reflect differences in the way countries define live birth, the comprehensiveness of the reporting of live births even by their own definitions, differences in the prevalence of congenital anomalies, the rate at which those congenital anomalies are diagnosed prenatally, and the percentage of pregnancies with congenital anomalies that end in abortion. This article reviews these differences and discusses the implications for the ways in which we think about international differences in decisions about life-sustaining treatment.

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1. Introduction: the unique moral status of the newborn

Consider the following two cases:

- Case 1: A previously healthy two-month-old baby presents to the emergency room with high fever, irritability, listlessness and a bulging fontanel. He has a rapidly spreading rash. The lumbar puncture is cloudy with many white cells.
- Case 2: A baby is born at 24 weeks of gestation weighing 650 g. In the delivery room, he is limp, not breathing, and has a barely detectable pulse.

In many hospitals and in most countries today, the initiation of intensive care treatment would be considered obligatory for the baby in case 1, but optional in case 2. In some countries, the baby in case 2 would be classified as a stillbirth [1–3]. This is true, even though baby 2 has a better prognosis for unimpaired survival than baby 1. These widely practised treatment differences lead to questions about the moral status of the newborn, especially the

premature newborn. These differences in treatment occur throughout the developed world and are likely to be even more stark in the developing world.

The Neonatal Resuscitation Program textbook, which is the standard neonatal resuscitation text used in North America and many other parts of the world, states: “The ethical principles regarding resuscitation of newborns should be no different from those followed in resuscitating an older child or adult [4]. This is clearly not the case in practice. Newborns are clearly treated differently than are older children or adults. As an example of the difference, the 1983 President's Commission on Bioethical Issues devoted a special section of its report to dilemmas surrounding the treatment of newborns, thus distinguishing these dilemmas from the more general dilemmas addressed in its discussion of withholding and withdrawing life-sustaining treatment in adults [5].

Such distinctions, though well intentioned, have kept neonates in a separate moral universe. The value of neonatal intensive care has been scrutinized far more than pediatric intensive care and adult intensive care. Treatment for babies requires a higher standard of justification than does treatment of older patients [6]. This remains true even after numerous studies showing that neonatal intensive care units (NICUs) are far more cost-effective than medical intensive care units (MICUs) [7,8].

* Address: 2401 Gillham Road, Kansas City, MO 64108, USA. Tel.: +1 816 701 5283.

E-mail address: jlantos@cmh.edu.

Many professional societies recommend using gestational age as the sole criterion for deciding whether to initiate or withhold resuscitation and intensive care. Thus, a baby presenting with signs and symptoms of meningitis or a 50-year-old with an extensive hemorrhagic stroke would be likely to have immediate resuscitation and institution of care, despite broadly similar risks of death or disability when compared to the extremely preterm infant. This is notwithstanding the fact that the 24-week preemie, if he or she has access to high-quality neonatal intensive care, has a far better prognosis than these other patients.

In this article, I explore some of the implications of the unique moral status of the newborn. That status is one of the reasons why infant mortality rates remain stubbornly high in many parts of the world.

2. International differences in neonatal mortality

Neonatal mortality rates vary widely among countries throughout the world. According to data from the World Health Organization, the overall world infant mortality rate has decreased from an estimated rate of 63 deaths per 1000 live births in 1990 to 34 deaths per 1000 live births in 2013 [9]. Annual infant deaths have declined from 8.9 million in 1990 to 4.6 million in 2013. In 2013, 4.6 million (74% of all deaths of infants aged <5 years) occurred within the first year of life. Nearly 18,000 children worldwide died every day in 2012. Neonatal mortality rates varied widely between countries. In low- and low–middle-income countries, ~30 per 1000 babies died in the first 28 days of life. In upper-middle-income countries, that number was just 10 per 1000. In the highest-income countries, it was <5 per 1000.

The infant mortality rate in the USA is nearly 50% higher than the rate in Europe [10]. In 2005, the USA ranked 30th in the world in infant mortality, behind most European countries, Canada, Australia, New Zealand, Hong Kong, Singapore, Japan, and Israel [11]. But are these numbers about infant mortality accurate?

Joseph and colleagues studied international differences and found some quirky features of the ways in which data are recorded [12]. There are consistent and well-documented reporting differences between countries. These account for some of the differences in preterm birth and infant mortality rates.

Joseph and colleagues analyzed pregnancy outcome data in the USA, Canada, and some European countries. They found that different countries use different approaches to decide when to classify a newborn as a stillbirth or as a neonatal death. In order to try to regularize the data, they assessed the overall reported rates of infant mortality and of stillbirth in these countries. They then did the same analysis with two modifications. First, they excluded babies <500 g. Then, they excluded babies <1000 g.

They did this in order to show that many countries do not report the tiniest babies as live births and that therefore their reported infant mortality rates are much lower than their actual infant mortality rates. By comparing mortality rates after completely excluding these tiny babies, Joseph et al. could test their theory about unreported exclusions.

They found wide variation in the reported proportion of live births with a birthweight of <500 g. Reported rates of live birth at <500 g were <1 per 10,000 live births in Belgium, Ireland, Latvia, Poland, Portugal, and the Slovak Republic. In England and Wales the rate was 6.1, in Canada was 10.8, and in the USA was 16.9 per 10,000 live births. Neonatal death rates were correspondingly low in the countries that reported few such live births. They were <17% in all European countries (and <10% in most) compared to rates of ~30% in the USA and Canada. Countries with the lowest reported rates of infant mortality had the highest reported rates of stillbirth. This also supports the theory that, in some countries, babies born at the

borderline of viability who die quickly are categorized as stillbirths rather than as neonatal deaths.

They suggest that the best measure of overall mortality therefore is one that combines fetal mortality and neonatal mortality into one statistic called “perinatal mortality.” The perinatal mortality rate is a measure of deaths between 20 weeks of gestation and one month of age after birth.

Another big difference between countries is in the rate at which congenital anomalies are diagnosed prenatally and the rate at which pregnancies are terminated by induced abortion. Many countries track congenital anomalies. Europe has an international registry of congenital anomalies, EUROCAT, which records live births, fetal deaths after 20 weeks of gestation, and terminations of pregnancy for fetal anomalies (TOPFA) [13]. Between 2003 and 2007, in 22 European countries, the total prevalence of major congenital anomalies was 23.9 per 1000 pregnancies (at 20 weeks of age). Of these, 80% resulted in a live birth. Two percent were stillbirths after 20 weeks of gestation. In 17.6% of cases, pregnancy was terminated due to the diagnosis of a congenital anomaly. No similar statistics are available for the USA, so it is hard to compare outcomes. One might imagine, however, that the rate of abortion for congenital anomalies is lower here, both because of religious or cultural attitudes and because abortion is often not covered by health insurance. This could lead to higher rates of congenital anomalies among live births and higher infant mortality rates.

International comparisons therefore reflect differences in the way countries define live birth and in the comprehensiveness of the reporting of live births even by their own definitions. Those comparisons may also reflect differences in the prevalence of congenital anomalies, the rate at which those congenital anomalies are diagnosed prenatally, and the percentage of pregnancies with congenital anomalies that end in abortion. Any truly accurate international comparisons would have to account for all these factors, and none of the present comparisons do so. Thus international comparisons of infant mortality rates are likely to overestimate the differences between the USA and other countries. The only way to be sure would be to have in place comprehensive and standardized public health reporting systems that keep accurate records of pregnancies, stillbirths, prenatally diagnosed congenital anomalies, induced and spontaneous abortions, live births, and infant deaths. Such systems do not now exist are unlikely to exist in the future.

These differences in reporting are even more pronounced in developing countries where infant mortality rates are higher and reporting systems are less sophisticated.

3. Ethical differences between countries in neonatal treatment decisions

It is clear that there are differences between countries in their approaches to the treatment and non-treatment decisions for newborns. In developed countries, these manifest as differences in policies regarding babies born at the borderline of viability. In developing countries, the range of treatment differences is wider and more likely reflects lack of resources and training than fundamental disagreements about ethical principles.

Babies born at 23–25 weeks of gestation are relatively similar throughout the developed world. Generally speaking, these babies' problems arise not because of disease but because of developmental immaturity. Developed countries all have similar technology and professional staff in their NICUs. The doctors attend the same professional meetings. They read the same journals. They are aware of the data on outcomes from around the globe. Thus, differences in the treatment approach to babies at the borderline of viability do not reflect a lack of information. They reflect different

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