PEDIATRICS PERSPECTIVES

Children's Right to Health: Implications for Decision-Making in Newborn Medical Care

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The 1989 United Nations Convention on the Rights of the Child (UN Convention)[1] provides children with the right of the highest attainable standard of health (article 24). All countries in the world except the United States have now ratified this convention, which has implications for national health policy and priorities regarding health care for every child. The convention places an obligation on all public and private health institutions to ensure that the best interest of the child is assessed and taken as a primary consideration in all actions affecting children. The important point emphasized by the United Nations Committee on the Rights of the Child is that, based on the UN Convention, each child has a right to be assessed individually before a decision is made regarding proper treatment. As a consequence, the UN Convention may change practice in handling of newborns in a wider perspective.

In neonatology, decisions to initiate or forego intensive care for certain infants such as the extremely immature or those with certain syndromes have been heavily debated. However, in recent years, there has been some change in attitudes compatible with the UN Convention.

For instance, The International Liaison Committee on Resuscitation (ILCOR) and the American Heart Association's guidelines on newborn resuscitation of 2000[2] contained a list of diagnoses not compatible with resuscitation in the delivery room: (1) confirmed gestation <23 weeks; (2) birth weight <400 g; (3) anencephaly; and (4) confirmed trisomy 13 or 18. The rationale was that resuscitation of these newly born infants is unlikely to result in survival or survival without severe disability.

The ILCOR guidelines published in 2005[3] reiterated this list; however, the parent's view are now given more weight: "In conditions associated with uncertain prognosis, when there is borderline survival and a relatively high rate of morbidity, and where the burden to the child is high, the parent's view on starting resuscitation should be supported." This less paternalistic view also remains in the 2010 ILCOR guidelines; any specific reference to diagnosis not compatible with resuscitation has been removed completely. The guidelines instead state that resuscitation is not indicated when gestation, birth weight, or congenital anomalies are associated with almost certain early death and an unacceptably high morbidity. The 2015 guidelines have kept this wording.[4]

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The introduction of a fixed lower gestational age limit for treatment of newborn infants, as was practiced in the Netherlands and other countries, may violate the UN Convention. Furthermore, the evidence base providing support for such an absolute rule is, in fact, limited. First, it is known that the uncertainty of determining gestational age between 20 and 30 weeks' gestation is ~1 to 2 weeks. In addition, other factors (eg, female gender, singleton birth, higher birth weight, exposure to antenatal steroids) are each associated with an increased survival approximately corresponding to a 1-week increase in gestational age. Thus, Tyson et al[5] estimated that for an infant born between 24 and 25 completed weeks of gestation, the risk of death or profound impairment may vary 2.5-fold. A 750-g, appropriate for gestational age female singleton who received antenatal steroids has a risk of death of 33% versus 87% for a 525-g, small for gestational age male twin who did not receive antenatal steroids. Thus, the definition of viability is not absolute, and absolute gestational age limits are therefore not acceptable. The 2015 ILCOR/American Heart Association guidelines emphasize that in addition to gestational age, including additional variables such as gender, use of maternal steroids, and multiplicity improves prognostic accuracy.[4] Every newborn, regardless of gestational age, therefore has the right to be assessed beforehand in case a decision is made not to provide intensive care treatment.

The recent published data regarding between-hospital differences in the treatment of extremely preterm infants from the National Institute of Child Health and Human Development Neonatal Research Network[6] indicate that highly variable policies and attitudes are found among NICUs across the United States regarding treatment of newborns; this outcome is especially true for infants of 22 and 23 weeks' gestation. Perhaps the consideration in this commentary could be helpful in reducing these large differences in practice and outcome.

In fact, it is peculiar why there has been such a strong focus on immature infants when discussing nontreatment when many other groups of children may have similar outcomes. Selected groups of children with congenital cardiac defects, for instance, develop developmental delay as often as immature infants.[7] Follow-up of children with congenital diaphragmatic hernia at 5 years of age show that 7% had severe neurologic delays.[8] However, nobody would argue that surgical repair of these conditions should never be performed.

Another potential issue in conflict with the UN Convention was the previous tacit consensus that trisomy 13 and 18 are lethal, which led to their classification as conditions for which resuscitation was not indicated. However, there has clearly been a change in clinical practice, with more frequent initiation of intensive care therapy for this group that has led in some cases to sustained survival.[9] Parent groups have fought for the right of their children with trisomy 13 or 18 to receive treatment or at least be assessed at birth. Thus, for these infants, decisions of nontreatment should not be made against the parent's will. An individualized comprehensive assessment can be conducted after birth stabilization, and the options and likely consequences of continued supportive medical care and/or surgical intervention can be discussed.

In 2016, there are situations for which survival is truly and unambiguously nil, either due to lack of technology and/or will. In these cases (eg, birth before 20 weeks, birth of a true anencephalic), the medical team acts in the best interests of the child to provide comfort care only. Moreover, in some low-income areas, because medical resources are limited, prioritization of available resources leads to the inability to support some infants who would clearly survive in more resource-intensive areas.

When viewing the best interests of the child as a primary consideration with regard to health care, this approach requires a willingness to give priority to the individual child's interests, especially when the medical decision has an undeniable impact on the child concerned.

The UN Convention obviously has practical implications for treatment strategies and should be considered carefully by health workers, administrators, and politicians and be included in the ongoing debate regarding treatment or nontreatment of children.

ABBREVIATION

ILCOR: International Liaison Committee on Resuscitation

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