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EDITORIAL

Ethical Issues in Pediatric Surgery

The Pediatric Surgeon is often faced with ethical dilemma regarding surgical intervention in a seriously malformed newborn baby. Severe neurological anomalies like anencephaly, extensive meningomyelocele with hydrocephalous and gross neurological deficit, extensive body wall defects, parasitic twins, multiple anomalies involving several systems are some of the examples. Decision-making is always by surrogate, which is in most of the time, the parents or near relatives. The Pediatric Surgeon often has to face a situation in which a severely malformed baby is brought to him for opinion regarding the surgical procedure of which the success is uncertain. Prenatal ultrasonography diagnosis of a serious malformation of the fetus leads to another complex situation in which any one or both the parents may express their doubt about successful outcome of treatment and may desire to terminate the pregnancy. With the advent of prenatal intervention and fetal surgery, legal and ethical questions are being raised. Whatever may be the severity of the fetal malformation, it hardly ever affects the mother's health; but during fetal surgery, complications may occur to the pregnant woman, and could negatively influence the viability of the pregnancy. Decision making in circumstances like these are associated with ethical questions.

Over the years several legal issues had been raised regarding decision making as in the cases of Baby Doe (1984), Baby Jane (1985), and Baby Stephanie Keene (1995) in the USA. Baby Stephanie Keene was born on October 1992 at Fairfax Hospital in Virginia, USA with Anencephaly. After being the center of a major US court controversy and public debate, she remained on intermittent ventilator support for 2 years 174 days and died on April 5,1995. This raised several issues of bioethics like sanctity of life, definition of death, the concept of futile medical care and allocation of scarce resources by the hospital authority for an otherwise hopeless case.

Baby Doe law passed in 1982 in the United States laid down specific criteria and guidelines for the treatment of seriously ill and/or disabled newborns, regardless of the wishes of the parents. Baby Doe was born with Down syndrome. Parents declined surgery for esophageal atresia with tracheoesophageal fistula, leading to the baby's death. Everett Koop, the famous Pediatric Surgeon of USA argued that the child was denied treatment and nutrition not because the treatment was risky but rather because the child had Down syndrome. Koop commented publicly that he disagreed with such withholding of treatment.[1]

A similar situation in 1983 involving a Baby Jane Doe[2] again brought the issue of withholding treatment for newborns with disabilities to public attention. Baby Jane Doe was born on October 1983 in New York City, with an open meningomyelocele, hydrocephalous and microcephaly. Surgical treatment would have prolonged her life, but

she would be bedridden with severe neurological deficit. The parents refused surgery. Baby Doe Amendment came into effect in June 1985, defining child abuse to include the withholding of fluids, food, and medically indicated treatment from disabled children.

However, there was public debate and both American Hospital Association (AHA) and the American Medical Association (AMA) opposed the amendments. The issue was taken to the US Supreme Court in 1986, and the court ruled in favor of the AHA. The court concluded that the Baby Doe rules interfered with the best interests of the child, interfered with medical decision-making representing an unjustifiable intervention into medical standards. The debate continued in Senate, the Child Abuse Amendments of 1984 was approved by both Houses, and went into effect. Under the rules, withholding treatment is only permissible if the newborn is irreversibly comatose, if treatment would only prolong its death, or if treatment would be inhumane. Furthermore, the law also holds that a physician's decision for neonatal care cannot be based on quality of life, or other abstract concepts. Currently, if a case involves parents or their doctors choosing to withhold treatment, the review boards are obligated to report the case to child services as an instance of medical neglect.

In India, there had been no public debate or legal battle similar to what happened in USA regarding similar issues. In hospitals dealing with such cases, it is usually agreed upon a consensus decision taken by the parents of the child and the team of doctors attending to the case. In most of the cases the attending doctors do not insist on a policy decision by the hospital administration, neither there is any government directives supported by the legal system of the country.

Another important area of controversy is the ethical issues involved in withdrawal or withholding of life saving medical treatment (LSMT) in a terminally ill baby. Unlike the adult patients and their near relatives who can very well take part in decision making regarding the continuance or withdrawal of LSMT, the baby's parents have to approach the treating surgeon for opinion regarding the best interest standard, which includes not only prolongation of life but also improved quality of life.[3]

Some new ethical issues have come up in recent times involving organ donation after circulatory determination of death (DCDD) with the increasing need for organ transplantation in children.[3] The concept of DCDD is dependent on the understanding of death and controversies existing around it. Under the circumstances, after obtaining consent from the parents for organ donation, the patient under LSMT is taken to operating room where LSMT is withdrawn and patient is allowed to die before organs are harvested for transplantation. This requires a complete ethical counseling of the parents of the child before deciding about DCDD.

The ethical issues surrounding fetal surgery are complicated, as it influences the quality of life for both the pregnant woman and the fetus. What may be beneficial for the fetus should not do any harm to the mother. Risks to the pregnant woman include preterm membrane rupture, preterm labor, wound infection, hemorrhage, and rarely death. The improvement in the future quality of life for the developing fetus is uncertain, and the risks and benefits of fetal surgery must be well explained to the pregnant woman and her husband and other near relatives before planning. Such surgeries fall under the category of clinical trials, and as such are subject to approval of Institutional Ethical Committee. Since the outcome of surgery in the fetus in-utero is still unpredictable, the well being of the pregnant woman must be fully assured before undertaking such procedure. Although fetal surgery is not yet practiced in our country as a routine procedure, necessary rules and regulations need to be formulated before hand.

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