Editorial

ETHICAL ISSUES IN PERINATAL MEDICINE: INDIAN PERSPECTIVE

Ethics refers to. moral principles or set of moral values which determine the code of conduct as stipulated by the medical profession. The ethical decisions are based upon a system of moral values that serve the best interests of society in a humane and caring way(l). The motal values are governed by the society and they eulogize what is correct, righteous, virtuous, noble, desirable and acceptable. The physicians are both morally and legally accountable to the society. Due to tremendous advances in teclu1ology, the care of critically ill and tiny newborn babies has unfolded complex medical, social, ethical, philosophical, moral and legal issues. Apart from tremendous financial cost of neonatal intensive care to the parents and society, there is incalculable cost in terms of pain, grief, frustration and guilt with survival of a severely handicapped child(2,3).

Principles Governing Ethical Decisions

Ethical decisions are based on the four principles of beneficence, nori maleficence, parental autonomy and justice(4). Beneficence bequeaths that we should be the best advocates of our patients and ensure their best interests in accordance with the age old Hippocratic tradition. The physicians should be concerned with saving life and avoid doing any wilful harm to their patients, *i.e.,* they should be non-maleficence in their therapeutic actions. The parental autonomyshould be honored and they should be given the right and taken into confidence while making a decision regarding the medical care of their children. We should assist parents to make an informed decision. The principle of justice demands that we seek the morally correct distribution of resources, ensure cost-effectiveness of therapeutic measures by balancing medical benefits and burdens to the family and society. The decisions should be taken jointly after discussion with the concerned consultants and nurses and by taking parents into confidence. While making a decision there are several other issues which must be carefully looked into. Is there any reasonable chance of survival of the infant with available technology? Would quality of life be worth living if the child survives with aggressive management? Can the family afford expensive management? Are we concerned with the best interests of the patient alone or global interest of the family, society and State? And of course there are cultural considerations, the fertility of the couple, gender of the child, the concept of destiny or will of God, the doctor-knows-the-best attitude, socio-eco-nomic status, education of parents, social support and national priorities(4). However, whatever is the final decision it must be made clearly in concrete terms and the decision should be justified and recorded in the case file.

Personhood of Petasand the Indian Law

Nearly 4000-5000 years ago when we had no legal system, as per "Manusmriti", fetus was recognized to have the right to live and inherit property. According to Indian Penal Code, way back in 1860, it was recognised that fetus is a living being and any person causing wilful death of the fetus in the womb shall be accountable. However, if in the opinion of a doctor termination of pregnancy was considered to be in the interest of the mother, it was legally permitted. The Medical Termination of Pregnancy Act (MTP) was enacted by the Parliament in 1971 further liberalising abortion for family welfare purposes. According to the provisions of MTP Act if pregnancy is less than 12 weeks of gestation it can be terminated on the advice of one registered medica1 practitioner but if the pregnancy is more than 12 weeks but less than 20 weeks, the opinion of two medical practitioners is mandatory before undertaking abortion. However, selective abortion of female fetuses by antenatal determination of sex is highly unethical which has been legally banned in Haryana and Ra1asthan and needs to be universally banned throughout the country. Under section 5 of MTP Act, even if the duration of pregnancy is more than 20 weeks, the physician has the right to terminate pregnancy in order to save the life of mother. The physicians caring for the pregnant women are concerned with the welfare of two lives and of the two, the mother is considered as more precious than the fetus.

Termination of Pregnancy Beyond 20 Weeks

According to MTP Act, pregnancy beyond 20 weeks can be terminated for maternal and not for fetal reasons. However, premature induction of labor is routinely done for maternal and fetal indications (unfavourable maternal environment) without raising any ethical or legal issues. If a seriously malformed fetus is diagnosed after 20 weeks of gestation, it is illegal to abort but many a times it is morally justified. It is justified though illegal to abort a malformed fetus after 20 weeks if both of the following conditions are fulfilled(5):

(i) Fetus is afflicted with a condition that is incompatible with postnatal survival beyond few weeks or survival is likely to be associated with total/virtual absence of cognitive functions later in life.

(ii) Prenatal diagnosis of the condition is highly reliable.

These criteria are adequately met by the fetus having anencephaly. The other conditions which can be considered for abortion after 20 weeks include trisomy 18, renal agenesis and thanatophoric dysplasia. It must be kept in mind that medical uncertainty regarding correct diagnosis and prognosis in fetal medicine is profound. The decision for termination of pregnancy should, therefore, betaken after due consultations with a group of experts and by informed consent of parents.

There is thus a need to revise the law to justify and legalize termination' of pregnancy after 20 weeks of gestation. Life is life irrespective of gestation cutoff. The life is not smaller or lesser when a baby is small.

Is it Justified to Establish Neonatal Intensive Care Facilities in a Developing Country?

In a developing country like India, a large number of salvageable babies are dying in the community without receiving even basic or essential care. It is logical to ask whether we should waste our meagre resources for a cost-intensive and cost-ineffective intensive care for critically sick and tiny newborn babies? According to the principle of justice and fairness, there is macro-allocation of resources by the society for various activities like defence, agriculture, industry, power and health. Allocation of budget for health shall compete with preventive, promotive and curative services at all age groups depending upon the national priorities. The neonatal care becomes one competing component of these multiple areas for "micro" allocation of resources. In view of fact that over 60 per cent of infant deaths are accounted by neonatal deaths, there is an urgent need to establish special neonatal care units to reduce neonatal mortality. However, the improvements in the neonatal care should not be restricted to specialized neonatal units but globally at all levels *i.e.,* home, primary healthcentre, community health centre, district hospital, medical college hospital, private nursing homes *etc.* It is desirable to ensure equitable development of health carec9f neonates at all levels, be it at the grass roots or tree tops. To ensure effectivity and credibility of the referral system, it is mandatory to establish specialized units of neonatal care where sick and small babies from the community health centres can be referred for optimal management. There is certainly a need to develop and establish NICU facilities in the country in a phased manner. In order to stabilize the population dynamics there is a need to reduce infant mortality rate because enhanced survival of babies would discourage parents to produce more children.

Withholding and Withdrawing Life Support from a Critically Sick or a Tiny Newborn Baby

According to _ the controversial and historical "Baby Doe" regulations all newborns should receive maximal life prolonging treatment(6). This policy is not uniformly followed. In an infant who is inevitably destined to die or likely to survive with a profound risk of severe neuromotor disability, "selective non-treatment" is legally acceptable(7). These infants should be provided with loving tender basic care with nutrition and hydration but no heroic or aggressive therapeutic measures should be tried. This approach of withholding active treatment applies to all those conditions listed for termination of pregnancy after 20 weeks of gestation, infants with gross lethal congenital malformations and extremely tiny babies « 750 g at our Institute). It is generally believed that duodenal atresia in an infant with Down syndrome should be operated and only conditions worse than Down syndrome should be considered for non-treatment. However, in clinical practice certainty of death (> 90% chance of dying) and inevitability of cognitive or neuromotor disability are extremely difficult to predict with accuracy. The decision for "selective non-treatment" should be recorded in the case file along with clinical justifications and parental consent. Every NICU should clearly define its policies

for "selective non-treatment" to avoid guilt feelings and confusion.

The same reasons that justify withholding of treatment also justify stopping treatment. The withdrawal of life support treatment like assisted ventilation is ethically acceptable if infant is diagnosed to have brain death, likely to die regardless of any existing medical treatment, and should he live, he would have virtually no chance of leading an acceptable life(8,9). These conditions include extremely preterm baby with massive intraventricular hemorrhage, CNS malformations, severe birth asphyxia with lack of breathing efforts for several days *etc.* In these situations death is considered as more humane option than a life filled with suffering and misery. Moreover, in several cases the daily cost of NICV care may be more than the monthly salary of the family. The financial burden, misery and mental agony of looking after a child with extremely poor quality of life are profound especially in India where there is lack of social support system and inadequate facilities for management of children with serious neuromotor disabilities.

Ethics of Organ Transplantation

It is legally justified to remove organs from brain dead patients. However, the criteria for brain death are not well defined in preterm babies and term neonates less than 7 days old thus posing difficulties for donation of organs for transplantation(10). But merely one per cent of all perinatal deaths are due to brain death. Anencephalic infants are inevitably destined to die and logically should constitute good sources of sound heart, liver and kidneys for transplantation. In Europe physicians have removed organs from anencephalic infants without waiting for their death on the ground that these infants are "brain-absent"(11). This approach is not generally approved and is illegal at present. If one waits for an anencephalic infant to die, most deaths occur due to cardio-respiratory failure thus compromising the perfusion and viability of organs required for transplantation. They would thus need a life sustaining support and allowed to die by virtue of cessation of functioning of the brain stem. It is controversial though logical that a legislation should be enacted to consider all anencephalic infants as legally dead for purposes of organ donation. However, medical benefits are likely to be minimal due to low incidence of live born anencephalic infants and even lower incidence of infants whose lives could be prolonged by transplantation(12). There is a potential fear that such a law may lower the sanctity of life and organs may be surreptitiously removed from patients not fully brain dead.

Perinatal HIV Infection

Physicians are obliged to provide competent and humane care without any discrimination to all patients including those with HIV infection(l). The denial of appropriate care to any class of patients for any reason is unethical. The risk of vertical transmission of HIV infection varies between 15-30%(13/14). The transmission rate can be reduced by treatment of the mother and by chlorhexidine douches of the vaginal canal before delivery. The definitive diagnosis of HIV infection at birth is difficult due to difficulties in culturing the virus and unreliability of IgM antibody as

says. There is a 15% chance of transmission of HIV infection ~rough breast feeding which should discourage breast feeding by HIV -positive mother even in the developing countries. There is a need for selective HIV screening in high risk populations(14). The infected mother should be told about the risk of vertical transmission to her offspring and given the option for abortion if desired by her.

The confidentiality should be honored and maintained at all costs.

Conclusions and Recommendations

Ethical decisions in perinatal medicine are difficult and often complicated by profound medical uncertainty for making a correct diagnosis and prognosis in maternal, fetal and neonatal medicine. Ethical issues are indeed complex and often affected by economic and social realities, gender of the child and attitude of 'paternalism' by the pediatricians in a developing country. The narrow principle of 'best interest' of the child should be replaced by global beneficence to the family, society and State. Medicine is enigmatic and many a times it is difficult to be certain which interest is the 'best' -withholding treatment or treating aggressively. Medicine is dynamic and medical ethics are much more dynamic. Medical disorders considered lethal in the past can be salvaged ,by newer technology thus changing ethical perspectives and decisions. One should always put oneself in the parental situation and ask "would I want the child to live if it were mine"? We should take joint decisions within the legal framework after due consultations with a group of medical and nursing experts and by taking the family into confidence. Above all, we should avoid dumping decisions to the parents alone and deny unbridled autonomy to them. We should evolve a rational process and sound mechanism to make correct ethical decisions. Ethics Committees should be constituted in all hospitals which should serve as a watch dog to monitor and maintain the sanctity of all ethical decisions. Apart from science of medicine, the art and ethics of medicine should also be regularly taught to the medical students. The teachers should exhibit exemplary humane behaviour worth emulation with compassion, tact and concern towards their patients and serve as role models to their students(15).

Meharban Singh,
Professor and Head,
Department of Pediatrics and
Neonatal Division,
All India Institute of Medical
Sciences,
New Delhi 110 029.

REFERENCES

1. American College of Physicians. Ethics Manual, 3rd edn. Ann Int Med 1992, 117: 947-960.
2. Stahlman M. Implications of research and high technology for neonatal intensive care, JAMA 1989, 261: 1791.
3. Stahlman M. Ethical issues in the nursery: Priorities versus limits. J Pediatr 1990,116:167-170.
4. Pellegrino ED. The metamorphosis of medical ethics. JAMA 1993, 269: 11581162.
5. Chervenak FA, Farley MA, Walters Le Roy, *et al.* When is termination of pregnancy during the third trimester morally justifiable? N Engl J Med 1984, 310: 501-504.
6. Kopelman LM, Irons TG, Kopelman

AE. NeonatologiSts judge the "Baby Doe" regulations. N Engl J Med 1988, 318: 677-683.

7. Doyal L, Wilsher D. Withholding cardiopulmonary resuscitation: Proposals for formal guidelines. Brit Med J 1993, 306: 1593-1596.

8. Doyal Len, Wilsher D. Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. Arch Dis Child 1994,70: F66~F70.

9. Sauer PJJ. Ethical decisions in neonatal intensive care units: The Dutch experience. Pediatrics 1992, 90: 729-732.

10. Ashwal S. Brain death in the newborn. Clin Perinat 1989,16: 501-518.

11. Post N. Removing organs from anencephalic infants: Ethical and legal considerations. Clin Perinat 1989, 16: 331-337.

12. Infants with anencephaly as organ sources: Ethical considerations. Committee on Bioethics. PediatriCs 1992, 89: 1116-1119.

13. Nolan K. Ethical issues in caring for pregnant women and. newborn at risk for human immunodeficiency virus infection. Sem Perinat 1989, 13: 55-65.

14. BonkoVsky FQ. Ethical issues in perinatal HIV. Clin Perinat 1994, 21: 15-29.

15. Brewin TB. How much ethics is needed to make a good doctor? Lancet 1993,341: 161-163.