

Ethical and Social Issues in the Care of the Newborn

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Abstract. Ethical and social issues are based upon a system of moral values that serve the best interests of the society in a humane and compassionate manner. The ethical decisions should be based upon the well-enunciated principles of beneficence, non-maleficence, parental autonomy, correct medical facts and justice. In view of our economic constraints, we should follow the philosophy of utilitarian ethics based on the concept of "value for money" and focus our resources and efforts for the care of salvageable babies. Nevertheless, we should try to ensure equitable development of health care of neonates at all levels, and NICU facilities should be developed in the country in a phased manner. In order to ensure justice and cost-effectiveness, the narrow principles of "best interest" of the child should be replaced by the concept of global beneficence to the family, society and the state. Neonatologists are often faced with a large number of ethical issues and dilemmas in the care of critically sick newborn babies and they should be resolved jointly by taking nurses, sub-speciality colleagues and family members into confidence. The technology should not be allowed to further dehumanize medicine and we must establish rapport and provide emotional support to the family members by showing our concern, sympathy and compassion in the care of their critically sick and extremely preterm babies. It is desirable that all the medical and nursing schools in the country should initiate regular education programs in the field of behavioural sciences, communication techniques and medical ethics for the benefit of graduate and postgraduate medical and nursing students. [*Indian J Pediatr* 2003; 70 (5) : 417-420]

Key words : Ethical issues; Ethical dilemmas; Doctor-patient relationship; Art of medicine

Ethics refers to moral principles or set of moral values that determine the conduct of doctors as stipulated by the medical profession from time to time. The moral values are governed by the society by promoting those practices that are correct, righteous, virtuous, noble, desirable and acceptable. Due to tremendous advances in technology, the care of critically ill, congenitally deformed and grossly premature newborn babies has unfolded complex medical, philosophical, moral and legal issues.

The Basis for Making Ethical Decisions

The ethical decisions are based upon a system of moral values that serve the best interests of society in a humane and caring way. The principles governing ethical decisions include beneficence, non-maleficence, parental autonomy, correct medical facts and justice^{1,2}. In accordance with the age-old Hippocratic oath, we should be the best advocates of our patients and uphold their best interests. The physicians should be concerned with saving life and avoid doing any willful harm to their patients i.e. they should be non-maleficent in their therapeutic actions. The sanctity and dignity of life should be maintained and doctor's professional capabilities should be effectively harnessed to strengthen doctor-patient relationship. Parental autonomy should be honored and they should be taken into confidence while making a decision regarding the medical care of their children. The sound ethical

decisions are based on correct medical facts which must be brought to the notice of parents to assist them to make an informed decision. The principle of justice demands that we should seek the morally correct distribution of resources and ensure cost-effectiveness of therapeutic measures by balancing the medical benefits and burdens both to the family and society. It must be ensured that the essential perinatal services must be made available to all members of the society without any discrimination on the basis of socio-economic status, religion, caste, creed and habitat.

The Need and Justifications to Establish Neonatal Intensive Care Facilities

It is a said reality that in our country a large number of salvageable newborn babies are dying in the community without receiving even basic or essential neonatal care. Therefore, it is logical to ask whether we should waste our meagre resources to establish cost-intensive and relatively cost-ineffective intensive care neonatal services. But in view of the fact that over two-third of infant deaths occur during neonatal period, there is certainly a need to establish special care neonatal units to reduce infant mortality rate. Moreover, saving the life of a newborn baby is more cost-effective for the society as it is associated with life-long productivity as opposed to saving a life due to cardiac or cerebral stroke and cancer in the elderly which is usually followed by a survival of 2-5 years. There is considerable interest on the part of

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government and corporate organizations to earmark funds and resources for creating advanced centers for care of senior citizens afflicted with degenerative, cardiac, neurologic and oncologic disorders. It is but appropriate and justified to establish specialized or intensive care facilities for care of high-risk and sick newborn babies and children. It is immoral and unethical on the part of any society to neglect the health needs of children who are indeed the foundation of a nation.

It is, however, desirable that the improvements in the neonatal care facilities should not be restricted to specialized neonatal units and they must be made available globally at all levels i.e. home, primary health center, community health center, district hospital, medical college hospital, corporate hospitals and nursing homes. It is desirable to establish equitable development of health care of neonates at all levels, be it at the grass roots or sky high. There is certainly a need to develop NICU facilities in the country in a phased manner with an effective and well-functioning referral system. However, it is unwise to establish ventilatory facilities in a district hospital without first strengthening the crucial components of essential newborn care. The benefits of specialized conservative management of high-risk newborn babies should be fully exploited to bring down neonatal mortality rate to less than 30 per 1000 live births before introducing assisted ventilation facilities in a district hospital.³

The Rights of the Fetus

Almost 1000 year ago, when there was no legal system, it was ordained by *Manusmriti* and ingrained in our culture that fetus has the right to live and inherit property. According to Indian penal code, way back in 1860, it was recognized that fetus is a living being and any person causing willful death of the fetus in the womb would be accountable. However, if in the opinion of a doctor, termination of pregnancy was considered to be in the interest of mother, it was legally permitted. The Medical Termination of Pregnancy Act (MTP) was enacted by the Indian Parliament in 1971 which further liberalized abortion for family welfare purposes. According to provisions of MTP Act, if pregnancy is less than 12 weeks of gestation, it can be terminated on the advice of one registered medical 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 and a criminal offence in our country.³ There is a need to launch concerted efforts by the government and human rights activists to curb this menace which has assumed epidemic proportions.

According to section 5 of MTP Act, pregnancy beyond 20 weeks can be terminated in order to save the life of the mother. However, premature induction of labor is routinely undertaken both for maternal and fetal indications without raising any ethical or legal issues. It

seems to be morally justified, though illegal, to abort a malformed fetus after 20 weeks if both of the following criteria are fulfilled:

- (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 or virtual absence of cognitive functions later in life.
- (ii) Prenatal diagnosis of the underlying fetal malformation is highly reliable.

However, it must be kept in mind that there is a profound medical uncertainty for making correct diagnosis and prognosis in fetal medicine. The decision for termination of pregnancy, therefore, should be taken after due consultations with a group of experts and by informed consent of parents.

Withholding and Withdrawal of Life Support

In view of the economic constraints and lack of mediclaim insurance facilities in our country, it is recommended to follow the philosophy of utilitarian ethics based on the concept of "value for money" and focus our efforts and resources for the care of salvageable babies. In order to ensure justice and cost-effectiveness, the narrow principle of "best interest" of the child should be replaced by a concept of global beneficence to the family, society and state.

In case of an infant who is inevitably destined to die or likely to survive with profound risk of severe neuromotor disability, "selective non-treatment" is legally acceptable. The withdrawal of life support measures like assisted ventilation is ethically justified if infant is diagnosed to have brain death or is likely to die regardless of any existing medical treatment.⁴ And should he live, he would have virtually no chance of leading a socially acceptable life. These conditions include extremely preterm baby with massive intraventricular hemorrhage, CNS malformations, severe birth asphyxia with lack of breathing efforts for more than 30 minutes and persistent vegetative state etc.^{5,6} In these situations death is considered as a more humane option than a life filled with suffering and misery. Above all, we must accept death as the ultimate truth because medicine can never achieve immortality.

Ethical Dilemmas

In perinatal medicine, it is often difficult and at times impossible to correctly prognosticate immediate survival and later neuromotor outcome.⁷ The "futility" issue often becomes controversial because as rightly said by Sir William Osler, "medicine is a science of uncertainty and an art of probability". Due to profound economic disparities, there is lack of social justice and non-availability of equitable health care to all segments of society. It is unfortunate that even salvageable babies with treatable conditions are denied essential life sustaining

therapies either due to non-availability of technology or because of their non-affordability by the parents. A large number of pediatricians and perinatal health care professionals face a number of ethical issues and dilemmas which are listed below :

- (i) At times it is difficult to know which interests are 'best' for the baby, withholding treatment or treating aggressively.
- (ii) Should we be concerned with the "best interests" of the child alone or global interests of the family, society or state?
- (iii) Should NICU facilities be denied if family cannot afford it?
- (iv) Should fertility of the couple or gender of the child affect our ethical decisions?
- (v) The concept of destiny, will of God and the doctor-knows-the-best attitude and illiteracy etc. often mitigates the concept of parental autonomy and informed consent of parents.
- (vi) At times, the daily cost of NICU care may be more than the monthly salary of the family.
- (vii) When survival of a high-risk baby is associated with neuromotor disability, it may be unbearable for the family due to lack of social support system and inadequate facilities for the care of children with severe neuromotor disabilities?
- (viii) Should a high-risk extremely LBW baby be taken off the ventilator to provide assisted ventilation to a more salvageable bigger baby?
- (ix) What should be done when the family cannot further afford the expenses for providing medical care to their critically sick baby in a private hospital?
- (x) Is it worthwhile to provide hi-tech and extremely expensive intensive care to a tiny baby of illiterate and economically destitute parents who are unlikely to provide basic care to the baby after discharge from the hospital?

The fundamental principles governing ethical decisions should be effectively harnessed to find the most suitable options to resolve the aforementioned ethical dilemmas.⁷ Nevertheless, it is unfortunate but true that in a developing country, economic and social realities may at times outweigh and override ethical considerations.

Perinatal HIV Infection

There is an increasing risk of vertical transmission of HIV from infected mother to her baby during delivery and breast feeding. There is a need for selective HIV screening of high risk populations. The risk of vertical transmission of HIV infection during pregnancy varies between 15-30 percent and there is additional 15% risk of HIV infection through breast feeding. The infected mother should be told about the risk of vertical transmission of HIV to her offspring and given the option for abortion if desired by her. She should be encouraged to take an informed

decision regarding breast feeding. The confidentiality should be honored and maintained at all costs. Physicians are obliged to provide competent and humane care without any discrimination to all patients including those with HIV infection.^{8,9}

Surrogate Motherhood

The advances in assisted reproduction techniques (ART) have raised several ethical and legal issues. The reality of genetic engineering and cloning capabilities is likely to further complicate ethical concerns and dilemmas. The commercial hiring and subletting of womb for monetary gains need to be discouraged. Impregnation of a hired womb through a sex act raises additional concerns regarding morality and its acceptability by the society. The government of India is considering to introduce an Act in the near future to control various ARTs.

Communication as the Key to Boost Doctor-Patient Relationship

The parents should be kept informed about the condition of their critically sick baby in a simple, easily understandable language. Humility, concern, empathy and compassion are crucial to generate faith and provide emotional support to the family.¹⁰ The health team should not only try to do their best, but the family must perceive that whatever was humanely possible in the circumstances was actually done for their child. The parents should be encouraged to touch and "talk" with their critically sick neonate in order to transmit healing messages. The religious faith of the family should be honored and if the parents wish they may be permitted to use any *mantras* or amulets to enhance the process of healing through faith.

It is unfortunate that physicians are becoming more of technocrats and gradually losing the art of medicine. We have allowed technology to dehumanize medicine thus eroding the faith and confidence between patients/parents and the physician.¹¹ It is timely and desirable that all medical and nursing schools in the country should initiate regular education programs in the field of behavioral sciences, communication techniques and medical ethics for the benefit of graduate and post graduate medical and nursing students.¹² The physicians should make concerted efforts to resurrect the dwindling art of medicine and acquire the divine gift of healing.

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