Editorial

Ethical Considerations in Pediatric Intensive Care Unit: Indian Perspective

"No other gift is greater than the gift of life! The patient may doubt his relatives, his sons and even his parents, but he has full faith in his physician. He gives himself up in the doctor's hands and has no misgivings about him. Therefore, it is the physician's duty to look after him as his own".

(Charak)

There is a tremendous age old faith, trust and respect towards physicians in Indian culture. The doctor is often viewed as a demi god and his advice, is usually considered as a gospel truth without any doubt and misgivings thus imposing an onerous responsibility on him for an ethical, correct and honest approach in his dealings with his patients. However, the physicians must realize that they are both morally and legally accountable to the society. Till recently, the acts of omissions and commissions by the physicians, were never challenged by the patients in India. The increasing public awareness and literacy with inclusion of services rendered by the physicians under the purview of the controversial Consumer Protection Act 1986 has exploded the myth of infallibility of Indian physicians. The doctors are equally to blame for the erosion of patient-doctor relationship and trust. Medicine is no longer considered as an art and divine task for allaying the suffering of ailing humanity, it has merely become another profession with all the unfortunate attributes of commercialism.

Due to rapid strides in medical technology over the years, the care of critically ill children with life threatening disorders in the Pediatric Intensive Care Unit (PICU) has unfolded complex medical, social, ethical, philosophical, moral and legal issues. Apart from tremendous financial cost of pediatric intensive care to the parents and society, there is incalculable cost in terms of pain, suffering, grief, anxiety, inadequacy, frustration and guilt not only to patients and their parents but also for the treating medical and nursing team of PICU.

Basic Correlates of Ethical Decisions

Ethical decisions are based on the four principles of beneficence, non-maleficence, parental autonomy and justice (l,2). Beneficence refers to the mandate that we should be the best advocates of our patients and safeguard their "best interests" in accordance with the age old Hippocratic tradition. It stipulates that physicians should be concerned with saving life and they should avoid doing any willful harm to their patients, *i.e.,* they should be non-maleficence in their diagnostic and therapeutic actions. The autonomy and wishes of parents should be honored and they should be taken into confidence while making a decision regarding the medical care of their children through a process of informed consent. The principle of justice demands that we seek the morally correct distribution of resources, ensure cost-effectiveness of therapeutic interventions by balancing medical benefits and burdens to the family and society. A large number of other factors and considerations

are taken into account while making a decision for various complex issues prevailing in the PICU, Is there a reasonable chance of survival of the child with the available technology or are the efforts going to be futile? In what clinical situations, medical intervention is considered as futile at present? Would the quality of life be worthwhile if the child survives with aggressive management? How to assess the burdens and benefits of a therapy? Can the family afford expensive management? Should we be concerned with the "best interests" of the patient alone or global interests of the family, society and state? In what clinical situations intensive life support therapy should be withheld? Should an unsalvageable child be hooked off the ventilator when a relatively better risk child who needs assisted ventilation is admitted to the PICU? There are several other confounding variables like cultural considerations, fertility of the parents, inter-parental harmony, gender of the child, the concept of destiny or will of God, the doctor-knows-the-best attitude, education and economic status of parents, available social support system and national priorities, *etc.* However, whatever final decision is taken jointly by the medical team of experts and parents, it should be without any ambiguity and recorded in the case file with full justifications.

The Need and Quality of Pediatric Intensive Care Facilities

It is not only justified but highly desirable to establish PICUs in all district and state level hospitals both in the private and government sector in a phased manner throughout the country. It is mandatory to ensure equitable development of health care services for children at all levels. In order to ensure effectivity and credibility of the referral system, it is desirable to establish highly specialized medical care facilities for children suffering from life-threatening critical disorders. If cardiac intensive care units and cancer critical care units for adults are an accepted norm by the society, establishment of PICUs should be more readily acceptable because they are more cost-effective. Saving the life of an adult with stroke or cancer provides a lease of longevity for 2 to 5 years but saving the life of a child is associated with a productive life of several decades. Moreover, it is easier to salvage the life of a critically sick child due to their better reparative capabilities and lack of degenerative changes and functional derangements in the body organs.

The modern PICU should be equipped with the state-of-the-art technology and run with business-like efficiency. It should be staffed with skillful, dedicated and trained paramedics, nurses and resident doctors. But above all, they should be enthused and equipped with qualities of human warmth, compassion and consideration. The general atmosphere of PICU should exude overall optimism rather than the gloom of hopelessness despite all the odds. It is desirable to maintain a balanced approach in various management protocols in order to avoid both under and over treatment. The PICU procedure manual should outline details of admission policies and indications for do-not-resuscitate (DNR) and for withholding/withdrawing life support systems(3,4).

Parental Expectations in PICU

In view of the shortage of nurses and local cultural considerations, at least one of the parents should be allowed to remain with the critically sick child and perform certain dedicated tasks and a routine conventional parenting role. They should be provided with an accurate information regarding the condition of the child on a regular and continuous basis in an easily understandable language without any

medical jargon. There should be one identifiable physician for regular interaction with the family in a relaxed manner in a rest room located adjacent to the PICU. Above all, the parents greatly honor the availability of a caring, credible, considerate and compassionate health team. They need the assurance and transparency that every possible effort is being made to save the life of their sick child.

Communication as the Vital Link

Most parental complaints in PICU originate due to lack of communication or because of abrasive and callous attitude of the members of the health team rather than due to lack of skills or fruity technical management of the patient. It is an amazing fact that most parents are grateful even when we are unable to save the life of their child especially if one showed concern, care and compassion and they were made to perceive that whatever was humanely possible was done for the care of their child. It is crucial to *listen* and *talk* to the parents at least twice a day in a relaxed unhurried manner(4,5). Humility, concern, empathy and compassion are crucial to generate faith and provide emotional support to the family at this critical juncture. The pediatrician should be careful and tactful not only in deciding *what* to tell the parents but also *how* to tell it. The parents should be told about the condition of the child in a simple language. Try to be pragmatic and honest but always keep the *hope* alive which has tremendous healing capabilities. Avoid creating confusion in the mind of parents due to conflicting messages given by different physicians. In a critically sick child, always give a guarded prognosis which can be tampered with hope and godly benevolence. The health team should not only try to do their best, the family must perceive and appreciate 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 child, whether he is an infant or a child in coma, because it transmits healing messages. The religious faith of the family should be honored and if the parents wish they may be allowed to use any mantras or charms to enhance the process of healing through faith. By and large, efforts should be made to honor all the wishes of the parents of critically sick child if they are not obviously harmful or contrary to the recommended therapies in a specific situation.

The Concept of Medical Futility

Despite tremendous advances in medical knowledge and technology in the recent past, medicine cannot ever achieve immortality. Based on known medical facts when an intended therapy is likely to fail in 100% cases, it is considered as futile to continue with aggressive management (6). The medical therapy that merely prolongs life of a patient with permanent unconsciousness in a persistent vegetative state (PVS) or when survival is likely to be associated with virtual or total lack of cognition without any meaningful existence, the therapy becomes meaningless or futile effort. However, in actual clinical practice these decisions are rather difficult as rightly said by Sir William Osier, "medicine is a science of uncertainty and an art of probability".

Persistent Vegetative State (PVS)

Ethics and Humanities Subcommittee of the American Academy of Neurology has provided clear clinical guidelines for the diagnosis of PVS(7,8). The common etiologic syndromes of PVS in children include near-drowning, hypoxic-ischemic encephalopathy, meningitis, encephalitis/

encephalopathies and degenerative CNS disorders. It is characterized by protracted coma with open eyes. There is no voluntary action or behavior of any kind though they do have periods of wakefulness and physiological sleep. They are unable to experience any suffering, pain and pleasure. They lack coordinated chewing and swallowing is usually absent. They are likely to have prolonged survival if provided with fluids and nutrition. In view of their meaningless existence without any purpose, the American Academy of Neurology has sanctioned the withdrawal of nutrition and fluids in patients with PVS if agreed by their care providers and parents through the process of informed consent. However, this approach is controversial on basic humanitarian grounds because feeding hungry people is considered as a great act of compassion while starving a dependent person is viewed with utmost abhorrence and disbelief.

Financial Considerations

The PICU care is highly cost-intensive and daily cost of care may be more than the monthly salary of the family. Apart from out of pocket expenses for PICU care in private sector, there are additional financial implications to the family due to lost wages, travel expenses, expenses on drugs, special diets and disposables, *etc.* Lack of medicare insurance coverage and profound economic disparities and inequitable social justice in India further complicate the complex economic realities. The patients are often completely drained off monetarily by private nursing homes and then referred to the government hospitals when they are at the brink of bankruptcy and near the threshold of death. The overall gloomy prognosis and outcome both in terms of immediate survival and quality of life after survival, often makes economic drainage unbearable leading to several adverse consequences to the family dynamics for several months and years.

The Decision Making Process

Ethical decisions are based on clear understanding of a large number of complex issues. The underlying medical facts pertaining to the patient should be properly analyzed in the light of available information and technology. Sound ethical decisions can only be based on correct medical facts(9,10). It should be known with fair degree of confidence whether the intended therapy in a particular patient is likely to be rewarding or futile. Carefully evaluate the burdens (suffering, death, disability) and benefits of the proposed intervention to the child, family and society (value conflicts). A team approach should be followed by taking into confidence all the medical and nursing experts for identification of various options and for making a reasonable and right opinion. The issue should be discussed with the parents to seek their opinion through a process of informed consent. The various confounding conflicts should be resolved to arrive at a mutually acceptable option through a process of consensus. The final decision should be recorded in the case file with full justifications and endorsement by the parent/s.

Withholding/Withdrawing Life Support Therapies

There is no significant medical and moral distinction between withholding and withdrawing treatment. When it is futile to treat because the condition is either irreversible or terminal or patient is in PVS or brain dead, it is undesirable and unrealistic to continue with overzealous aggressive therapy. The core consideration in making such a decision is evaluation of burdens and benefits of a therapy to the Child, family and the society ("best interest standards").

Instead of continuation of life prolonging therapy, it is desirable to provide palliative care to relieve pain and suffering. Humanistic teachings in general and philosophies of all the major religions of the world recognize that there comes a time in the care of every patient when it is appropriate for the doctor to stop further attempts to prolong unnecessarily the process of dying. A policy of passive euthanasia is followed by withholding CPR, life saving surgery, assisted ventilation, dialysis, vasopressors, blood and blood products and expensive antibiotics, *etc.* The provision of fluids and nutrition is also a form of medical therapy but its denial is controversial and often considered inhuman. Although switching off a ventilator is an "act" of commission but active euthanasia (say by intravenous administration of potassium chloride) is considered as morally and ethically unjust. There is a risk of error, possibility of an abuse and likelihood of erosion of trust in the doctor-patient relationship(9). The sanctity and dignity of life should not be sacrificed at any cost. However, unintended but foreseen consequences of over dosage of conventional drugs in the management of terminally sick patient, *e.g.,* overdose of analgesic-sedative to a patient with cancer is practiced at times without raising any eyebrows.

Cardio-pulmonary resuscitation is withheld if a patient is terminally sick or it is believed that the available therapies are likely to be futile and in the event of survival there will be virtual or total loss of cognition for any meaningful existence *(Table I).* The decision should be taken after due deliberations among various experts and by taking family into confidence through the process of informed consent. The decision should be recorded in the case file along with full medical justifications and should be duly signed by the parent/surrogate. This approach is duly approved by the leading professional and academic bodies of the world. The policy is rational and logical and is aimed at reducing the suffering and misery of both the dying patient and his close relatives but it lacks legal sanction and protection. There is a need to accord legal sanctity to the act of passive euthanasia in order to avoid unnecessary litigations.

Criteria for Death

Availability of advanced life support systems has posed practical difficulties in making the diagnosis of death. When there is irreversible cessation of circulatory and respiratory functions and CPR efforts diligently performed over a period of 30 minutes have failed, death can be certified. In patients maintained on assisted ventilation, criteria of brain death are used for declaring the patient as dead *(Table II).* They are based on absence of brain stem responses(11). There are no reliable clinical criteria of brain death in preterm babies and term babies below the age of 7 days. In infants between the age of 7 days to 2 months, the brain stem responses should be absent during an observation period of 48 h, between 2 months to 1 year for 24 h and children older than 1 year for 12 h. Due to increased potentialities for recovery, the observation period is

TABLE I— *Indications for Do-not-resuscitate (DNR) Orders.*

1. Advanced metastatic malignancy
2. Multisystem end-stage organ failure
3. Severe irreversible CNS disorder: trauma, bleeding, tumor
4. Severe known underlying neuromotor disability
5. Persistent vegetative state
6. Brain dead*

* Usually an indication for withdrawal of life support.

prolonged in children with narcotic poisoning, exposure to severe cold, near-drowning, head injury, neuromuscular blockade, *etc.* In view of the increasing importance of early diagnosis of brain death due to the emerging possibilities of cadaveric organ donation for transplant programmes, a large number of sophisticated laboratory procedures are available though the lack of their portability undermines their practical utility *{Table III).*

How to Communicate the Death of the Child?

Although we are all destined to die and death is the greatest truth, it is always unacceptable especially so when life is cut short in the bud without fulfillment of purpose of existence. It is easier to face death when it is anticipated and family is adequately prepared for the eventuality. If death is sudden and unexpected, the family should be prepared emotionally before declaration of death(12). The family should be informed with compassion and utmost care but in no unmistakable terms that the child has died despite our best intentions and efforts. A large number of emotions like anger, hostility, shock, grief, guilt, denial, depression, *etc.* need to be handled with poise, sympathy, utmost care and compassion so that reality is accepted with grace as a will of God or nature's ordain. While CPR is provided (if DNR not applicable), the relative/attendant should be escorted to the rest room and allowed to ventilate his/her feelings. Family's wishes for religious support and ceremonies or their desire that death should occur in the familiar atmosphere of home rather than hospital, should be honored as far as possible(13,14). When a child is conscious and dying, the family should be at his bed side and talk with him to allay his fears and assist him to express his concerns, desires and emotions. Silent listening and support at this stage is valued more than unnecessary talking. During their earlier career some resident doctors/nurses may feel extremely frustrated and angry due to their inadequacy and inability to save life despite maximal efforts. They also need emotional support, guidance and advice to avoid unnecessary identification and attachment with the family. They should be assisted to learn the art of detachment, imperturbability and poise at all odds. After taking relevant postmortem biopsies, family should be approached with caution and tact to seek permission for autopsy. Do not give the impression that autopsy is needed for making a diagnosis but for helping the medical science and family regarding the prevention of disease among contacts and siblings and for possible genetic counselling. The enaction of Human Organ Transplant Act by the Indian Parliament in 1994 has opened opportunities for cadaveric transplant

TABLE ll-*Clinical Criteria for Brain Death*

1. Coma and apnea
2. Dilated and fixed pupils
3. Absent corneal reflex
4. No movements of eyes or dysconjugate movements of eyes on Doll's head-eye movements maneuver
5. Lack of response to cold caloric test
6. Absent gag and cough reflex

TABLE III-*Laboratory Criteria of Brain Death*

1. Electro cerebral silence on BEG for at least 30 min
2. Lack of brain stem evoked responses
3. Radio isotopic bolus angiography*
4. Xenon CT*
5. Digital substraction angiography*
6. Gamma-scintigraphy*
7. Four-vessel intracranial angiography*

* Absence of cerebral blood flow on dynamic brain scanning

of heart, lungs, liver, kidneys, pancreas, *etc*. which should be fully exploited. The possibility of a positive contribution through their tragedy that their child may be able to see the world or live through somebody else's eyes and body, may be accepted with enthusiasm. The issue of organ donation should not be broached if there are well recognized contraindications for donation of organs(15). After completing urgent formalities, a detailed death certificate should be prepared. Provide courtesy, compassion and conveyance to the family for a dignified journey of the dead child to the mortuary or home. The coping of the death of a child in PICU is a painful and challenging experience but one that can also provide profound respect for humanity and life. Death punctures our ego and teaches us humility and provides strength to face the greatest reality and truth of life.

Resurrection of Medical Ethics

The continuing process of erosion of doctor-patient relationship and trust due to insensitive and commercialized attitude of upcoming physicians (especially due to exorbitant cost of medical education in private sector) and over demanding attitude of better educated and well informed patients need to be checked against further disintegration. In view of the fact that services of doctors have been included in the purview of Consumer Protection Act for redressal of grievances and grant of compensation by the consumer courts, it is essential for the doctors to be more cautious, considerate and ethical in their dealings with their patients to avoid any unnecessary legal actions. It is desirable that all medical colleges in the country should initiate regular education programme in the field of behavioral sciences and medical ethics for graduate and postgraduate medical students(16). Ethics committees should be established in all hospitals and they should serve as a watch dog to monitor and maintain the sanctity of all ethical decisions. The physicians should be enthused and imbued with the qualities of sensitivity, compassion and genuine concern towards their patients through a process of role modeling by the teachers. If is nice to be a well informed doctor but it is much nicer to be a good human being in order to provide *holistic care* rather than mere cure to one's patients.

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