ETHICAL GUIDELINES
ON MEDICAL TREATMENT OF HIGH-RISK INFANTS

1. The Treatment Dilemma

As medical technology has advanced, outcomes for high-risk newborn infants have greatly improved. If intensive treatment uniformly resulted in saving infants at risk, it would be the obvious choice for all severely ill infants. This outcome, of course, does not always occur. Intensive care has also been successful in rescuing infants with conditions where it can be predicted, with reasonable degree of certainty, that permanent and crippling disability will result. On the other hand, if intensive treatment is not provided to very ill infants, some of them will die, but some may survive with significant neuro-developmental disability, in part because specific treatments were withheld. The overall outcomes of failure to provide appropriate treatments or the indiscriminate use of technology are disappointing.

2. "Best Interest" of the Infant

The medical treatment of infants should be based on what is in their best interest. However, the infant's 'best interest' is not always clear and his/her interest may be violated in a number of ways - through being allowed to die without sufficient reason, by being kept alive for a fate worse than death, or by prolonging the process of dying through insistence on futile treatment. It is perceived that the parents are most likely to have their infant's best interest at heart and doctors are trusted to make decisions responsibly; but ignorance, prejudice, grief, eccentricity, self-interest and other considerations occasionally will intrude. As each infant in each family is unique and the circumstances of each case so complex, only general guidelines can be provided and much latitude in decision-making should be expected and tolerated.

3. The High-Risk Infants

Three groups of high-risk infants always present with difficult treatment decisions:
   a. Infants around the threshold of viability (<25 weeks gestation or <700 grams birthweight)
   b. Infants with major and/or multiple congenital abnormalities
   c. Infants severely damaged by complications of pregnancy, delivery, or the early neonatal period.

4. Resuscitation at Birth - Initiation of Treatment

When it is clear that a high-risk infant will result, it is important to use the time before delivery for consultation with the family. The parents should be given some idea of the nature and extent of the problems, immediate and long-term. Sometimes, they may be totally unprepared for the situation, and they have to be much guided by the advice of their obstetrician, paediatrician and other relevant physicians. It is necessary, therefore, to take some stance and allow them to give agreement or disagreement rather than throwing the entire weight of decision in their laps.
If there is good reason to treat an infant and resuscitation becomes necessary, it should be started immediately to maximum efficiency and capacity. If death is inevitable or if it has been decided with the parents in advance that aggressive treatment is inappropriate, resuscitation should be withheld. It may not be possible to give an accurate prognosis at the time of birth. Therefore, the approach to this dilemma should be always to initiate maximum treatment, including endotracheal intubation and assisted ventilation if necessary, thereby favouring possible intact survival, until a more considered judgement can be made on the advisability of continuing life support. If further developments or later assessments indicate that there is a high likelihood of extensive brain damage, treatment will be stopped.

5. Continuation of Curative Treatment

Treatment of a curative nature should always be continued where there is a medical consensus that it would provide a net benefit to the infant. The infant's medical condition should be the sole focus of any decision-making process. Decisions to continue, stop, or alter care must not be based on the financial status of the parents or the financial interests of the physicians, the hospitals, or the insurance carrier or other third-party payer. If there is any lack of clarity of whether curative treatment will be beneficial, the bias should always be in favour of its continuation. Only when the medical facts reveal the futility of further curative efforts should the difficult decision to discontinue life support and to provide palliative treatment be made.

6. Withdrawal of life-sustaining treatment

It will be easier to initiate treatment and begin intensive care if it is clear that this care can be withdrawn if it proves futile or ill-advised. When the burden of curative efforts lacks compensating benefit or such treatment is no longer of any avail, there is no need to continue or pursue it. Therapies lack compensating benefit when they merely prolong the dying process, when the infant suffers from severe pain which cannot be alleviated by medical treatment, or when the infant will be unable to participate even minimally in human experience.

Active measures to terminate life is not allowed, as it is equivalent to active euthanasia.

7. Palliative Treatment

Withdrawal of life-sustaining treatment is not tantamount to withdrawing care. When a firm decision has been made, it is not unethical, with parental agreement, to forgo all means of life-sustaining medical treatment if these measures are considered not appropriate and futile. Medical treatments include medication and artificially or technologically supplied respiration.

Since every infant is unique, the specifics of palliative treatment must be individualised. The infant and the family should be treated with dignity and compassion. Measures for the comfort of the baby, the avoidance of unnecessary and painful interventions, opportunity for interaction of the family with the infant, baptism when appropriate, swaddling and holding, presence and support by the medical team: these are vital aspects of care that cushion the impact of an unavoidable death.
8. The Decision-Making Process: Physician's Role

There is no distinction between initiation or withdrawal of life-sustaining treatment. An individualised prognostic strategy is recommended. In this setting, care is provided for the individual infant at the appropriate level based on the expected outcome at the time care is initiated. This approach places significant responsibility on the attending physician and health care team to evaluate the infant accurately and continuously. He/She should consult with colleagues and other appropriate sub-specialists and employ all available technologies to thoroughly assess and confirm the diagnosis and prognosis of the infant - good ethical decisions begin with good facts. Together, they attempt to define the issues, outline options and decide on the nature of treatment. By following this course, the risk of placing undue reliance on a single person's judgement is avoided.

As an individual with an overall perspective of the medical realities of the case and who also is in close contact with the family, the attending physician is in the best position to make a sound recommendation of the preferred treatment option to the parents, based on the projected benefits and burdens of treatment, recognising that parents may perceive and value these benefits and burdens differently from medical professionals. The decisions should be made openly and documented so that doctors are seen to be accountable for their actions. They should be prepared to defend them in court if necessary.


The effectiveness of the medical team depends on the extent to which the relationship between it and the parents is based on frank and open discussion and trust from the outset. The parents of the infant must be kept informed of the infant's current status and prognosis. In this way, the parents would have been in close communication and by the time a medical consensus is reached for discontinuation of curative efforts, they would appreciate that all reasonable hope has been exhausted.

Parents should be actively involved in major decisions that ultimately could alter the infant's outcome. The parents bear the principal moral responsibility for the well-being of their infant and should therefore be the surrogates for their infants. The pre-eminence of the parents' decision does not preclude the attending physician's responsibility to make a definite recommendation on the preferred treatment option. It is incorrect to provide a mass of medical facts and leave the parents adrift without specific guidance. The attending physician may have to guide parents towards what is acceptable not only medically but morally and socially, and what is within the law. He/She must also be sensitive to the parents' concerns and desires, which are often based on a complex combination of values and influences derived from their cultural, religious, educational, and ethnic backgrounds.

10. Resolving Differences

The decisions involved in shifting the emphasis from curative to palliative treatments are difficult and come about gradually as the infant's physical condition deteriorates. Sometimes a waiting period is required when the worsening condition becomes more evident before a time comes when discontinuation of curative efforts can be jointly resolved.

The rights and decision of the parents should always be respected. However, physicians should not be forced to under-treat or over-treat an infant if, in their best medical judgement, the treatment is not in compliance with the standards of care for that
infant. Although it rarely ever happens, when there is a conflict or disagreement between the recommendations of the physician and the desires of the parents, one option is to consult with the hospital ethics committee. Another option is for the physician and family to seek another physician willing to provide care for the infant in the manner desired by the family. In rare instances, it may be necessary to invoke established child protective mechanisms if parents wish to forgo life-sustaining treatment, physicians disagree, and the parties cannot resolve their differences with help from sub-specialists or ethics committees. In that case, the physician should continue to serve as advocate for the infant.

11. Ethics Committees

The decision-making process between the doctors and the parents is an intensely private affair and interference by outsiders like the ethics committees may cause confusions and complications. The role and objective of the Ethics Committee should be well-defined.

Ethics committees can be effective in an advisory capacity. They provide a good mechanism to review decisions for critically ill infants to ensure the best care for them and to assure the public that ethically sound decisions are being made in the Intensive Care Units. It can also assist in resolving differences in opinion among those involved in decision-making. Furthermore, by increasing discussion and deliberation of the complex issues, the professional staff will be better able to deal with exigent situations and to provide thoughtful decision making in difficult cases. Finally, the role of the ethics committee will be to provide 'ethical comfort' and give some legal protection for staff and family alike in carrying out these difficult decisions for some of the most critically ill patients in the hospital.

12. Aftercare and Support

Support should be provided to the family by physicians, nurses, and other staff beyond the time of the infant's death. Support groups, intermittent contact by phone, and a later conference with the family to review the medical events surrounding the infant's death and to evaluate the grieving response of the parents may be considered.

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REFERENCES


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