

Ethical Dilemmas in Perinatal and Neonatal Care: Tough Questions, Fuzzy Answers

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Abstract

Medical ethics and laws in many developed countries would permit limitation of neonatal intensive care (withholding or withdrawing) and shift towards palliative and comfort care in critically sick neonate with poor outcome. Recent advances in the management of these neonates in developing countries have led to the improved survival which is associated with increased risk of morbidities thus creating the ground for ethical issues and conflicts. There is no “clear cutoff point” or “right answer” to this question and there are many ethical issues behind this concept. This paper discusses the relevant ethical issues in the decision making and management of four neonatal cases. We conclude that there is substantial disagreement about these ethical issues, how they need to be resolved along with their legal repercussions creating a biggest challenge how we can arrive at sensible judgments to base public policy.

Keywords: Medical Ethics; Neonatal Intensive Care; Ethical Issues

Introduction

Neonatal intensive care units (NICU) are increasingly contributing to survival of the most critically ill neonates on account of sophisticated technological advances and rescue strategies. A diverse range of ethical dilemmas are emerging. Perspectives on biomedical ethics issues in the NICU vary and consensus (on consistent approaches to resolve these conflicts) is often elusive [1]. The core of the ethics related conflicts in decision making in the NICU involve provision and withdrawal of treatment [2]. Ethical perspectives of the decision-makers i.e. physicians, nurses and parents often turn out to be widely divergent.

Laws and norms of medical ethics in many developed countries permit limiting neonatal intensive care (withholding or withdrawing), accompanied by a shift towards palliative and comfort care in critically sick neonates with poor outcomes [3]. These practices represent a more humane and reasonable alternative that is geared towards minimizing pain and suffering, and improving wellbeing of the family, rather than maintaining or prolonging life at any cost [2,4,5]. Understandably, there are difficulties in determining “clear cut-off points” or “right answers” to several of these situations that we shall seek to demonstrate through some case scenarios in this paper.

Case Scenarios

We describe four diverse scenarios encountered at a tertiary care NICU of a post-graduate and research hospital of New Delhi.

Case 1

Baby X (female) was delivered by caesarean section (on account of an obstructed labour) of a primiparous mother at term gestation. She suffered perinatal asphyxia and subsequently developed severe encephalopathy with organ dysfunction. Her clinical status continued to deteriorate and she subsequently became brain dead on the 19th day. Parents were routinely counseled regarding the adverse outcome and on the 21st day they left with the baby against medical advice.

Medical concerns: Treatment being given is only supportive might lead to more harm than good, human resource wastage as the outcome is invariably going to be grim, wastage of expensive hospital supplies in resource limited settings.

Parental concerns: High expenses despite poor outcome; parents taking leave from their professional commitments; anxiety about suffering and outcome of the baby; and, prolonged stay at the NICU.

Case 2

Baby Y (female) was born at term at home and required hospitalization on the 6th day due to difficulty in breathing and bluish discoloration of the body. Diagnostic evaluation revealed complex cyanotic congenital heart disease that was incompatible with life in the absence of immediate therapeutic intervention. Prostaglandin infusion was initiated; parents were asked to procure additional doses as the hospital supply was limited. The parents were unable to afford the prostaglandin therapy. Surgery was ruled out as an option both due to limited availability of expertise as well as the requirement of considerable expenses on the part of the parents. Consequently, they left the hospital against medical advice.

Ethical concerns: Leaving against medical advice was likely to accelerate mortality; and, economically weak parents asked to procure expensive medication that would only provide a bridge therapy before an even more expensive corrective surgery could be undertaken.

Case 3

Baby K (female) was born at 36 weeks of gestation and found to be dysmorphic during routine examination at birth (micrognathia, short neck, clenched hands with overlapping fingers and, rocker bottom feet). Echocardiography revealed a large ventricular septal defect. Karyotyping showed trisomy for chromosome 18. Caregivers were counseled regarding a poor prognosis; they decided to discontinue further treatment and left the hospital against medical advice.

Ethical concerns: Justification of medical care with a median duration of survival of about 2 weeks (90 - 100% die by 1 year of age); majority of these cases shall have a life threatening anomaly that require highly skilled surgical expertise as well as a large commitment of resources; and, unfavorable rehabilitation outcomes on account of global developmental delay with mental retardation.

Case 4

Baby A (female) was born to a primigravida mother after 25 weeks of gestation and weighed 490 grams. She developed severe respiratory distress at birth; resuscitation at birth was withheld in view of remote chances of survival, in concurrence to parental wishes. She was offered only comforting care till she expired at the 4th postnatal hour.

Ethical issues: Decision to withhold resuscitation due to extreme prematurity and potentially violating the “sanctity of life”; and, feasibility of providing prolonged intensive care in resource constrained settings.

Discussion

Duff and Campbell were the first to draw attention to ethical and moral dilemmas faced by physicians and nurses in NICUs [6]. Their paper elicited considerable debate in the medical community and emphasized conflicts of interests that may arise among decision-makers such as medical professionals, and the parents [7]. They suggested two different philosophies of care: the traditional “disease oriented” approach, aimed at achieving survival at any cost; and a new, more flexible philosophy - “person oriented” - which takes into consideration the “quality of life” and considered catastrophically compromised existence as a more adverse scenario than death [7]. Other authors across countries reported similar experiences in their NICUs [5,8]. The EURONIC study involving neonatologists across various European NICUs practicing end-of-life limitation of treatment showed variable response to decision-making. Culture-related and other country-specific factors are more relevant than characteristics of individual physician or unit in explaining such variability [9]. However, the major principles driving biomedical ethics related intensive care decisions entail honoring the four basic principles: autonomy, beneficence, non-maleficence and justice. Significant differences in decision making can be expected between parents and health care providers while considering continuation of treatment in conditions such as severe perinatal asphyxia with major vital impairment with health care providers putting more emphasis on ‘quality of life approach’ in contrast to parents adopting a ‘sanctity of life approach’. The final decision is critically dependent on the decision of parents for continuation of vital support (surrogate decision) [10]. Physicians need to talk to parents as soon as possible after the birth of an asphyxiated infant to provide them with the diverse therapeutic options in a non-directional manner and offer assistance as it is asked for or becomes necessary [11,12]. However, before this conversation physicians should be aware of their hospital statistics regarding both short term and long term outcomes of such babies. The decision to continue, stop or withdraw vital support must be autonomously made by parents, based on objective information provided by health professionals and in the best interest of their child [13,14].

The ethical dilemma associated with the management of extreme preterm infants are two-fold; ethical dilemma for resuscitation at the time of birth and the dilemma in providing full medical support after they have been born [15].

Fetal viability is defined as sustaining life outside the womb, with or without medical assistance. The definition has changed with advances in technology and may vary in different countries depending upon availability of technology and other resources. This threshold gestational age can be 23 - 24 weeks in developed countries compared to 28 weeks or more in developing countries [16-18]. The birth of an extreme preterm infant poses complex medical, social and ethical challenges not only to the family but also to the health-care professionals. According to the 2015 American Academy of Pediatrics and American Heart Association guidelines for resuscitation, when counseling a family and constructing a prognosis for survival and morbidity at gestational age below 25 weeks, it is reasonable to consider variables such as accuracy of gestational age assignment, the presence of chorioamnionitis, and the level of care available in the index institution. It is also recognized that decisions about appropriateness of resuscitation below 25 weeks of gestation will be influenced by region and centre specific guidelines [19].

Withholding and withdrawing of medical care in the NICUs based on grounds of futility and quality of life have important ethical implications [20]. Counseling of parents in complex clinical scenarios is influenced by deterioration of their infant despite maximal support or the discovery of devastating congenital or acquired neurologic abnormalities after a period of hope and anxiety. These end-of-life decisions may produce conflicts between medical team and parents as well as even amongst the medical team member themselves [21]. When the best interests of the baby are not evident and where treatment is only marginally beneficial, parental autonomy should be upheld. It can be done in three possible ways: withdrawal of intensive care, do not resuscitate (DNR) decisions, and withholding of further care; the first being the most common practice amongst European countries as evidenced in the EPICure study in the UK and Ireland [3], EPIPAGE study in France [3] and LFUPP study in the Netherlands [3]. These babies are then placed on palliative care which focuses on relief of physical pain and suffering [3].

Concluding Remarks

These case scenarios highlight that improvement in perinatal and neonatal medicine have enabled newborns (who previously would have died) to survive and lead healthy lives. Simultaneously, there are additional social, ethical and legal dilemmas for both families as well as health care professionals in making complex and emotionally demanding decisions that may have lifelong consequences. We identified some difficult questions in perinatal and neonatal medicine concerning a number of (recurring) ethical issues. These include the value of life at different stages of development, distinctions between active ending of life and death resulting from withholding or withdrawing treatment, and balancing interests of affected newborn and their families. Undeniably, there is substantial disagreement about these issues, and how they need to be resolved. Health care professional themselves hold diverse opinions on these matters. These dilemmas in neonatal care are yet to be addressed in a broad public health ethics framework.

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Conflict of Interest

None.

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