

Ethical and moral dilemmas in neonates

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Background: Among the many neonatal ethical problems, the one which neonatologists are faced with on a regular basis involves the issue of selective non-treatment, that is, clinical decisions made after the birth of a liveborn infant to either withhold or withdraw treatment in certain clinical situations.

Data resources: Original data from national surveys performed in Australia and the Neonatal Intensive Care Unit (NICU) at Monash Medical Centre (MMC) were reported. The policy underlying clinical practice of selective non-treatment at MMC was reviewed and compared to that reported from other NICUs in both developed and developing countries.

Results: If doctors believe that the infant has little prospect for intact survival, their management would be suboptimal and they create a self-fulfilling prophecy. A policy establishing criteria for initiating life-sustaining treatment must be developed with proper consideration of the cultural, social and economic factors operating in the developed or developing country. There are infants whose subsequent clinical course after initiation of neonatal intensive care will indicate that further curative efforts are futile or lack compensating benefit. A policy establishing criteria for withdrawing life-sustaining treatment must also be developed to allow the appropriate use of palliative care in these instances. The clinical situations in which selective non-treatment is taking place in the neonatal intensive care unit are: (1) when death is considered to be inevitable whatever treatment is provided; (2) even when death is not inevitable, there is a significantly high risk of severe physical and mental disability should the infant survive; and (3) when survival with moderate disability is possible, but the infant is likely to experience ongoing pain and suffering, repeated hospitalization and invasive treatment, and early death in childhood.

Conclusions: The principles underlining clinical practice should be the same for developed and developing countries. However, compared to developed countries, communications between the medical and nursing staff and the parents are less adequate in developing countries. Less medical paternalism and more informed parental involvement are encouraged in developing countries in addressing ethical and moral dilemmas in neonates.

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Introduction

Among the many neonatal ethical problems, the one that neonatologists are faced with on a regular basis involves the issue of selective non-treatment, that is, clinical decisions made after the birth of a liveborn infant to either withhold or withdraw treatment in certain clinical situations such as in extreme prematurity.^[1] A study conducted in Australia, Hong Kong, Japan, Malaysia, Singapore and Taiwan, has shown considerable variation in the beliefs and practices of neonatologists with respect to their ethical decision-making.^[2] This review examines the ethical and moral principles and dilemmas that underline the decision to either withhold or withdraw treatment, the clinical settings whereby it is appropriate to consider selective non-treatment, practical aspects of achieving consensus, protocol for palliative care, and the role of a bioethics committee.

Decision to withhold treatment

A decision to withhold treatment is uniformly accepted as an appropriate option in lethal congenital malformations such as anencephaly. However, studies have shown great variability in doctors' attitudes and their management policies for prematurity. There is a tend-

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ency for both obstetricians and neonatologists to underestimate the potential for survival and overestimate the risks of disability for preterm infants.^[3-5] Many neonatologists selectively resuscitate preterm infants at birth, which means that liveborn infants are left to die through withholding of neonatal intensive care. If doctors believe that the infant has little prospect for survival or survival without disability, it is probable that their clinical management would be less than optimal and they may in fact be creating a self-fulfilling prophecy. Common reasons for this practice of withholding treatment are that the parental wish is not to treat, that the treatment costs are high, and that more mature infants with a better prognosis should have a higher priority for treatment if medical resources are limited.

In the majority of tertiary perinatal centers within developed countries, all infants with a birthweight of greater than 500 g or a gestation of 24 weeks or more are offered neonatal intensive care. At the Monash Medical Centre in Australia, 10% of 442 extremely preterm livebirths born at 23-28 week gestation over a 10-year period, 1977-1986, were not offered neonatal intensive care; 4% had obvious major malformations and 6% were considered 'nonviable' for which resuscitation at birth was not offered or not successful.^[6] The proportion of livebirths in which treatment was offered at the time of delivery was 63% at 23 weeks, 83% at 24 weeks, 92% at 25 weeks, 99% at 26 weeks, 99% at 27 weeks, and 100% at 28 weeks. This proactive approach to offering neonatal intensive care was considered ahead of its times even in developed countries 10-20 years ago.^[7,8] The Royal College of Pediatrics and Child Health has published a recommendation in 1997, which stated that it might be reasonable to consider withholding treatment in an infant born at 23 weeks weighing little more than 500 g.^[9] There is a general consensus in developed countries that parents of a 22 week infant should be discouraged from seeking active treatment, while those of a 25-26 week infant should be encouraged to consent to neonatal intensive care.^[10] It is reasonable not to offer resuscitation for all 23-24 week infants who should be assessed on an individual basis at the time of birth.

Decision to withdraw treatment

In the event that the infant's subsequent clinical course after the initiation of neonatal intensive care indicates that further curative efforts are futile or lack compensating benefit, life sustaining treatment should be discontinued and palliative care, which provides symptomatic relief and comfort, should be introduced.^[11] This ap-

proach, termed the 'individualized prognostic strategy' has been advocated as an acceptable and preferred mode of operation in the NICU,^[12] and one which has been endorsed by the Committee of Bioethics, American Academy of Pediatrics.^[13,14] The attending neonatologist has the primary role as advocate for the infant and medical advisor to the parents, while the parents act as surrogates for their infant. The shift in emphasis from curative to palliative treatment requires consensus among all those involved in the care of the infant, both medical and nursing staff, as well as consent from the parents who should be closely involved in this widely shared decision-making process.

At the Monash Medical Center over an 8-year period 1981-1987, life sustaining treatment was withdrawn prior to death in 65% of 316 deaths.^[15] Among these infants, death was considered to be inevitable in the short term even with continuation of neonatal intensive care in 70%. In the remainder, the risk of severe brain damage was considered to be so great that death was considered preferable to a life with major disability. Therefore in our NICU, full treatment until death is uncommon and occurred in only one-third of cases. This experience is not unique as studies from the UK, the Netherlands and New Zealand showed that 30% - 80% of deaths in their NICU follow a deliberate withdrawal of life sustaining treatment.^[16-18]

Principles of selective non-treatment

There are three clinical situations in which selective non-treatment is appropriate. (1) There are few who would disagree that selective non-treatment is morally and ethically acceptable when death is considered to be inevitable and the infant is in the process of dying whatever treatment is provided. The initiation or continuation of life sustaining treatment would be considered in these cases a futile exercise and not in the best interest of the infant. Examples in this category include most infants <500 g birthweight and <24 weeks gestation, and those infants with severe respiratory failure or fulminating sepsis who have persistent or worsening hypoxaemia, acidosis and hypotension unresponsive to ventilatory and inotropic support. There is no obligation to provide futile medical care in such cases, as no infant with progressive multiple organ failure survives even without withholding cardiopulmonary resuscitation. (2) It is appropriate also to consider selective non-treatment even when death is not inevitable with treatment, but there is a significantly high risk of severe physical and mental disability should the infant survive. Such a decision should not raise too many

moral and ethical problems if the infant's development of self awareness and intentional action is believed to be virtually impossible or there is no prospect of the infant ever being able to act on his or her own behalf. A preterm infant with large, bilateral parenchymal hemorrhages and/or leukomalacia in the brain, and a term infant with severe perinatal asphyxia and stage 3 hypoxic-ischemic encephalopathy are examples in this category. (3) A more controversial issue is when survival with moderate disability is possible with treatment but the infant is likely to suffer persistent pain, to require recurrent hospitalization and invasive treatment throughout life, and to experience early death in childhood or early adulthood. This situation may arise with a high spina bifida lesion associated with lack of bladder and bowel control, paresis of the legs and hydrocephalus. If treated, the infant would suffer a childhood most doctors and parents would regard as intolerable and the child would face a demonstrably awful life.

The Royal College of Pediatrics and Child Health (RCPCH) in the United Kingdom stated that there are five situations where the withholding or withdrawal of curative medical treatment might be considered appropriate: (1) the brain dead child; (2) the permanent vegetative state; (3) the 'no chance' situation; (4) the 'no purpose' situation; and (5) the 'unbearable' situation.^[9] It is unusual for the first two situations to occur in a neonate. The remaining three situations in the RCPCH report correspond to the three situations which have been referred to in the previous paragraph. In the 'no chance' situation, the infant has such severe disease that life sustaining treatment simply delays death without significant alleviation of suffering. In the 'no purpose' situation, although the infant may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect the infant or family to bear it. In the 'unbearable' situation, the infant and family might feel, in the face of progressive and irreversible illness, that further treatment is more than can be borne.

The Bioethics Committee of the Canadian Pediatric Society has proposed criteria, which forbid hastening death but permits selective non-treatment for the above situations.^[19] Specifically, they recommended that infants of below 23-week gestation should be given compassionate care rather than active treatment but treatment for those who are more mature should be tailored to the individual infant and family.^[11] The one principle with which all the guidelines proposed in the UK, Canada, USA and Australia, is that if continued life for the infant with treatment is a worse outcome than death, then the principle of *primum non nocere* imposes a professional, moral and humanitarian duty

upon neonatologists to withhold or withdraw life sustaining treatment.^[20] Infants cannot benefit from such treatment and death is not the worst outcome for them if they cannot be rescued from irreversible medical deterioration and death, cannot have life prolonged without major sensorineural sequelae, and cannot be relieved of ongoing pain and suffering. When the process of dying is being artificially prolonged, most would agree that the harm of continued treatment exceeds any potential benefit. However, decisions based on quality of life considerations are more difficult as there is inevitably imprecision in predicting the risk of intolerable disability or suffering.

The medico-legal perspective

Very few cases of selective non-treatment have reached the courts. It is considered appropriate for these difficult decisions to be made within the context of the infant/neonatologist/parent relationship and experience has shown that there is no excessive abuse in such private decision-making processes. The legal position appears to recognize the importance of respecting parental decisions but emphasize that the law court has the right to intervene and overrule a decision should it be necessary to protect the best interests of the infant. The British legal system, for example, had upheld selective non-treatment in the three categories of neonatal conditions referred to previously. Firstly, selective non-treatment was ruled to be legally acceptable when death was inevitable in the case of a hydrocephalic preterm infant on the verge of death. Secondly, legal precedence for selective non-treatment for an infant with severe brain damage, who was neither dying nor in severe pain, was found in a case presenting to court with a high risk of multiple sensorineural disabilities. Thirdly, selective non-treatment was considered lawful in an infant where the benefits of life with treatment failed to outweigh the burdens of a 'demonstrably awful life' of pain and suffering.

The decision-making process

The importance of less medical paternalism and more informed parental involvement in the decision-making process of selective non-treatment must be emphasized. The neonatologist should never make unilateral decisions regarding the right to die alone. Adequate and consistent parental communication carried out by medical and nursing staff must begin with the admission of all infants into the NICU so that trust can be de-

veloped between the parents and staff irrespective of outcome.^[21] An open-visiting policy for families is essential to promote such parental contact.^[22] A realistic assessment of the infant's clinical condition should be given by the neonatologist to the parents as soon as possible. The medical facts should be presented with an honest, sympathetic and caring attitude. Often the information has to be repeated and reinforced by the entire staff. Otherwise, misunderstandings and unrealistic expectations can lead to confusion, suspicions, bitterness and frank hostility. As with most medical decisions made by neonatologists which require parental informed consent, much of the discussion on selective non-treatment depends on trust in the knowledge, judgement, and integrity of the doctor. When a consensus has been reached by the NICU staff that selective non-treatment is an appropriate option to raise with the parents, one or more intense and intimate meetings would be required so that the crucial set of discussions could take place and in which a decision could be reached on the matter. These meetings usually involve both of the parents, the attending neonatologist, a nurse representative and a non-medical staff member who can act as the parents' advocate, such as a medical social worker.

Palliative case

The neonatologist's duty does not end with the decision for selective non-treatment. The principles and guidelines for palliative care demand that basic nursing care should continue with the emphasis to provide comfort to the infant. Electronic monitoring of physiological parameters, diagnostic investigations (such as X-rays and blood tests), medications (including oxygen and antibiotics) and therapeutic procedures (including resuscitation, all forms of assisted ventilation and intravenous infusion) which might prolong the dying process, should be discontinued. Prolonged terminal weaning, defined as a stepwise or gradual decreasing of ventilator support over a period of hours, is considered inappropriate. Dragging out the withdrawal serves only to prolong the dying process and any attendant suffering. The argument that the sudden withdrawal of ventilator support resembles an intentional killing does not hold merit, as in both cases, a treatment on which the infant depends for life is being discontinued and death is the expected outcome. The infant should be nursed in a normal cot, and warmth provided by light clothing. If the infant has apparent distress, symptomatic relief should be provided, such as suctioning to remove oropharyngeal secretions and sedation with normal

therapeutic doses of morphine, on a p. r. n. basis, even if the pain relief measures may inadvertently shorten the dying process.

A controversial issue involves the withdrawal of enteral nutrition and hydration during palliative care. Preterm or sick infants require gavage feeding and although it has been advocated that this feeding method is part of medical treatment and should therefore be discontinued during palliative care, others consider it as basic nursing care which must not be withheld under any circumstances.^[23] A number of court decisions have supported the withdrawal of nutrition, thus equating the administration of artificial nutrition with other medical procedures.^[24] Precedence has been set in a British court on the legality of withholding gavage feeding. Nevertheless, most neonatologists would be reluctant not to provide gavage feeding, even when it might be lawful and appears to be in the infant's best interest. There is an obvious perception of a moral difference between withdrawing ventilatory support and withholding fluids or nutrition with selective non-treatment. The underlying principle is that naturally or artificially administered hydration and nutrition may be given or withheld, depending on the infant's comfort.

Parents need a quiet place to be with their infant during the dying process. They may wish that other family members and religious advisors be present. Hospice concepts have been applied to neonatal care by providing a family room which is private yet close to the NICU and by training NICU staff in more supportive approaches towards the families.^[25,26] Such a program allows the staff to cope better with the dying infants offered selective non-treatment and facilitates the grieving process in the parents. In certain circumstances, withdrawal of intensive care may be arranged to take place in the home, so that death can occur in more comforting environment for the family.

Roles of an infant bioethics committee

The functions of infant bioethics committees include (1) education of staff and parents on relevant ethical principles and provision of literature and resources, (2) policy development and establishment of ethical principles, (3) prospective review through consultation in cases being considered for selective non-treatment and resolution of disagreements among staff and families, and (4) retrospective review of relevant medical records to determine the appropriateness of hospital policies and whether these policies are being followed.^[27,28] A concern has been expressed that when they attempt to fulfill so many roles, they will do nothing.

ing well. The general opinion is that such committees should serve only on an advisory basis without authority to implement any decision. An important function of an infant bioethics committee or consultative group is to provide ethical solace and support for neonatologists who have to face difficult and disturbing decisions.

Conclusions

Continued advances made in the knowledge and technology in neonatal intensive care will necessitate ongoing revisions of the medico-legal and ethical guidelines. The principles behind decision-making on selective non-treatment will however remain interpersonal and intimate, respectful to the infants' lives and their parents' autonomy, and sensitive to the emotional concerns of parents and staff. Both developed and developing countries and both Western and Eastern cultures should take these principles seriously. Neonatologists have to be prepared to live with doubts regarding the correctness of some of the decisions they have made. William Osler has been quoted as saying, 'Errors of judgement must occur in an art which consists largely of balancing probabilities.' Teaching and evaluation of interpersonal skills with parents and staff and of the ethical decision-making process are recommended as part of the postgraduate education and training of a neonatologist.^[29] Clinical management principles in the NICU can be described as follows: (1) provide optimal care and assess the results of treatment, (2) alleviate suffering always, (3) cure sometimes, and (4) allow death with dignity occasionally. This concept is based on the definition of the art of medicine in the Corpus Hippocraticum which states: 'I will define what I conceive medicine to be. In general terms, it is to do away with the suffering of the sick, to lessen the violence of their diseases, and to refuse to continue to treat those who are overmastered by the diseases, realizing that in such cases medicine is powerless.' Neonatologists making selective non-treatment decisions collaboratively with staff and parents are involved in a process built on trust and which requires time, information, honesty and empathy. In the NICU, the intensive measures that are always necessary are extreme responsibility, extraordinary sensitivity and heroic compassion.

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References

- 1 Yu VYH. The extremely low birthweight infant; an ethical approach to treatment. *Aust Pediatr J* 1987;23:97-103.
- 2 Martinez AM, Partridge JC, Yu VYH, Tan KW, Yeung CY, Lu JH, et al. Physician counseling practices and decision-making for extremely low birthweight infants in the Pacific Rim. *J Pediatr Child Health* 2005;41:209-214.
- 3 deGaris C, Kuhse H, Singer P, Yu VYH. Attitudes of Australian neonatal Pediatricians to the treatment of extremely preterm infants. *Aust Pediatr J* 1987;23:223-226.
- 4 Mulvey S, Partridge JC, Martinez AM, Yu VYH, Wallace EM. The management of extremely premature infants and the perceptions of viability and parental counseling practices of Australian pediatricians. *Aust NZ J Obstet Gynaecol* 2001;41:269-273.
- 5 Munro M, Yu VYH, Partridge JC, Martinez AM. Antenatal counselling, resuscitation practices and attitudes among Australian neonatologists towards life support in extreme prematurity. *Aust NZ J Obstet Gynaecol* 2001;44:275-280.
- 6 Yu VYH, Gomez JM, Shah V, McCloud PI. Survival prospects of extremely preterm infants; a 10-year experience in a single perinatal center. *Am J Perinatol* 1992;9:164-169.
- 7 Yu VYH. The dilemma of providing neonatal intensive care for the very low birthweight infant. *J Sing Pediatr Soc* 1982;24:59-62.
- 8 Yu VYH. Selective non-treatment of newborn infants. *Med J Aust* 1994;161:627-629.
- 9 RCPCH Ethics Advisory Committee. Withholding or withdrawing life saving treatment in children. A framework for practice. London: Royal College of Pediatrics and Child Health, 1997.
- 10 Rennie JM. Perinatal management at the lower margin of viability. *Arch Dis Child* 1996;74:F214-218.
- 11 Fetus and Newborn Committee, Canadian Pediatric Society; Maternal-Fetal Medicine Committee, Society of Obstetricians and Gynecologists of Canada. Management of the woman with threatened birth of an infant of extremely low gestational age. *Can Med Assoc J* 1994;151:547-553.
- 12 Infant Bioethics Task Force, American Academy of Pediatrics. Guidelines for infant bioethics committees. *Pediatrics* 1984;74:306-310.
- 13 Committee on Bioethics, American Academy of Pediatrics. Ethics and the care of critically ill infants and children. *Pediatrics* 1996;98:149-152.
- 14 Committee on Bioethics, American Academy of Pediatrics. Treatment of critically ill newborns. *Pediatrics* 1983;72:565-566.
- 15 Carse EA, Yu VYH. Deaths following withdrawal of treatment in a neonatal intensive care unit. In: Proceedings of the 5th Asia-Oceania Congress of Perinatology. Denpasar: Indonesian Society of Perinatology, 1988;55.
- 16 Whitelaw A. Death as an option in neonatal intensive care. *Lancet* 1986;2:328-331.
- 17 deKleine MJK, De Leeuw R, Kollee LAA, Berger HM.

- Voortzetten of staken van levensverlengend handelen bij pasgeborenen: een onderzoek in 4 centra voor neonatale intensieve zorg. *Ned Tijdschr Geneesk* 1993;137:496-500.
- 18 Kelly NP, Rowley SR, Harding JE. Death in neonatal intensive care. *J Pediatr Child Health* 1994;30:419-422.
- 19 Bioethics Committee, Canadian Pediatric Society. Treatment decisions for infants and children. *Can Med Assoc J* 1986;135:447-448.
- 20 Whitelaw A, Yu VYH. Ethics of selective non-treatment in extremely tiny babies. *Sem Neonatol* 1996;1:297-304.
- 21 Yu VYH. Caring for parents of high-risk infants. *Med J Aust* 1977;2:534-537.
- 22 Yu VYH, Jamieson J, Astbury J. Parents' reactions to unrestricted parental contact with infants in the intensive care nursery. *Med J Aust* 1981;1:294-296.
- 23 Doyal L, Wilsher D. Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. *Arch Dis Child* 1994;70:F66-70.
- 24 Mirale ED, Mahowald MB. Withholding nutrition from seriously ill newborn infants: a parent's perspective. *J Pediatr* 1988;113:262-265.
- 25 Yu VYH. Death as an option in the neonatal intensive care unit. The ethics of withdrawal of life-support. In: Burrows GD, Petrucco OM, Llewellyn-Jones D, eds. *Psychosomatic aspects of reproductive medicine and family planning*. Melbourne: York Press, 1987;112-119.
- 26 Whitfield JM, Siegel RE, Glick AD, Harmon RJ, Powers LK, Goldson EJ. The application of hospice concepts to neonatal care. *Am J Dis Child* 1982;136:421-424.
- 27 Edens MJ, Byler FD, Wagner JT, Eitzman DV. Neonatal ethics: development of a consultative group. *Pediatrics* 1990;86:944-949.
- 28 Infant Bioethics Task Force, American Academy of Pediatrics. Guidelines for infant bioethics committees. *Pediatrics* 1984;74:306-310.
- 29 Yu VYH. The training of a neonatologist. *Early Hum Develop* 1992;29:121-123.

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