

MEDICO-LEGAL AND ETHICAL ISSUES IN NEONATOLOGY

T C Chao

ABSTRACT

Very small and sick neonates are being saved with modern technology. However, the cost is high. Obstetricians and neonatologists are often faced with the difficult task of deciding who is to be saved and who is not. In the USA, virtually all infants with any chance of survival are aggressively treated and stabilized until the future outcome can be certain. In addition, Infant Bioethical Review Committees are formed. In the UK such committees do not exist. Decisions are made by doctors together with parents. The practice in Australia is similar to that in the UK. It is recommended for Singapore that decisions should be made jointly by doctors and parents after thorough discussion. The formation of an Ethics Committee would lend support to the decision making. However, it is urged that prevention of low birth weight infants and congenital abnormalities would reduce the dilemma of the doctors.

Keywords: Neonates, impaired newborns, withholding treatment, doctor-parent consultation

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INTRODUCTION

Recent advances in the technological care to the newborn have resulted in the possibility of saving the very small and sick neonates. In some centres, infants of 600g birth weight and/or 26 weeks gestation have a 20% survival rate, while infants formerly thought to be at the threshold of viability at 28 weeks and/or 1000g birth weight have more than 90% chance of survival (1). Diagnostic aids can pick up abnormalities and can predict at-risk pregnancies early so preparation can be arranged for a safe delivery. Surgical techniques developed over the years can correct or ameliorate congenital abnormalities that were difficult to correct previously. Sick infants unable to be fed orally can be sustained on parenteral nutrition for months or even years. All these advances in neonatal medicine enhanced the survival rates of the neonates but brought with them ethical and medico-legal problems.

Obstetrics is not without its anxious moments. There is an old Chinese saying that "To deliver a child is like reporting to the Emperor of Hades". Modern obstetrics has made the delivery room a much safer place now but obstetricians still have to make treatment decisions by weighing the risks and benefits of such treatment to both mother and child. At times the decision is shared between the doctor and the parents, but most of the time the doctor has to make paternalistic decisions that are considered to be in the best interest of the patient. Thus the heavy burden of deciding who shall live and who shall die, who shall receive the expensive and aggressive technological intervention and who shall receive other

forms of medical treatment rests on the doctor in the delivery room. Sometimes the decision can turn out to be erroneous and therefore it is found necessary to involve other professionals in the decision making to lessen the burden.

DECISION ON WITHHOLDING/WITHDRAWING TREATMENT IN IMPAIRED NEWBORNS

Practice in U S A

In the USA, the practice of withholding and withdrawing medical treatment from patients in neonatal intensive care units is very much influenced by the well known 'Baby Doe' case in Bloomington, Indiana in 1982. This was a case of a baby with Down's syndrome and oesophageal atresia who was allowed to die when the physicians recommended no surgical intervention and the family concurred. This resulted in a series of administrative rulings issued by the US Department of Health and Human Services. It was mandated that a sign be posted in all delivery rooms and nurseries in all hospitals in the USA which said that treatment should never be withheld or withdrawn from a handicapped or defective newborn and if anyone observed such treatment being withdrawn, he could phone a hotline number direct to a government agency in Washington DC. In response, a 'Baby Doe' squad would be despatched to investigate the alleged discrimination against a handicapped newborn. This had become unacceptable and after repeated defeats in the US Courts, this legislation was incorporated in a modified form as an amendment to the Federal Child Abuse Law:

A new definition of withholding of medically indicated treatment is added in Section 3 of the Act to mean the failure to respond to an infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration and medication) which in the treating physician's reasonable medical judgement will be most likely to be effective in ameliorating

Department of Forensic Medicine
Outram Road
Singapore 0316

T C Chao, PPA, FRCPath, FRCPA, FCAP, FCLM
Medical Director

or correcting all such conditions. Exceptions to the requirement to provide treatment may be made only in cases in which: [1] the infant is irreversibly comatose; or [2] the provision of such treatment would merely prolong dying or not be effective in ameliorating or correcting all of the infant's life-threatening conditions or otherwise be futile in terms of the survival of the infant; or [3] the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

In addition, the Federal regulations strongly urge the formation of Infant Care Review Committees or Infant Bioethical Review Committees to facilitate decisional review and to assist the interaction among physicians, family, hospital and the Child Protective Services Agency of the state (1). The Committee is proposed to have a minimum of eight members: a nurse, two physicians, an ethicist or member of the clergy, a hospital administrator, a lawyer, someone familiar with disabilities, and a lay community leader. For those who support this concept, these committees not only protect the interests of infants who may have treatment inappropriately withheld, but also protect the interests of infants who can no longer be benefited by medical intervention. By discussion and deliberation on these complex issues, the staff would understand better and be able to deal with such situations. The committee would lessen the burden of decision making for the doctor and family (2).

In the USA, virtually all infants with any chance of survival are aggressively treated in the delivery room and stabilized in the intensive care unit until data can be generated which increase the certainty about the future outcome. Another important feature in the USA is the fear of Medical Malpractice suits. Thus the response is to aggressively treat such infants no matter what conditions they are in so that the physician will not be held responsible for non-intervention.

This practice had been criticised, as the effect of government intervention and the publicity that accompanies a case have created an atmosphere of uncertainty, insecurity and even fear of legal retribution in the treatment of the newborn. The dying, damaged or severely handicapped newborn are being aggressively treated sometimes to the detriment of the infants and families. Paediatricians would not make non-treatment decisions even if they are convinced of the hopelessness and futility of continuing such treatment, for fear of legal action. And the hospital administrators in the Infant Bioethics Committee are afraid that the legal action and the publicity that ensue would harm the reputation of the hospital and would affect hospital fund raising. Therefore they are less likely to agree to withholding treatment (3).

An example of parental disagreement with the hospital authority's decision of continuing treatment on a hopeless case happened in Chicago. On 26 April 1989, Rudy Linares armed himself and unhooked his comatose 15-month old son from the respirator and held him till he died. His son had become comatose since he accidentally swallowed a balloon in August of the previous year. Officials at Rush-Presbyterian-St Luke's medical centre had refused the family's request to withdraw life-support. Linares was charged with murder of his son. But Cook County medical examiner Dr. Robert Stein ruled that the boy had died of brain death when he swallowed the balloon. What was done subsequently was only to keep the organs alive. Thus the death was an accidental death

and the murder charge was dropped. The State Attorney did not proceed with other felony charges as he considered the young father "had suffered quite enough" (4). The Law does take into consideration the agony, torment and distress parents undergo in the care of a hopelessly ill infant.

Non-action would also land doctors in trouble. In the Straits Times of 14 June 1989, it was reported that in a Philadelphia Court a doctor was convicted of infanticide after the death of an eight-month old baby. Dr. Joseph Melnick performed an abortion on a 13-year old girl believing she was four months pregnant. But when he saw the size of the baby he froze with fear and though the baby gasped, moaned, had a heartbeat and showed other signs of life as witnessed by a nursing supervisor, he chose to ignore the fleeting signs of life he observed. He considered the baby to have been stillborn (5).

Practice in the UK

In the UK it is believed that parents' right to information and their participation in decision-making are fundamental to an informed consent. In certain circumstances the infant's quality of life was viewed just as important, if not more important than the fact of life in determining treatment alternatives.

It is noted that in the last few years the problems of congenital abnormalities have been overtaken by those of extreme prematurity. Low birth weight and short gestation period infants have been salvaged but at a price in terms of equipment, running costs, nursing and professional care. The prognosis for this group of extreme low birth weight babies is poor, and it is deemed a cut-off point must be decided taking into account the gestational age, the vigour of the infant at birth and other factors weighing against a satisfactory outcome. Some units in the UK and USA are achieving survival rates of over 50% for infants with birth weights between 500g and 750g. Thus it is suggested that 500g birth weight and a gestational period of 22-24 weeks be the cut-off point as beyond that it will be simply trying to retrieve the irretrievable and to salvage the unsalvageable (3).

Parents and the doctors responsible should confer and decide on the action to be taken. Ethics Committees similar to that of the Infant Bioethical Care Review Committee of USA do not yet exist in the UK. It is viewed that by abdication of the primary decision-making role by doctors, the transfer of responsibility to a committee and the intrusions of lawyers may prolong the suffering of infants and the agonies for families, and totally devalues the leadership role of the doctor to whom the parents look for help in times of need. People on committees, no matter how able or how sincerely motivated to help families, do not and cannot understand all the details and implications of tragic situations unique to individual families.

In 1981, a paediatrician Dr. Arthur was charged with murder on the initiation through pressure of a pro-life organisation as he wrote in the notes of a newborn baby with Down's syndrome: "Parents do not wish it to survive. Nursing care only" and he prescribed large doses of drugs to inhibit appetite. The baby died 69 hours later and following autopsy, the cause of death was certified as "pneumonia due to lung stasis due to Dihydrocodeine poisoning in an infant with Down's syndrome". The diagnosis was reached after consultation between the forensic pathologist and a paediatric pathologist. At the trial the paediatric pathologist produced further slides pre-

pared from the same specimen of brain to show that the baby was abnormal at birth. The charge of murder was reduced to attempted murder and Dr. Arthur was acquitted (6). This case had sparked off a lively debate on the role and the ethics of an expert witness in court.

As opposed to the 'Baby Doe' legislation of USA at the time of the trial, the public voted overwhelmingly to leave these matters in the hands of parents and doctors. Further, a Limitation of Treatment Bill was proposed which, with appropriate safeguards, would allow the killing of severely abnormal infants up to 28 days after birth. However, it is felt that the state should not be involved either to enforce life or to dictate death. Such matters should be left to the parents and doctors. A group of British and American legal experts had proposed the following guideline as a Mid-Atlantic view:

The parents, who have conceived the infant and who have the responsibility to raise it, should be given the right, within closely and carefully drawn confines, to elect non-treatment when their child is born severely deformed. Additionally, society should not, without strong reason, dictate standards to physicians, which compel treatment in circumstances in which many ethical minded doctors would feel it was medically inappropriate.

And quality of life was defined as:

Quality of life - not in the sense of social utility or worth but solely as judged by a physiological existence without intolerable pain or suffering - may properly enter such treatment decisions. (3)

A recent case reported in the *Lancet* reflects the view of the British judges. On 14 April 1989, a High Court judge in Leeds decided that a very seriously handicapped 4-month old baby with hydrocephalus, blind, probably deaf and spastic in all four limbs be allowed to die and that no further attempts should be made to prolong her life. On 20 April 1989, the Appeal Court endorsed the High Court decision to allow the baby, known as "C", to die with as much comfort and dignity as possible.

In making the decision, the judge had distinguished her case from *In re B* ([1981] 1 WLR 421), where a 10-day-old Down's syndrome baby required an immediate operation to remove an intestinal obstruction to survive. The baby's parents refused consent, believing her death to be nature's release. A social worker applied to have the baby made a ward of court. Ewbank J said that the parents' wishes should be respected, but the Court of Appeal ordered the operation on the basis that there were doctors ready, willing and able to perform it on the grounds that the baby's welfare was best served by the operation, and the baby's interests and not the parents' wishes were paramount concern for the Court in wardship. The Court said that her life could not be shown to be so demonstrably awful that she should be condemned to die. However, the Court accepted that there could be cases "where the future was so certain and the life of the child was so bound to be full of pain and suffering that the court might be driven to a different conclusion."

In C's case, Ward J observed that "any quality of life has already been denied to this child because it cannot flow from a brain incapable of even limited intellectual function." The Law has ensured that the doctors and nurses have the discretion to implement the decision to

allow the baby to die in the way they see as most kind to the baby.

The article further stated: "Doctors will and should continue to bear their traditional responsibility for deciding, with the patient and family, when treatment should be withdrawn and for implementing such decisions. It should be undesirable for the courts to usurp the doctor's role and to become routinely involved in a medical decision which is the prerogative of the patient (if capable), family and doctors in privacy" (7).

Practice in Australia

In Australia, it is recognised that the cost of intensive and special care of the newborn is expensive. For those of 24-28 weeks' gestation, the costs per additional survivor in 1984-1986 period averaged \$99,574, and it is likely to go up further (8,9). To improve survival in the most-immature infants by increasing resources for assisted ventilation only can be more difficult and more expensive and even less cost-effective. The long-term survival cannot be confidently predicted, and that adds on to the dilemma of the doctors. A study of the survival rates of very immature infants born in Victoria shows that almost one quarter of those born at 24-26 weeks were disabled to some extent and 19% were severely disabled. It is further pointed out that the value of aggressive intensive care has not been proven in babies weighing less than 800g and those born at less than 26 weeks gestation. There are also intangible costs which include emotional and marital stress, grief, social disruption and the pain and suffering of parents and families.

The decision on whether to give full neonatal support to a sick baby currently rested with and should remain with the parents and the medical team. The concept of an ethics committee is rejected as the complexities of each case are such that no committee, regulatory body or government, however sympathetic, could effectively legislate to take into account the range of problems which can be encountered with.

According to current Australian laws, a doctor could face criminal charges if an infant is not provided with the "necessities of life" and subsequently dies. But a practical question is "are there sufficient intensive care resources to treat all live born infants who need this facility?" Reducing such needs can be achieved by better antenatal care and education programmes to identify pregnant mothers at high risks of premature delivery.

Position in Singapore

Before we go into discussion on the situation in Singapore, we must examine what are the facilities available in the resuscitation of such infants. The problem becomes less complex if there are insufficient neonatal intensive care resources as there is simply no capacity to cope with the demand.

I would take the UK and Australian stand in decision-making, i.e. this should be discussed thoroughly between the doctor and the parents. The parents must be told of the possible consequences of long-term prognosis of the impaired infants. Some of them may need continuous care and multiple operations to correct their congenital abnormalities. It is important to ascertain that parents are prepared emotionally, mentally and financially to look after such an infant. If it is agreed between parents and doctors that the neonate is unsalvageable, it must be

allowed to go in the most humane way. The formation of an ethics committee by the hospital would lend support to the decision-making but it should not be prohibitive.

As to dealing with low birth weight infants, the important task is to prevent premature births. In the USA it is said that prematurity is mainly a social problem as the majority of cases of prematurity happened in the socially disadvantaged, the poor, the unemployed, social welfare recipients, the under-educated, the school drop-outs, teenage mothers. In many cases those affected are blacks, hispanics, and other minorities and displaced rural whites. It is suggested that by increasing job opportunities, improving education and living standards and medical care, prematurity may be reduced. Though there are less such social problems in Singapore, prematurity occurs in those with medical problems or those without adequate antenatal care. Rates of prematurity can be lowered as shown by the Scandinavian countries. I believe that we can also lower the rate of prematurity by public education, improving the health of the mothers and good antenatal care. Then we do not have to be worried unduly about low birth weight infants.

Since we are able to detect high-risk pregnancy early, arrangement can be made at time of delivery for a neonatologist to be in attendance. This is essential for the maximum possible care for both mother and child, as in time of emergency both mother and child need special attention and a single doctor would not be able to handle such a situation adequately. Such expertise is available and there is no excuse not to make use of it.

To reduce the ethical and medico-legal problems in neonatology, a multi-prong approach is needed:

1. Prenatal genetic counselling;
2. Public education on how to carry on a healthy pregnancy;

3. Improve the health of the mothers;
4. Provide adequate antenatal care;
5. Detect high-risk pregnancy early and make preparations;
6. Have neonatologist in attendance at delivery of high-risk pregnancies;
7. Establish adequate neonatal intensive care facilities

In an editorial in the *New England Journal of Medicine*, it is stated that:

Twenty years ago we hoped that with the advent of fetal-maternal medicine as an obstetric subspecialty, prematurity-and especially the problem of very low birth weight in infants-would gradually disappear. We should perhaps have anticipated what has happened instead: we now have better medical management of high-risk pregnancies, which produces live born infants who might have died without such advances. Neonatal intensive care has perpetuated this situation by saving previously unsavable high-risk infants, especially those of progressively lower birth weights. We obstetricians and neonatologists are caught in a trap of our own design. We can save high-risk and early gestation pregnancies and their fetuses after delivery, but we cannot ensure an outcome approaching that of more mature infants. (10)

By merely providing treatment to premature babies without measures to prevent prematurity will end up with spending larger and larger sums of money in equipment and manpower to maintain neonatal intensive care units that will never meet the demand. And neonatologists will always face the dilemma of deciding on withholding or withdrawing treatment. Emphasis should be placed on prevention.

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