

ETHICAL DECISION-MAKING IN NEWBORN INFANTS

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S U M M A R Y

One ethical dilemma which neonatologists are faced with on a regular basis is selective non-treatment, that is, clinical decisions made after the birth of a liveborn infant to withhold or to withdraw treatment in certain circumstances. Although the outcome of extremely preterm or critically-ill infants has significantly improved over the last decade, many are often left to die at birth by withholding resuscitation or neonatal intensive care. Criteria for initiating life-sustaining treatment must be developed with proper ethical considerations. There are other infants whose clinical course after initiation of intensive care will suggest that further curative efforts are futile or lack compensating benefit. Criteria for withdrawing life-sustaining treatment must also be developed, and palliative care measures defined. Clinical situations in which selective non-treatment is taking place in neonatal medicine 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 hospitalisation and invasive treatment, and early death in childhood. The decision-making process of selective non-treatment should involve less medical paternalism and more informed parental involvement. The process is built on trust between the neonatal staff and parents, and requires time, information, honesty and empathy. Ethical issues must be approached with extreme responsibility, extraordinary sensitivity and heroic compassion.

R E S U M O

Temas Éticos na Medicina Neonatal

Um dilema ético que os neonatólogos defrontam regularmente é o não tratamento selectivo, isto é, a decisão clínica feita após o nascimento de um nado vivo, de recusar ou retirar o tratamento em certas circunstâncias. Embora o prognóstico de crianças muito precoces ou em estado crítico tenha melhorado na última década, algumas morrem ao nascer, pela recusa de ressuscitação ou de cuidados intensivos neonatais. Há crianças que, após a iniciação dos cuidados intensivos, têm um percurso clínico que indica que mais esforços curativos serão fúteis ou sem benefício compensador. O critério de negar tratamento de manutenção de vida também deve ser desenvolvido, e as medidas de cuidados paliativos definidas. As situações clínicas em que o não tratamento selectivo ocorre na medicina neonatal são: (1) quando a morte é considerada inevitável seja qual for o tratamento prestado, (2) mesmo quando a morte não é inevitável, existe um alto risco de incapacidade física ou mental em caso de sobrevivência, e (3) quando a sobrevivência com uma incapacidade moderada é possível, mas é provável que a criança tenha dores e sofrimento contínuos, repetidas hospitalizações e tratamentos invasivos, e morte precoce na infância. O processo de decisão de não tratamento selectivo deve envolver menor paternalismo médico e maior participação informada dos pais. O processo é baseado na confiança entre os profissionais de cuidados neonatais e os pais, e requer tempo, informação, honestidade e empatia. Os temas éticos devem ser abordados com extrema responsabilidade, extraordinária sensibilidade e compaixão.

INTRODUCTION

Advances in medical treatment and technology have created numerous medico-legal and ethical dilemmas in perinatal medicine. These include general issues such as abortion, family planning, sex selection, value of human life, economics, religion, politics and malpractice. Examples of specific issues include gene manipulation, fetal therapy, in vitro fertilisation, extreme prematurity, selective non-treatment, anencephalic organ donor, technology invasion and chronic care. To provide a neonatologist's perspective on one of these dilemmas, this review considers the issue of selective non-treatment, that is, medical decisions made after the birth of an extremely preterm and/or critically-ill infant to withhold or to withdraw treatment in certain clinical circumstances.

DECISION TO WITHHOLD TREATMENT

A decision to withhold treatment is uniformly accepted as an appropriate option in lethal congenital malformations such as anencephaly. One grey area in which there is little consensus and for which neonatologists have to deal with almost on an every day basis is extreme prematurity. Studies which investigated the variability in the doctors' attitudes and in their management policies with extreme prematurity have shown that among many practising obstetricians and paediatricians, there was a tendency to underestimate the potential for survival and overestimate the risks of disability for extremely preterm infants.¹⁻³ Our own national Australian survey in 1987 showed that about 40% of neonatologists selectively resuscitate extremely preterm infants at birth, suggesting that many of these livebirths were left to die through withholding of neonatal intensive care.³ The three most common reasons given by the respondents were that the parental wish was not to treat, that the treatment costs were high, and that more mature infants with a better prognosis should have a higher priority for treatment if medical resources are limited. Unfortunately, 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. The remaining 60% of neonatologists gave as their main reason for always attempting to resuscitate at delivery, even for extremely preterm infants, the impossibility to predict the individual infant's prognosis at the time of birth.

Our ethical approach established in the Neonatal Intensive Care Unit (NICU) at Monash Medical Centre, with respect to the management of extremely preterm infants, has been published in detail.⁴ We agree with the policy which advocates that all infants with a birthweight of greater than 500g or a gestation of 24 weeks or more should be offered neonatal intensive care.⁵ The only exception suggested are those with a birthweight <750g who do not respond to intubation, ventilation and cardiac massage with improvement in Apgar score in the delivery room.⁶ We have published our experience on 442 extremely preterm livebirths born at 23-28 weeks gesta-

tion in Monash Medical Centre over a 10-year period 1977-1986.⁷ Overall, only 10% of these infants were not offered neonatal intensive care: 4% had major malformations and 6% were considered *nonviable* for which resuscitation at birth was not offered or not successful. The proportion of livebirths in which treatment was withheld because they were considered *nonviable* was 36.7% at 23 weeks, 17.4% at 24 weeks, 8.5% at 25 weeks, 1.4% at 26 weeks, 1.0% at 27 weeks and 0% at 28 weeks.

This relatively active management policy for extreme prematurity was unique in 1977-1986 and even today it might still be considered too aggressive by some NICUs. In view of the fact that individual hospitals and their respective NICUs may have different attitudes and different clinical practices in regard to the management of extreme prematurity, it is important to be able to compare the effects of varying policies on their short and long-term outcome. When the NICU at Monash Medical Centre was first established in 1977 with a strong emphasis towards the provision of neonatal intensive care to extremely preterm infants, we initiated a collaborative study with another large NICU in Melbourne which had a considerable more conservative approach. The two NICUs worked together to standardise definitions and documentation, used identical methods of assessment of the survivors in their respective Growth and Development Clinics, and analysed data in the same manner. The consequences of contrasting management policies in these two separate institutions on the outcome of extremely preterm infants have been published.⁸⁻¹² Our comparison suggested that the more frequent use of mechanical ventilation, parenteral nutrition and phototherapy in the NICU at Monash Medical Centre was associated with a higher survival rate in our infants born <1000g.⁹ The improved survival was not achieved at the expense of more survivors with disability, who otherwise would have died with a more conservative management policy.¹⁰ Children in whom major neurodevelopmental disability developed could not have been identified from the perinatal data, suggesting that prevention of disability by selective withholding of treatment would have no prospect of success.¹⁰ Nevertheless, the difference in management policy prevailed for some time between the two institutions and it was possible to carry out a subsequent comparison over a full 10-year period of the outcome of inborn infants of 24-26 weeks' gestation. During the period 1977-1986, 42% of their livebirths at 24-26 weeks' gestation were not offered assisted ventilation, all of whom died,¹³ while at Monash Medical Centre over an identical time period, the equivalent figure was 8%.⁷ Consequently, their survival rate was lower compared with ours (29% vs 44%) in this group of infants over the same period of time. The controversy and debate on the viability of extremely preterm infants and its effect on ethical decision-making of withholding treatment has continued for the past decade without real consensus being reached.^{5,14-23}

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, we believe that it is appropriate for life sustaining treatment to be discontinued and palliative care, which provides symptomatic relief and comfort, be introduced.²⁴ This approach has been termed the *individualised prognostic strategy* and has been advocated as an acceptable and preferred mode of operation in the NICU.¹⁹ 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. The mode of death based on these practice guidelines has been documented in a report from our NICU at Monash Medical Centre over an 8-year period 1981-1987.²⁵ Life sustaining treatment was withdrawn prior to death in 65% of 316 deaths. Among these infants, death was considered to be inevitable in the short term even with neonatal intensive care in 70% and 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 was uncommon and occurred in only 35% cases. This experience is not unique as one study from the U.K. showed that 30% of deaths in the NICU follow a deliberate withdrawal of life sustaining treatment.²⁶ Another study from four NICUs in Holland indicated that only 40% had full treatment until death, while 31% had treatment withdrawn because death was considered inevitable and 19% had treatment withdrawn for poor prognosis in the quality of life.²⁷ The latest study from Auckland, New Zealand showed that neonatal intensive care was withdrawn in 78% of their neonatal deaths.²⁸

PRINCIPLES OF SELECTIVE NON-TREATMENT

There are three clinical situations in which selective non-treatment are taking place in the NICU. (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 <500g 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. (2) Most are prepared 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.^{29,30} An extremely preterm infant with large, bilateral parenchymal haemorrhages and/or leukomalacia in the brain and a term infant with severe perinatal asphyxia and stage 3 hypoxic-ischaemic encephalopathy are examples in this category. (3) More controversial an issue is when survival with moderate disability is possible with treatment but the infant is likely to suffer persistent pain, to require recurrent hospitalisation 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 Bioethics Committee of the Canadian Pediatric Society has proposed criteria which forbid hastening death but permits selective non-treatment for the above situations.³¹ Specifically, the Canadians recommended that infants of below 23 weeks 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.³² Guidelines have also been proposed from the U.S.A.,^{21,33,34} U.K.³⁵ and Australia.^{4,23,36} The principle with which these guidelines were established 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. 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.³⁷ Six ethical propositions have been published which ensure that decisions for selective non-treatment can be made in the best interest of the infant.³⁸

THE MEDICO-LEGAL PERSPECTIVE

In 1983, the Department of Health and Human Services in the U.S.A. published rules to ensure that newborn infants with disabilities, no matter how severe, are provided with all possible life sustaining treatment, unless death is imminent or the risk of treatment is considered excessive. This had elicited mainly negative responses from health care professionals directly involved in the care of such infants and their opinions had indicated that such an edict is unacceptable.³⁹⁻⁴³ Alternatives have been formulated to such rules which have ensured that clinical decisions are made in the best interests of the infant and that they are made only after

careful thought.^{22,38} 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 relationship⁴⁴ and experience has shown that there is no excessive abuse in such private decision-making processes. The legal position appears to recognise the importance of respecting parental decisions but emphasis 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.⁴⁵⁻⁴⁸

References have been made in a recent publication to instances in which British law courts had upheld selective non-treatment in the three categories of neonatal conditions referred to previously.⁴⁹ 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.⁵⁰ 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 presented to court with a high risk of multiple sensorineural disabilities.⁵¹ 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.⁵² Neonatologists and paediatric neurologists have advised selective non-treatment in many severely damaged infants with spina bifida based on some of Lorber's criteria without threat of prosecution. In spite of the presence of legal precedence, lawyers have continued to urge further clarification of the law to provide doctors with protection from charges of unlawful killing.²²

THE DECISION-MAKING PROCESS

The importance of less medical paternalism and more informed parental involvement in the decision-making process of selective non-treatment has been emphasised for over 20 years.⁵³⁻⁵⁶ Unilateral decisions regarding the right to die should never be made by the neonatologist 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 developed between the parents and staff irrespective of outcome.⁵⁷ An open-visiting policy for families is essential to promote such parental contact.⁵⁸ 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.⁵⁹

As with most medical decisions made by neonatologists which require informed parental consent, much of the discussion on selective non-treatment depends on trust in the knowledge, judgment, and integrity of the doctor. However, subjectivity is not always easy to avoid

even with experienced neonatologists when the condition of a critically-ill infant is being appraised. It is therefore important to recognise deceptive signals before voicing an argument for selective non-treatment in infants and before initiating discussion with their parents on the matter. The four questions which one should ask are: (1) Am I being driven by despair? (2) Am I being unduly influenced by the external appearance of the infant? (3) Would I think differently if the parents had been visiting the infant every day? (4) Are my predictions about outcome based on current scientific knowledge?⁶⁰

Five decision-making principles have been published which define the obligations of the neonatologist and parents to ensure that decisions are made only after careful thought.³⁸ 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 the social worker. Ten questions have been suggested which will elicit the parents' perspective, communicate the neonatologist's empathy and commitment, and help the parents reach an appropriate decision.⁶¹

One exception to the above policy was reported from Japan.⁶² Although the Japanese neonatologist does listen to what the family thinks, the parents are not asked to make a decision involving selective non-treatment. This approach is a total anathema to western medical practice. However, it was suggested that because of the paternalistic relationship between doctors and patients in Japan, the doctor's opinions are highly respected and influential to the extent that a "parental decision" is likely to be that made by the neonatologist anyway. In view of this, it is considered inappropriate to put an unnecessary burden on the parents by involving them in the decision-making process. Such concerns that participation by the parents in a shared decision for selective non-treatment would adversely affect their psychoemotional health have however not been substantiated.^{24,63,64} These studies showed that informed parents can accept the responsibility for the decision to withdraw life sustaining treatment for their infant, can feel they have made the right decision without carrying a burden of guilt for their participation, and can adjust to their loss with a healthy grieving process.

PALLIATIVE CARE

The neonatologist's duty does not end with the decision for selective non-treatment. Principles and guidelines for palliative care have been published.^{4,23,49,65} Basic nursing care should continue with emphasis on providing 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. Warmth is provided by clothing the infant who should be nursed in a normal cot. 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,⁴⁹ others consider it as basic nursing care which must not be withheld under any circumstances. A number of court decisions have supported the withdrawal of nutrition thus equating the administration of artificial nutrition with other medical procedures.⁶⁶ A precedence has been set in a British court on the legality of withholding gavage feeding.⁶⁷ Nevertheless, a survey in Australia has shown that 80% of neonatologists would be reluctant not to provide gavage feeding, even when it might be lawful and seem to be in the infant's best interest.³ There is an obvious perception of a moral difference between withdrawing ventilatory support and withholding fluids or nutrition with selective non-treatment. The statement that "naturally or artificially administered hydration and nutrition may be given or withheld, depending on the patient's comfort" has been made in an attempt to develop universally acceptable guidelines in terminally ill adults⁶⁸ but the opinions on this aspect of neonatal palliative care remain different on an individual case basis.

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.⁶⁹⁻⁷¹ Such a programme allows the staff to cope better with the dying infants offered selective non-treatment and facilitates the grieving process of the parents. In certain circumstances, withdrawal of intensive care may be arranged to take place in the home, so that death can occur in a more comforting environment for the family.⁷²

In some societies, withdrawal of life sustaining treatment which could result in the death of an infant remains unacceptable to society. One report showed that 55% of the deaths in a Japanese NICU occurred after a decision was made either not to initiate treatment or not to continue to provide all possible treatments.⁶² However in the latter group, the infants were managed by continuation of their pre-existing treatments, although no new therapeutic measures were introduced. This approach was considered appropriate for that particular society even though it was understood that such a practice of limiting rather than withdrawing life sustaining treatment might not be in the best interest of the infants by protracting their death.

ROLES OF AN INFANT BIOETHICS COMMITTEE

Guidelines for infant bioethics committees have been published.^{4,38,73-75} Their functions 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. Favourable experiences have been reported on the workings of such ethics review committees⁷⁵⁻⁷⁷ although a concern has been expressed that when they attempt to fulfill so many roles, they will do nothing well.⁷⁸ The opinion is that such committees should serve only on an advisory basis without authority to implement any decision.^{21,38,73} 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

In addition to the literature quoted above, a number of commentaries on neonatal medico-legal and ethical dilemmas have been published in the U.S.A.,⁷⁹⁻⁸³ U.K.,⁸⁴⁻⁸⁷ and Australia.⁸⁸⁻⁹² A number of surveys have served to determine the attitudes and moral reasoning among staff and parents,⁹³⁻⁹⁷ and the contribution to ethical decision-making on stress and mental health among NICU staff.^{98,99} Furthermore, abundant resource material has been published on neonatal ethical issues and are available for detailed study and reference.¹⁰⁰⁻¹¹² Nevertheless, 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. 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 judgment must occur in an art which consists largely of balancing probabilities."¹¹³ 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.^{114,115} Clinical management principles in the NICU have been 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.¹¹⁶ 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, realising 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.⁶⁸ The personal qualities required by neonatologists in dealing with ethical dilemmas are courage, compassion and humility: "He showed you, O man, what is good. And what does the Lord require of you? To act justly and to love mercy and to walk humbly with your God" (Micah 6:8).

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APPENDIX 1.**Ethical propositions for decision-making**

1. Each infant born possesses an intrinsic dignity and worth that entitles the infant (within constraints of equity and availability) to all medical and special care that is reasonably thought to be conducive to the infant's well being.
2. The parent(s) bear the principal moral responsibility for the well-being of their infant and should be the surrogates for their infant, unless disqualified for one of the following reasons: decision making incapacity, unresolvable disagreements between parents, or choosing a course of action that is clearly against the infant's best interests.
3. The primary role of the attending physician is to be the advocate for his/her patient, the infant. The attending physician must take all reasonable medical measures conducive to the well-being of the infant.
4. When the burden of treatment lacks compensating benefit or treatment is futile, the parent(s) and attending physician need not continue or pursue it.
5. Therapies lack compensating benefit when: (a) they serve merely to prolong the dying process; (b) the infant suffers from intolerable, intractable pain, which cannot be alleviated by medical treatment; (c) the infant will be unable to participate even minimally in human experience.
6. In the care of an infant from whom life-sustaining support or curative efforts are withheld, certain provisions are necessary to continue to respect the intrinsic dignity and worth of that infant. These include: (a) warmth and physical and social comforting; (b) enteric feeding and hydration, if compatible with the above ethical propositions; (c) freedom from pain, even if administration of analgesia may inadvertently hasten death.

APPENDIX 2.**Principles for the decision-making process**

1. All decisions will give primary importance to the intrinsic dignity and worth of the infant and to the infant's best interests.
2. The decision to discontinue treatment requires sufficient observation, assessment and parental involvement in the decision-making process.
3. As the parent(s) bear(s) the principal responsibility for the well-being of their infant, they are the primary decision makers. It is the parent's right to involve individuals of their choosing in a resource and/or support role. While the parent(s) may be unable or unwilling to make decisions, medical professionals should accept the principle that the responsibility should, if

possible, be born by the parent(s) and attempt to help, but not force, the parent(s) to make a decision.

4. In addition to being an advocate for the infant, the attending physician has the responsibility to be the primary medical consultant to the parent(s). In this role, the attending physician shall (a) obtain consultation as needed to thoroughly assess and confirm the diagnosis and prognosis of the infant; (b) communicate this information to the family in a fashion they can understand; (c) counsel the parent(s) and provide access to others who may help them reach a decision; (d) involve nursing staff and any other individuals designated by the parent(s) in the assessment and information-gathering phase of decision making; (3) provide the parent(s) adequate time and an appropriate environment to reach a thoughtful decision.
5. All relevant considerations should be documented in the patient's progress notes.

APPENDIX 3.**Questions for parents to consider**

1. How do you understand Billy's medical problems?
2. Has anything like this ever happened to you before?
3. What do you feel may have contributed to Billy's illness?
4. Is there anything that we are doing or not doing to Billy that is worrying you?
5. Do you both see Billy's medical problems and the decision that we are facing in the same way? Do either of you see anything differently?
- 6a. Have you been able even to consider that Billy, being this ill, is in danger of not getting better or actually dying?
- 6b. Just as we fear not being able to save every child, we also fear going too far, even worsening their suffering, when our efforts are futile. Do you think that this could happen to Billy?
- 6c. If I am sure that certain treatments will cause suffering for Billy without really helping him then I won't be able to do those things. We always tell parents when we think this time is approaching. (Initially) For Billy things have not reached this point and we hope they do not. (Later) For Billy we could be there in a matter of hours. (A brief period of silence will allow parents to respond).
7. Do you feel I'm helping or guiding you too much or too little?
8. How do your religious or cultural values influence this decision?
9. What was your main reason for deciding the way you did?
10. How do you feel about holding the baby when the machines are removed?