

Perinatal Care at the Threshold of Viability—From Principles to Practice

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Abstract

The threatened birth of an extremely-low-birth-weight (ELBW) and gestational age infant presents complex medical, social and ethical issues for the family and the health professionals. Improved survival may be accompanied by increased risks of chronic medical problems and neurodevelopmental disabilities. It is difficult to define “how small is too small” and to decide “how much is too much” in providing optimal management of the mother and infant when delivery takes place at the threshold of viability. An individualised prognostic strategy appears to be the most appropriate approach. Through a process of communication and value exploration between the well-meaning parents and well-intentioned physicians, the goal is to reach a consensual decision that respects parental authority and promotes physician beneficence, with the best interests of the infant placed in the centre of the analysis.

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The Treatment Dilemmas

One of the major challenges in neonatal-perinatal medicine in the new century is the optimal management of the mother and infant when delivery is imminent or at the threshold of viability. Considerable debate has arisen regarding the appropriate approach and strongly polarised viewpoints are held with and without supporting data. There are neither easy answers nor straightforward protocols when faced with the question of how aggressively to manage preterm infants born at the lower limit of viability. Because of the complexity of the problem, no easy remedies can be anticipated in the near future. Moral, ethical, economic, social, religious and sometimes even judicial issues compound medical and technological issues. The database of sophisticated decision making is inadequate, so healthcare professionals are usually forced to straddle the decision line of how and when to provide appropriate care with a chance for a reasonable outcome, however defined, and not merely prolonging life and suffering.

Survival of infants with very low birth weight (VLBW <1500 g) and gestational age (<32 weeks) has increased since the early 1990s because of advances in perinatal interventions, such as improved assisted ventilatory techniques, surfactant replacement therapy, antenatal steroid therapy, and enhanced nutrition, and is likely to continue to

improve. The survival rate for infants born from 22 to 25 weeks of gestation increases with each additional week of gestation.^{1,2}

Although infants with a birth weight of below 1000 g currently account for only approximately 0.5% and those below 750 g for about 0.2% of all deliveries, the number of these extremely preterm births has been showing an increasing trend, partly resulting from assisted reproductive technology procedures.^{1,2} They are responsible for the bulk of the mortality and contribute disproportionately to the morbidity associated with childbirth. These relatively few deliveries tax the resources of any institutions and require coordinated efforts, skilled professionals and excellent communication to meet the needs of all the parties involved. Resource utilisation is excessive with prolonged technology-dependent intensive care after extensive periods of hospitalisation.

The dollar expenditure does not address the emotional costs and the wrenching burden of long-term disability. Survivors at the borders of viability continue to be responsible for sustained costs in the health sector after the infant's initial discharge from the hospital, as many require re-hospitalisation for chronic medical problems. The incidence of moderate or severe neurodevelopmental disability in surviving children assessed at the age of 18 to

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30 months ranges from 30% to 50% and does not appear to decrease over the 23- to 25-week gestation period.²⁻⁷ Many may have learning difficulties and subtle functional or behavioural disorders not fully apparent until school age. Therefore, they may also impose a significant burden on special education and social services, on families and caretakers of the infants, and on society in general, because the commitment for all aspects of care may be extensive, multidisciplinary, lifelong and costly.

The mixture of success and failure creates moral and ethical questions regarding the extent to which the new technology should be applied to the extremely-low-birth-weight (ELBW) and gestational age infants. There is clearly a diminishing return of healthy survivors and an increasing cost in both suffering and expense as smaller and smaller infants receive intensive care. Yet, occasional survivors from near the extreme lower limit of viability have proved to be completely free of problems on long-term follow-up. All costs, therefore, have to be balanced by the incredible joy that these infants may bring to their families and the contributions that they will make to society. Cost is important and may be a limiting factor for providing care at the borders of viability in societies with limited resources. In developed countries, however, decisions regarding the limits of viability should be made on the medical facts. In the midst of all the controversies and arguments surrounding the issues on providing the best possible care for these infants and their families, certain general principles should emerge and be accepted, so that they can be translated into practice guidelines that reflect current thinking.

Lower Limits of Viability: How Small Is Too Small?

Many reports and commentaries have attempted to define a limit of viability.⁸⁻¹¹ Improved survival of extremely immature infants with very low birth weight has blurred the definition of viability. Some have even considered the concept of a limit of viability to be vague and clinically and ethically simplistic.¹² At one end of the spectrum, viability has been defined as the point at which a newborn infant is capable of extra-uterine life, regardless of length and quality of life. At the other end, it has been defined as the ability both to survive and to grow and develop normally.^{11,13} The distinction between life and death is further confused whenever artificial life support systems are used. In most instances, however, it is not precisely defined, and the limits of viability will remain a moving target as long as viability means the ability to survive so that life would be considered worthwhile to the infant or the parents.

In physiological terms, viability of the foetus depends on the ability of the lungs to support life for a prolonged period with or without the aid of assisted ventilation. At

approximately 23 to 26 weeks' gestation (corresponding to about 500 to 600 g in the average gestation), the lungs undergo the developmental changes known as "alveolation", when differentiating capillaries will come in direct contact with the walls of alveolar sacs, thus allowing gas exchange across the alveolocapillary membrane. This is a process of gradual maturation that occurs over time and with biological variability. However, because of technological advances, the ability to resuscitate and temporarily support even pre-viable infants is available. Antenatal steroid therapy has been shown to accelerate the process of lung maturation. Recent research on liquid ventilation in extremely immature infants has further given evidence that science is again opening new frontiers.¹⁴ If premature infants can be supported by artificial means for prolonged periods, the lower limits of viability may be decreased.

In the past, newborn infants of less than 28 completed weeks' gestation (birth weight approximately less than 1000 g) rarely survived and were termed "pre-viable".^{7,15} At present, a physician is expected to resuscitate an apparently normal premature infant of 28 weeks' gestation and weighing 1000 g and to provide such an infant with ventilatory assistance, if necessary.¹⁵ However, how a physician should act when presented with a 500- or 600-g infant is not clear. Should the government define viability and mandate resuscitation of all infants weighing more than a certain weight and having a gestational age that is greater than an established limit? Should pertinent aspects other than weight or gestational age of an infant be considered before a course of resuscitation and assisted ventilation is undertaken? Would the decision be different if the mother were married or unmarried, the pregnancy wanted or unwanted, a support system available or unavailable for the infant after discharge, or financial resources available to pay for the hospitalisation?

In the midst of these controversies and uncertainties, some guidelines have been developed. In 1993, the World Health Organisation (WHO) defined the perinatal period as commencing at 22 completed weeks of gestation (154 days; birth weight approximately 500 g). Infants born 22 to less than 28 weeks' gestation (approximately equivalent to 500 to 1000 g) have been termed as having "threshold viability", though in developed countries this term is more often used in reference to infants of less than 26 weeks.^{15,16}

A statistical approach has been adopted as a strategy in dealing with prognostic uncertainty.^{17,18} A line is drawn at a certain level of risks of mortality and morbidity. The practitioner treats only infants above this line. This method is just in providing similar treatment or withholding of treatment to similar patients. It is socially aware in its hesitancy to provide intensive care to infants with a very

high risk of neurodevelopmental disabilities and a very uncertain benefit, the burden ratio as viewed from both the infants' and families' best interests; and is financially responsible in reserving healthcare resources for a higher cost-effectiveness rating. This strategy accepts the probability that it will fail to save some lives that would be individually, socially and economically worthy, in order to avoid saving those lives that would be accompanied by great costs, both short term in the intensive care unit and long term in the rehabilitation and remedial education programmes. Clearly, different societal contexts will determine where the line is to be drawn. Thus, the New York State Task Force on Life and the Law (1988) concluded that although technological advances may improve survival further among infants born after 23 or 24 weeks of gestation, they would not lower this threshold for survival.¹⁹

The Fetus and Newborn Committee, Canadian Paediatric Society, Maternal-Fetal Medicine Committee, and Society of Obstetricians and Gynaecologists of Canada have been very specific with regard to the management of women with the threatened birth of an infant with extremely low gestational age.²⁰

"Fetuses with a gestational age of less than 22 weeks are not viable and those with an age of 22 weeks rarely viable. Their mothers are not, therefore, candidates for caesarean section, and the newborns should be provided with compassionate care rather than active treatment. The outcomes for infants with a gestational age of 23 and 24 weeks vary greatly. Careful consideration should be given to the limited benefits for the infants and potential harms of caesarean section, as well as the expected results of resuscitation at birth. Caesarean section, when indicated, and any required treatment are recommended for infants with gestational ages of 25 and 26 completed weeks; most infants of this age will survive. And most survivors will not be severely disabled. Treatment of all infants with a gestational age of 22 to 26 weeks should be tailored to the infant and family and should involve fully informed parents."

Factors Determining Survival

Birth weight and gestational age are the key factors determining perinatal outcome. In fact, both birth weight and gestational age exert independent effects on survival,²¹⁻²³ although the degree to which these effects are the result of obstetric or neonatal philosophies of management that are based on gestational age or estimated or actual birth weight is not known.

Gestational age-specific outcomes are dependent on the criterion used to assess gestational age. Gestational age has traditionally been reported as completed weeks from the last menstrual period, although some round to the closest

week. The gestational age is also influenced by further adjustment according to ultrasound measures of fetal age. In many reports, gestational age was assigned by postnatal physical examination, in at least a portion of the cohort, when obstetric information was not available or when there was a significant discrepancy between the obstetric estimate and the postnatal examination. Survival is higher when gestational age is determined by postnatal examination compared with best obstetric estimates because the former significantly underestimates gestational age in infants less than 28 weeks.²⁴ Inaccuracy may occur when gestational age outcomes are reported by the number of completed weeks. Thus, the outlook for an infant delivered at 24.1 weeks who weighs 550 g is very different from that of an infant at 24.6 weeks who weighs 800 g.¹⁻⁴ Yet, both would be considered to have a gestational age of 24 weeks. A review of the world literature reveals that at 23 weeks' gestation survival rates range from 11% to 30%. At 24 weeks' gestation the range is 26% to 52%, and at 25 weeks' gestation, 54% to 76%.^{1,2,7}

The wide variations in the reported ranges of mortality are due to differences in population descriptions, prevalence of antenatal steroid therapy and postnatal surfactant therapy, policies of initiation and withdrawal of treatment, and the definition of survival (e.g., neonatal versus post-neonatal, discharge to home versus 1 year of age). It was estimated that if all infants weighing 501 to 800 g at birth were to receive mechanical ventilation, a modest improvement in survival (as high as 65% versus 57%) would have resulted.²⁵ This is not to imply that strategies to maximise survival should be used at all gestational ages and birth weights; it does mean that survival in the smallest and most immature infants could potentially be better than that reported.

The birth weight at any given gestational age varies enormously, as does the mortality rate. Birth weight-specific outcomes are influenced by the weight range used in the reports, e.g., 500 to 599 g versus 501 to 600 g. Because of the tendency to round off birth weight, such differences may influence survival rates. The mean survival rates were 11% for infants weighing 401 to 500 g, 27% for infants weighing 501 to 600 g, 63% for infants weighing 601 to 700 g and 74% for infants weighing 701 to 800 g.^{1,7} These numbers continue to change and should only be used as guidelines rather than absolute criteria when plans for resuscitation and ongoing intensive care are formulated. Despite the widespread publicity they tend to receive, very few infants with a birth weight below 500 g have survived; most are female small-for-gestational-age infants. The very poor neurodevelopmental outcomes and debilitating lung and eye morbidity seen in the surviving children probably reflect the combined effects of extreme prematurity and severe intrauterine growth restriction.

Gender is an important determinant of survival. Females have about 20% lower risk of mortality at all immature gestational ages.¹ Perinatal mortality and morbidity are also significantly increased in multiple gestation, and the incidence of severe handicaps is increased in survivors of multiple gestation. Decisions regarding active resuscitation and viability should take into consideration the combination of projected birth weight, gestational age and gender, as well as maternal history. Unfortunately, in many instances, the perinatal team is often confronted by a woman without prenatal care who will deliver imminently with uncertain dates, and neither birth weight nor gender is known.

Many factors may affect the probability of survival, but survival is rarely categorised by more than gestational age or birth weight. Even when these variables are included, the numbers of livebirths reported at the extremes of the low range are too small to allow survival to be estimated with confidence. Regression analysis has also not allowed survival to be predicted with sufficient accuracy to be clinically useful. An error rate of 52% in the prediction of death and 21% in the prediction of survival had been reported using a logistic regression analysis, which included birth weight, antenatal steroids, gender and size for gestational age.²⁵

Factors Determining Neurodevelopmental Outcomes

Children with ELBW and gestational age have poorer outcomes than normal-birth-weight term-born controls in terms of neurological and health status, cognitive-neuropsychological skills, school performance, academic achievement and behaviour. Outcomes are highly variable but are related to neonatal medical complications of prematurity and social factors.¹⁻⁷

The major factors significantly associated with a poor neurodevelopmental outcome include bronchopulmonary dysplasia, the severity of cerebral ultrasound abnormality (e.g., grades III and IV intraventricular haemorrhage, periventricular leukomalacia and persistent ventriculomegaly), necrotising enterocolitis, nosocomial infections and septicaemia, severe retinopathy of prematurity and growth failure. Morbidity increases with decreasing gestational age and birth weight and varies according to demographic and clinical therapeutic practice differences. At 23 weeks' gestation, chronic lung disease occurs in 57% to 86% of survivors; at 24 weeks, in 33% to 89%; and at 25 weeks' gestation, in 16% to 71% of survivors. Rates of severe cerebral ultrasound abnormality range from 10% to 83% at 23 weeks' gestation, 9% to 64% at 24 weeks, and 7% to 22% at 25 weeks' gestation. Fifty per cent of survivors less than 750 g and most at 24 to 25 weeks' gestation have one or more neonatal complications.^{1,3}

Most reports of early childhood outcomes consider

children to be severely disabled or impaired if they have a major neurological abnormality such as cerebral palsy, unilateral or bilateral blindness, deafness requiring hearing aids, or cognitive functioning less than 2 SD of the mean (Mental Developmental Index less than 70). These measures have, however, been criticised, but few measures of functioning and quality of life have been validated during early childhood. At 23 weeks' gestation, 34% had severe disability. At 24 weeks' gestation, rates of severe neurodevelopmental disability range from 22% to 45%, and at 25 weeks' gestation, from 12% to 35%. Many of the severely disabled children have multiple impairments.^{1,3}

The overall consensus has been that despite improvements in survival after the introduction of surfactant therapy, rates of neurodevelopmental disability have remained unchanged in the early to mid 1990s. However, there appears to be a worrying trend of deteriorating developmental outcomes for infants 23 to 25 weeks' gestation born during the latter part of the 1990s despite a further increase in the survival rates, and this has been attributed to the increased and prolonged use of postnatal corticosteroids for chronic lung disease.¹⁻⁷

"Best Interests" of the Infant

While many parents, physicians or nurses do not subscribe to a pure sanctity of life philosophy, there is often conflict and difficulty in quality of life judgements. The most reasonable approach is that medical care decisions should reflect the best interests of the infant. Because critically ill infants are unable to articulate or advocate for their own interests, it is important that there be societal safeguards to assure that these vulnerable patients are protected. "Best interests" is an inherently subjective concept whereby surrogates employ this principle to maximise benefits and minimise harms to newborn infants. But who decides, and on what basis, what constitutes a benefit and what constitutes harm? This procedural question is important because benefits and harms often lie in the eyes of the beholder (i.e., parents and health professionals), whose perceptions are influenced by personal values and experiences. Even if we can articulate the principle of "best interests" and to explain the obligation that physicians and parents bring to making choices for infants, it is hard to define what is the right choice and the right process in individual cases.

It is believed that virtually all parents love their children and wish them to be healthy and happy members of the society. As such, parents can and do assess what they believe to be in the best interest of their child. This authority, however, is not absolute, and their assessment can be challenged. In the complex cases in which there is conflict concerning the right choice for a critically ill infant, parents quickly realise that the best interest of their child is often unclear and uncertain. When parents and

health professionals disagree, it is most often because there is no single objective criterion to guide their judgement.

Health professionals play an important role in assessing what is in the interest of their patients. When parents cannot make autonomous choices and have not previously voiced their preferences, which are the case for all infants, physicians have a greater obligation to assess what is in the interest of the patient and to advocate for these interests when critical choices must be made. These obligations require judgements, independent of family wishes, concerning what is the right choice for the infant. Physicians stand as societal representatives to assure that choices parents make are within a range of acceptable options and based on a reasonable assessment of the interests of the child.

Health professionals also have difficulty in making an objective assessment of the interest of their infant patients. They also bring personal values and experiences to their decisions. They respond to their awesome responsibility in varying ways. Some wish to maintain control of the decision-making, some are worried that they will be criticised for their decision, others are concerned that the death of a patient is a failure and others are burdened by a desire not to inflict undue pain and suffering on their patients. It is therefore important for each health professional to explore his or her own values and motivations when attempting to define the best interest of an individual infant.

Another complicating factor is that the best interests of the newborn may conflict with the family's interests, possibly including the interests of the other children. Although the current wisdom is that the infant's best interests must be pursued, some questions this narrow perspective, arguing that it is legitimate for both parents and physicians to consider family interests in making decisions. We must not expect parents who love their child to be so separate and aloof as to be able to objectively define the interests of that child without at the same time taking into account their own feelings, and the impact of this decision on their lives and on other loved individuals in the family. We should not allow parental desire to avoid emotional, financial, or other hardships to deny clearly beneficial medical care to a critically ill child. However, we should not trivialise the importance of these issues to the family nor should we ignore the need to provide social supports to mitigate these concerns.

Ultimately, the most appropriate decisions should be made through a process of communication and value exploration between the well-meaning parents and well-intentioned physicians. It is possible to move closer to resolution of the dilemmas by encouraging open communication among the participants in the decision, and by the acceptance of all parties of the inherent value

conflicts that are at the basis of the disagreements. Physicians ought not to view their duty as blind advocacy for any chance of the continued life for their patients. Parents ought to be given wide latitude in their choices, particularly when the likelihood of benefits is marginal or uncertain. The basic goal is collaborative decision-making by placing the child, as much as possible, in the centre of the analysis in an attempt to ascertain his or her interests. The goal should not be making identical decisions in all medically similar cases. Rather, acceptance of differing family values will result in different decisions in medically similar cases out of respect for parental views, beliefs and wishes. This approach is consistent with our respect for personal values and family autonomy, while still protecting the rights and interests of the child.

Obstetric Management

The perinatal management of the threshold-viability foetus and infant is a multi-disciplinary matter requiring close collaboration between obstetricians, paediatricians, nursing staff and other supporting professionals.^{15,16} Forward planning and consensus between members of the perinatal team are essential. Failure of communication at the top can lead to paradoxes such as an inexperienced or unavailable neonatal staff when the obstetricians have just carried out caesarean section purely for fetal reasons, or the delivery of a bruised, acidotic, immature fetus after a prolonged unmonitored labour with untreated maternal chorioamnionitis, when parents are anticipating a good outcome from neonatal intensive care. It is therefore most critical that there be leadership or guidelines for junior staff when emergencies require decisions to be made in morally uncertain situations.¹¹

As soon as the birth of a threshold-viability infant is anticipated, the neonatal consultant, who will be responsible for the care of the baby after birth, should be informed by the obstetric team so that whenever possible he/she may introduce him/herself to the parents and counsel them prior to the delivery.¹⁵

The management of a mother who is threatening to deliver during this period should involve an attempt to establish the factors predisposing to the initiation of labour, including an evaluation of the condition of the foetal membranes for the presence of chorioamnionitis. Also, the likelihood of controlling labour with tocolytics in order to allow adequate time for corticosteroid administration should be evaluated. Every effort should be made to delay the birth because the chance of survival improves by 2% a day during this period of gestation.¹¹ Consideration should be given to transfer to a perinatal centre with maximum expertise in caring for such high-risk pregnancies. The best incubator in which to transfer a baby of this size is the

mother's uterus. In-utero transfer policies should be agreed in advance between receiving and sending maternity units and should be regularly updated. Women should be counselled to ensure that their expectations following transfer are appropriate and realistic.^{15,16}

When it is clear that a marginally viable infant will result, it is important to use the time before delivery for consultation with the family. Most parents are unfamiliar with the complexities of care required for the infant, both in the intensive care unit and after discharge from the hospital. Therefore, it is often necessary to provide the information in small segments at frequent intervals to allow the parents to comprehend the messages. The family should be given a clear explanation of the various supportive procedures that will likely be necessary after birth. Family members should also be provided with an overview of the potential complications of prolonged intensive care. They should also be informed of the range of survival rates and of the rates of long-term disabilities that can be expected, allowing for some error in the best estimate of gestational age and estimated foetal weight. In compiling such information, both data reported in the current literature as well as outcomes based on local and the specific institutional experience are relevant. It should also be noted that the available data pertain to groups but that decisions must be made for individuals. The discussions should include the possibility that the risks and outlook may change after birth and decisions about neonatal management made before delivery may have to be modified subsequently by the infant's condition and response to treatments.

Even then, parents may be totally unprepared for the situation and decisions often have to be made at very short notice. Therefore, they have to be much guided by the advice of their physicians who, then, have to take some stance and allow parents to give agreement or disagreement rather than throwing the entire weight of decision in their laps. If there is a departmental or institutional policy on resuscitation of the extreme prematures, it should be quoted and explained. Ideally, the obstetric and neonatal staff should confer before counselling the parents. Each member of the healthcare team should make every effort to maintain a consistent theme in their discussions with family members regarding the assessment, prognosis and recommendations for care. The moment of delivery is the worst time to attempt such a discussion. Counselling should be sensitive to cultural and ethnic diversity, and a translator should be available for parents whose primary language differs from the language of the care providers.

The best estimation of gestational age before preterm delivery forms the main basis for subsequent decision-making. Clinical assessment to determine gestational age is usually appropriate for the woman with regular menstrual

cycles and a known last menstrual period that was confirmed by an early examination. Intrapartum ultrasound should not be used to alter the estimated gestational age and is not reliable enough in predicting birth weight when small differences may tilt the scale between what is considered to be viable or non-viable fetus, unless there is a discrepancy of 2 weeks or more between the age by menstrual dating and the age derived from ultrasound or the woman is uncertain about the date of her last menstrual period. Ultrasonography may identify foetal malformations, severe growth restriction, hydrops fetalis or other conditions that could change the management plan. The accuracy of sonographic measurements and the ability to ascertain malformations, however, may be reduced in the presence of oligohydramnios. Physical examination of the infant after birth may lead to a revision of the original estimate. This needs to be explained in advance to parents who otherwise may be confused or feel that an error has been made.^{15,16}

Even in ideal circumstances, the 95% confidence limits for a formula-based estimate of foetal weight are plus or minus 15% to 20%.²⁶ Thus, an infant estimated to weigh 600 g may have an actual birth weight of less than 500 g or more than 700 g. Even relatively small discrepancies of 1 or 2 weeks in gestational age or 100 to 200 g in birth weight may have major implications for survival and long-term morbidity. This underscores the importance of counselling about range of possible outcomes. Furthermore, multiple gestation increases the difficulty of accurate gestational age assessment.

Physicians should avoid characterising managements of uncertain benefit as "doing everything possible" or "doing nothing". They should discuss with the family regarding available data and provide an explanation of the risks incurred by management options. There is clearly a need to balance maternal well-being against the likely neonatal outcome. One of the most difficult and debatable decisions concerns the safest route of delivery. There are no documented benefits of caesarean delivery for extremely premature infants,^{27,28} although analysis of the published work is difficult because large numbers of deliveries are carried out this way. It has even been difficult to document improved outcome with caesarean birth for extremely premature infants in the breech position.²⁸ Furthermore, injuries to the infant can occur during a difficult caesarean birth through thick myometrium. The risks to the woman by caesarean birth include not only those incurred during the perioperative period but also long-term implications for childbearing, since a vertical incision is often used, and such incision at this gestational ages may extend into the upper segment and would preclude the option of vaginal birth in future pregnancies. In most instances, caesarean

deliveries are performed strictly for maternal indications such as severe abruptio placentae and pre-eclampsia.

Another issue following counselling on the likely prognosis is whether there is a place for parents giving advance authorisation for non-resuscitation and non-provision of intensive care for their infants? It is important to note that in virtually all situations in which a physician agrees to a surrogate's request for a do-not-resuscitate order, the physician has assessed the patient's medical condition and concurs that non-resuscitation is a reasonable choice. Because of the uncertainty of the circumstances of an individual delivery, and the need to assess the patient before making the decision as to whether or not to resuscitate, a do-not-resuscitate order prior to delivery is inappropriate.²⁹⁻³¹ It is therefore necessary to make it clear to the parents that vigorous resuscitation, including endotracheal intubation, will be undertaken only if the newborn has at least the degree of maturity predicted by dates and/or ultrasonography, and if, in the judgement of the attending neonatologist at the delivery room, the newborn has reasonable chances of responding to resuscitation. The initiation of resuscitation and subsequent treatments in the neonatal intensive care unit do not preclude discontinuation of therapy if a major complication is detected in the hours or days following birth.

Resuscitation at Birth

The successful management of the ELBW infant begins in the delivery room. A well-organised and equipped delivery room and the presence of experienced and competent members of the obstetric and neonatal teams are essential components to the proper reception of these very fragile newborns. The basic principle guiding successful management should be directed toward prevention of any physiological deviation from normality, such as hypothermia, acidosis or hypoxia. It is also important that each intervention during resuscitation process be adapted carefully to the size and the needs of the tiny infant. Excessive positive pressure with bagging, or inappropriate administration of drugs and fluids can induce permanent brain or lung injuries.

Most of the extremely premature infants are potentially normal at birth, especially when the perinatal management has been optimal. They rely on prompt and adequate treatment to protect them from death or permanent damage in the first few weeks after birth. It has been documented that for those with a potential for survival, their mortality and disability rates are significantly increased by suboptimal and half-hearted resuscitative efforts and delay in initiating appropriate care in the first vital minutes and hours after birth. The decision not to resuscitate is essentially an irreversible step: a change of heart and belated rescue of a cold, acidotic premature infant is an invitation to intracranial

haemorrhage and further disability.³²

If there is good reason to treat an infant and resuscitation becomes necessary, it should be started immediately to maximum efficiency and capacity, thereby favouring possible intact survival, until a more considered judgement can be made, usually by a senior doctor, on the advisability of continuing life support.

Some neonatal ICUs recommend a "cut-off" birth weight of 500 to 700 g, but this only makes sense if it remains flexible and is used as only one of a number of criteria that should be considered before coming to a decision. The approach should be individualised. Factors that may make a physician decide not to resuscitate would be: birth weight <500 g, length <12 inches, and/or gestational age <24 weeks as determined by physical characteristics, one of which is eyelid fusion. However, the decision to resuscitate or not to must be made rapidly, usually without a precise weight measurements and without time for consultation with the family. If the physician, especially when he or she is a relatively junior doctor, is unable to make a decision in the delivery room, it is best for him or her to fully resuscitate the infant and to postpone re-evaluation until conditions are less stressful.

An important issue that needs a clear and firm stand is the approach to an infant born with signs of life after an attempted "therapeutic abortion". It is the primary responsibility of the gynaecologist to ensure accuracy in foetal diagnosis and gestational assessment before a decision is made with the parents on terminating the pregnancy. A paediatrician may be asked to resuscitate and treat a tiny liveborn "abortus" in spite of the fact that a short time earlier a gynaecological colleague made a deliberate attempt to end its life with the consent of the parents. These infants may have been damaged as part of the abortion procedure. It is unlikely that they will be wanted by the mothers who earlier sought their demise. They will be difficult to place for adoption. They should be allowed to die and aggressive resuscitation and intensive care are not indicated.

Continuation of Treatment

After the initiation of treatment at delivery and subsequent stabilisation in the neonatal intensive care unit, treatment of a curative nature should always be continued where there is a medical consensus that it would provide a net benefit to the infant. The infant's medical condition should be the sole focus of any decision-making process. If there is any lack of clarity of whether curative treatment will be beneficial; the bias should always be in favour of its continuation.^{32,33} If a baby is intubated and on a ventilator, he/she should also receive thermoregulation, nutritional and metabolic support, protective isolation, antibiotics if appropriate, and so on. There is no real place for half-hearted care. Intensive care is only justified if the intent is

to save the infant's life and avoid any superimposed brain damage. Anticipated limited potential of the infant falling short of expected physical or intellectual norms and suboptimal family or community resources must not be the sole determinant of the decision regarding the discontinuation of curative efforts.

Neonatal Intensive Care for Threshold-Viability Infant is not "Experimental"

Some have argued that neonatal intensive care and other risky interventions with a relatively low likelihood of a successful outcome are clinical experiments rather than therapy. It follows then that participation in clinical research has always been viewed as optional and requiring the full and informed consent of the patients or in the case of children, of the parent. Clinical interventions that are experimental require assessment by independent review committees and may be refused without question by families. Although many interventions in the neonatal intensive care unit are of high risk, the majority have been subjected to scientific verification, and parent's choice ought not to be based on the assertion that these therapeutic interventions are experiments. The successful implementation of surfactant replacement therapy is the result of one of the most rigorous clinical trials in neonatal medicine.

Appropriateness of Treatment

In debating the justification of omitting or continuing certain treatments, terms such as "ordinary" and "extraordinary" are often used. The argument is that one has an obligation to provide ordinary care, whereas the provision of extraordinary care is morally optional. However, such distinctions founder in practice because of the difficulty that arises in defining the word "extraordinary" in a consistent or practical way.²⁷ A treatment considered extraordinary a decade ago may be very ordinary today, and what is extraordinary in some circumstances may be very ordinary in others. For example, mechanical ventilation would be considered extraordinary in prolonging the life of an anencephalic infant but very ordinary care for the postoperative patient. Therefore, there is nothing intrinsic to the technology that makes a ventilator extraordinary. Surely, the important point is whether or not it is a good thing for life to be prolonged? Does prolonging this life offer a reasonable hope of benefit to the individual concerned? If so, then "ordinary" and "extraordinary" treatments may be appropriate. If not, then both of them may be inappropriate with the exception of those treatments usually ordinary that are necessary to relieve distress.

"Treat until Certainty"

As we enter the new century, the question regarding ELBW and gestational age infants is obvious: How much

is too much? In dealing with prognostic uncertainty, a "treat until certainty" approach has been adopted in the past and it still dominates the practice in many neonatal intensive care units.^{20,33} This approach favours fully aggressive support in almost every infant who is believed to have any chance of survival until death or severe, adverse medical findings become unequivocally evident. Its most significant drawbacks are that it creates a momentum in favour of treatment that may be difficult to stop, that it tends to relegate parents to the role of bystanders, and that it denies the ethical complexity of situations by failing to address moral as well as medical uncertainty. Another problem is that even with the passage of time, uncertainty still remains. The enthusiastic use of technology until the gadgets prove useless or harmful, and its general disregard of the costs, may not serve an individual infant's best interests and will not be affordable in the future.

Withholding versus Withdrawing Treatment

It is widely accepted that there is no moral distinction between withholding and withdrawing treatment. Historically and psychologically, physicians are more reluctant to discontinue a treatment once it has begun.

Withdrawal of treatment is more justified for two reasons. First, the withdrawal of treatment has the benefit of coming after a clinical trial, resulting in more data regarding the likely outcome than if treatment had been withheld. Second, the traditional prohibition of withdrawing treatment led some physicians to withhold treatment from some infants who had reasonable prospects of benefit, for fear that if the outcome was later shown to be bleak, there would be no recourse other than to keep the patient alive as long as technology would allow.

Withdrawal of Life-sustaining Treatment

Withdrawal of life support has a place in the care of the high-risk infants. It will be easier to initiate treatment and begin intensive care if it is clear that this care can be withdrawn should it later become evident that it is ineffective or it has not achieved its beneficial intent.

When the burden of curative efforts lacks compensating benefit or such treatment is no longer of any avail, there is no need to continue or pursue it.³² Therapies lack compensating benefit when they merely prolong the dying process, when the infant suffers from severe pain which cannot be alleviated by medical treatment, or when the infant will be unable to participate even minimally in human experience.³³

The Royal College of Paediatrics and Child Health has delimited three areas where the withholding or withdrawing of life-sustaining treatment might reasonably be considered in the newborn period.¹⁶

1. In the *no hope or no chance situation*, life-sustaining treatment is simply delaying death without improving life quality or potential. If suffering were not to any significant extent alleviated, medical treatment would be deemed inappropriate. There is no legal obligation for the doctors to provide medical treatment to this situation that cannot be in the best interest of the patient. Indeed if this is done knowingly, it is futile treatment.
2. The *no purpose situation* describes the case where the infant's potential of having an extremely significant degree of impairment is inevitable, and it would not be reasonable to expect him or her to bear it. Such an impossibly poor quality of life may relate to the future, in which case treatment might reasonably not be initiated or to the present, with the likelihood of it continuing with no foreseeable improvement, in which case the treatment might reasonably be withdrawn. This might apply to the severely asphyxiated infant where microcephaly, profound developmental delay, blindness and quadriplegia are believed to be inevitable. This could also reflect conditions where brain damage is not necessarily the worrying outcome, e.g., the ventilator-dependent infant with bronchopulmonary dysplasia in cor pulmonale, and the hyperalimentation-dependent infant with short bowel syndrome from necrotising enterocolitis.
3. The third situation is the *unbearable situation*, where a family may feel that further treatment is more than can be borne. They wish to have treatment withdrawn or wish to refuse further treatment irrespective of medical opinion. Parents may be able to recognise that it is reasonable to put up with short-term suffering for a good later outcome. There is a limit, however, to this tolerance – if there are likely to be repeated and severe problems and invasive therapy, parents may feel that treatment withholding or withdrawal is the most appropriate option. An example might be the newborn infant with hypoplastic left heart syndrome, where successful survival is likely only to be possible with multiple and severe cardiac operation.

These criteria illustrate the relationship between beneficence and non-maleficence – harm must always be exceeded by benefit.

When decisions are made to withhold or withdraw life-sustaining treatment, the term “futility” of continued medical treatment has been used extensively.³⁴ What constitutes “futile” treatment has not been resolved.³⁵ In brief, a life-sustaining treatment is considered futile if it cannot benefit a patient in the narrow, strictly physiological sense. For example, mechanical ventilation is physiologically futile when it will not maintain adequate ventilation or oxygenation. In practice, however, few interventions are

physiologically futile. More common are interventions of which the probable effectiveness is low and the anticipated quality of life for the patient is unacceptable, from the observers' perspectives.³⁵

Palliative Treatment

When a decision is made to withhold resuscitation, discontinue resuscitation, or forego life-sustaining treatments, the family should be treated with dignity and compassion, focusing on their needs. Humane and compassionate care must be provided to the non-viable or dying infant, and to the family. This includes careful handling, maintaining warmth, avoidance of unnecessary invasive and painful procedures, and unobtrusive monitoring – sometimes called “comfort care”.

When medical support is discontinued or death is inevitable, time and opportunity should be provided for the parents and other family members to hold, touch, and interact with the infant before and after the infant dies. Simple personalising acts, such as naming the infant; obtaining a photograph, cot card, name band, footprint, or even a lock of hair; recording birth weight and other measurements; and baptism when appropriate, may be important to the parents and should be provided. The presence and support of the medical team are also part of the vital aspects of care that cushion the impact of an unavoidable death.

Since every infant is unique, the specifics of palliative treatment must be individualised. If a decision has been made that continued survival is not in the infant's interest, it would seem irrelevant whether he or she died by active or passive means. However, there are big differences between active measures to terminate life (euthanasia) and allowing a patient to die owing to some intrinsic disease or defect. The objections to euthanasia are based, in part, on the swiftness and irreversibility of action, precluding the possibility of changing course if it is discovered that the decision was wrong. The greater concern, however, has been for “slippery slope” effects: that lowering the barrier against killing will make it easier for physicians to kill others, that boundaries will become less distinct, and that patients without a clear interest in dying will be harmed.

In general, when a firm decision has been made, it is not unethical to remove all means of life-prolonging medical treatment. Although there are consensus in withdrawing medical treatments such as antibiotics and artificially or technologically supplied respiration, there are still controversies in the use of drugs to relieve pain and discomfort, and the withdrawal of hydration and nutrition. There are difficulties in determining whether infants perceive pain at the time of impending death. However, the use of analgesics may be considered part of the provision

of comfort care, despite the potential respiratory depression of opiates.³⁶ On the other hand, withdrawal of hydration or nutrition is extremely difficult and requires support of the family and members of the healthcare team.³⁷ It may create great stress for caregivers and the family and is in fact seldom entertained. The practice may be easier when an infant with a hopeless prognosis cannot be fed orally, and feeding via other routes is a burdensome technological support.

Decision Making in the Intensive Care Unit: Physician's Role

The decisions involved in shifting the emphasis from curative to palliative treatments are difficult and come about gradually as the infant's physical condition deteriorates. Fundamentally, they are medical decisions requiring sufficient observation and expert assessment of the prognosis and likely effectiveness and risks of therapy. Sometimes, a waiting period is required when the worsening condition becomes more evident, before a time comes when discontinuation of curative efforts can be jointly resolved. The range of complexity in these medical complications makes it impossible to define clinical criteria for discontinuing curative efforts. The relevant factors are at times imprecise and include value considerations. Strictly objective criteria, checklists or cumulative scoring systems are unlikely to improve the quality of decision-making.

A reasonably acceptable approach is a family-centred "individualised prognostic strategy".²⁷ In this strategy, care is provided for the individual infant at the appropriate level based on the expected outcome at the time care is initiated. The infant is constantly re-evaluated, and the prognosis is reassessed based on the best available information in conjunction with the physician's best medical judgement. This approach avoids the extremes of withholding treatment from all infants who fall below a minimum threshold and treating all infants until the outcome is certain.³⁸

With statistical outcomes as baseline background data, each individual infant with a reasonable chance to survive, generally accepted as an appropriate for gestational age infant of at least 500 g or 24 weeks' gestation, is aggressively supported in the delivery room, and then the individual infant's response to initial aggressive intensive care is assessed. With that information, the primary physicians and other healthcare team members meet with the family to discuss treatment options. The critical part of this strategy is the multiple options. It recognises and openly accepts the uncertainty of prognosis, that is, there is more than one possible outcome, the plurality of societal views in that there is more than one possible choice, and the appropriateness of the surrogate decision maker, usually the parent, to choose among medically, ethically and legally

sound treatment options, when the benefit/burden ratio is uncertain.³⁹

This approach places significant responsibility on the physician and healthcare team to evaluate the infant accurately and continuously. The importance of a primary physician taking charge of the decision-making process and counselling the parents cannot be overemphasised. There are two worrisome trends emerging in some neonatal intensive care units.³⁸ First, is the increasing involvement of subspecialists in the care of the infant with complex problems. Although the responsibilities of each discipline are generally known, boundaries may be difficult to define in certain situations and patterns of responsibility and communication may be affected. There is the potential not only for team members but also for pregnant women and parents to be confused or unsure as to who is responsible for what. Organ-specific specialisation may also result in individual medical problems being treated and managed separately, usually without any consideration of long-term sequelae. Second, is the designation of neonatologist as an intensivist, with responsibility limited to immediate care in the intensive care unit and longer-term issues left to individuals involved in the developmental follow-up of the high-risk survivors. This compartmentalisation of care leads to diffusion of medical responsibility and concerns for the infant as a whole and for their long-term outcomes. It establishes a momentum towards continuing treatment at all costs and risks alienating parents from the decision-making process.

The role of the primary physician is to be the advocate for the infant, to whom he has moral and legal obligations. The primary physician should be a senior and experienced member of the team. He will unite the team into an effective common cause, with a clear understanding of the differences in responsibility between conveying day-to-day information versus information about severe diagnoses and prognostic significance of specific findings. He will consult with colleagues and other appropriate subspecialists and employ all appropriate technologies to thoroughly assess and confirm the diagnosis and prognosis of the infant - good ethical decisions begin with good facts. Together, they attempt to define the issues, outline options and decide on the nature of treatment. He should then be able to integrate all the important information and maintain a consistent pattern of communication with the parents. As the individual with an overall perspective of the medical realities of the case and who also is in close contact with the family, he is in the best position to make a sound recommendation of the preferred treatment option to the parents. The decisions should be made openly and documented so that doctors are seen to be accountable for their actions. By following this course, the risk of placing undue reliance on a single

person's judgement is avoided.

Parental Participation in Decision Making

The effectiveness of the medical team depends on the extent to which the relationship between it and the parents are based on frank and open discussion and mutual trust from the outset. Physicians will provide parents with accurate and timely information on the infant, and as much medical certainty as possible. Effective communication entails more than mere disclosure of information. It also means encouraging the parents' active participation in discussion and assuring them that their views are fundamental to the decision-making process. In conversation with the physician, parents will identify and re-examine their values and treatment preferences, which on reflection they may either affirm or alter. In this way, the parents would have been in close communication and by the time a medical consensus is reached for discontinuation of curative efforts, they would appreciate that all reasonable hope has been exhausted.

Parents should be actively involved in major decisions that ultimately could alter the infant's outcome. The parents bear the principal moral responsibility for the well-being of their infant and should therefore be the surrogates for their infants. The pre-eminence of the parents' decision does not preclude the primary physician's responsibility to make a definite recommendation on the preferred treatment option. It is incorrect to provide a mass of medical facts and leave the parents adrift without specific guidance. The basic prerequisites are that the decision is made voluntarily and without coercion and that the parents have full understanding of the options and implications. The primary physician may have to guide parents towards what is acceptable not only medically but also morally and socially, and what is within the law. He must also be sensitive to the parents' concerns and desires, which are often based on a complex combination of values and influences derived from their cultural, religious, educational and ethnic backgrounds. Belief in spiritualism and forces greater than science and medicine may be values held by some families. The medical team must maintain respect for their views and values, even when they do not agree and cannot concur. Respect of an opinion does not imply capitulation. The doctor counselling parents should be careful not to impose his own cultural and religious convictions on those whose beliefs may be different.

Studies have shown that parental participation in decision making in the intensive care unit did not interfere with mourning or burden them with guilt. It may even ameliorate their subsequent grieving process. The more open, informed, and collaborative the process, the better the quality of decisions and the comfort with which they are made.⁴⁰

Resolving Differences

The rights and decision of the parents must always be respected. However, physicians should not be forced to undertreat or overtreat an infant if, in their best medical judgement, the treatment is not in compliance with the standard of care for that infant. Although in most instances, a morally sound decision regarding the best course of action in a particular situation can be agreed upon, such attempts at consensual decision-making may sometimes be unsuccessful.

It may be unrealistic to expect agreement from the parents the first time a difficult option is raised, and time should be allowed for further clinical observation. It is important to ensure full parental comprehension of the medical information and continue to discuss and explore the underlying reasons for the differences in choice. Sometimes, an interdisciplinary case conference, with or without the presence of parents, may help to discuss differing viewpoints and work towards consensus.^{15,16,41}

Although it rarely ever happens, when there is a serious and intractable conflict or disagreement between the recommendations of the physician and the desires of the parents, one option is to consult with the hospital bioethics committee. Another option is for the physician and family to seek another physician willing to provide care for the infant in the manner desired by the family. In rare instances, it may be necessary to invoke established child protective mechanisms if parents wish to forgo life-sustaining treatment, physicians disagree, and the parties cannot resolve their differences with help from subspecialists or ethics committees. This disagreement between the physicians and the family may result in the involvement of the court. In that case, the physician should continue to serve as advocate for the infant.

Bioethics Committees

In an attempt to ensure that morally acceptable decisions are being made, there is increasing support for a procedural approach based on the "Ideal Observer Theory." An ideal ethical observer has five characteristics: (1) *omniscience*, the decision has included all the readily and relevant facts; (2) *omnipercipience*, the decision has empathetically taken into account the feelings of those involved; (3) *disinterest*, the decision is not based on vested interests; (4) *dispassion*, the decision is not made under conditions in which strong emotions obscure critical thinking; and (5) *consistency*, that similar cases are decided similarly. Because no person can attain this ideal, a collaborative process is used to approximate these characteristics. It has been proposed that hospitals should set up bioethics committees to advise on controversial management issues such as decisions on the care of high-risk newborns.⁴² Whether they will lead to

'better' decisions for infants remains to be seen. Their establishment is voluntary but their role and objective should be well defined and will differ from one hospital to another.

The decision-making process between the doctors and the parents is an intensely private affair and interference by outsiders like the bioethics committees may cause confusions and complications. Members of the bioethics committees, no matter how able or sincerely motivated, may not understand all the complexities and implications of the situations that affect individual families. The more remote the decision-makers, the more remote will be the decision from infant and family realities. Committee members may disagree among themselves, and some members may dominate others. They may also be more concerned with the institutional impact of a decision rather than with the specifics of the case.

Bioethics committees, however, can be effective in an advisory capacity. They provide a good mechanism to review decisions for critically ill newborn infants to ensure the best care for the NICU patients and to assure the public that ethically sound decisions are being made within the NICU. By increasing discussion and deliberation of the complex issues, the professional staff will be better able to deal with exigent situations and to provide thoughtful decision making in difficult cases. A further role of the bioethics committee will be to provide 'ethical comfort' and give some legal protection for staff and family alike in carrying out these difficult decisions for some of the most critically ill patients in the hospital. It should rarely be called upon to play the main consultative role in assisting in resolving differences in opinion among those involved in decision-making.

Support and Aftercare

Physicians, nurses and other staff from both the obstetric and neonatal team should provide support to the family beyond the time of the infant's death. Support groups, intermittent contact by phone and a later conference with the family to review the medical events surrounding the infant's death and to evaluate the grieving response of the parents may be considered. Parents will require further counselling on the outlook for future pregnancies. Threshold-viability infants may suffer from a number of problems and disabilities requiring management from a variety of medical disciplines over a long period. A full summary of perinatal and postnatal events should be prepared and made available to all the healthcare teams that may be involved in the follow-up care.

It is imperative that centres that provide neonatal intensive care must also provide a mechanism to ensure continuing care and evaluation of their high-risk survivors. There may

be problems encountered in providing follow-up services, often constrained by limited resources. Therefore, individual follow-up programmes must clearly define their own goals and objectives and then organise their roles and activities accordingly. Besides providing a continuum of specialised medical after-care for the high-risk graduates of neonatal intensive care unit, the main objectives of follow-up programmes are quality control and perinatal audit. Data on both short-term and long-term outcomes are important for counselling and decision-making.

Allocation of Resources and the Responsibility of the Neonatal Intensive Care Units

No nation, no matter how affluent, can hope to provide unlimited resources for healthcare or keep pace with costly advances of high-technology medicine. Resource allocation questions are important, particularly in this era of healthcare reform and cost-consciousness. At the level of *macro allocation*⁴³ (decision about which services to provide to which groups), the society must decide on the status of the high-risk infants as a group, the resources that can or cannot be devoted to their immediate care, the extent to which support can be offered for the longer term aftercare, and the degree of latitude that parents and their physicians can exercise in making decisions. Limited resources may require equitable limits on medical treatment. Such restrictions require careful consideration of their social, cultural, political, and economic consequences and deserve to be made at a public policy level. Such decisions, generally speaking, are not clinical decisions, and physicians should avoid such "bedside rationing". Although it is certainly appropriate for physicians and others who are making choices concerning technological interventions for infants to be aware of the amounts of money to be spent on such treatments, it is inappropriate for them to discontinue treatment using "squandering" of societal resources as the rationale. It is also naïve to believe that money saved by not treating a critically ill newborn in a neonatal intensive care unit will go directly to preventive services or the purchase of a needed piece of equipment for that unit.

At the level of *micro allocation*⁴³ within a neonatal intensive care unit (choices about which individuals should benefit from the resources available), deciding to be selective in the use of skills and technology on the basis of what seems best for the infant has already been discussed. This is morally at least as defensible as a decision to refuse admission because the unit is full, short of nurses, or lacking in medical staff; deciding not to ventilate an infant because there are no more ventilators. Yet these decisions will become necessary everywhere on purely economic grounds if we shrink from developing criteria based on what is best for the infants and families. Providing intensive

care for all infants whatever their weight, gestational age, or condition, apart from the potential for harm to them and their families, may seriously affect the ability of an overloaded and understaffed unit to provide adequate care for other infants. This may have serious consequences for some who might otherwise have had every expectation of survival and a healthy future.

Neonatal intensive care should be subject to rigorous cost-benefit analysis, but with economic costs being only a part of the equation. The staff of intensive care units must document their performance and results in ways that can be compared and analysed. Guidelines for neonatal intensive care will continue to change. Change must be based on accurate information. Increasingly hard choices may be necessary that will require strong medical leadership and the most careful consideration of all relevant moral, ethical, social and legal issues that are inseparable from providing intensive care at any age. The perinatal high-risk team should be more than a group of healthcare professionals working in an isolated area of the hospital, trying to master new technology and break new ground. It should be an open, analytic, self-critical and responsible group providing care of the highest ethical standards to pregnant women, newborn infants and their families.

Conclusion

One of the most significant healthcare challenges of this century is the prevention of very premature birth. Measures designed to prevent prematurity are definitely more efficient, compared to intensive care of the premature once born. Great inroads are being made in determining both the mechanisms that contribute to premature birth and the early markers of preterm birth with the potential for developing intervention strategies. However, until significant changes can be made to reduce the rate of prematurity, we will still have to care for the tiny prematures.

The threatened birth of an ELBW and gestational age infant presents complex medical, social and ethical issues for the family and the health professionals. Improved survival of these infants over the past two decades is laudable, but is also accompanied by increased risks of chronic medical problems and neurodevelopmental disabilities among the survivors. There is a continuing need for additional works on better life support of the extremely preterm infant and the impact of obstetric and neonatal management on the survival potential, short-term morbidities and long-term disability rates of the extremely preterm and ELBW infants. In addition, studies of optimal counselling and bereavement management and the societal impact of extremely preterm births would enhance support of families.

The last word on “how small is too small” and “how

much is too much” in providing optimal care to the mother and infant when delivery takes place at the threshold of viability is yet to be said. It is always a moving target and the dividing line will vary from one country to another depending on the available resources. Regardless of the prevailing philosophy on these pregnancies, the best interests of the infant should be placed in the centre of decision-making. An individualised prognostic strategy appears to be the most appropriate approach. Through a process of communication and value exploration between the well-meaning parents and well-intentioned physicians, the goal is to reach a consensual decision that respects parental authority and promotes physician beneficence. The practice of perinatal medicine shall remain a scientific art and an artistic science.

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