

The limits of perinatal viability: grappling with the “grey zone”

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On balance, new guidelines for parents and practitioners are helpful and workable

Which infants at the margins of viability should receive neonatal intensive care and how should such decisions be made? These challenging questions are posed in this issue of the Journal by Lui and colleagues (*page 495*).¹ Their answers, arrived at by means of a multidisciplinary conference, are presented as a consensus statement that makes several recommendations for practice.

Although similar multidisciplinary conferences have been held in Australia over the past 20 years, there are no contemporary publications on the subject and this statement is timely. As has been apparent from other commentaries both here and overseas,² these guidelines for New South Wales and the Australian Capital Territory confirm that the area of most debate concerns infants of

23–25 weeks’ gestation. However, several important questions can be asked about the consensus statement itself, including: How appropriate was the process undertaken to arrive at the statement? Was consensus reached? And, are the recommendations helpful and “workable”?

As to the appropriateness of the process, there are several options for dealing with these difficult ethical and management decisions. I recall that, at two earlier conferences held at Westmead, Sydney, in 1985–1986, four approaches were identified:

- a “look to the courts” approach (this approach is not readily available, is expensive and generally produces conservative rulings);

- a “right to life” approach or, “if it can be done, it should be done”, whatever the burden this imposes on the patient, their family and society;
- a “muddle through” approach or, “doing what seems best at the time”; and
- an “institutional” approach.

The “muddle through” approach has been a pragmatic solution in the past, leading to a great deal of sensible practice, and it is increasingly subject to controls, including audits and peer review. However, the “institutional” approach — particularly in the guise of a multidisciplinary conference — was, at that time, put forward as the most logical and coherent way of informing community debate and public policy. This approach has worked well in other areas (eg, providing guidelines for human organ transplantation). It would also seem very appropriate for this current debate.

A prerequisite for this process would be that good data are available on the consequences of choosing resuscitation over comfort care. In this instance, the process worked well, because the workshop was presented with comprehensive population-based data from NSW and ACT on survival after live birth and neurodevelopmental status at 2–3 years of age. Although the numbers of infants at each gestational age were relatively small, the data are similar to those obtained from other Australian population-based studies.³ A longer-term follow-up would have been preferable, but such data are subject to the problem that elements of neonatal intensive care change over time.

On the question of whether consensus was reached, the statement revealed that not all recommendations were agreed to by all participants; not surprisingly, there was considerable divergence of views in some areas. Delegates were asked to vote anonymously (using a five-point scale) on a range of scenarios and related statements. “Consensus” was defined as more than 90% “agree” or “strongly agree” or, for some statements “of lesser gravity”, as 75% “agree” or “strongly agree”. The process was rigorous and likely to have honestly reflected the group’s views. However, only 72% of participants agreed with a statement about not initiating resuscitation at a gestational age of between 25 weeks and 25 weeks 6 days (25⁰⁻⁶) if requested by parents in an otherwise uncomplicated pregnancy. Although this was clearly a majority view, it did not, strictly speaking, reach the stated definition of “consensus”, but was incorporated in the consensus statements.

The composition of the multidisciplinary group would also seem crucial to the process. Here, perhaps, there were some shortcomings. The group of 112 delegates convened by Lui and colleagues were mainly health professionals, although eight were non-clinical health administrators and seven were parents or community advocates. Including others, such as educationalists, ethicists, lawyers and religious leaders, would have made the delegates more broadly representative of society, and possibly different views would have emerged. However, various professional and consumer groups as well as the NSW Health Clinical Ethics Advisory Panel have subsequently reviewed the agreed guidelines.

Are the guidelines helpful and “workable”? Certainly, it is helpful to have widely agreed and ethically approved written guidelines in this area of neonatal practice. In a commentary published in 2004, Jerold Lucey, the long-serving Editor-in-Chief of the leading United States journal *Pediatrics*, made it clear that in his view any treatment of these infants is experimental.⁴ In some sense, all medical treatment is an experiment, although commonly the outcome is more predictable than in the case of extreme

prematurity. At these gestational ages, there are too few data relating to treatments found to be effective in more mature infants (eg, exogenous surfactant) to pretend that their use is evidence-based. Thus, as a key consensus recommendation says, within this gestational age range (23 weeks to 25 weeks 6 days) when gestation is known with reasonable certainty, “parents’ involvement in the decision-making process during prebirth counselling or subsequent management is mandatory”.

The issue of non-directive counselling was discussed at the workshop. Not all parents demand total autonomy in decision making;⁵ indeed, some may be impossibly overburdened by the prospect.⁶ The important issue, as emphasised in these and earlier guidelines on preterm care,⁷ is that good communication is at the very core of the partnership between the medical team (the current caregivers) and parents (the future caregivers) that unfolds as perinatal and neonatal intensive care progresses. Information provided to parents by different members of the team should be consistent. Having appropriate written material, which will be available as a result of this consensus workshop, will facilitate this process.

Perhaps the most important consensus recommendation states that, at gestational ages between 23 weeks and 25 weeks 6 days, treatment is discretionary. Lui and colleagues use the term “grey zone” to emphasise that, at these gestations, there is a complexity of maternal, obstetric and clinical factors known to influence outcome that need to be considered in making individualised decisions.

Sex of the infant was not included in the discussions because it was stated that it was not usually known before birth. However, there is now extensive evidence that, at these short gestations, female infants do have a better survival rate, to some extent a better long-term outcome, and essentially are the equivalent of a week more mature than their male counterparts.⁸ Increasingly, the sex of the neonate is known before birth, and otherwise is immediately apparent at birth. It could be argued that there should be different grey zones for female and male infants. Certainly, not to consider the infant’s sex may be to discriminate against female infants.⁹

Many factors, including the sex of the neonate, should influence decisions not only within the zone but at its margins. Data from the Australian and New Zealand Neonatal Network show that survival rate at these short gestations increases by about 3% with each day of increased maturity.¹⁰ This, added to the fact that gestational age is often an estimate, means that the margins of any grey zone are somewhat indistinct.

The consensus statement’s abstract states that “poor condition at birth” has an important influence on the decision not to initiate intensive care in this zone. However, there are few data to support the predictive value of condition at birth for survival and certainly not for neurodevelopment.¹¹ A prediction that an infant of a certain gestational age will do poorly, coupled with non-aggressive resuscitation, is likely to be a self-fulfilling prophecy. However, a poor response to adequate resuscitative measures must clearly be a factor in decisions about ongoing intensive care.

In their statement, Lui and colleagues have provided valuable guidelines for parents and practitioners dealing with impending extremely preterm delivery; they should be congratulated on the rigour of their process. It is now up to others to use these guidelines wisely. In the abstract (which may be the only part some people will read), the description of the grey zone seems a little too black and white, with clear margins. The main text of the statement — which should be read in its entirety — makes it clear that this zone is not uniform grey and that its limits are indistinct.

EDITORIALS

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