

Respiratory Report: The Edge of Viability Tiny Patients, Big Questions

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I dedicate this column to the late Dr. Andrew (Andy) Shennan, the founder of the perinatal program at Women's College Hospital (now at Sunnybrook Health Sciences Centre). To my teacher, my mentor and the man I owe my career as it is to, thank you. You have earned your place where there are no hospitals and no NICUs, where all the babies do is laugh and giggle and sleep.

That NICU staff typically view potential outcomes of the smallest, most premature infants more negatively than published evidence would suggest is not a new phenomenon. (1) As we push the limits of what we can and cannot do for these patients, I suspect this view will become even more commonplace. It is unquestionable that there is a line to be drawn when it comes to viability but where to draw that line is a subject of debate.

Anyone who works in an NICU has seen one of their "graduates" who was never expected to survive, come back to visit looking far better than anyone expected. While this is unquestionably a great outcome, it can be a source of moral distress for caregivers. No health care professional takes withdrawal of care (or the withholding of resuscitation) lightly, even when the circumstances suggest that doing so is the correct course of action. Adding to that emotional burden is the knowledge that, no matter how bad things seemed, every now and again, there will be that one child who beats the odds and may well come back with "You wanted to turn me off."

But that babies were born with a label: "Keep," or "Return to sender." Unfortunately, they are not. Here, on the edge of viability evidence takes over and we must rely on that data and our experience as clinicians to try and suss out which babies are viable and which are not. I believe that all life deserves a chance. When life-sustaining interventions are started; however, there is great reluctance to stopping them once a baby demonstrates their inability to survive in an extra-uterine environment. At this point, the question must be asked: are we helping, or harming?

The debate over who should make decisions regarding end of life care has raged for as long as life support has been available to clinicians. In Western healthcare, these decisions predominantly fall on the parents. Some ethicists do not favour this approach. While deference to parents should always be maintained, placing the burden of making the decision to end their baby's life is, I believe, inherently unfair. Parents do not have the knowledge or experience of the NICU team, and there is the possibility that parents will carry a burden of guilt over that decision. (1) In addition, parents typically do not fully understand what "I want everything done" means, and will hold on to the faintest glimmer of hope in the face of overwhelmingly poor odds, as is human nature.

Medicine has a history of throwing treatments and therapies at patients whose prognoses are hopeless to demonstrate to families that everything has been done. I believe the sentiment behind this is, although honourable, ought to be examined. We are loath to assign a cost to human life; however, when treatments are futile and expensive, clinicians must account for costs associated therewith and be transparent with loved ones. Be it for insurance

providers or, as is the case in most of the first world, the cost to the public purse, I believe it is counterproductive to spend scarce healthcare dollars in a futile attempt to sustain a life which cannot be sustained.

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Let us consider the use of nitric oxide (iNO) as an example. Despite the National Institute of Health (NIH) consensus opposing this treatment for premature infants, this treatment continues to be utilized and, in some cases, has escalated in frequency. Is it responsible to spend money on a treatment for which there is no evidence to support its use? iNO does not improve outcomes in very premature infants, and to date, researchers have failed to replicate Dr. Roberta Ballard's results. (2,3) Indeed, at the NIH consensus conference on the use of iNO in prematurity, researchers were urged not to study iNO unless attempting to replicate Dr. Ballard's research. Data indicates the practice is widespread in NICU's in the U.S. (and I suspect, although lacking hard evidence, Canada) evidence to the contrary notwithstanding. Reference 3 suggests a small segment of these infants may benefit from iNO, but that widespread use is not indicated.

The decision to resuscitate is, of course, made at birth. Until the baby hits the admission bed, the team has only obstetrical information on which to base decisions. Parents are offered resuscitation on an extremely premature infant based on gestation age and any gestational complications but are they truly aware of the expected outcomes?

When I started my career in the NICU thirty years ago, resuscitation was recommended at 25 weeks gestation (GA), discouraged at 24 weeks, and not offered at 23 weeks. Where resuscitation was offered, parental wishes to the contrary were always respected. Keep in mind this was before antenatal steroids were routinely given, and ventilator technology was very basic and offered only one mode: intermittent mandatory ventilation (IMV). Not surprisingly, chronic lung disease (CLD) rates were astronomical.

Thirty years later, technology has advanced significantly. We now have sophisticated ventilators that offer multiple modes and are capable of providing more lung-protective ventilation than those of old, provided they are used correctly. As the technology available improved, we began to push the limits of viability. Now the resuscitation of 23-week GA babies is offered routinely, and many units are resuscitating babies at 22 weeks GA. This trend may be based on evidence that indicates that while the mortality rate increases as gestational age decreases, especially below 25 weeks, outcomes between 23-25 weeks are similar. Other data,

however, show a statistically significant increase in major neurodevelopmental disability with each declining week of GA.⁴ More worrisome is that as few as 4% of infants survive at 22 weeks GA, and at 22-23 weeks GA less than half survive. Of those, 66% will have more than one major disability. Of course, there is considerable variance in outcomes between NICU's.⁵ Typically, those that treat more micro-prems have better outcomes than those who do not, although that is not a guarantee. Compounding this is the fact that those unfortunate infants born in a centre without a level 3 NICU are not only less likely to survive, but also more likely to suffer major morbidities.⁶ This reality bodes poorly for these infants since the costs associated with disabilities are very high.

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In Canada, what little support available for special needs children ends at 25 years of age, at which time long-term financial support is directed primarily to the patient rather than the family. This support is well below the poverty line. In the U.S. available support for these children hinges on a myriad of factors, predominantly financial. Lack of funding for follow up care is a travesty, since children with developmental problems can only be helped if they are diagnosed, and the earlier remedial treatment is started, the better the results.

In addition to the obvious concerns associated with the long-term financial burden, other factors pose significant concerns. All parents and all families are not created equal. There are those who can take on the enormous task of caring for a profoundly disabled child and find joy in that task, and those that simply cannot. Emotional and psycho-social factors must be considered, as well as the impact on siblings if there are any. We have all seen families disintegrate under the pressure of caring for a completely dependent child, and as is the predominant nature of our society, the mother is most often left to pick up the pieces. We must be careful not to judge, but rather respect parental ability or inability to cope with their reality

Looking back to the days when resuscitation was not offered to infants under 24 weeks GA, one must consider the reasons for this, and how much has changed since then. The lack of antenatal steroids made the ventilatory management of these infants extremely difficult, and CLD rates were already high in those of significantly greater GA. Surfactant was just coming onto the scene, and ventilator functionality was limited. We have always known that premature infants not delivered in a perinatal centre do not do as well as those that are. This concept is especially true as GA decreases. (My personal experience with 23-week GA infants transferred in from peripheral hospitals reflects this.) Exacerbating this is that not having time to transfer in utero often means not having sufficient time for antenatal steroids to take effect if they are given at all.

A 23-week GA infant of a mother who did not receive antenatal steroids is substantively different from one whose mother has. For this reason, it calls into question, should micro-preemies born at

peripheral centres be offered resuscitation at all and are parents given the information they need to appreciate and understand the likely outcomes for a micro-prem to make an informed decision? I submit the current approach to the management of expectant micro-prems at peripheral centres is sub-optimal, and that the outcomes thereof could be improved with a radically different approach.

Finally, we must be pragmatic. Physiology is physiology. There is the issue of endotracheal tube (ETT) size. Ventilatory management of a baby with a 2.0 ETT in situ is impractical, to say the least. Airway resistance increases exponentially as size decreases, making high-frequency jet ventilation the mode of choice for tiny patients in my opinion. Additionally, the tiny lumen of a suction catheter small enough to insert in a 2.0 ETT makes effective suctioning nigh to impossible. Declining survival rates as GA decreases allude to a GA limit on viability. There are many who say we have already reached this at 22 weeks GA. Of course, back in the day, many said the same thing about 25 weeks GA, and before that 28 weeks GA, and so on. Be that as it may, the lack of pulmonary and gastrointestinal development, the size of the airways, oropharynx, tiny veins (peripheral and umbilical) and the limited capability of current technology conspire to thwart whatever motions we make to keep these babies alive.

References:

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