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End of life decisions for newborns: an ethical and compassionate process?

Brian S Carter

In their report on neonatal death from Canada, Hellmann and colleagues indicated a propensity for neonatologists to employ a consensus deriving process that engages both families and the neonatal intensive care unit (NICU) interdisciplinary team. This is certainly in alignment with the process of shared decision-making, a strategy espoused by the American Academy of Pediatrics, the Nuffield Council and others. To their credit, the authors excluded stillbirths and infants <500 g and/or <23 completed weeks of gestation, but included infants admitted to the NICU, who may have died elsewhere in the hospital or at home receiving palliative care.

Within Hellmann et al’s report, three things stand out.

First, certainty in a poor prognosis was reported to be from moderate to absolute by 88% of physicians. Clinicians may occasionally be confronted by colleagues, staff members or families who ask, ‘How certain are you?’ The degree of certainty need not be absolute in order to make recommendations for implementing, or withdrawing, care. There is an often missed, or misread, notion of certainty that characterises physicians in the intensive care unit. We expect of ourselves relative certainty—as best discernible by available evidence—in a scientific sense as we go about diagnosing and treating critically ill newborns. Yet, our practice involves a practical application of knowledge coloured by our best understanding of evidence and outcome expectations based on our experiences and those shared by others. Can we prognosticate with certainty? No, not absolutely, but our Canadian colleagues may be more accepting of this reality than what is practised by our Canadian colleagues may be more accepting of this reality than what is practised in the USA.

Second, despite this reported acceptance of certainty, there remained a marked variation across centres around offering withdrawal of life-supporting medical technology (LSMT) for severely impaired preterm and term infants with widely different neurological injury. Perhaps variability should be expected as it is not uncommon in reports from large research collaborative. Recent evidence from the USA speaks of a similar variability across 24 different hospitals within the National Institute of Child Health and Human Development Neonatal Research Network, but the factors that contribute to the extent of variability require further inquiry. Is it institutional policy, fear of litigation, personal beliefs or something else?

Third, the quality of life motive was quite prevalent and apparently agreed upon by parents who, we are told, agreed to the withdrawal of LSMT ‘with relative ease’—and similarly agreed upon by the NICU team. How might these conversations go? When and where did they occur? How were issues framed? Was withdrawing or withdrawing (WHWD) LSMT described as the ‘default’ action or presented as ‘this is what we do in these situations?’ These things matter.4

A fair portion of the reported deaths occurred in the delivery room (129/942 or 14%) for which there was no obvious record of discussions about WHWD-LSMT—though they very well may have occurred. It may be presumed that these were extremely premature, borderline viability cases or severely malformed or impaired more mature newborns for which resuscitation may have been attempted, but failed.

The NICU is an environment full of clinicians poised to be welcoming and life-affirming for humanity’s most vulnerable newly born members. On any given day, however, clinicians in the NICU hold in tension the reality of fragile lives dependent on LSMT with attendant hope and the concomitant risk of death. Indeed, the greatest rate of human mortality plays out in the first 1–28 days of postnatal life. How do clinicians respond to the needs of babies and families confronted with life—and death—in such proximity? Is it by the directive counselling of parents to accept the limits of neonatal intensive care technology and cease otherwise appropriately applied and well-intended interventions that can no longer accomplish what they were employed to do? Or assisting them in redirecting the goals of care away from unattainable cure with its burdensome and non-beneficial interventions and towards comfort and a preparation for the impending death of their loved one? Does such direction or assistance seem too paternalistic?

Faced with rising certainty of either death before NICU discharge or severe neurodevelopmental impairments, physicians and other caregivers often provide counsel to families about limiting any escalation of support, withholding certain interventions or withdrawing others. When does a treatment no longer serve its original intent to accomplish its goal of attaining physiological stability and facilitating transition to a stable life? When is an originally intended treatment solely an intervention—one that holds no further promise of benefit, but merely holds off death? And how can we communicate these realities to parents?

Hellmann et al appealed to the sense of both families and clinicians in being able to assess a baby’s quality of life. How can one do this well? How can the words ‘pain and suffering’ or ‘survival with a poor quality of life’ be said and heard to mean the same thing amid a multicultural and morally pluralistic populace? Certainly, the ability to envision a newborn’s course through and beyond the NICU is not even something that neonatologists can claim to do with great confidence. Each child is different; his response to treatments unique; her recovery from surgery similarly unique and yet collective resiliency of the very young and those most critically ill remains surprising to this writer after 30 years of practice. Population statistics and outcomes data do inform our experiences and language as we care for critically ill newborns and speak with families. We do well to generate these data, know them and use them. Yet, they fall short of answering imploring parents’ questions of ‘What should we do?’

In response to uncertainties in prognosis, pluralities of values and a diversity of faith and other contexts that shape decision-making for and with patients and families, non-directional counselling by healthcare professionals of many disciplines has been the norm, but in some situations, counsel may need to be more forthright. Professional responsibility speaks of the clinician’s obligation towards truth-telling; the employment of technology requires a moral assessment of applicability and benefit; and avoiding difficult conversations is a practice of ethical evasion. Truly directional counselling may benefit patients and families who are encumbered by any number of...
cognitive, emotional–psychological or social–cultural factors that contribute to protracted emotional recovery given a loved one’s illness, decisional paralysis or frankly maladaptive coping.5

Responses to crisis vary across parents and families. Some require greater support. All require empathic communication. Perhaps this was accomplished in Hellman’s study. How might we similarly move forward when things seem to be ‘stuck’ and all involved simply maintain the status quo—more technology, more medication, more time? Phrases to consider might include:

We have reached the limit of what medical science and technology can provide to help cure your son/daughter.

The extent of injury from [extreme prematurity; hypoxic-ischemic encephalopathy] is beyond what we can overcome in modern neonatology.

We have all tried everything that could benefit your son/daughter and at this point s/he is experiencing more harm [burden; adverse effects] than benefit and as responsible professionals we need to stop.

You may have read about [ECMO or other technology; medication; CPR] for similar cases, and we have considered it, but it is not going to help your son/daughter.

While we may limit certain technologies and interventions, we will always ensure your son/daughter is comfortable and provide opportunities for you to create lasting memories.

Death will not leave the NICU, and clinicians need to have a manner of addressing it, coping with it and helping their patients and families through these most difficult times. Learning from other disciplines and colleagues around the world is a good start.

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