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EDITORIAL

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More than medication: perinatal palliative care

In this edition, Garbi et al. (1) present a case for what they refer to as 'Delivery Room Hospice' by reporting an illustrative periviable 23-week-gestation infant whose mother reports angst in watching her struggle to breathe. The authors suggest a tension between the infant's 'rights' and the authors' perceived limits of parental authority. They ask whether ethical constructs of personhood can be ascribed to the newborn, and legal protection be conferred, that might supersede maternal decisional authority. They propose delivery room hospice as a solution.

What to do for 'foetal neonates' is a decades-old question (2–5). Do periviable newborns – born at an age at which mothers might yet legally have an abortion – have rights to which others have compelling duties to respond? If so when, and how, and perhaps even, why? What motivates physicians towards interventions to treat or providing only comfort care? These are moral questions, informed by empirical facts, but their address varies across disciplines and jurisdictions. In Japan, the Eugenic Protection Act mandates resuscitation for all newborns at or beyond 22 weeks of gestation (6). Hence, the data are provided in Tables 1 and 2 (1). But is this mandate for care good for the baby or simply a relief from anxiety for the doctor (5)? Garbi et al. (1) yearn for more explicit guidance for action, seeing the New York State Perinatal Health Code as too 'porous' and the American Academy of Pediatrics resuscitation guidance as 'not operationally pragmatic'.

It appears to this author that the clinical judgement of the neonatologist – to guide resuscitation dialogue and provide for resuscitation and a trial of therapy in the NICU, or to provide supportive palliative (comfort) care – can be, and historically has been, honoured by parents, clinician colleagues and outsiders. What, precisely, comprises supportive perinatal palliative and comfort care, however, is much more than the simplistic proposal of opioids in the delivery room.

Perinatal palliative care requires attention to the uniqueness of the pregnancy and childbirth experience among human activities. Maternal attachment to the unborn foetus recognises a new and different relationship – one acknowledging the foetus as *other than self*, and being both distinct from the mother and unique among other pregnancies past or future. Such recognition and relationship likely contributes to maternal–foetal (and anticipated maternal–infant) attachment as well as to the value ascribed by mothers to their pregnancy. This may also be a factor in how, when and why mothers may decide – or even change their minds – about plans for care at birth and afterwards for their foetus/newborn (7,8). Mothers attach to periviable preemies carefully and cautiously, and fear loss even as they may in pregnancies complicated by foetal anomalies (9).



Lessons learned by this author over the past 30 years include that parents need to hear the full spectrum of possibilities, and providers need to be prepared (have a plan). Failure to address all possibilities (and dwell only on an anticipated early demise) can lead to parental frustration, confusion, anger and even moral angst or guilt. We can teach and model for parents how to 'expect the unexpected' and adapt to 'a new normal' only when the breadth of possibilities is presented. This advance care planning in the neonatal–perinatal context is very fluid.

Palliative care has many domains that, if attended to from the point of discovering a life-limiting condition forward, may allow for supportive transitions towards death without fear, isolation or sense of abandonment (10). A mother anticipating an extremely preterm delivery requires support that entails a respectful provision of information and an ascertainment of her hopes, values and notion of the 'good' to be pursued that is culturally and spiritually nuanced, and acceptable within the breadth of societal norms. Deference to parental wishes is prudent, not simply out of respect to autonomy (what they wish for themselves), or even parental authority (what they wish for their children), but truly out of respect to them as individuals with free moral agency. Their choices may result in a trial of therapy that reflects hopefulness of benefit while balancing the potential(s) of harm – those due to the fragility of their extremely preterm infant and also those which may be iatrogenic, coming as a consequence of well-intended efforts to save and support the infant's life.

Attention to the many domains of palliative care will ensure adequate psychosocial support for the expectant family of a periviable newborn. Such planning may include developing a birth plan – even for pregnancies that are anticipated to result in premature death – that addresses both maternal and neonatal matters. When a mother is admitted for labour and delivery, what monitoring (if any) will be done? How will the delivery be accomplished (spontaneous, induced, operative), and with what type of anaesthesia? These matters should be addressed openly – especially if they limit the mother's consciousness during a

time when bonding will be important or even brief (especially in a comfort care paradigm). Will delivery be in a community hospital or tertiary centre? What management of mother might be considered burdensome and what might be seen as beneficial will depend upon maternal (and family) values. Who will be in attendance may reflect 'who' matters and what they bring with them (skills, support or perceived psychological stress). After delivery, the mother's care would ideally include nurses and social workers trained in perinatal loss and bereavement, clergy, and a paediatrician, neonatologist or palliative care clinician who can explain the dying process, provide support and guide the mother (and father) through changes that precede death.

For the newborn, specified components of resuscitation and care should be discussed and agreed upon: will there be intubation, nasal continuous positive airway pressure (CPAP) or nasal cannula oxygen? Symptoms can be managed, and often a bulb suction device, warmth, human touch, and at times medication provided in a noninvasive manner (e.g. intranasal midazolam or fentanyl, or buccal/sublingual oral morphine solution) and a private setting is all that is needed. With foresight and planning, the imminently dying infant can be attended to with grace and ease, and he will be comfortable, valued and cherished; his family will be supported; and his siblings may know him, and his community remember him, facilitating a healthy bereavement. Where the baby is cared for and by whom should be part of a birth plan. Will a palliative care consultant make referral to a community hospice (with experience)? How the baby will be fed or hydrated can be a contentious issue, but need not be if caregivers are open to and respectful of family perspectives, cultural norms and even religious dictums. Feedings may prove difficult. Their goals should be discussed – to fulfil parental obligations, be supportive and nurturing even when they will not have 'normal' volumes directed at long-term growth and development. Parents can be taught to breastfeed and give expressed breast milk in a bottle, oral-gastric or nasogastric tube, by cup, eyedropper or even simply a finger or pacifier dipped in milk.

Neonatal palliative care must also attend to meaningful family events, rituals or spiritual care for the baby, however frail, within the family and faith community. NICU staff may assist by providing positive memories, mementoes,

rituals and photography. Finally, as many newborns will survive birth and initial transitions, caregivers for the newborn need to have a contingency plan for discharge to home or hospice, or even a general paediatric inpatient unit room with palliative care, hospice or home-health support. Neonatal-perinatal palliative care-givers must partner with the patient/family and even the professional staff. The process of support is as important as the final product: a respectful and comfortable death among caring family – no matter how brief the life. The story that families are left to tell, complete with memories and messages, is their own to write. What an honour if we should be privileged to join them in that narrative. But far be it from us to presume to write it for them.

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