

# Ethical Decision Making: The “Age of Viability” Debate

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## Abstract

In the last few decades, medical advancements in the field of neonatology has sparked heavy ethical debate concerning the resuscitation of low gestational age (GA) infants. As medical treatments, such as respiratory support has improved the “age of viability” for neonates has shifted towards a younger GA. In general, fetal viability refers to the GA at which critical organs such as the lungs are developed enough to sustain life. Consequently, GA is arguably the primary guiding factor for resuscitation efforts in neonatal patients. However, based on this notion many health care facilities have developed rigid rules and guidelines based predominantly on GA and neglect other important outcome indicators including fetal birth weight, antenatal corticosteroids, and congenital anomalies. This poses problems such as overtreating microprems and raises ethical concerns including autonomy, beneficence, nonmaleficence, and justice. This paper argues that strict resuscitation guidelines may hinder the ability to make unbiased decisions. Subsequently, infants born at the margins of viability should be assessed individually allowing patient-specific care plans to be developed.

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The delivery of extremely low gestational age newborns presents challenging ethical issues for health care providers (HCPs) and parents. Although there is no universal agreement on approach and management, there seems to be an overall understanding that a “grey zone” exists when addressing medical care of premature infants (1). This “grey zone” primarily focuses on patient gestational age (GA), and with advancements in neonatal care, there has been a shift in this “grey zone” towards an earlier GA (1). For example, under a decade ago, the “age of viability” in Canada was defined as birth at 24 – 25 weeks gestation which was swiftly shifted to 23 - 25 weeks GA (2). Furthermore, in recent years, the survival of infants born at 22 weeks has been increasingly reported which has challenged this “grey zone” age criteria even more so and encouraged more aggressive treatments in microprems (3). However, extremely premature newborns often have severe long-term challenges such as cerebral palsy, cognitive impairments, and

vision or hearing impairments (4). Consequently, there has been ongoing debate about when a premature infant should be resuscitated and when efforts are futile. This raises the question of whether patient families and HCPs are overtreating premature newborns who meet the “age of viability” without considering other confounding factors. This paper will take the stance that GA should be used as one of the guiding principles for resuscitating newborns but there should be considerations of other factors including: estimated fetal weight, administration of antenatal corticosteroids, singleton versus multiple pregnancy, fetal status and anomalies (noted on fetal diagnostic imaging), and family dynamics. Prolonged and unnecessary treatments can be minimized by employing flexible guidelines and individually assessing neonates.

Many countries have used GA as the primary and sometimes sole guideline for neonatal resuscitations as it is arguably the best predictor for fetal stage development (3).

However, a large concern with focusing on GA as a predictor of survivability is reliability of GA estimates (4). GA assessments are typically made using two methods: the mother's reported last menstrual period or ultrasonography (5). The estimation via menstrual cycle has a deviation of up to 14 days while the ultrasonography, which is considered best practice, still has a high variability rate of  $\pm 7$ -10 days (6). This margin of error can alter the distinction between a fetus who is greater than the "age of viability," one who is within the "grey zone," and a fetus who is <22 weeks GA which has been advised as "non-viable" universally (7). From personal experience, during an emergency case involving a 24 week and 0 days old neonate, GA discrepancies play a large role in treatment planning and heavily influences the course of treatment offered to parents. After the delivery and initial resuscitation there was significant doubt and questioning about the infant's prematurity. It was soon discovered that the parents had lied about the patient's GA as they were concerned that the patient would not receive optimal health care. As a result, this patient had a long-term stay in the neonatal intensive care unit, enduring multiple surgeries and interventions, and at 5 months of age passed away. Although, patient outcomes were discussed with the family, the discussion was tailored towards the prognosis of a 24-week-old newborn as opposed to the true GA of ~ 22 weeks. Likely, some of the options offered to this family would not have been discussed if the patient's whole clinical picture was considered as antenatal drug abuse and extreme low birth weight were also present in this case. Subsequently, GA should be used with caution and never as a sole predictor in treatment success (6).

Moreover, following the recommended "viable" GA for survivability poses an alternative path for overtreating patients. HCPs and patients' families can often become hyper-focused on the patient being of adequate GA and lose sight of the overall status of the fetus (6). Factors such as birth weight, administration of antenatal corticosteroids to promote fetal lung maturity, and congenital anomalies can be overshadowed (7). For example, GA is often considered over birth weight although birth weight is arguably just as strong if not a stronger predictor of patient outcomes because it is not as variable as GA (8). The disregard of the whole clinical picture of the patient often leads to aggressive treatment which may not be the best care option for the patient. This is evident in the British news article "The Guardian" in which Alexia Pearce, a young mother, recounts of her experience during the delivery of 23-week-old son, Nathan(9new). She describes the guilt she feels for

choosing to resuscitate her premature son and states that "if I'd known then what I know now about what extremely premature babies have to go through, I would not have chosen that for my little boy." In the article she describes the multiple interventions and treatments Nathan had to endure during his prolonged hospital stay, including 22 blood transfusions in the first 3 weeks of his life. Although Nathan was in the "grey zone" of GA he had multiple risk factors that contributed to his prognosis and perhaps if this was discussed with the Pearce and his full clinical picture was considered, they would have made a different choice. Another important ethical issue highlighted in this article is the issue of surviving versus living. Although survival has improved for preterm babies, the neurologic and developmental sequelae they experience have not (3). Some argue that microprem survivors may have such diminished quality of life that death would have been a reasonable alternative (6). This is reflected in the same news article mentioned previously; Pearce states, "He can't walk or talk. He's oxygen dependent, although hopefully that might change. He has chronic lung disease, cerebral palsy and global developmental delay. He has diabetes insipidus..." However, it is important to note that quality of life is subjective, but all possible outcomes should be made aware to families in a realistic manner to help them determine the best course of action for the newborn.

Lastly, this paper wants to touch on the point that decisions regarding resuscitations/medical treatment for premature infants are heavy topics and they should be re-visited frequently. Often, conversations with the medical team and family about treatment options occur ahead of time and while under pressure. As a result, many parents report feelings of regret for choosing to resuscitate their newborn and the feeling of being unable to change their decision once it was made. For example, Pearce states, "...but by then it's too late to go back. You can't just say 'Switch off the machines and give him to me, let him go, stop this'... You're damned if you do and damned if you don't." She also states that she feels as if she just prolonged the inevitable. Pearce alluded to overtreatment after the initial resuscitation which seems to be a common occurrence in health care but particularly in the neonatal population (1). HCPs and patient families are often hesitant to withdraw care once it has been initiated, which can prolong unnecessary treatments (1). Perhaps at a different time and under changing circumstances, previous goal of care no longer aligns with what is best for the patient and the family. Therefore, it is vital that

HCPs reinforces the idea of re-visiting care goals and that withdrawing care is sometimes what is best for the patient.

The overtreatment of premature newborns secondary to strict GA guidelines arguably compromises all four of the basic principles of biomedical ethics: autonomy, beneficence, nonmaleficence, and justice (6). Parents are generally considered to have authority to make treatment decisions based on their perceptions of their child's best interests since newborns are unable to exercise their right of autonomy (6). However, whether the parents act in the child's best interest is highly debatable. Beneficence and nonmaleficence can also be compromised as HCPs can be inadvertently harming the patient instead of treating them, for instance, the physical strain of numerous blood tests, scans, and interventions inflicted on these newborns. Additionally, determination of benefits and burdens of a treatment should include the chance of survival, pain of resuscitation/interventions, and benefits or burdens that continued living with potential disability may bring, which is a weak area of discussion in neonatal medicine (6). Lastly there is a heavy debate on the allocation of resources – medical equipment/supplies as well as hospital beds for patients with such poor prognosis such as premature infants raises many questions and concerns in an already strained healthcare system (6).

There are a host of ethical issues when discussing resuscitation of premature infants, however, one that is often not considered is whether the strict guidelines and reference standards created by HCPs to help focus medical treatment are contributing to these issues. Some physicians and ethicists still defend the use of strict guidelines as they believe there is high risk of death or serious disability underdeveloped infant and these guidelines lend to accurate and efficient patient assessments (3). However, this paper and others argue strict guidelines, particularly GA, is too difficult to pinpoint accurately and may hinder HCPs and families' ability to make unbiased decisions therein contributing to overtreatment of microprems. Although strict GA guidelines are discouraged, it is still a very important indicator of viability and should be used in conjunction with other prognostic factors. This was echoed by the Canadian Pediatric Society who released a revised position statement in 2017 proposing to use a prognosis-based approach in determining premature infant viability as opposed to a GA based guideline (3). This paper suggests utilizing flexible guidelines while focusing on individual assessments encompassing the patient's whole clinical picture including: GA, weight, antenatal corticosteroid, congenital anomalies, and parental preferences. This allows HCPs and families to provide the best care

for the neonate. Moreover, flexible guidelines help improve knowledge, consistency, and promote continued education as well as frequent family discussions.

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