Resuscitation of the preterm infant against parental wishes

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Over the past 40 years, the norms on who is to make treatment decisions for newborns, and on what standards, have been significantly altered and revised. Today the standard for treatment of newborns is the “best interest” of the child. A recent ruling of the Texas Supreme Court authorising a doctor to resuscitate a potentially viable very premature newborn over the parents’ objection is a challenge to that standard.

In a recent commentary in The New England Journal of Medicine, George Annas reviews a Texas Supreme court opinion, Miller v HCA, in which that court became the first to authorise a physician to resuscitate an extremely premature infant over parental objections. The case raises anew an issue that the EPICure study describes as among the most difficult and trying clinical problems for obstetricians and paediatricians—the care of the fetus considered to be at the threshold of viability. More specifically, it examines one of the unresolved questions in that area: who decides for the extremely premature newborn, and on what basis, when there is a conflict between parents and physicians?

Although over the past 40 years, the norms on who is to make these treatment decisions and on what standard have been significantly altered and revised, there is now a strong consensus in the medical and bioethics community that for extremely premature infants—where the risk of mortality or morbidity is significant and the prospects of benefit is suffused in ambiguity and uncertainty—the decision on whether or not to institute medical treatment properly belongs to the parents. Reflecting on that consensus, Jerold F Lucey, the Editor in Chief of Pediatrics, recently wrote, “We should admit how little we know, explain the present bleak outlook, and ask the parents what they are willing to accept. Some will choose active resuscitation, others will not.”

The widespread agreement in both North America and the United Kingdom with that approach has come under challenge with the Texas Supreme Court’s ruling in Miller v HCA.

THE CASE
The case arose when Kara Miller presented at Woman’s Hospital of Texas in premature labour. The ultrasound assessment was an estimated fetal weight of 629 g and a gestational age of 23 weeks. Tocolytics were administered to stop the labour, but were discontinued when it was learned that the mother had a life threatening pulmonary infection (HCA), the largest for-profit healthcare system in the United States. A jury found that the hospital, its parent corporation Columbia/HCA Healthcare Corporation (HCA), the largest for-profit healthcare system in the United States. A jury found that the hospital,
without the consent of the parents, had resuscitated their infant. It also found that negligent action was the cause of the
daughter’s injuries. The jury awarded the family $29 400 000 in
actual damages for medical expenses, $17 503 066 in pre-
judgment interest, and $13 500 000 in punitive damages. The
latter payment was designed as punishment for improper
behaviour of the hospital and a deterrent to others from
engaging in similar behaviour. The jury verdict was overturned
by the Texas Supreme Court.

TEXAS SUPREME COURT OPINION
The Texas Supreme Court posed the question raised in Miller
v HCA as follows: “This case requires us to determine the
respective roles that parents and health care providers play in
deciding whether to treat an infant who is born alive but in
distress and is so premature that despite advancements in
neonatal care, has a largely uncertain prognosis.” In arriving
at that question, the Court relied heavily on the testimony of
the neonatal fellow who had attended the delivery as to why
he had overridden the parents’ refusal of treatment. When
asked if he could predict where on the continuum from
stillborn to a normal child the Miller child would fall, the
neonatal fellow replied, “No.” He then continued, “This is a
baby that is not necessarily going to have problems later on.
There are babies that survive at this gestational age—with
this birth-weight—that go on and do well.”
Consent in cases involving infants has till now been the
prerogative of the parents. The state, acting as parents patriae,
can and does intervene to protect children from neglect and
abuse or to prevent parental choices that would produce such
results. But as long as parents choose from a professionally
accepted option, the choice is rarely challenged or super-
vended. The Texas Supreme Court acknowledged that parental
role, but in this instance the Court ruled that when a doctor is
confronted in a case where there are “emergent circum-
stances”—that is, where death of a child is likely to result
immediately unless treatment is administered—he/she can
intervene even over parental objections.

The Texas Court, citing the testimony of the neonatal
fellow, ruled that the infant “could only be properly
evaluated when she was born.” Consequently, in the
Court’s view, “Any decision by the Millers before [the
infant’s] birth would necessarily be based on speculation.”
Further, the Court opined that “As the Texas Supreme Court
saw it, the doctor present at the delivery had to make “a split
second decision on whether to provide life-sustaining
therapy.” In that situation, it held, “there simply was no
time to obtain [the parents’] consent to treatment or to
institute legal proceedings to challenge their withholding of
consent without jeopardizing [the infant’s] life.”

DISCUSSION
This is a ruling of enormously sweeping scope, albeit in a
narrowly circumscribed situation. It applies, as the Court
would have it, only to children and “only when there is no
time to consult the parents, or seek court intervention if the
parents withhold consent before death is likely to result.” In
reaching that conclusion, the Texas Supreme Court rejected
the policies of the American Academy of Pediatrics and the
“Good Medical Practice” guidelines of the Royal College of
Paediatricians and Child Health (RCPCH) of counselling
parents on the survival and outcome prospects of strikingly
premature deliveries and involving them in decisions for their
infants. And although Lord Donaldson in In Re R’ high-
lighted the doctor’s duty to treat in an emergency without
consent if in the doctor’s judgment such a treatment would
be in the best interests of the child, in the case of a baby with
only a small chance of survival and even then with a high risk of
handicap, it would not be unreasonable under the standards
of the RCPCH’s Framework of practice sections on “No purpose” or the “Unbearable situation” not to initiate resuscitation.10

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A helpful framework for decision making in these types of cases is found in an essay by Tyson and colleagues11 on viability and morbidity of very low birthweight neonates. Rather than an either/or designation of parent or doctor as the decision maker, the authors propose that the treatment options should be governed by the prospects for the individual infant. To make that assessment, the authors divide treatment decisions for newborns into four categories: mandatory, optional, investigational, and unreasonable. They are explained as follows.

- Mandatory: if the parents ask the physician to withhold or withdraw ventilatory support that has a very high likelihood of benefiting a child, the treating physician’s independent obligation to foster the best interests of the patient prohibits following the parents’ request. An example would be parents who ask the physician to remove ventilation from a full term newborn unless the physician can guarantee that their child will be “normal.”12
- Optional: when the risks are very high and the benefits are at best uncertain or extremely low, the parents have the option of accepting or rejecting the proposed resuscitation. In this “grey zone” the parents’ decision to either accept or reject ventilatory support should be followed.13
- Investigational: for resuscitation for babies of very low birth weight, the outcome data are such that, in the words of Lantos et al, “The best we can tell parents is that this intervention is so new or its effects on this class of patients so unproven that it is an ‘innovative’ or ‘experimental’ procedure.”14 Such procedures, as the Nuremberg standards inform us, necessarily require patient or proxy consent.
- Unreasonable: if the parents are demanding attempts at resuscitation, when in the physician’s best judgment there is no expectation of efficacy—for example, on a child born with Potter’s syndrome or a 20 week, 298 g delivery, there is no obligation to attempt resuscitation. Indeed to attempt resuscitation or other medical treatment when there is no possibility of benefit to the patient would constitute an assault or battery.15

A newborn’s prospects vary from the complete uncertainty of a “normal” future for a full term baby experiencing a post-delivery respiratory episode, to the very high probability of mortality and significant morbidity awaiting a 23 week 614 g infant. The EPICure study, for example, reports a survival rate to discharge at 23 weeks—the age of the Miller child—of 11%. The most recent outcome data on extremely premature
infants, the 2004 Vermont/Oxford Network study of 4172 infants born with very low birth weights, notes an increase in the percentage of survivors (17%), but in the words of the authors, the results are “not encouraging.” The vast majority (83%) died before discharge, and over half of those (52%) did so in the delivery room. Those who did survive almost always suffered from severe complications. As the effectiveness of neonatal intensive care technology for this class of newborns is “essentially unknown,” the authors conclude that treatment of those infants is “a large, uncontrolled experiment.”

Contrary to the ruling of the Texas Supreme Court, ventilation is not necessarily justified simply because it offers a modest chance of survival. As Francis Moore, the distinguished Harvard surgeon, reminds us, imposing a medical procedure on a patient requires a greater justification than mere survival. In his words, “There must be a rationale on which the desperately ill patient may be offered not merely pain, suffering and cost, but also true hope of prolonged survival [without devastating sequelae].”

Although clearly premature infants will die without mechanical ventilation, the decision whether or not to initiate resuscitation ought not be based solely on a doctor’s assessment of potential viability. Survivability is not the only issue at stake. Although death is unquestionably a bad outcome, imposing mechanical ventilation can make for a worse situation—demise after days or months of predictable morbidity so severe it might be judged an even greater tragedy than death.

To avoid that possibility, resuscitation decisions for extremely premature neonates should be based on the prospects for a particular child. To achieve that goal, as the EPICure study group put it, professionals must provide parents with “reliable outcome data based on gestational age that will allow the parents to plan care around the time of birth.” Evaluating the significance of those data in an individual case and determining whether or not the risks and benefits warrant the use of aggressive technology is a value judgment, not a medical assessment. As such, it properly belongs to those who, along with the infant, will bear the burden of a decision to resuscitate: the parents.

CONCLUSION

The Miller case confirms the adage that “bad facts make bad law.” The mis-statement of institutional policy by a hospital administrator led the medical staff to abandon the well thought through parent-physician decision to omit resuscitation of an infant at the very margins of viability, a decision that was well within the standard of care. The determination to resuscitate was based on the mistaken belief that the law required the resuscitation of any infant with a delivery weight >500 g. The record does not indicate why once the child was resuscitated and subsequently suffered significant neurological insult that the use of aggressive medical interventions was not re-evaluated and discontinued.

The only issue raised in the case and addressed by the Texas Supreme Court was whose decision is it to determine whether or not to omit resuscitation for an extremely premature infant. In the Court’s view, that role belongs exclusively to the physician. The Court did not mandate that physicians resuscitate all potentially viable newborns. It did, however, authorise physicians to decide whether or not to resuscitate in these cases when the outcome is “essentially uncertain and when failure to resuscitate would result in the infant’s death.” In such instances, the physician may resuscitate the extremely preterm infant even over parental objections.

In the United Kingdom when there is disagreement between the medical staff and the parents the opinion of a court has been sought, such as in the recent cases of Charlotte Wyatt and Luke Winston-Jones, judges have normally ruled in favour of the medical viewpoint, and have applied the RCPCH framework for practice as in the “no chance situation” applied with Baby C with spinal muscular atrophy type 1. Only rarely has the sincerely held view of caring parents won the ruling against unanimous medical opinion. However, in the Miller case it appears as though the disagreement was less with the parents than between members of the medical and nursing staff involved. And although it might have been reasonable for the neonatal fellow in the obstetrical suite to have opted to resuscitate on the basis of a post-delivery assessment of potential viability, there appears to have been no attempt to reassess the clinical situation and the likely outcome after birth, particularly when a major intraventricular haemorrhage had been identified.

The danger with the Texas Supreme Court’s ruling in Miller v HCA is that, under it, a physician who wants to resuscitate a neonate may do so no matter how premature, how unlikely to survive, how likely to incur severe disabilities, or how strongly the parents object. This substitution of the physician’s values for those of the parents of infants delivered at the extreme margins of viability is a significant shift from present standards in neonatology. We believe such a change is neither good policy nor good medicine.


REFERENCES

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