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Ethics and Medico-legal implications in delivery room emergencies

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A B S T R A C T

There is very little law-either case law or statutory law - that regulates delivery room decisions about resuscitation of critically ill newborns. Most of the case law that exists is decades old. Thus, physicians cannot look to the law for much guidance about what is permissible or prohibited. Local hospital policies and professional society statements provide some guidance, but they cannot be all-inclusive and encompass all potentially encountered scenarios. Ultimately, the physician, the medical team, and the parents must try to reach a shared decision about the best course of action for each individual infant and each unique family. In this paper, we review some of the case law that may be applicable to such decisions and make recommendations about how decisions should be made.

Imagine for a moment you are a neonatologist taking overnight, in-house call at your community delivery hospital. You are paged urgently at 0200. A woman has presented at 22 and 5/7 weeks gestation, fully dilated, with a bulging bag of water. The mother was late in seeking prenatal care and is uncertain about her dates. She speaks only Spanish. You do not speak Spanish. One of the labor and delivery nurses, whose Spanish is clearly rudimentary, is trying to translate. The certified interpreter has been called but has not yet responded.

The woman is writhing in pain.

You and the obstetricians have to make some quick decisions. Clearly, this is not an ideal circumstance for her to make an informed decision regarding her wishes in the resuscitation of her "soon to be delivered" extremely premature baby.

What do you, as the neonatologist, do once the baby is born? Do you initiate intensive resuscitative efforts? Provide comfort measures only? If you choose to resuscitate, how far do you go? Chest compressions? Epinephrine? What if you decide upon comfort care, and you tell that to the patient as best you can, and she gives what seems like tentative approval, and then the infant appears more mature than 22 weeks? If you go against parental wishes, could there be legal ramifications?

While delivery rooms are typically a venue for joyous celebrations of the miracle of life, they are, unfortunately, also a place where doctors face emergency situations and ethical dilemmas for which they must make immediate decisions. In this review, we will examine some of the most commonly encountered delivery room emergencies. These arise following deliveries at the limits of viability, when infants have significant congenital anomalies, and when there is a non-reassuring fetal heart rhythm and subsequent concern for hypoxic ischemic encephalopathy. We will review landmark legal cases and describe ethical principles that may assist in decision making.

1. The borderline of viability

Of the 3.86 million births in the United States in 2017, nearly 26,000 infants were born extremely premature (< 28 weeks gestation) [1], with a smaller subset between 22 and 24 weeks gestation-the "Gray Zone" of viability. The American Academy of Pediatrics (AAP), The American College of Obstetrics and Gynecology (ACOG) and other governing bodies agree that, to some extent, parental wishes should guide decisions regarding the extent of resuscitative efforts afforded to infants born within this uncertain periviable state [2]. [3]. Sometimes the medical team has the time and opportunity to adequately counsel parents so that they can make an informed decision as to what they feel is in the best interest of their child. At other times, imminent delivery, pain, extreme emotion, language/educational barriers, provider bias, and other factors may hinder ideal counseling. Sometimes the medical team and family may agree regarding how best to proceed at the time of delivery. Other times viewpoints may be in opposition. One of the most well-known legal cases surrounding resuscitation at the limits of viability is that of *Miller v. HCA*. [4].

In August of 1990, Sidney Miller was born at 23,1/7 weeks gestation, weighing 615 g. Sidney's mother, Karla, had presented in preterm labor to Woman's Hospital of Texas. After receiving counseling by the physician team, she and her husband, Mark, decided that they did not wish to pursue heroic measures for their daughter. Thereafter, the leadership of the hospital met, and decided that a hospital policy required resuscitation for any infant > 500 g. (It was later determined that such a policy did not exist.). By that policy, a neonatologist must be present at the time of delivery, assess the gestational age and weight, and decide whether or not to proceed with resuscitation. When informed of the hospital's policy and decision, Mark refused to sign a consent form and asked what could be done to prevent resuscitation

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attempts. The only choice given was for his ill wife to leave the hospital.

Approximately 11 h later, Sidney entered the world. She was cyanotic, limp, and bradycardic. She cried spontaneously in the delivery room. She received bag-mask-ventilation and was intubated. Apgar scores were 3 at 1 min and 6 at 10 min. The neonatal fellow stated that he decided to proceed with resuscitative efforts "because this baby is alive, and this is a baby that has a reasonable chance of living." Even though the parents had previously stated that they did not want resuscitation, they apparently did not object, in the delivery room or the NICU, to Sidney's treatment after birth. Early in Sidney's NICU course, she had a severe intracranial hemorrhage. This resulted in long-term sequela. By the time Sidney was seven years old, according to court records, she "could not walk, talk, feed herself, or sit up on her own. [She] was legally blind, suffered from mental retardation, cerebral palsy, seizures, and spastic quadriparesis in her limbs. She could not be toilet-trained and required a shunt in her brain to drain fluids that accumulate there and needed care 24 h a day. The evidence further demonstrated that her circumstances will not change." [4].

The Millers filed a lawsuit against Woman's Hospital of Texas and its parent cooperation Columbia/HC Healthcare Corporation (HCA) alleging battery and negligence in the resuscitation of their daughter. The couple did not name any individual physicians in the lawsuit. In the original trial, the jury sided with Millers, awarding a $60 million dollar verdict, which included $13,500,000 in punitive damages, designed to serve as a warning to other institutions should they proceed with similar actions. The verdict was appealed to the 14th District Texas Court of Appeals which overturned the lower court's verdict in a 2-1 decision.

The Court of Appeals based its reversal on their interpretation of the Texas Natural Death Act. By that interpretation, parents are only legally authorized to withhold medical treatment for a child if the child's condition has been determined to be "terminal." While a court order is generally required to override parental refusal of treatment, such an order was deemed unnecessary when a physician faced an urgent need for life-sustaining treatment of a child who was not terminally ill. This ruling was then appealed up to the Texas Supreme Court.

The Texas Supreme Court appropriately summarized what was being asked of them in *Miller v. HCA* by stating "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." [4].

Prognostic uncertainty is one of the fundamental issues impacting decision making for infants at the limits of viability. Nowadays, approximately 38% of infants born at 23 weeks gestation and admitted to a neonatal intensive care unit will survive and around 35% of survivor will have no significant neurologic impairment [5]. While population statistics provide clinicians with a starting point for prognostication, they provide much less assistance in determining if an individual infant will be one of the survivors. Factors such as birth weight, antenatal corticosteroid use, sex, and a singleton pregnancy can influence survivability and parental counseling, but these factors still provide little in the way of certainty for any individual infant [6]. Significant long-term morbidity and neurologic impairment is influenced substantially by complications endured during the neonatal course, (i.e the intracranial hemorrhage sustained by Sidney Miller), and this information will clearly be unavailable to the physician at the time of prenatal counseling. If a clinician could say with certainty that an individual infant will be survivor and a survivor without significant impairment, it would make it much easier to determine rather or not it is appropriate to override parental authority. All good ethics begins with good facts, and unfortunately at the limits of viability the facts remain murky.

Ultimately, the Texas Supreme Court upheld the 14th District Court's ruling and the $60 million verdict was negated. The Millers were awarded nothing. Citing a case from 1920, the court ruled that under emergent circumstances a physician may provide life sustaining treatment without obtaining parental consent. Further, they ruled that, in a case of extreme prematurity, a decision about resuscitation could not be made prior to birth. The ruling sparked controversy in the legal, medical and ethics communities alike. While this decision gives wide latitude to the physician under emergent circumstances and sets the precedent that the delivery of a periviable infant will always be an emergency, it has no impact on the role of parental authority in non-emergent circumstances. Should the Millers have requested to have life sustaining therapies discontinued following Sidney's intracranial hemorrhage, they would have maintained the parental authority to do so and the medical team likely would have been supportive of such a request. In essence, doctors in the delivery room are playing the odds. While it is impossible to know for certain, it seems likely that the Millers would not have pursued legal action if Sidney's neurological outcome had been better.

In a 2004 New England Journal of Medicine article, George Annas made the claim that even though Sidney Miller's birth took place back in 1990, "nothing has changed in the practice of neonatal medicine since then that would prevent repetition today." [7] Fifteen years later, this likely still holds true. Through the currently adopted shared decision-making model, when outcomes are uncertain (falling within the "gray zone") parental values should determine what decision is made [8]. By that approach, the Miller's decision should have been respected. Nevertheless, sometimes doctors override parents' requests. Babies in the same circumstances as Sidney Miller might still be resuscitated today. The Miller decision is one case decided by one state's judicial system. In a different case, courts might decide differently.

From a legal perspective, the most important thing would seem to be for a hospital to have a policy dictating its approach to these decisions and for each hospital to follow its own policy. That clearly leads to different approaches at different hospitals. Rysavy and colleagues recently showed that, for babies born at 22 weeks of gestation, some hospitals resuscitate all such babies, some resuscitate some, and some resuscitate none [9]. Remarkably, these variations in hospital practice have not led to litigation. Clearly, there is no hard and fast legal rule about resuscitation decisions at the borderline of viability.

2. Congenital anomalies

Approximately 3% of all infants born in the United States each year have a major structural or genetic birth defect [10]. Luckily, many of these anomalies (i.e. cleft lip, club foot) do not impact delivery room management or long term survival. Nonetheless, a smaller portion of birth difference can greatly influence initial neonatal management. Dilemmas arise particularly when the anomaly was unknown prenatally and there are multiple malformations. The presence of, or suspicion for, an underlying genetic syndrome may also influence decision making and parental counseling. The Baby Doe case and subsequent regulations have impacted decision making for infants with congenital anomalies and genetic syndromes.

In 1982 in Bloomington, Indiana an infant, "Baby Doe" was born with Down Syndrome and a tracheoesophageal fistula. The parents and the medical team decided it was in the infant's best interest not to proceed with surgical interventions and to withhold parenteral nutrition. The infant was prescribed morphine and phenobarbital for pain and restlessness [11]. The family physician and a local pediatrician disagreed with the plans and sought legal and adoption resources. An Indiana court deferred to the parental authority and ruled that the baby should be given comfort care only, in line with the parental wishes. The verdict was appealed to the Indiana Supreme Court. While awaiting a ruling, the infant died at six days of life. General C. Everett Koop was Surgeon General at the time and was outraged by the situation. He cited a nearly 100% success rate with tracheoesophageal fistula in his own experience at Children's Hospital of Philadelphia and felt the decision made to forgo treatment was made only on the basis of the diagnosis of Down Syndrome and was thus discriminatory [12].

While the Baby Doe case itself did not unfold in the delivery room,

the subsequent Baby Doe regulations issued by The Department of Health and Human Services (DHHS) had implications for delivery room management. Under these regulations, based on section 504 of the Rehabilitation Act of 1973, federal funding could be withheld from any organization not complying with the Baby Doe rules. DHHS initially mandated that posters be displayed in all delivery rooms, nurseries and maternity wards that stated, “Discriminatory failure to feed or care for handicapped infants in this facility is prohibited by federal law.” [13] A toll free number was included to report violations to the Infant Doe Hotline. Then Secretary Richard Schweiker stated, “The President has instructed me to make absolutely clear to health care providers in this nation that federal law does not allow medical discrimination against handicapped infants.” [14].

The Baby Doe policy stirred political, legal, ethical and medical debate and the American Academy of Pediatrics amongst others brought suit against the DHHS. US District Court Judge Gerhard Gesell found the regulation invalid. DHHS made minor modifications, reissued the rules, and opened the proposed rules for a 60 day comment period. Of the 16,739 comments DHHS received, 97.5% were classified as supportive, yet 72% of pediatricians opposed the regulations [14]. Opponents believed that the regulation provided no useful guidance to physicians but only frightened them into over treating at the potential expense of increased suffering.

It wasn't long before the Baby Doe rules were tested judicially. On October 11, 1983 an infant known as Baby Jane Doe was born in New York with spina bifida, hydrocephalus, kidney damage and microcephaly [15]. Her parents were counseled that she would be paralyzed below the levels of the lesion, severely retarded and prone to frequent urinary tract infections. The physician team disagreed and argued that surgical interventions and intensive treatment was appropriate for the infant. The parents felt that palliative care was in their child's best interest. The case found its way to the courts and was appealed up to the level of the US Supreme Court.

In *Bowen v American Hospital Association* the Supreme Court struck down the federal regulations [16]. They endorsed the best interest standard stating that “concerned and loving parents had chosen one appropriate medical course over another and made an informed decision in the best interest of the infant.” The legal decision supported parental rights, but the societal controversy changed the landscape of decision making forever [17]. [18] While the legal precedent of the Baby Doe case would suggest that parents have the right to refuse surgery for a baby with Down Syndrome and a correctable surgical anomaly, it seems unlikely that a future court would take the same stance.

Medical ethics always finds itself at the crossroads of societal views and cultural norms, legal and political influence, and medical advancements and knowledge. Thus, positions can shift overtime. While in 1982, granting parental authority to decline a straightforward surgery simply because the infant had Trisomy 21 may have been ethically permissible, nowadays it almost certainly is not. Today, treatment decisions for an infant with Trisomy 18 (and to a lesser extent Trisomy 13) have moved from the zone of futility into the gray zone of parental discretion [19].

One could speculate that, in the not too distant future, medical knowledge and societal values may change yet again and interventions for infants with Trisomy 18 may become defined as clearly beneficial and therefore once again outside the allowed realm of parental discretion. As technology advances and our understanding of genomic medicine continues to improve, the potential for genetic discrimination could become even more relevant.

If there were not a Baby Doe, would there be a Sidney Miller? Certainly one could argue that the culture and climate created by the Baby Doe regulations could have played a role in Women's Hospital of Texas's feeling that they were required to resuscitate Sydney Miller. When asked about his through on the *Miller v HCA*, General C. Everett Koop responded “I don't think parents should have the discretion to kill their children. I'm a great believer in the slippery slope. You get into the terrible quagmire of having only perfect children, and nobody can guarantee that.” [20].

3. Hypoxic ischemic encephalopathy

When labor is progressing expectantly and then, suddenly, fetal heart monitoring reveals decelerations and fetal bradycardia, there is a true delivery room emergency. Such emergencies also arise when there is placental abruption, umbilical cord prolapse, or uterine rupture. In such cases, since two patients' lives are at stake, the actions of two different medical teams, obstetrics and neonatology, must be coordinated and mobilized rapidly. When newborns are born depressed, life saving interventions must be initiated rapidly. However, when infants fail to respond to medical interventions, the potential for devastating neurologic sequelae must be considered and clinicians are faced with the difficult decision of when and if it is in the infant's best interest to cease resuscitative efforts. Unfortunately, this scenario and these cases have been a frequent target for medical malpractice claims. Of the top 10 pediatric malpractice claims, the brain-damaged infant tops the list and has an average payout of $524,047 per case [21].

Emotional responses tend to be more raw and more intense in cases of unanticipated delivery room emergencies than in situations where there has been a prenatal diagnosis. The family has likely lived in a state of naive bliss, anticipating a delivery at term in which everything will be fine. And then suddenly it isn't fine. There has been no warning of trouble, no time to prepare. Adding insult to injury, many cases lead to an emergent cesarean section, with the mother under general anesthesia. Obviously, this greatly inhibits the ability to communicate effectively with the family. The mother cannot be updated on the infant's clinical response to interventions and the clinician is unable to elicit her views and wishes. Perhaps one of the worst tasks in the job description of a neonatologist is telling a mother who has just awoken from general anesthesia that her baby has died.

Guidelines from the American Heart Association and the Neonatal Resuscitation Program state “An Apgar score of 0 at 10 min is a strong predictor of mortality and morbidity in late preterm and term infants. We suggest that, in infants with an Apgar score of 0 after 10 min of resuscitation, if the heart rate remains undetectable, it may be reasonable to stop assisted ventilation; however, the decision to continue or discontinue resuscitative efforts must be individualized [22].” The language is left intentionally vague and ambiguous, as variables such as the quality of resuscitation, availability of therapeutic hypothermia, circumstances prior to delivery and family wishes should be taken into account. The recommendation is based on analysis of 6 studies, deemed very-low-quality evidence, that report a collective 42% survival at 22 months of age for infants > 36 weeks gestational age with an Apgar scores of 0 or 1 for > 10 min. Looking specifically at the 3 studies performed after 2009, when therapeutic hypothermia was available, of the 56 cooled infants, 27% survived without major/moderate disabilities [23]. The recommendation was opened for public comment and generated much discussion and debate. The group felt that the decision to continue or discontinue resuscitation efforts should be based on consultation with the family, but they also felt that parents tend to choose continuation even when data are presented. Thus, as in cases of periviability and congenital anomalies, clinicians are left in the gray zone of parental discretion and clinical uncertainty.

4. Conclusion

The seventh edition of the Textbook of Neonatal Resuscitation states, “There is currently no federal law in the United States mandating delivery room resuscitation in all circumstances … In most circumstances, it is ethically and legally acceptable to withhold or withdraw resuscitation efforts if the parents and health care providers agrees that further medical intervention would be futile, would merely prolong

Table 1

1. **Be okay with the gray.** Complex decisions deserve complex individualized analysis for each case and scenario. Attempting to create broad, overreaching, black-and-white guidelines for all extremely premature infants is taking the easy way out. Decisions about infants at the borderline of viability must enter into the gray zone, so proper due diligence regarding decision-making is awarded to the tiniest of humans. This means, however, that the treatment plan for the infant born to a mother in preterm labor at 23 weeks might not be decided before the baby is born. It also means that two 22 5/7 week gestation infants born on the same day, but with different characteristics, might not be managed in exactly the same way. That's okay.
2. **Do not place too much emphasis on gestational age**. If every fetus came with a stamped 'conceived on' date, then gestational age might carry a bit more weight. Given the imprecision of dating methods at up to ± 2 weeks, the utility of gestational age decreases substantially. Even if every infant was conceived by artificial methods and gestational ages were exact, other factors greatly impact both survival and long-term outcomes.
3. **Dying is usually not in an infant's best interest** – at least not right away. Whereas long term outcomes, QOL, and the burden of care are clearly important, if the infant is not allowed a 'trial of life', s/he will never have the opportunity to confront these future obstacles in care. It is hard to argue that death without a proper chance at life is ever in the best interest of an infant.
4. **Impairment does not necessarily equal poor QOL.** To high functioning adults, the thought of being blind, deaf, or having any degree of cognitive impairment would easily equate to a poor QOL. However, as former 'preemies' and ELBW infants reach young adulthood, their self-reported QOL scores equal those of their normal birth weight counterparts. Perhaps there is an element of blissful ignorance or denial, but this goes to show that one cannot be the judge of someone else's QOL.
5. **Just because the train has left the station doesn't mean you can't get off.** Just because the decision was made to attempt resuscitation at 23 weeks in the delivery room, it does not mean that the baby is automatically committed to a tracheostomy, gastrostomy tube, and home ventilator at the age of 6 months. Discussions about the care of extremely preterm infants must be ongoing. Parents and the medical team are welcome to alter the course of treatment at any time, should complications arise. It must be remembered that withdrawal of care is ethically equivalent to the withholding of care.
6. **Respect powerful emotions. They reveal moral truths.** It is clear that parents serve as the best surrogate decision-makers for an extremely premature infant (at least most of the time anyway). They should be appropriately informed about what the infant may endure, and they should play an active role in decision-making. However, not all the burden should fall on the parents. It is appropriate for the medical team to be somewhat directive. Making the decision to resuscitate an infant at the borderline of viability is not the same as obtaining informed consent prior to a surgical procedure and should not be met with the same rigor. Childbirth is a highly emotionally charged event and typically there is not the luxury of time. Even if all available outcome data were eloquently described to parents in the most dismal of settings, it is still quite likely the parents would request to have 'everything' done. Emotion and feelings of parental duty will overrule logic without direction and guidance from the medical team.
7. **Be aware of the self-fulfilling prophecy.** Several of the available policies and practice guidelines cite low survival rates as the premise for not recommending resuscitation at 22 weeks' gestation. If resuscitation is never attempted at 22 weeks, then of course no infants will survive at 22 weeks, adding merit to the original recommendation. Thus, a self-fulfilling prophecy is created. This may or may not explain the increased survival rates seen in the Japanese population and should be considered when making decisions about infants at the borderline of viability. In the 1950s, the survival rate at 26 weeks was close to zero, because resuscitation was not even attempted. Today, it is > 80%. Granted, size and state of embryologic development likely play a greater role at 22 weeks.
8. **Time lag likely skews all outcome data.** An infant admitted to a NICU today does not receive the same care as an infant born in 1995, or even in 2013 for that matter. By the time data can be collected, analyzed and published, advances in neonatal care undoubtedly will have occurred. Progress in neonatal care may not be as dramatic today as it was in the second half of the 20th century, but nonetheless long-term follow-up data must be interpreted cautiously when applied to an infant born today.
9. **Statistics can be both confused and confusing.** Available outcome studies and calculators describe population statistics but do not predict the individual outcome for a specific infant. A father could be told that 26% of infants born at 23 weeks' gestation survive, but there is no way to predict whether his daughter will be one of the 26 of the 100 who survive. For parents, ultimately statistics become an all-or-none retrospective phenomenon. If their child lives, survival is 100%. If their child dies, survival is zero. There is no such thing as 26% survival for an individual baby.
10. **Above all, never abandon parents.** Parents of babies in the NICU are on an emotional roller-coaster. They may behave badly. Some get angry. Some don't visit their babies. Others can be intrusive or critical of staff. Parents need the support and guidance of doctors and nurses. The parents who are the most difficult to get along with are often the ones who need support the most.

Table 1 (*continued*)

dying, or would not offer sufficient benefit to justify the burdens imposed on the baby." [24] Remarkably, there is very little case law and no statutory law that regulates or governs delivery room decisions. Thus, for good or bad, physicians are left with a lot of discretion. Local hospital policies should provide guidance and following hospital policy is always a good legal defense. But policies cannot be all-inclusive and encompass all potentially encountered scenarios. Ultimately, the physician and the medical team must simply do what they feel is best for infants based on their clinical judgment. They must use their experience and knowledge to decide what seems to be the best course of action for each individual infant. The decisions are often made in the split seconds allowed by medical emergencies.

In 2015, we offered ten suggestions for assistance with decision making at the limits of viability [25]. Many of these suggestions apply to emergency room deliveries as well (Table 1).

Physician vow to first do no harm. But it may be difficult to decide how to define "harm" in the setting of an emergent delivery with a vulnerable infant who will certainly die without intervention, whose future is radically uncertain, and for whom any choice might lead to harm. Letting a baby die who might have survived is one sort of harm. But it may not be the worst harm. Attempting resuscitation when resuscitation seems futile is another sort of harm. Much of the time in delivery room emergencies the line between futility and harm remains blurry and gray. Often, the best course is to provide immediate stabilization in order to allow for additional time to gather prognostic information and to facilitate further conversations with families. Delivery room decisions are not irreversible. If life-sustaining treatment is initiated in the delivery room, and the baby does not do well or the family wishes to withdraw life support later, then it is permissible, in some circumstances, to withdraw life support. Withholding life support initially or withdrawing it later are legally and ethically equivalent decisions [26]. Each baby is different. Each case needs to be evaluated individually. There are no hard and fast, black and white rules (either ethically or legally) for babies born at the borderline of viability. Thus, communication with parents and colleagues remains evermore essential.

Practice points

Do not place too much emphasis on gestational age. It is both inexact and an imperfect predictor of prognosis. Evaluate each infant as if you don't know the gestational age.

Impairment does not necessarily equal poor QOL. The self-reported quality of life of individuals with disabilities equals those of their non-disabled peers.

Discussions about the care of extremely preterm infants must be ongoing. Parents and the medical team may alter the course of treatment at anytime. Withdrawal of treatment is ethically and legally equivalent to the withholding of treatment.

Statistics can be both confused and confusing. The same statistics can reveal that "90% of babies born with Condition X either die or survive with severe disabilities" and that "50% of survivors with Condition X have no disabilities." Presenting statistics always requires choices about how to frame and explain the data.

Never abandon parents. Parents of babies in the NICU are on an emotional roller-coaster. They may behave badly, get angry, not visit their babies, or criticize staff. They all need the ongoing support and guidance of doctors, nurses and social workers.

Research Agenda

Why do significant practice variations exist in delivery room decisions?

What is the optimum way to engage parents in a process of shared decision making?

Conflicts of interest

Jessica Brunkhorst has no conflicts of interest to disclose.
John D. Lantos has no conflicts of interest to disclose.

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