Ethical Issues in the Determination of Death -Pediatric Grand Rounds-2-14-25-Meeting Recording

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1h 0m 15s

Calderon, Delia started transcription

Calderon, Delia 0:08

OK, recording has started.

Wu, Theodore 0:13

Good morning, everybody.
Thanks for joining us for grand rounds this morning.
I'm Ted Wu, one of the pediatric intensivists here at UT Health San Antonio, and brings me the honorable pleasure to introduce Doctor Jones, Caroline Jones.
She's a assistant professor here in the Division of Pediatric Critical Care.
Doctor Jones brings a strong background in both clinical care and medical ethics.
Uh, having learn earned a bad master's degree in ethics from Vanderbilt University.
Before attending medical school, she served as an adjunct professor of medical ethics at Allegheny University in St.
Christopher's Children's Hospital, contributing to the education of future healthcare professionals.
Doctor Jones completed her pediatric residency and Critical Care Fellowship at UT Health, San Antonio and in volunteer training. She joined the medical staff at Methodist Children's Hospital.
In San Antonio, where she held the role of chair of the Medical Ethics Committee.
There, reinforcing her expertise in.
Ethical decision making in pediatric care and then in September 2020, she returned to our group UT Health.
It's Utl San Antonio, where she currently serves as our medical director of the Pediatric Intensive Care Unit and is also the Chair of the University Health Ethics Committee.
Her leadership and commitment to patient care and medical education and ethics continue to have a real, profound impact on our institution.

And broader medical community.
So with that, please join me in welcoming my Steam colleague, Dr. Caroline Jones.

Jones, Caroline 2:02

Thank you very much for that introduction, Dr. Wu, and thank you everybody for logging on today.
I realized when I was doing my title slide that today is Valentine's Day and I didn't choose the most uplifting topic, but to put a positive spin on it. The reason we constantly have to revisit this topic about how we determine death is that our technology is always.
Evolving and what we're capable of doing in medicine is remarkable. So that challenges challenges us to.
Re examine what it means to be dead.
And how we determine when death has occurred, that's what we'll discuss this morning, and we'll focus mostly on brain death because that has been the most conceptually difficult and controversial topic when it relate as related to determination of death.
So I do not have any disclosures and in terms of objectives, we'll examine the the history, some of the development and medical medical technology to examine the legal requirements for determination of death, and we'll briefly review some of the most recent guidelines that set the medical standard for.
How we determine how testing is done?
We'll then talk about some of the ethical controversies and how we can approach those.
Throughout the topic of the presentation, I'll use the abbreviation BD/DNC for Brain death slash death by neurologic criteria, but I'll usually refer just as brain death because the rest is a little bit of a mouthful.
So how should we think about questions about death?
What are some of the questions that we should ask?
Is it a biologic event or is it a social, cultural and religious construct?
How do we legally define it and what are our responsibilities as physicians?
And then how does the way we determine death impact other important things that we do like organ transplantation?
So death is not as straightforward as we might think.
And Edgar Allan Poe put that nicely when he when he said.

The boundaries which divide life from death are at best shadowy and vague.
Who shall say when? Where the one ends and where the other begins?
So we'll start with looking at some of the history, key events in the evolution of this concept and how we got to where we are today.
So before the mid 20th century it was pretty easy to determine when somebody had died. The they stopped breathing and then the heart stopped.
And in the case of patients who had severe neurologic injuries, the respiratory center was damaged, so they stopped breathing and that ultimately led to cardiac arrest.
So the final pathway was the same, but in the mid 20th century some major advances in medicine really changed the way we think about death and the way we can take care of patients. One was the invention and widespread use of the mechanical ventilator.
This is Forrest Byrd, who was an aviator and biomedical engine.
And he's credited with inventing some of the most reliable and mass produced ventilators, and this is his Mark 7 model at the top.
And then the baby bird, which is used on infants and neonates.
So the ventilator dramatically changed our perspective on death in the way that we're able to treat patients with severe neurologic injury.
We can sustain their respiration and thus maintain a heart rate, so they don't.
Progress to that final pathway.
Of cardio pulmonary death.
The other milestone in the midnight in the mid 20th centuries was the progress in organ transplantation. We were doing kidney transplants from living donors starting in the in the 1950s, but the first heart transplant took place in 1967.

Ted Cieslak 5:47
Thank you.

Jones, Caroline 5:54
It was in South Africa.
The surgeon was Christian Bernard and the challenge with any deceased donor.
Organ transplant is that we need a a living viable.
Organ from an individual who has been declared dead.
In the first organ transplant, in that case, the donor was a young woman in her early 20s who was hit by a car.

Ted Cieslak 6:15
Early 22.

Jones, Caroline 6:18
And she sustained a severe traumatic brain injury and the family consented to organ donation.
That situation ended up being more like a donation after cardiac death, but it really pushed the question about whether donors who are severely neurologically damaged.
If we procure those organs, is the is the donor dead at the time of organ procurement or does the procurement cause the death?
So the ability to sustain patients with severe neurologic injuries really raise some practical concerns about using resources for patients who are irreversibly comatose.
And also the question about when is it acceptable to procure organs from those patients if the family consents for that?
So physicians started to grapple with these these challenges in 1968.
Henry Beecher, who was an anesthesiologist, formed a committee known as the Harvard Ad Hoc Committee.
The committee was mostly made-up of physicians, but there was also a theologian, a law professor and a science historian.
And they recognized that advances in resuscitation and supportive measures create situations in which a person's brain is irreversibly damaged, but the heart continues to beat.
They also recognized that using obsolete criteria for defining death can lead to controversy and obtaining organs for transplantation. So their goal was to change how death is determined, both legally and medically.
And they established these criteria that define irreversible coma.
They're known as the Harvard criteria.
There are six of them and they confirmed that the patient is unconscious, has no brain stem reflexes.
And that the condition is permanent by excluding.
Other conditions, like hypothermia and the presence of central nervous system depressant medications.
So the committee said that patients who meet these criteria can be considered dead.

And understandably, there was some hesitancy about that concept that seemed more like a moral judgment rather than a biologic phenomenon.
That didn't really fit intuitively what we we think about when we think about an Organism being dead.
A patient with a neurologic injury on a ventilator is warm.
The other organs work.
The chest is moving up and down.
So understandably, it there was some confusion.
The other issue was that some states started to adopt the Harvard criteria into legislation.
So legally, a person could be alive in one state and dead in another by 197924 states had already adopted an assortment of laws and statutes that incorporated these criteria.
But there was number consistency.
So in 1979, President Carter formed the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research.
And they had the task of tackling this question of how we define death.
And they sought to explain why patients who met the Harvard criteria should be considered biologically dead.
And they argued that death had actually already occurred and the technology was only masking that.
Their theory was based on the observation that when patients had a severe neurologic injury, they often had a cardiac arrest within just a few days to a couple weeks.
So they suggested that the brain was necessary to function as an integrator.
It integrated all the other necessary bodily functions, and if the brain stopped working, then basically the body would fall apart, and that's what was observed at the time.
But we'll talk about how that's controversial now, now that we know what we know.
And we can do what we we do.
But their goal was not to define two different kinds of death.
Their goal was to say that brain death and cardio pulmonary death are biologically the same.
So the Commission proposed model language that was incorporated into the uniform determination of Death Act, and this is the legislation that governs how we

determine when death has occurred, and it includes 2 clauses.
So it states that an individual who has sustained either irreversible cessation of circulatory and respiratory function or irreversible cessation of all functions of the entire brain, including the brain stem, is dead.
And it left a determination of death.
Up to accepted medical standards.
So the uniform determination of Death Act did not not outline the medical test that needs to be done to determine death. They left that up to medical standards and medical societies.
So every state adopted brain death as equivalent to cardio pulmonary death.
But there was some variability and you know across states, in terms of the requirements for the person doing the examiner, the specialty of the physician, if it specified it had to be a physician and also whether they accommodate religious and moral objections.
New York, Illinois and California.
The statutes mandate that hospitals make reasonable accommodations for families who object to.
Brain death testing based on religious, cultural, or moral beliefs that usually translates into allowing more time between the determination of brain death and removal of the ventilator.
New Jersey is unique because it actually prohibits determination of brain death in patients whose religious beliefs oppose it.
So New Jersey is a unique situation.
So it's possible to be declared dead by neurologic criteria in New York.
Cross across the George Washington Bridge and then legally be alive in New Jersey.
So some inconsistency there.
But legislation as I mentioned, left testing standards up to medical societies.
So the American Academy of of Neurology took on the responsibility of creating guidelines for adults who adult patients who have sustained neurologic injuries.
And the AAP Society of Critical Care medicine and Child Neurology Society created guidelines relevant to Pediatrics. But despite the existence of professional standards and guidelines, there was still a lot of variability across institutions in terms of how physicians determined whether brain death had occurred.
A 2012 study examined policies pertaining to brain death in hospitals in the United States only in adult patients.

And they found significant variability across institutions.
They they looked at over 500 policies and estimated that they captured about 85% of the hospitals that were equipped to do brain death testing.
And they found, as I mentioned, significant variability in several categories.
One was the prerequisite requirements, another was the qualifications of the Examiner. 30% of these policies didn't even mention qualifications.
43% specified that the examiner.
Needs to be an attending physician.
There was also variability in the number of exams required and also in the use of ancillary testing.
I was surprised that it was a small percentage, but still some policies mandated ancillary testing regardless of the situation.
So because of this inconsistency in practice and as well as advancement in technology, even from the time of the updates of these guidelines and expert panel from multiple professional societies came together and updated the guidelines on determination of brain death.
And they published that consensus statement in early or late 2023. It's a long document.
It includes 85 recommendations and unifies guidelines for adults and pediatric patients into one document, and their goal was to create consistency across institutions by clarifying some topics that were previously seem to be confusing and also by addressing topics that previously had not been covered. And I'm not.
And to go into the nitty gritty of this document, because most of you will not be doing brain death testing and those who do have already been subjected to some of my lectures.
But I want you to be aware of some basics that are in the guidelines.
So the guide, the 2023 consensus statement, updated recommendations on prerequisites on the exam itself, on the apnea test. When we take the patient off the ventilator monitor for respiration and draw blood gases.
And then also on ancillary testing and one of the notable changes is that an EEG is no longer considered an acceptable ancillary test.
So the guideline also addressed topics that had not previously been covered. For example, how to determine brain death in patients who had interventions to lower ICP intracranial pressure, and that covers a lot of the patients who have severe neuro injuries in this situation.

Also, patients who have sustained primarily infratentorial injury patients who have undergone targeted temperature control patients on ECMO, pregnant patients it also addressed.
Qualifications of the examiner.
And issues related to consent. It specifically said that consent is not necessary from the family and then it also added a recommendation that every institution create a policy for managing disagreements with families.
So we had updated or renewed our institutional policy on determination of death and that is 9.05 in October of 2023. And then these guidelines came out just a few weeks later.
So with that, the Ethics Committee took on the task of updating our institutional policy, and it's important to realize that there is still variation across states.
So our policy is compliant with the Texas Statute, which it which is the Texas Health and Safety Code and it incorporates the 2023 guidelines, which is considered the the medical standard of care.
One topic that is is unique is.
Some states allow APPS to do brain death exams.
Texas, the Texas Statute specifies that the Examiner has to be a physician, but doesn't mention anything about the qualifications.
So according to the Texas law, an intern fresh out of medical school could do a brain death exam.
But the 2023 consensus statement was very clear that if it's a physician doing the exam, it must be an attending physician or a trainee.
A physician trainee under direct supervision.
So it was very clear about that.
So we incorporated all of those standards into the institutional policy and it's in the final stages of review.
But I wanted to point out where we can find that policy. If you go to the info net and go to the publications column, that third column click down on corporate policies and type in determination of death and it'll pull up our our policy.
And it's a kind of lengthy policy with the overriding policy statement.
And then we have several attachments that are our clinical references.
We have one that pertains to testing and Pediatrics, one for adults.
There's an adult checklist.
We also have a policy on ECMO and we've added a new policy on guiding families

through this process and dealing with conflict.
And there's also an attachment that has a lot of information on the historical background of brain death determination.
So the legislation pertaining to brain death has been around for over 40 years and we have clear clinical guidelines about how to do the testing.
But there's still a lot of controversy about the topic, and we're seeing that the number of cases involving families who object to the diagnosis is increasing, and that's even more common in Pediatrics than in adult medicine.
And that's understandable, because the percentage of patients who.
Are declared brain dead?
Is is higher than in adults.
Overall, of hospital deaths that are that 20, only 2% of are based on neurologic criteria. But in Pediatrics it's 21%.
So it's understandable we would, we would deal with this more because a greater percentage of our patients meet criteria for for brain death. And interestingly, a 2016 survey of pediatric intensivist found that 61% had been asked to continue organ support after the determination of.
Brain death.
The most common reason cited for that request was the family's belief that the patient would regain some neurologic function, and 48 of those 48% of those cases did not end until the patient had a cardiac arrest.

DeForest, Patricia Kelley 19:31
I didn't do any hair.

Jones, Caroline 19:43
So I I want to talk about one of the most well publicized cases. Many of you will have heard about this one. And then as we talk about some of the other controversies, we'll refer back to that case.
So Jahae Mcmath was a 13 year old.
Who had a history of sleep apnea?
Obstructive sleep apnea. In December of 2013, she underwent a tonsillectomy and adenoidctomy, and had a revision of her soft palate.

DeForest, Patricia Kelley 20:01

Yeah, Croatia. Psychology for.
My.

Jones, Caroline 20:09
So it was a complex repair.
On just a few hours after surgery, she developed bleeding and then most likely had a hypoxic cardio cardiac arrest.
She was intubated, placed on a hypothermic protocol, but a couple days later on the 11th around midnight, actually.
Her pupils became fixed and dilated, and a neurologist performed a brain death exam later that morning.
Interestingly, in reviewing the the details of that brain death exam, she actually didn't meet criteria according to the current guidelines at that time, they hadn't allowed enough time for the fentanyl to clear out of her system.
So you couldn't exclude CNS depression from fentanyl. And then on the apnea test, we normally look for a rise in the the PCO 2 by 20 points when we take them off the ventilator and hers only rose by, I think it was 18.
So she didn't quite meet criteria.
I don't know that that changed the overall outcome in this case, but it does highlight that there is a lot of variability and not consistent adherence to guidelines.
So in a pediatric intensivist performed the second exam the next day at 1:00, and she was declared dead.
The family did not accept the diagnosis and they requested that treatment be continued so the medical team agreed to give them some time for other family members to arrive.
But on the 15th, the hospital of inform the family that the ventilator would be removed the next morning and so the family retained an attorney and a temporary restraining order was issued to keep her on the ventilator.
The court appointed the Chief of Neurology at Stanford to serve as an as a consultant and Jahi had an EEG that was isoelectric shows.
So it showed no no activity and that was actually her 4th EEG, the.
Was flat. Now, as I mentioned, an EEG is not considered a an ancillary test, but she also had a radionucleotide flow scan that that is a standard for ancillary testing and it showed no cerebral blood flow. Then on the 23rd, the neurologist performed a third clinical exam.

Where we look at the pupils and look for, you know, movement. And we did the apnea exam.
Those are just a few of the the components and that exam was also consistent with brain death.
So the judge ruled that Jahai was in fact dead, but required that the hospital continue the vent for the family to get the family some time to explore other options and ultimately the hospital agreed to release her body to the coroner, who would issue a death certificate and.
That death certificate was issued for the 12th, so the date of that second brain death exam.
And then they would release the body to the family. And so the body was released on.
The 5th of January to the mother's custody and then was taken to a hospital in New Jersey.
And remember, New Jersey is the state that allows an exemption to brain death determination.
So shortly after she arrived in New Jersey, she underwent a trach in ag tube and stabilized over the next few months.
But no long term care facility would take her.
So she stayed in the ICU until August and finally in August of 2014, she was discharged to her mother's care.
And they stayed in an apartment in New Jersey.
She was Drake and vent dependent and G tube dependent.
She had 24 hour nursing and required supplemental hormones.
But she did grow and develop, and she even went through puberty.
So during this time, so this is, you know for period of 4 1/2 years since the initial injury, she was very stable. The parents insisted that that that she actually followed commands and they brought in consultants from all around the country. And one was a NE.
Who became particularly close to the family and involved in the case, and he reviewed a lot of videos that the family had taken, and he concluded that the movement some of the movements on the videos.
We're more than just spinal reflexes.
There was also a claim that she had Eegs that were performed at home in the in New Jersey that were not ISO electric, but when she was admitted for short hospital stays

for various things tracheaitis you know, the typical things that we see the EE GS were in.
In fact, isoelectric so they could never replicate those things in the hospital.
She also, interestingly, had an MRI about nine months after her injury that showed overall intact or more intact structures than we would expect if she had a prolonged period of no blood flow to the brain.
So the family interpreted these things as she's alive.
It's a miracle.
And she really did stay very stable for 4 1/2 years. But in June of 2018, she started developing episodes of intestinal pneumatosis.
She actually had ax lap.
Nothing was noted to resect, but she was left open.
She had an episode of Pneumonal Sepsis, Dic liver failure, and then in late June, she developed a perihepatic hematoma and profound instability and was taken back to the operating room.
So a lot of things were done.
To her during this time.
But she was very unstable and she coded shortly after she got back to the PICU and was pronounced dead by cardio pulmonary criteria on June 22nd.
So she actually has two death certificates.
One was from the initial initial brain death declaration in 2013, and the second was from 2018 based on cardio pulmonary criteria.
The family actually filed a lawsuit to revoke the 2013 death certificate, and if jurors decided that she had in fact died in 2013. If they did not revoke that death certificate, then the family could only seek damages for medical malpractice.
Which in California law is limited to 250,000 per plaintiff.
So shortly after she died, she actually had an autopsy at the hospital where she died, but it's unclear if that autopsy included the brain.
There was a note in one of the articles that her brain was stored for later review by a pathologist of the family's choosing.
But it didn't specify if an autopsy had actually been done.
Interestingly, in February of 2019, so the year after she died, the case to revoke that original death certificate was dismissed by the family.
And then the results of the limited brain autopsy by the pathologist that the family chose were published in tooth in 2023, so fairly recently, and as I mentioned, it was

limited.
They didn't have the full brain specimens.
The the parts of the brain that govern neuroendocrine function, for example, were not included, and that would have been interesting.
But the autopsy showed widespread necrosis and there was no evidence of perfusion to the deep structures.
She did have some superficial revascularization, but there were no findings that would support the observations that she had purposeful movement or preserved structures on MRI.
So this case is really interesting and it's tragic, and it raises a number of questions.
It brings up some of the controversies that we'll talk about in the next section.
One of those is this idea that brain death and cardio pulmonary death are the same.
We still see that language and in articles and and used when described describing brain death, but it's based on the false premise that the body falls apart if the brain no longer functions.
And we now know that that's not true.
That theory has been proven wrong.
There are multiple cases of prolonged somatic survival following the declaration of Brain death.
The most dramatic was a four year old who was diagnosed as as brain dead after an episode of bacterial meningitis.
And he was supported for 20 years on a ventilator and feeds and then developed cardiac, then had a cardiac arrest and on autopsy.
His brain was completely calcified.
There was no.
Evidence of any any neurons that were were functional.
So that theory has been proven wrong and I think saying that they're the same just adds to the confusion for jihi MC math. Her mother repeatedly said expressed that she was confused.
How can she be dead?
She's warm.
And then they thought that she was responsive.
And then she existed for 4 1/2 years.
So it's important to realize that we don't have to say that they're the same, that the biologically the same.

In order to treat them in the same way, legally and morally, I think doing so just adds to the confusion.
So another point of objection is this idea of whole brain versus the brain as a whole and then some would add higher brain.
The legislation requires irreversible cessation of all functions of the entire brain, including the brain stem. But many patients who meet the criteria for brain death retain neuroendocrine function. 50% of patients who meet those criteria have osmow regulation.
They do not go into diabetes insipidus.
So.
This is a point of contention. The relevance of that is a point of controversy.
We don't require the absence of neuroendocrine function and we don't test for it.
So in reality, we're not guaranteeing absence of functions of the entire brain, but people argue that what we really mean is irreversible loss of those functions that are necessary for consciousness and respiratory drive.
But what we say and what we do doesn't, you know exactly align with the law.
Another point of contention that.
Also reflects what we say in the in in the law is not exactly what we do. Is this concept of irreversibility, the requirement of irreversible loss of function, and what we mean by irreversible isn't really clear in this context.
Normally we would think a function is irreversible if it's physiologically impossible for that function to recover. But as we know, that depends a lot on technology, and it it also depends on how long we wait.
And this is relevant in cardio pulmonary death, especially when we're thinking about organ transplantation and as a little aside, there are two types of deceased donation for organ transplantation.
One is organ donation from brain dead donors and one is from donation after cardio cardiac death or DCD.
For DCD donors, the family, they don't meet neurologic criteria for brain death, but the family has decided to.
Withdraw support and wants the organs to be donated so the patient is taken to the OR.
Compassionately extubated, and then once the heart stops, most institutions set a time period of standoff period of 5 minutes because 5 minutes is the point at which.
The possibility of the heart restarting on its own is almost 0.

There is some variability, but most institutions choose 5 minutes.
But we all know that the cessation of a heart rate is not irreversible at that time. If if we attempted to restart the heart, we could do that after 5 minutes.
Now, if we waited longer, you know it gets harder and harder the longer we wait.
But the 2023 guidelines interpret irreversibility as really permanent.
That is that the function will not recover spontaneously and there won't be efforts to restore it. So that aligns more with the technology that's available today and our capabilities that are available today.
But it doesn't exactly align with what the law says.
So a lot of these controversies relate to how our practices.
Is actually aligned with the the law, and it's important to recognize the limitation of laws when we're talking about biologic processes.
Robert Truog is a intensivist and ethicist.
Described this this dilemma nicely. He said that the loss the law tends to prefer draw to prefer to draw bright line distinctions between categories, whereas biological categories tend to fall along a spectrum without sharp distinctions.
And he used the nice example of the need to set a legal distinction for age, for the age of maturity.
And we set that at 18.
Because that changes rights and responsibilities.
It's important to be that we have that line, but we all know that nothing magic happens at the age of 18.
I have a 18 year old son and I can absolutely attest to that.
So it's important to realize that the the law is limited there. It doesn't automatically.
Represent maturity or biologic events and it's also important to realize that death is a process.
But we have to be able to define it as a moment in time, because that moment in time changes our behavior as physicians.
That moment defines when we're no longer obligated to treat a patient for families that time triggers the grieving process.
It also defines when life insurance would pay claims or health insurance would cease to pay claims, and then it also.
Defines the time when it's acceptable to procure organs if the family has.
Consented to that.
Robert Truog also had this nice chart that describes the relationship between law and

biology. When we're thinking about brain injury.
And he describes the the spectrum of brain injury and where we have to draw or where we have drawn the line that defines brain death.
So it's a spectrum from uninjured brain to liquefied necrotic brain, and we set the line of brain death at irreversible apnic unconsciousness.
Now, is it possible that some patients and maybe even jehi MC math?
At some points while she was on a ventilator just barely crossed over this line and other points was just barely below it.
It is possible, but we we have to be able to set a legal line and it's important for everybody to know for us to know that no patient who has been correctly diagnosed is brain dead, has ever crossed this line.
Into consciousness.
So given that it's not a perfect concept and our law is a little bit antiquated, it hasn't kept up with with technology.
It was enacted in 1981, so that's there's a lot has happened since then.
What are our options?
Some might say, well, we should just get rid of the concept of brain death, but that's not a very desirable option because we all know that organ transplantation creates miracles.
And eliminating brain death would significantly impact organ transplantation.
In 2020, three 85% of deceased donor transplants or 85% of transplants were from deceased donors.
And of those, 75% were from donors who had been declared brain dead.
And then eliminating brain death would would actually likely not align with what most people want.
Most families don't request to continue organ support after a brain death diagnosis.
They mostly want reassurance that the diagnosis is correct.
And that their loved one will not wake up or recover.
So other approaches one would be to revise the legislation to align.
To align with what we do today and we actually tried to do that, the Uniform Law Commission worked on this from 2020 until 2023 and there was a lot of disagreement and ultimately the effort was paused due to concern that it was not feasible to.
Create enactable revisions.
And we have to be careful because.

You know what we create may not be as.
As useful as this, what the legislation that we already have, but another option would be to revise our clinical practice to align with the legislation.
But we've already said that the legislation is out of date, so it doesn't make much sense to to change our practice to meet a antiquated law. Also for, you know, an example of that would be to add testing for neuroendocrine function.
To require the loss of neuroendocrine function.
But that would eliminate about 50% of our.
For our donors, and they still would not.
They would meet criteria of apneic irreversible unconsciousness.
Another proposal is that perhaps we should increase accommodations for for families to object.
Laney Friedman, Ross.
Who's a pediatrician and an ethicist, said proposed that we allow stakeholders to choose their own definition within a reasonable range of options, and part of that would be requiring that families give consent for brain death testing, and that's not currently required.
And this approach has has.
Good things. The pros are that it does acknowledge that death has moral, religious.
And philosophical meanings it takes into account different perspectives and different beliefs, and it respects the autonomy of patients and surrogates based on religious beliefs.
The cons are concern for utilization of resources for patients who are irreversibly unconscious.
It also would place a burden on those families who don't want a loved one to be sustained on technology if there's no chance of waking up.
As you know, the legal definition actually takes the burden of decision making off of families in that situation.
And then we also have to think about the moral distress of healthcare providers taking care of individuals who are considered dead.
We see a lot of moral distress in healthcare providers in cases involving, you know, what we perceive as as futile care. And we could argue that this would be.
Futile care to the Max.
Extreme futile care.
So we would have to be worried about moral distress for caretakers.

So the final option, and it's really the one that we're left with and it's probably the best one at this point.
Is to maintain the status quo.
As I mentioned, if we if we revise the law, what we get may not be as useful as as what we have now. And so we should place greater emphasis on education, on consistency and practices and on our communication with families.
So I would say that we need to do better, but I'm going to adopt the language of our quality improvement colleagues and say that we have opportunities for improvement and a big opportunity is that we really.
We do need to strictly adhere to the guidelines. The last you know, our our goal should be avoiding false positives in determination of brain death.
We've all seen headlines of miracles where somebody wakes up after being declared brain dead.
The one on the right is Zach Dunlap, who had aatv accident and a severe neurologic injury, and reports are that he was declared brain dead.
And as he was being wheeled out to donate organs.
He signaled to his family that he was, in fact, alive.
So going back to my statement, we have to remember and the public needs to know as well that when brain death is determined correctly to date we we have had no patients who actually regained consciousness.
So highlights the importance of getting it right.
Other opportunities for improvement we need to do a better job educating healthcare providers. A 2019 study surveyed healthcare providers working in an ICU. At or in Icus at a transplant center.
So a place like University Hospital and the goal was to evaluate understanding of brain death.
The survey included 21 questions and they found significant variation among healthcare providers. About 95% of attendings had a basic understanding of brain death, so they did pretty well. About 72% of nurses and 50% of students and residents.
So it's concerning that only 50% of students.
And resident physicians had a basic understanding. But interestingly, the majority of the people who responded to this survey reported that they have conversations routinely with families about brain death.
So we really need to work on educating the people who are having these

conversations and in terms of formal training, only 78% of attendings, 23% of nurses and 23% of residents had formal training on brain death.
So that's definitely an area where.
And improve.
Other opportunities for improvement. So when we're dealing with families who have experienced a tragedy and they have a loved one who is likely to meet brain death criteria, it's important to step back and and be humble.
Recognize that this is not a clear concept and even health, healthcare, profession professionals get it wrong and misunderstand.
Articles and news reports on the Jihi MC Math case.
Repeatedly mentioned that the family was confused about why she would be considered dead when she was warm and her chest was moving up and down and her other organs functioned and that in a meeting with the family, a health administrator said, what don't you understand? She's dead.
So that's not the best way to approach that. And if and if we approach it with humility and recognize that it's a, it's a complex concept, then it would have been better to to step back.
And acknowledge that it is confusing. The other point is that we really should slow down.
We know that we can sustain patients sustained cardio pulmonary function with ventilation for a long period of time. So there's really no rush to get to that brain death diagnosis and sometimes the family may be in shock and they just need more time to process the information.
Sometimes it's I I I believe that it's better to address potential conflict before death is declared.

Robert Wymer 43:21
Play.

Jones, Caroline 43:26
And you have a body on a ventilator for a prolonged period of time, and the 2023 guidelines actually place a lot of emphasis on this concept and the importance of the observation period before testing even begins so slow down.
All right. Other other opportunities for improvement in these cases, it's very important to establish trust and sometimes there's one provider who has a rapport

with the family and can do a lot of the communication.
It's important to acknowledge that some groups may be more hesitant to trust the medical system, and so we need to take more time and make more effort to explain everything that's going on.
It's really important to listen to the family, families, concerns. Almost all of these cases involving families objecting to the diagnosis mentioned that the families say that the medical team wasn't listening.
They didn't feel heard, and that was certainly the case in Jahaiz.
Situation.
There was another case in Canada of a a woman in her 20s who overdosed and had a cardio pulmonary arrest and had a hypoxic injury, and the family objected to the brain death diagnosis and one of the articles really highlighted the discussions with the families, the communication and.
It was really fascinating to see what the families latched onto, how they interpreted things that were being done and and this goes into the next. The next opportunity is that we really need to choose our words carefully.
They mentioned that a doctor at some point early on in the the course said that there's nothing that we can do, but the family saw that lots of things were being done.
And they interpreted sedation as they didn't understand why sedation was being used, and they thought that was actually harming her and preventing her from waking up.
They also thought that the apnea test, when it got to that point, was causing her stress and also causing her to not recover, so there should have been better communication there.
We also have to choose our words carefully and when we use, when we talk about stopping the ventilator, it's really easy to slip up and say once you know, we do this testing. If everything is consistent with brain death, then we stop life support. And so we have.
To be very careful that it's organ support or a mechanical ventilator, it's not life support. And then finally we should step back and really try to identify the reasons that a family is objecting. As I mentioned some.
A lot.
May be in shock and it's an emotional response. And in that case, taking some time may help.

My also their their objection may be based on misunderstanding or poor communication among the healthcare providers.
Guilt may also play a role, and that's particularly true in Pediatrics.
And so it's important to address that if it's present. And then finally tease out whether there are in fact religious or cultural objections and in that case, it's unlikely that better communication.
Or taking more time is going to resolve that conflict.
So in conclusion, brain death is a complex topic that has religious, cultural and moral influences, and the uniform determination of Death Act has served us very well, especially when we consider the difficulty of crafting legislation to align or describe biologic processes.
It's unlikely that we'll ever reach full consensus.
And so, instead of dissecting the.
Terms and debating adequacy of the legislation. We probably should focus on the concept of the greater good and how we can achieve that and a couple things that we really can do. Discrete things is improve education for healthcare providers and also for the public.
But if healthcare providers understand the concept, then the communication with the public should be better.
And then we can also focus on optimizing communication and building trust when families are going through this difficult experience.
So that does it.
I'm happy to take questions.
I'll open up the chat.
Thank you for your attention and for logging on.

Wu, Theodore 47:42
Thanks Doctor Jones for very insightful talk and update.

Jones, Caroline 47:47
Thank. Thank you.

Wu, Theodore 47:49
Doctor Gross, you got a question? You had your hand up?

Jones, Caroline 47:51
Yeah.

Wu, Theodore 48:04
We'll wait for see if Doctor Gross comes up.
But again, again, thanks for bringing up the MC Math case, but you know from this update with the brain death guidelines.

Jones, Caroline 48:07
OK.

Wu, Theodore 48:18
With Pediatrics as well.
And one thing unique with Pediatrics is we do 2 exams.

Jones, Caroline 48:24
Mm hmm.

Wu, Theodore 48:24
Is that a still a historical precedent, or is there still is there any data showing that?
Is there any utility in that second exam from a more of a clinical standpoint?
Know, you know, like 2 exams are better for one and really one is one time in Pediatrics that we really wanna make sure that that diagnosis is is is true and they were doing the right thing.

Jones, Caroline 48:37
Thanks.

Wu, Theodore 48:50
But we've never had a second exam that that's different from the first exam.

Jones, Caroline 48:55
Yeah. Now that's a great question.
I did not see any data that showed a percentage of that second exam that didn't

correlate with the first one.
Interestingly, in Jehimat maths case, there might have been a a difference because the first exam actually wasn't valid.
But I think so.
There's no data to support that, but I think it's actually a very useful tool for us in Pediatrics because we use that.
It just extends the required time that we have to take with a family for communication.
And often we use that second exam to prepare the family if they want to have other family members arrive from out of town, we give them time to do that before we do that second exam, and it also gives us another out to say, you know, we're going.
To do everything absolutely to ensure that there is no chance of recovery.
And so I think the second exam helps with that.
But the new guidelines we we used to have to wait 2424 hours.
For the younger kids. But now the timeline between exams and Pediatrics is just 12 hours.
So that has narrowed down, but for adults the minimum is is one exam.
Great question.

Wu, Theodore 50:08
Thank you.
Did doctor Weimer?

RW

Robert Wymer 50:13
Yes.
This, yes, this this may be off topic, but have you had any experience or problems with near death experiences?

Wu, Theodore 50:16
You had a question, yeah.

Jones, Caroline 50:18
Go ahead.
Not in Pediatrics.
I don't know if I didn't see any any case reports of that in the adult literature either,

but that's an interesting question. I know there have been some fascinating books published recently on that.
But no, I'm not aware of that.

Robert Wymer 50:49
OK.
Thank you.

Jones, Caroline 50:51
Of course.
Sorry, sorry I don't have more data on that.
And there's one question in the in the chat, any data comparing countries where families have to pay for care versus the US?
And no, that that didn't come up.
Actually, it's a fascinating question because brain death guidelines do vary from from country to country.
Some, for example, in Britain, focus on just brainstem activity rather than higher brain activity.
But it's a national healthcare system, so families wouldn't have to pay.
I and I didn't see any.
Any information about the Jihi MC Math case and whether the family actually had to pay because that that first brain death or first death certificate was not revoked and she stayed in the ICU for months from January until August after of, you know, 4 1/2 years.
After she was declared brain dead.
But I didn't see any information about whether they actually had to pay.
I know there was a lot of go fund me type things and.

Wu, Theodore 52:00
They. Yeah, I remember. They were trying to rescind the first death certificate because they were trying to reapply for Medicaid.

Jones, Caroline 52:02
Solicit.

Right.
Yes.


Wu, Theodore 52:13
Because Medicaid saying they're legally dead, they're not, you know, a person.


Jones, Caroline 52:15
Mm hmm.


Wu, Theodore 52:17
So. So there was that. But some questions that are coming on the chat here. Doctor Akbar's is asking was there any more guidelines on neonatal death exams for ones less than 38 weeks of gestation? I've been in this situation before, but.


Jones, Caroline 52:32
Yeah.


Wu, Theodore 52:33
I'm interested in this answer as well.


Jones, Caroline 52:35
Yeah, no, there wasn't.
And the guidelines?
The 2023 guidelines define child as 37 weeks gestational age up until 18, so they didn't even address that.


Wu, Theodore 52:37
OK.


Jones, Caroline 52:46
So for our needle neonatal colleagues, I'm sorry you had to be subjected to this discussion, but great question and it seems like we we should do more research on that.

Wu, Theodore 52:47
OK.

Jones, Caroline 52:59
Alright.

Wu, Theodore 52:59
Doctor Garcia canet.

Jones, Caroline 53:01
Done.

Wu, Theodore 53:05
Any questions regarding miscommunication between primary providers?
Do you see a role of palliative and supportive care being involved and timing?
When should they get involved?

Jones, Caroline 53:14
Yeah, absolutely.
And there was a great article on Brain death in Pediatrics and the importance of palliative care engagement. And when you asked me about any any topic related to this, I'll say yes, we should get palliative care involved and and do it earlier.

Lynch, Jane L 53:18
Thanks.

Jones, Caroline 53:30
But I I don't.
We do a great job at that because.
Often the families don't object.
It's a fairly straightforward process, but I think it would be helpful as we as we're more conscious about slowing down.
And working on communicating with families, I think we should get get you guys involved earlier. So great question.

Wu, Theodore 53:53
Doctor Lynch.

Lynch, Jane L 53:54
Yeah, I had it. That's crazy.
That 37 weeks is the limit for all this. That's interesting.

Jones, Caroline 54:00
Yeah.
Yeah.

Lynch, Jane L 54:03
I did question about just ethics.
Where there are some religions where suicide is not an acceptable cause of death is that sometimes a negotiated reason for the delay in final death certificate.

Jones, Caroline 54:05
Yes.
I didn't see that mentioned at all. That's a great insight.
Yeah, I don't know if if.
Yeah, I that that's interesting.
I don't know if a family in that situation would object to the diagnosis entirely or and how that fits into cardio pulmonary death.
Do you know what religions have that belief?
I didn't see that mentioned anywhere.

Lynch, Jane L 54:47
No, but I did have a couple years ago.

Jones, Caroline 54:48
OK.

Lynch, Jane L 54:50
I just had a family that said it is not acceptable for our child to have committed

suicide for our religion and that was, you know, they were not gonna even. It was just.

Jones, Caroline 54:57

OK.

OK.

No.

Lynch, Jane L 55:06

Kind of a negotiated final.

Importance to them of what went on the death certificate.

Jones, Caroline 55:10

Yeah.

OK, OK.

That's that's interesting.

I don't know that I've never put suicide on a death certificate.

They always require us to put the the in physiologic process.

Lynch, Jane L 55:21

OK.

Yeah.

Jones, Caroline 55:27

But that's really interesting.

I have not encountered that and I didn't see that that mentioned in the literature on brain death, but I'll have to go search for that and see.

All right.

Wu, Theodore 55:41

Doctor Weimer again. You had another question.

Robert Wymer 55:44

Yes, Sir.

It's been.

I haven't worked in neonatology since about 2004, but at that time there was an age for premature wear. The parents did not have a choice in terms of application of CPR.

Jones, Caroline 55:52
Uh huh.

Robert Wymer 56:03
Because I forget what that age was.
But, but is there a cut off age where?
The the parents are not given a choice.

Jones, Caroline 56:13
Oh, that's a that's a great question.
I'm not a neonatologist, so I would if if we have any neonatology.
Colleagues online who could answer that, that'd be great. I know that when I was a resident.
I don't.
I wasn't aware of.
A.
A fine cut off, but of course the age of of viability keeps decreasing with our technology.
So if somebody online knows the answer to that I I would love assistance that didn't come up in the literature on brain death.
All right.
And doctor Gross had a questions. Good question.
I've always considered absence of blood flow as synonymous with brain death.
Is that still accepted?
Yes, we we do not require ancillary testing unless some part of the other exam either cannot be done. Sometimes the patient's too unstable for an apnea test and sometimes we're not able to correct electrolyte abnormalities or or other factors.
And so the we require ancillary testing in those situations.
And the flow study or 4 vessel 4 vessel.
Cerebral study is is the are the standards of care.
So when ancillary testing is required, it's based on blood flow.
Does that answer the question?

Alright, and let's see.
Final question. Or do we have time for one more?
All right, just a couple minutes, OK.

Wu, Theodore 57:45
Think so?

Jones, Caroline 57:49
Let's see. NDPHD student did a PhD in pediatric Dr. Drowning.
That's interesting.
Wondering if you had any thoughts on the 72 hour rule being used in acute care despite evidence now available that it's not sufficient time to determine prognostic outlooks.
So let's see if I'm understanding the question.
So a drowning would be a hypoxic injury and for brain death determination we actually require it's 48 hours for hypoxic ischemic injuries for both adults and Pediatrics.
So I'm not sure the 72 hour rule.
So we we have to wait 48 hours to start brain death.
A brain death exam if the.
Mechanism of injury has been hypoxic ischemic.
Also, lots of other prerequisite criteria, often drowning patients, are hypothermic.
We have to warm them up to a temperature of 36 and then wait 24 hours after that, and that's also relevant in patients who have had targeted temperature management, so have to be 36° or higher for at least 24 hours before we start.
The brain death exam so often we are extending beyond that 72 hours.
Rule.
And there is no evidence that.
That hypoxic injury.
That we're not waiting long enough. As long as we meet those criteria, the minimum of 48 hours.
And that's a great question and I'd love to read your your dissertation.
OK. And thank you Doctor Seidner.
So currently no resuscitations for 21 weeks or or under for gestational age.
So I appreciate that.

All right.
Any other questions?
If not, we'll give you back one minute and.
I appreciate the insightful questions and and your participation.
So happy Valentine's Day.

Wu, Theodore 59:55
Alright, thank you.

Jones, Caroline 59:56
Alright, thank you.

Wu, Theodore 59:57
Have a good day everybody.

Calderon, Delia stopped transcription