

Jahi McMath: Lessons Learned

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Jahi McMath's story has been an important reference in medicine and ethics as the landscape of the understanding of death by neurologic criteria is shifting, with families actively questioning the once-firm criterion. Palliative care providers have a role in seeking understanding and collaborating with families and clinical teams to navigate the many challenges that arise when a medical team has determined that a child has died, and their parents disagree. In this case-based narrative discussion we consider the complexity of the family experience of brain death.

abstract

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I first learned about Jahi McMath as her story was unfolding in the news. It was compelling: a 13-year-old in Oakland, California, declared brain-dead after a tonsillectomy, with her family at odds with that determination. The headlines were gut wrenching, with media locally, nationally, and internationally reporting on the case of the family who was fighting against the brain death determination of their previously healthy child.

As a palliative care consultant, I consider families and their experiences holistically. We work to understand who families are in their world, who they are in our medical world, how they make decisions, and how their lifetimes of experiences guide them in that process. We work to understand how parents and loved ones and their deep connection to their children can guide us in supporting them through what comes next: often the series of decisions or circumstances leading up to their child's death.

Over the course of my career in palliative care, I have met a number of families whose children have likely already progressed to death by neurologic criteria or have some sort of event when death by neurologic criteria becomes the primary question. I understand how the landscape of the understanding of death by neurologic criteria is shifting from a family perspective. I also have experienced how deeply uncomfortable that is for clinicians and institutions where the once-firm criterion is being actively questioned by parents. How do we bridge the chasm that exists when the medical community determines a child has died, and their parents disagree?

JAHI MCMATH STORY

Jahi awoke from her surgery and began to spit up blood an hour later. Her stepfather, advocating for intervention because of the continued

bleeding, was asked to leave. Jahi's chart reflected a passive response to the concerns of her family. Physicians were notified, but a watch and wait approach was used. Just after midnight, she had a code event, which, in its entirety, lasted >2 hours. Just 2 days later, she was declared brain-dead.¹

It was only in more recent articles describing Jahi being buried "nearly 5 years after being declared brain-dead"² that more information about her was published: that purple was her favorite color, that she wanted to be a doctor when she grew up, that she wanted to be married and have twins. It was profound to find this information reported, but it was just as striking that it was not reported previously. Why does it matter that she likes purple? From the 10 000-foot view, maybe it does not, but the elements of her humanity, of her personhood, matter so much. This understanding guides our language and support of her family. We, as clinicians, are skilled in disassociating the child from the patient. Jahi's family saw their defenseless, purple-loving child needing help. In the language used to describe her by some of the people charged with caring for her: they saw a corpse.

JONATHAN

The idea that a family could dispute what, in the view of some, is a definitive medical diagnosis is unfathomable to many clinicians,³ but it is increasingly common in my practice as a palliative care provider. In response, I will present a case from my own practice. To respect patient privacy, this is an amalgamation of several brain death cases.

Jonathan was a 17-year-old young man who spent a lot of time outdoors to escape the stressors of depression and anxiety (a relatively new diagnosis for him), for which he was undergoing treatment. He arrived at our institution with an intentional

suffocation injury and was admitted to the ICU for multisystem organ failure and an anoxic brain injury.

Palliative care was consulted nearly 3 weeks after the initial injury to work with his family to understand their goals of care. In talking with his medical team, we learned that his family was active in their resistance to formal brain death studies because they "didn't believe in it."

We heard that his family had a Christian faith background and that they were seeing signals that Jonathan was responding. We learned that Jonathan's mother, Tara, would not engage in a meaningful way with the medical teams that were supporting them. Because of this, we decided to forego many elements of our initial consultation and try to engage with her in shorter increments. We would not discuss brain death. Instead, we emphasized that medical teams ask us to meet families so that we can be a more neutral-sounding board for all of the medical information, dialogue with them as their understanding evolves, and be a bridge between the family and the medical team. Our goal was not to make gains, but to be invited back.

As we talked about the joyful and Snapchat-filtered pictures papering the room, Jonathan's family pointed to a photograph of a healthy-looking child, a church friend, and chimed in that she was pronounced brain-dead some time ago, but she miraculously survived. They were a prayerful family and held a vigil with their community before, so why wouldn't it work again? They had done their research and knew of other cases in which the medical community was wrong in their determination: patients showing the same signs that Jonathan was showing who were still alive. We thanked them for sharing such an important part of their story, finally understanding their resistance.

There would be no brain death testing, they informed us flatly, because they felt the warmth of his skin and saw the color of a person who was very much alive, even noting that if they talked with him and touched him, he was able to give a thumbs up. We understood this to be a Lazarus sign, a common reflex, but also illustrated how confusing it must be to see such understandable signs from your child and be told that they meant nothing. His family stated many times that his other organs were not dying, so how could he possibly be dead? How could life support, as they understood his ventilator to be, support a dead body?

The medical team noted different findings, including absence of cough or gag and the presence of spinal reflexes, which elicited his movement. His family heard this information but felt their evidence was just as strong. They had experience and faith backing them up. They also had their own data: other cases and a member of their own community who proved everyone wrong. Tara asked us why people expected her to be sitting bedside and sobbing. She was not mourning. Jonathan was right here. She asked aloud where Jonathan would go for care after the hospital.

PROGNOSIS AND UNCERTAINTY OF RECOVERY

Each time another person tried to discuss neurologic testing with Tara, she became more steadfast in her resolve that Jonathan would be okay. Jonathan's family described their sense that each new provider was coming in to "take a swing at it" and that we as an institution were "playing God." Playing God meant that we could be the arbiters on Jonathan's status as a living being, that our limited view as medical staff with a concrete and often unmovable definition of life prevented us from connecting to the voice she was listening to, their higher power. This echoes the perception of Jahi's

mother, Nailah Winkfield, who spoke of the medical team at Jahi's funeral: "Stop pulling the plug on your people. The doctors – they are not God."²

Jonathan's family asked for outcomes, a prognosis, and for thoughts about what kind of care he would need to get back to normal. This is common in medicine, with physicians and clinicians, often at the request of families, asked to anticipate outcomes and provide a firm prognosis. And sometimes, when those expectations are long surpassed, the parents are understandably and righteously indignant. This survival becomes an integral part of the narrative of that family and that child. Their pride in their miracle child who is walking despite being told that it would never happen or who lives long past what was supposed to be their last birthday is common. The pride in their child is balanced with a healthy dose of "I told you so" and often impacts the ability to hear new prognostications. If we were wrong before, what makes us right this time? Families can perceive this cycle as a medical team underestimating, not believing in, or giving up on their child: a judgement on the child's worthiness to live and the child and family's determination to fight against the odds.

Essentially, the way we frame prognostications with families can create a profound sense that the line between fighting for their child and protecting their child from us becomes blurred.

SPACE AND TIME

Ultimately, Tara walked out of the room and said she was ready for the neurologic tests to begin. Everyone was a bit surprised, maybe even Tara herself. She was admittedly shocked when the first test was complete, in disbelief that the signs they so badly wanted to see were absent. A day later, Tara sat in a chair at the foot of the bed and listened to Jonathan's

favorite Christian song on repeat as the second and conclusive test was completed. No words were spoken. She silenced her music, and we followed her cues that it was time to leave.

In the following days, she no longer questioned the validity of the results of the examination but described what she saw: her son, who looked the same as he did on the day he arrived at our hospital. He did not look like a corpse. His skin was perfect, and he was not decaying. Ultimately, Tara decided to donate Jonathan's organs, which was the only way she could make sense of what happened. She unpeeled each photograph from the wall of the ICU room where they had held the vigil and began her journey back home, many weeks after the initial suspicion of brain death was discussed.

I have thought about Jonathan and Tara and the other families that I have met along their journey to understanding and accepting brain death. I have wondered how a family that felt so certain that Jonathan would wake up with a wry smile and return to himself could move through their resistance from not allowing for brain death testing to then donating his organs. Was it the element of uninterrupted time to process the initial trauma and see no miracle improvement that allowed Tara to let him go? Jahi's brain death testing began just days after her surgery and code event. Jahi's mother said, "[Y]ou need to step back and let God have some time to heal my daughter."⁴

The voices of Tara and Nailah, despite being separated by miles and years, seemingly were asking for the same thing. Did the introduction of a legal progress in the early stages of their trauma drive their efforts? I believe uninterrupted time is essential in cases like these. However, time is not enough. Navigating the complexity of brain death, especially when there is a traumatic element to the injury,

requires medical institutions and clinicians to use a trauma-informed approach to care combined with limitless compassion and empathy. Trauma-informed care means acknowledging the ongoing trauma of the family and responding to their grief and trauma appropriately.⁵ This work requires a multidisciplinary team who can acknowledge the grief associated with an ending no one was expecting and the ability to say, "I'm sorry," and mean it. Families benefit enormously from the empowerment that comes from telling their stories, sharing their beliefs and hopes, and being heard and taken seriously.

OTHER CLINICIAN'S DISTRESS

I have wondered how ICU and neurology clinicians who walk with families facing this diagnosis far more frequently than I do felt when asked to effectively avoid the topic. Exasperated? Likely. Frustrated and even disrespected? Potentially. Concerned about allocation of limited and precious ICU resources? Definitely. We asked to set aside the discussion about the validity of brain death testing and focus on the only thing we could do, which was to figure out how to minimize the additional trauma to Jonathan's family, and see if time and support would allow for more clarity.

How did the bedside nurses, with each titration of medications and introduction of antibiotics, feel? The question they began to ask, "What am I doing to this patient?" was so different from the nursing ethos, which asks, "What can I do for this patient?" I imagine those same questions were present for the bedside nurses in Oakland who were caring for Jahi as the chaos around her swelled.

Did Jonathan's family's politeness or whiteness factor into the way they were approached? They were not staging protests outside of the doors of our institution, like Jahi's family.

They were agreeable in their firm stance and unemotional in their delivery. It mirrored the calm and passive communication culture of our institution. Would the outcome be different had we done things differently? Did we do anything new? And now, would Jahi McMath's family have walked a different pathway with her had the team caring for her responded to their anger, grief, and denial and approached them differently? With these questions in mind, I return to the words of those closest to Jahi: her family. Her grandmother, Sandra, asked, "If the hospital had been more compassionate, would we have fought so much?"⁶

THE MCMATH EFFECT AND LOSS OF TRUST

The "McMath Effect,"⁷ the rejection of a brain death determination by families, has been written about in the years after her brain death determination. Families are more aware than ever that they can refuse brain death testing or refuse to accept the results. Religious leaders and family and community members implore their loved ones to fight, to have faith, and to remain steadfast. In many other circumstances, clinicians are asking families to do this very thing. Yet we, as clinicians, wonder why family members, as nonclinicians, feel they have enough information and the right to question a clinical diagnosis, or in this case, the legal definition of death. "It's like they don't trust us," many people say.

My hope is that each family that walks into a hospital seeking care for medical concerns leaves feeling a sense of trust in medicine. Unfortunately, that is not always the case. Families come with generations of histories, personal experiences, and narratives that reinforce the untrustworthiness of medicine, my family included. I want to say that as a medical social worker, a parent of a patient, a participant of medical

care for myself, and a child of aging adults, I have unlearned the stories of Tuskegee, the data on health disparities, and the narratives of families in my community, but that is not so.

The painful reality is that my personal and professional experiences have reconfirmed the sense of hypervigilance that I see in many families that I support. It is painful to consider the reality of the flaws of the system that we rely on, even more so when that consideration asks us to evaluate our own biases.

It is important to consider the ways in which we, as providers and staff, reinforce the fears people have about us. Nailah Winkfield said, about the care Jahi received, "It was like he thought we were dirt.... No one was listening to us."¹ These words are staggering but serve as a reminder of my point. The way families experience care at our institutions profoundly affects the way they make medical decisions for their children.

This is evidenced by my own experience working with families who feel marginalized or voiceless in the machine of their child's care. More than one family, when considering organ donation after a brain death diagnosis, have asked me which floor the child is on whom we are giving the organ to, having heard that "harvesting organs for transplant" drives a brain death diagnosis. Once, a family whom I met while their child was on extracorporeal membrane oxygenation at the age of 19 recalled the misguided efforts to place their child in foster care while she was in the NICU and the trauma that remained. Their ability to process new changes and trust diagnoses was clouded by those memories, and their resolve to fight was strengthened by their history.

As a palliative care consultant, I have been in many rooms, behind closed doors, when discussing the attempts to explain brain death and have heard

that although there are potentially ancillary studies to aid in diagnosis, they should not be offered because a “whiff” of blood flow on the scan would only introduce doubt that the diagnosis was correct. It could only muddy the picture for the family, prolonging what we knew to be inevitable: the withdrawal of life-sustaining treatment and the death of their child. So if death by neurologic criteria is muddy for us, how can we expect a family who has experienced the trauma of their child going into a surgery, and then later exsanguinating, to find it to be clear?

Families are desperate for their doctors to be wrong, and in my experience, when the doctors are not wrong, and their child is dying or already has died, they are desperate for there to be some meaning in all of this, some legacy that matters.

CONCLUSIONS

Severe brain injury and brain death is a tragedy. The families whom we meet in these cases will start and end each day with the pain of their loss. They will also recall those of us who did or did not see the humanity of their child as they navigated this journey. When we leave the person out of the medical story, or separate the person from their death, we are forgetting the human story and

forgetting that the words we use do not die with our patients.

My hope is that even in our frustration as providers with how Jahi’s McMath story played out and regardless of how you view brain death, we can step back and remember that Jahi McMath is not just a lesson learned but someone’s child. She was a daughter who loved the color purple and dreamed of being a doctor and mothering twins. Her humanity should always be a central part of the discussion.

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