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### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

#### What Should We Do When Families Refuse Testing for Brain Death?

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##### Abstract

Two commentaries respond to a case about apnea testing to confirm death by neurologic criteria.

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##### Case

BJ is a 10-year-old who was pulled from a pool. He was intubated in the field by emergency medical technicians. Cardiopulmonary resuscitation was performed for 30 minutes before his heart started beating again. Upon arrival in an emergency department, BJ was unresponsive, with sluggishly reactive pupils, but no other brain stem reflexes. After being admitted to the pediatric intensive care unit (PICU), BJ was minimally over-breathing the ventilator. Sedated and cooled to 33 °C for 24 hours, BJ was then gradually rewarmed over the next 24 hours. Three days after rewarming and discontinuation of sedation, BJ did not over-breathe the ventilator and remained comatose with no brain stem reflexes. After another 3 days, BJ's condition did not improve.

Eight days after BJ's admission to the PICU, Dr F obtained a cranial computed tomography scan that showed diffuse sulcal and cisternal effacement, loss of gray-white borders, and herniation. Dr F now explains to BJ's parents that BJ is probably "brain dead" and that the next step in BJ's care is to perform a clinical examination to look for evidence of brain activity. Dr F further explains that patients with no signs of brain activity are taken off the ventilator to see whether they breathe spontaneously. Although BJ's parents are upset, they express understanding and agreement with Dr F's assessment plan.

Dr F performs the clinical assessment in accordance with the Society of Critical Care Medicine, American Academy of Pediatrics, and Child Neurology Society 2011 standards<sup>1</sup> and concludes that BJ is comatose with no brain stem reflexes. With BJ's parents at the bedside, Dr F performs an apnea test, regarded as a critical part of a

brain death diagnosis examination,<sup>2</sup> and finds that BJ does not breathe, despite a rise in carbon dioxide partial pressure to 110 mm Hg.

BJ's parents express concern that BJ looked uncomfortable being off the ventilator during the apnea test. Dr F responds, however, that the apnea test results<sup>3</sup> suggest that BJ is brain dead and that the exam and the apnea test must be repeated to confirm this conclusion. BJ's parents state that they've read online that apnea testing can be dangerous, emphasize that they never consented to an apnea test, and reiterate that they refuse to allow the apnea test to be repeated.

Dr F wonders how to proceed.

### **Commentary 1**

by Robert D. Truog, MD, MA

As a pediatric intensive care physician and anesthesiologist, I have diagnosed brain death more times than I can remember, and I have been in Dr F's shoes on many occasions. Based on this experience, I have come to believe that the medical profession has not been truthful with patients and families about the **meaning of brain death**. Drawing from the well-known case of Jahi McMath, the medical literature, and my own experience, I have suggestions for how we can communicate more honestly and effectively with patients and families. I will also offer some concrete advice that I would give to Dr F about how to proceed.

#### **Jahi McMath**

Jahi McMath was a healthy 13-year-old when she underwent pharyngeal surgery for obstructive sleep apnea.<sup>4</sup> That evening, she began spitting up blood. This progressed to a massive hemorrhage and cardiac arrest. She was successfully resuscitated but suffered severe hypoxic brain injury and was diagnosed as brain dead 3 days later.

For readers unfamiliar with what patients who are brain dead look like, it is likely that Jahi looked very similar to other sick children in the intensive care unit (ICU): her eyes were closed, she did not respond to her mother's voice, and she needed a ventilator to breathe. Visually, it would not seem unreasonable for Jahi's mother to question why clinicians were telling her that Jahi was dead; other children in the ICU that looked just like Jahi were getting better. Nevertheless, when Jahi's mother asked about the discrepancy between what she saw and what she was being told, one clinician allegedly responded, "What is it that you don't understand? She's dead, dead, dead."<sup>5</sup> This response seemed to imply that Jahi's mother was simply unable to understand what was obvious to everyone else. In fact, however, Jahi's mother was perceiving the situation clearly. Let me explain why.

#### **Origins of the Concept of Brain Death**

Brain death was standardized in US law in 1980 with the Uniform Determination of Death Act (UDDA). The UDDA provides 2 pathways for diagnosing biological death: (1) the irreversible loss of cardiorespiratory function (how most people die) or (2) the irreversible loss of all functions of the entire brain (a way of dying that can only happen when patients are being mechanically ventilated in an ICU). Its framers were very careful to state that they were not "redefining" death.<sup>6,7</sup> Death was, they insisted, characterized biologically as irreversible loss of integrated functioning of the organism as a whole. Scientifically, death is fundamentally the same across the biological spectrum; we speak

of dead animals, dead plants, and dead people. Death is always followed by disintegration and putrefaction. Dust to dust.

The reason brain death is just an alternative way of diagnosing biological death, Bernat et al explained, was because the diagnosis was invariably and quickly followed by disintegration of the body.<sup>7</sup> Use of a ventilator could slow the process down, but only temporarily. Even with mechanical life support, they claimed, the heart would stop and a body would begin to decompose within a week or two.<sup>7</sup>

These concepts have been taught to physicians ever since the UDDA was introduced. One international expert on brain death recently affirmed: physicians “globally ... now invariably equate brain death with death and do not distinguish it biologically from cardiac arrest.”<sup>8</sup> New guidelines on brain death from the American Academy of Neurology also consider “death to be a ‘unitary phenomenon’ regardless of causation, resulting from either irreversible failure of brain or circulatory function.”<sup>9</sup> When the physician asked Jahi’s mother, “What is it that you don’t understand?,” he was expressing what he, and I, and most physicians have been trained to believe: brain death is biological death, just as cardiorespiratory arrest is death. But there is a problem with this view: it is wrong.

### **Traditional Understanding of Brain Death**

Evidence of why this prominently accepted view of death is wrong comes primarily from the work of a pediatric neurologist, Alan Shewmon. Over the years, he has meticulously documented dozens of cases of prolonged biological survival after a diagnosis of brain death.<sup>10</sup> One of the most dramatic cases involved a young boy diagnosed as brain dead from bacterial meningitis at the age of 4, who was supported with a ventilator and tube feedings for 20 years before succumbing to cardiac arrest and biological death. At autopsy, he had a completely calcified brain. No neural tissue could be identified, grossly or microscopically.<sup>11</sup> As counterintuitive as it might seem, the biological truth is that the body does not need a brain in order to maintain integrated functioning.

Perhaps this should not be surprising. Across the biological spectrum, many organisms survive with only rudimentary nervous systems. While a human brain might be what makes human life worth living, it is not necessary for sustaining biological life. Cases of prolonged biological survival after a diagnosis of brain death happen regularly. Jahi McMath survived for almost 5 years—supported with tube feedings, mechanical ventilation, and occasional hospitalization. She lived with her family in their apartment, where she grew and went through puberty.<sup>4,5</sup> More recently, a woman was found to be 9 weeks pregnant after she was pronounced brain dead following a traffic accident.<sup>12</sup> After several months in the ICU, she vaginally delivered a healthy baby boy and then, remarkably, also donated organs for transplantation. It simply defies the laws of biology to think that any organism could give birth to offspring several months after being biologically dead. It may not be surprising at all, however, if we recognize that she was alive during that time, albeit with a severe and nonrecoverable brain injury.

One might ask why these cases are not more common. One answer is that a diagnosis of brain death is almost always a self-fulfilling prophesy. That is, once testing is complete, a physician completes a death certificate, and the patient’s family can then choose to donate their loved one’s organs or terminate ventilation, pathways that both lead rapidly to biological death. Most families have no desire to prolong the biological life of a loved one who will never recover consciousness. But in the rare cases in which

families refuse to accept a brain death diagnosis and mechanical ventilation is continued, we should not be surprised when prolonged biological survival is the outcome.

### **Explaining What Death Is**

If brain death is not biological death, then what is it? Brain death unquestionably involves an exceedingly severe brain injury. Although there is some debate (beyond the scope of this article), most neurologists believe that brain death represents a state of irreversible apneic unconsciousness. In other words, when a patient is correctly diagnosed as brain dead, we can be highly confident—even if not absolutely certain—that a brain-dead patient will never regain consciousness or be able to breathe on their own. So, how should Dr F explain this to BJ's parents? Let me suggest 3 approaches that I think could be helpful.

First, I would advise Dr F to remain nonconfrontational and to make every effort to understand the situation from the family's perspective. Specifically, I would explore whether family members are objecting to the diagnosis itself or instead taking a confrontational stance out of anger related to other aspects of their care. In the McMath case, for example, the parents primarily were angry because they believed that Jahi had not received appropriate care and that the hospital was not forthcoming in explaining what happened.<sup>4,5</sup> People of color are often distrustful of doctors and hospitals—and for good reason, since our health care system has a long history of racial injustice. At a later time, Jahi's mother stated: "If her brain is jelly, we are going to have to accept that. I don't think people should live on that way. If they're gone, they're gone."<sup>5</sup> In other words, had Jahi's family been treated honestly and with respect at the beginning, it's not clear that the family would have objected to the diagnosis of brain death. I would encourage Dr F to explore this possibility in the most compassionate way possible.

Second, if the family is truly objecting to the diagnosis of brain death, I would explore the reasons for their position. Of the many families that I have worked with that have refused testing for and diagnosis of brain death, I can remember only 2 cases in which the objection was based on deeply held religious beliefs. In all of the other cases, the parents were grieving and struggling to come to grips with the fact that their child had sustained a devastating brain injury, recovery from which was impossible. Objecting to the diagnosis or the testing was the only way they could put off the inevitable and avoid having to face the sad truth of their loss. In almost all cases, giving family members a few days to grieve, to allow the facts to sink in, and to receive the support of other family members, friends, social workers, and spiritual counselors will be sufficient to help them to accept the diagnosis. Most families don't want to sustain the life of a loved one who will never wake up, any more than clinicians want to participate in care that is essentially futile. I would therefore advise Dr F to work with his colleagues and the hospital administration to give the family a few days, knowing that in most cases time will resolve the conflict without confrontation.

Third, what should we do when the refusal of the family is not just denial or an expression of complicated grief but stems from deeply held moral or religious objections to the diagnosis of death by neurological criteria? It is widely known that some branches of Orthodox Judaism hold that as long as breathing is occurring (even if it requires a ventilator), then the patient is alive. In my mind, there is nothing illogical or inherently unreasonable about this position. How should we respond?

I'm not sure of my own views on this subject. On one hand, we know that New Jersey has had a religious exemption to the determination of death by neurological criteria for over 25 years.<sup>13</sup> To my knowledge, there is no evidence that this law has affected the utilization of ICU beds or the donation of organs for transplantation in any significant way. If we can respect individual religious beliefs without significant impact on others, I think there is a strong presumption that we should do so.

On the other hand, our government is not obligated to **respect all religious beliefs**. Many Mormons believe polygamy is ethical and a part of their religion, and yet polygamy is illegal and not tolerated in the United States. I do not think it would be unreasonable for the government to hold that ICU care for patients who are almost certainly never going to wake up is a misuse of the health care system, regardless of whether or not the family can pay for the services. Brain death is legal death in our society, and I can understand the logic of simply telling families that this is the law and that they must comply. Since I think it could be ethically justifiable to either defer to the family's religious beliefs or to overrule them, I would support whatever position was taken by existing state law and hospital policies. I would suggest that Dr F do the same.

### **Conclusion**

Devastating brain injuries that lead to the diagnosis of brain death are always tragic. This tragedy is further compounded when families find themselves in opposition to the doctors and nurses who are caring for them at a time when they are grieving the unexpected loss of a loved one. As I have described in this paper, I believe we wrongly and needlessly compound these problems by not being honest with families about the meaning of brain death. I have also outlined 3 strategies for compassionately but effectively addressing objections to the diagnosis: exploring sources of the family's anger and distress that may be unrelated to the diagnosis; being as accommodating as possible in giving the family time to grieve and to come to acceptance of the situation; and considering how to respond to families who hold deep religious views about the diagnosis of death by neurological criteria. Responding to families' religious objections is the least common but probably the most difficult scenario, and I think arguments in favor of deferring to the family or overriding their demands can both be supported.

### **Commentary 2**

by Wynne Morrison, MD, MBE and Matthew Kirschen, MD, PhD

Before discussing the "right" way to approach the case presented, it is important to acknowledge how horribly sad it is—devastating for this family, tragic for the child, and emotional for the clinical team. While our discussion will focus on areas of disagreement among the parties involved, all are connected as unwilling witnesses in this unimaginable situation.

When a patient has suffered a catastrophic brain injury that is complete and irreversible, the appropriate next step in the patient's care is to determine if the patient meets criteria for death by neurological criteria (DNC).<sup>14</sup> Some have argued that there is a medical duty to make this determination and therefore permission should not be sought from surrogate decision makers to initiate the evaluation.<sup>15</sup> Others have argued that respect for varied cultures within a pluralistic society mandates that surrogates be allowed to refuse the DNC evaluation if they do not accept the concept of using neurologic criteria to determine death.<sup>16</sup>

### **Risks of Apnea Testing**

The apnea test is of particular concern because of its risks, which include hypoxemia, hypotension, and arrhythmias. These risks are low, especially if standardized protocols—including preoxygenation—are followed.<sup>17,18,19</sup> If hypoxemia or hypotension occur during apnea testing, stability is usually rapidly achieved by aborting the test.<sup>20</sup> For patients judged to be at high risk of cardiopulmonary decompensation during apnea testing, ancillary testing can be substituted to support the clinician's DNC determination.<sup>14,21</sup>

We contend that these risks are similar to the risks of other procedures in critical care for which separate consent is not typically sought (eg, titrating vasoactive infusions, adjusting ventilators, transporting patients for diagnostic studies). For many such interventions in medicine, clinicians simply discuss the need for the intervention with the patient or family, answer questions, and proceed. The “informing” component is present, but the “consent” looks much more like tacit agreement or nonobjection.

### **Seeking “Permission” Is Problematic**

In our practice, we approach discussions about the determination of DNC—including apnea testing—as information sharing rather than decision making. We prepare the family members early for the range of possible outcomes from catastrophic brain injury, including death. We assure them—by both words and actions—that we are doing everything possible to facilitate recovery and prevent secondary brain injury. We use *aligning language* by explaining that if the outcome is a severe but nonfatal brain injury, “we” (family and team both) will have difficult decisions to make about whether to continue technological support. However, if the patient is determined to be dead by neurologic criteria, there is no need to make further decisions, as there is no indication to continue technological support.

When performing an evaluation for DNC, we inform the family that we are conducting a comprehensive and protocolized examination (with checklist in hand) to look for any sign of neurological function. By allowing families to be present for the examination and apnea test, we hope to give them an appreciation of the patient's lack of response to the varied stimuli. We have had family members afterwards say, “We saw how hard you tried.”

We do not usually ask family members if they *want* us to do the exam. How could anyone ever want such a thing? We explain that it is the medically appropriate time to do it, inform them about the process in an accessible way as best we can, and proceed. In that sense, we argue that *consent* is not necessary for the neurological examination or apnea test but that *informing* is mandatory. And just as we don't ask permission for the evaluation, we also do not ask permission to stop technological supports after the DNC determination. We simply explain that it is the appropriate next step.

### **Responding to Objections**

The case presented offers a different dilemma, however. This family is actively objecting to performance of the apnea test. We hope to avoid such situations, but it is not always possible. While we don't ask a family for permission to initiate the DNC evaluation, it is altogether different to override an active objection.

If we can't talk the family through why the evaluation is important, we pause. If the case is one of preexisting, culturally consistent objections to the concept of DNC, we involve

clinical and administrative leaders, as well as ethics and legal consultants, to determine a unified approach before deciding whether to proceed with an evaluation despite objections. Slowing things down can allow time for the medical team and family to listen to each other and hopefully agree on a common approach.<sup>22</sup> Team members may struggle if they feel they are providing **nonbeneficial care** and may need support. If it is the safety of the apnea test itself that concerns the family, then an ancillary test can be substituted.

For some medical choices, one path is clearly more appropriate than others.<sup>23</sup> In this case, determining whether the patient fulfills criteria for DNC is clearly the standard; avoiding the evaluation will not return the patient to health in the long run. We shouldn't offer choices that don't make medical sense.<sup>24</sup> And yet, at the same time, we believe that overriding active objections should never be done lightly.

Some would argue that these 2 positions are contradictory. We claim, instead, that they are both patient and family centered. Many families would indeed prefer not to be given a choice about initiating a process that could confirm their child has died. We have worked with families who initially objected to the evaluation but later expressed relief when it was explained that difficult decisions would be out of their hands if death was determined. The medical teams should be guides on this path, not bulldozers.

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#### Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

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Dr Truog serves as a paid consultant on data safety monitoring committees for Sanofi and Covance and Dr Morrison is the Children's Hospital of Philadelphia's liaison to the regional organ procurement organization and in that capacity has spoken at several conferences. Dr Kirschen had no conflicts of interest to disclose.

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