

This section provides reactions to current and emerging issues in bioethics.

“Brain Death,” “Dead,” and Parental Denial

The Case of Jahi McMath

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The case of Jahi McMath—a 13-year-old girl who, on December 9, 2013, suffered a massive hemorrhage following a tonsillectomy at Oakland Children’s Hospital and who three days later was diagnosed as “brain-dead”—has occasioned a widely publicized dispute between the girl’s physicians and her family on whether or not to withdraw “life-sustaining” medical interventions. Unlike the now-infamous Terry Schiavo case,¹ in which the patient was alive but in a permanent vegetative state, Jahi McMath is not only nonresponsive but also brain-dead. Given that medical finding, under California law (and that of every other state), she is legally dead.

California Codes Health and Safety Code section 7180 reads: “An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.”²

Jahi McMath’s determination of death was made in accordance with those standards.

Her parents, who had seen her alert after the surgery, were stunned when they were informed their daughter was brain-dead. Because Jahi was legally dead, the doctors told the family that they were going to remove life-supporting interventions. Jahi’s mother protested that because her daughter was breathing, her heart was beating, and her body was warm and moist, she could not be dead. Although the diagnosis of brain death was confirmed by two staff physicians and three independent specialists,³ the mother, now aided by an attorney, sought an injunction from an Alameda County Superior Court judge for the appointment of a “neutral” neurologist to assess the patient’s medical status. The court appointed the chief of pediatric neuro-oncology at Stanford University to examine the girl and report his findings to the court. In the meantime, the parents stated that they were praying for a “Christmas miracle.”

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After completing multiple tests on the girl, the neurologist concluded that she was, indeed, brain-dead. He reported his findings to the court on December 23rd. The judge accepted the findings as definitive: Jahi McMath was “legally dead.” The judge—who, when he accepted the neurologist’s report, was quoted as saying, “I wish I could fix it, but I can’t”⁴—noted he had no choice but to allow the hospital to remove the ventilator. But rather than immediately issuing an order authorizing the physicians at Oakland Children’s Hospital to withdraw all medical interventions, the judge instructed the family that they had until December 30th to appeal his decision. In the meantime, the ventilator was to remain in place. The delay had the effect of shielding the court and the hospital from the adverse publicity that would accompany the delivery of a corpse to the distraught family on Christmas.

Once the hospital and the family lawyered up, the issues spiraled out of control.⁵ The family joined demonstrators picketing the hospital and demanding “Justice for Jahi.” They also sought to have a retired Ohio neonatologist, Dr. Paul Byrne, who had published an article in *JAMA* opposing brain death,⁶ “examine” the girl. Byrne and colleagues insisted in their essay that destruction of the brain, not merely cessation of functions, is required for death. Lest there be any doubt as to their standard for irreversible function, the authors provide examples of evidence of death: “If someone’s head has been completely crushed by a truck or vaporized by a nuclear blast, or if his brain has been dissolved by a massive injection of sulfuric acid.”⁷

Historical Background on the Diagnosis of Brain Death

Alexander Capron, the executive director of a presidential commission that issued the definitive report on death, titled

Defining Death,⁸ wrote an article some twenty years after the publication of that report with the telling title “Brain Death—Well Settled Yet Still Unresolved,”⁹ in which he noted that until the middle of the twentieth century, the determination of death was a relatively simple measurement of vital signs: a beating heart and breathing lungs. With modern technological advancements, however, there are a growing number of patients who, though they suffer profound neurological injury, are able by mechanical means to maintain cardiac and respiratory functions.

As the McMath case demonstrates, the ethical dilemma is not how to apply medical treatments but whether to do so. The answer depends, in part, on defining our terms. Failure to distinguish between patients who are “dead,” “brain-dead,” “in a chronic vegetative state,” “minimally conscious,” “comatose,” or “terminally ill but conscious” is a source of endless confusion. In each of these instances, it might be appropriate to remove invasive technologies; in some of them it is morally imperative to do so. Medical resources ought not be expended ventilating someone who is dead.

How then do we know when a person is dead? The traditional answer, as Capron noted, was simple—if there is no pulse or respiration, the person is dead. In the postbiblical language of the theologians, “the soul has left the body.” What remains is no longer a person, but a corpse. Because death is a common phenomenon and every jurisdiction had statutes on that subject, one might legitimately inquire why the concern and, more importantly, why the expenditure of time and effort on defining death. In part, the need was a response to emergent technologies. A more significant rationale was the need for a broad-based social consensus on when death has occurred. The then mismatched understanding—according to which the

same body would be "dead" in one state and "alive" in another or, worse still, "dead" for some purposes but "alive" for others in the same state—resulted in widespread variations in medical practice, differences in legal expectations, and confusion among the general populace.

An example of the chaos that existed before the universal adoption of the Uniform Determination of Death Act¹⁰ was the case of Melanie Bacchiochi,¹¹ a twenty-three-year-old Connecticut woman who went to the dentist to have her wisdom teeth extracted. While under anesthesia, she suffered cardiopulmonary arrest, was rushed to a local hospital, and was intubated and mechanically ventilated. Despite the initial hopes that she would recover consciousness, after several days it was clear that she was brain-dead. Because Connecticut at that time had no brain-death statute, the common law understanding of death as irreversible cessation of the heart and lungs prevailed. Her physician, Dr. Evans Sawyer, announced that, even if he lived to be 150, he would not remove a respirator from a brain-dead patient without a court order that would immunize him from a potential homicide charge.

When the case went to court, the superior court judge found himself in a strange predicament. Connecticut has the Uniform Anatomical Gift Act, under which, had Melanie Bacchiochi been an organ donor, she would have been legally dead. However, the brain-death section of that act did not appear in the general statutes, and so its application was confined to organ donors. In a series of hearings over some three weeks, the judge wrestled with the dilemma of how to rule on the withdrawal of a ventilator from a patient who would be legally dead if she were an organ donor but who, in the absence of a signed donor card, was not legally dead. Ultimately, he returned the problem to the medical community by issuing a finding that the

patient was brain-dead and suggesting the physician act in a way consistent with that finding. The physician, without a grant of immunity, removed the ventilator. Shortly thereafter the patient's heart stopped. At that point the physician pronounced her dead.

A more complex case—and one in which the definition of "death" was badly confused by the appellate division of the New York State Supreme Court—was that of Brother Joseph Fox.¹² Fox, an 82-year-old religious brother from Chaminade High School in Mineola, New York, had entered Nassau Hospital for a hernia operation. While in surgery he suffered cardiopulmonary arrest, was resuscitated, and was placed on a mechanical ventilator. After several days of neurological examinations, the physicians determined that, though he was not brain-dead, Fox had suffered permanent, irreversible brain damage and would continue to exist in a chronic vegetative condition. His family and his guardian, Philip Eichner, asked the physician to remove the ventilator. The physician and the hospital refused, on the grounds that it was their moral duty to preserve life.

Eichner brought suit for injunctive relief, and the trial court authorized the removal of the machine. The district attorney appealed. In a comprehensive and wide-ranging opinion on the ethical and legal aspects of the removal of treatment from incompetent patients, Justice Milton Mollen of the appellate division upheld the trial court's decision. In the course of his opinion for a unanimous court, Justice Mollen explained that it was appropriate to remove a respirator from a chronic vegetative patient because

as a matter of established fact, such a patient has *no* health and, in the true sense, *no* life for the state to protect. . . . Indeed, with *Roe* (abortion opinion) in mind, it is appropriate to note that the State's interest in preservation of the

life of the fetus would appear *greater* than any possible interest the state may have in maintaining continued life of a terminally ill comatose patient . . . (whose) claim to personhood is certainly no greater than that of a fetus.¹³

Here, with no further warrant than the force of its own decree, an important appellate court issued a new definition of death. If that ruling stood unchallenged, patients in a persistent vegetative state—that is, patients suffering only upper-brain as opposed to whole-brain demise—would be dead. Under that standard, if she were transferred to New York, Karen Ann Quinlan, who was then in a persistent vegetative condition in a New Jersey hospital, would be dead. On further appeal, the New York Court of Appeals, that state's highest tribunal, voided all of the appellate division opinion except the ruling authorizing the termination of treatment.¹⁴

The confusion caused by piecemeal legislation and judicial decisions in an area as important as the determination of death led to the establishment of the president's commission with a mandate from Congress to formulate a socially acceptable, common understanding of death. In its year-and-a-half-long study of the problem, the commission solicited opinions and heard testimony from a wide variety of medical, legal, ethical, religious, and social viewpoints. It examined the emergence of a medical consensus in favor of the 1968 Harvard criteria for the determination of brain death¹⁵ and explored various philosophical and religious understandings of death. The transcripts of its hearings present a veritable treasure chest of opinions: death is when the soul leaves the body, death is the loss of "personal identity," death occurs with the loss of vital fluid flow, death is the moment at which the body's physiological system ceases to constitute an integrated whole,

and so on. Included among the views was the eighteenth-century text of Jacques-Benigne Winslow, *The Uncertainty of the Signs of Death and the Danger of Precipitate Interments*, in which the author argued that putrefaction was the only sure sign of death.¹⁶

Winslow's worry of premature burial found its modern iteration in the concern articulated in testimony before the commission by Paul Quay that medical science wants a precipitous declaration of death for the purpose of organ transplantation. Quay's fear and that of other critics of a change in the determination of death to include cessation of all neurological activity in the entire brain, including the lower brain stem, is that physicians would be willing to "kill someone who is alive" in order to obtain transplantable vital organs.¹⁷

The artificial respirator and concomitant life-support systems have changed the once-simple test of death as cessation of the heart and respiration. Without life-support machinery, respiration ceases when the neural impulses between the brain and the diaphragm are interrupted. However, an artificial respirator can be used to compensate for the inability of the thoracic muscles to fill the lungs with air. This process can disguise the physiological reality of what has occurred. The patient, though "clinically dead," can by artificial means be kept looking well, with a beating heart, respiration, and warm, moist skin. These ever more refined capabilities developed by biomedical science to support or supplant certain vital functions have created new problems in diagnosing death. What appears to be alive is in fact dead.

From the outset, the commission was determined to take "extreme caution" in formulating public policy in this area. To that end, it took a measured posture in its hearings, in its findings, and its final report. It evaluated, but did

not accept, the philosophical understandings of death as the loss of personality or personal identity. In its evaluation the commission noted that there was no consensus among the theorists on what constitutes personhood, nor is there an acceptance among physicians or the general public of such a definition. Furthermore, such an approach raises the problem of the "personality" of the severely senile and profoundly retarded as well as the specter of eugenic determinations of who should live and who should die. That prospect brought about the commission's condemnation of "any argument that classified these individuals as dead."¹⁸

The commission likewise studied and rejected the proposal that "death" be defined as the permanent loss of higher brain function. In the commission's understanding, those who, like Karen Ann Quinlan¹⁹ and Nancy Cruzan,²⁰ incur such massive brain cell destruction that they will never recover from the permanent vegetative state are not dead. In so finding, the commission rejected Justice Mollen's attempt to extend the definition of nonlife to those who have suffered a permanent loss of consciousness. The commission also dismissed the extremist position that death is not ascertainable until there is scientific evidence of "disintegration of individual organ and tissue."²¹ That theory not only defies common sense but also places intolerable costs on scarce community resources and an insufferable burden on grieving families.

The commission adopted the widely accepted whole-brain death standard: that is, death is established when "all functions of the brain including the brain stem have permanently and irreversibly ceased."²² The commission made it clear that, in measuring such functions, physicians are concerned not with isolated activity in cells or groups of cells but with what significance such activity

has for the organism as a whole. It was also clear that the commission recognized the fact that artificial supports may mask the loss of integration and thereby block off the traditional recognition that death has occurred. The brain-oriented criteria provide a new opening by which we may see the same phenomenon once measured by a loss of vital signs. Thus, even if life continues in individual cells or organs, without the complex integration of the entire system, "a person cannot properly be regarded as alive."²³

This distinction between systemic, integrated functioning and physiological activity in cells or individual organs is important for two reasons. First a person is considered dead under this concept even if oxygenation and metabolism persist in some cells or organs. There is no need to wait until all metabolism has ceased in every part of the body before recognizing that death has occurred. More importantly, this concept would reduce the significance of continued respiration and heartbeat for the definition of death. These, though necessary for life, are not sufficient in themselves to establish it. In the presidential commission's view, when an individual's breathing and circulation lack neurologic integration, he or she is dead. The commission proposed a uniform standard that has been adopted with slight variations in every state and in 79 foreign nations.

Despite the broad acceptance of the determination of death by neurological criteria, certain critics continue to assail that approach. Foremost among them are Robert Truog and Walter Robinson²⁴ of Harvard Medical School, Robert Veatch²⁵ of Georgetown, and D. Alan Shewmon²⁶ of UCLA Medical School. Veatch argues that the loss of "personhood" from a biological body would be a more societally acceptable norm for death. Shewmon maintains that a statutory definition that a brain-dead

body is “dead” is not an adequate biological assessment of the physiological reality. Truog and Robinson make a broader criticism. For them, brain death is not death. Instead, it is a useful fiction to facilitate organ transplantation. Truog and Robinson propose that, rather than adhering to a dead-donor rule before transplantation of vital organs, individuals who are neurologically devastated or imminently dying should be allowed to donate their organs without the necessity of being declared dead.

Another source of criticism comes from a group within the ultraorthodox Jewish community headed by Rabbi David Bleich, who insist that the Hebrew scriptures require irreversible cessation of cardiopulmonary activity as the exclusive determination of death. The political strength of that community led to legislation in New Jersey that provides an exception to brain-death criteria for those who have a deeply held religious objection to the determination of death other than by heart and lung criteria.²⁷ Although New York’s statute does not provide a religious exemption, it does call on hospitals to make a “reasonable accommodation” for families who reject neurological criteria.

Family Refusal to Accept Brain Death as Death

Capron has observed that because brain-dead patients show such traditional signs of life as warm, moist skin; a pulse; and breathing, it is not surprising that many people believe brain death is a separate type of death that occurs before “real death.” Jahi McMath’s mother is such a person. On seeing her daughter connected to machines, she commented, “She’s warm and soft. She is not cold and stiff like death. She smells good and when I rub her feet she pulls away. . . . She is not dead. She [just] needs time to get better.”²⁸ The mother went even

further when she declared, “In this country, a parent has the right to make decisions concerning the existence of their child: not a doctor who looks only at lines on a paper, or reads the cold black and white words on the law that says ‘brain dead.’”²⁹ The mother’s bottom line: “Jahi is dead only if her heart stops.”³⁰

Ongoing Action in the McMath Case

As the December 30th deadline set for the family to appeal his ruling neared, Alameda County Superior Court judge Evelio Grillo extended the deadline to January 7th. During that interval the girl’s family told reporters that they had located an unnamed facility in New York willing to take Jahi, and the family was seeking donations on GoFundMe.com to help defray the cost of transporting her to New York. By January 7th some \$58,777 had been raised.

Judge Grillo had decreed that Jahi was brain-dead on December 24, 2013. He then twice ruled that the hospital had to hold off on disconnecting life support to give the family time to come to some resolution. Because the girl’s body could not be released from the hospital without a death certificate, on January 3, 2014, the Alameda County coroner issued such a document. It listed the date of death as December 12, 2013, the date the Oakland Children’s Hospital neurologist had first determined Jahi McMath brain-dead.

Following the issuing of the death certificate, the coroner, with court approval, authorized the family to take custody of the “dead girl.” The family had already notified the media that they had arranged to transport the brain-dead girl to an outpatient rehabilitation facility in Medford, New York, called New Beginnings Community Center. The facility’s website states, “This child has been defined as a deceased person

yet she has all the functions attributable to a living person despite her brain injury." The site also informs the reader that New Beginnings's founder, Allyson Scerri, "graduated from cosmetology school in the early 1980s and immediately began her successful career as a hair stylist, continuing in this profession for some 25 years." There is no mention of any further "professional" training other than her "meeting many people and hearing their unique stories."³¹ All that is known of Jahi McMath's physical condition is that, after her transfer from Oakland Children's Hospital, she underwent a tracheotomy and placement of a gastrostomy tube, surgeries that the physicians at Oakland Children's Hospital had refused to perform as "unethical procedures on a corpse."³²

Earlier Cases of Parental Refusal to Accept Brain Death as Death

Jahi's mother was not the first parent to challenge a hospital's desire to terminate ventilator support for a brain-dead child. In 1994 the parents of a young girl at Florida's Sarasota Memorial Hospital refused to accept that the medical diagnosis of "brain-dead" meant their daughter was dead.³³ The patient, Theresa Hamilton, a 13-year-old severe diabetic, was admitted to the hospital on January 7, 1994, for flu-like symptoms. She soon lapsed into unconsciousness. When brain scans showed no neurological activity and no blood flow to her brain, she was diagnosed as brain-dead. Under Florida's statute she was legally dead.

As frequently occurs in such cases, rather than declaring the patient dead, hospital officials and doctors urged the family to discontinue the life-support systems that were still oxygenating her body. The family, presented with that option, refused. They would not authorize the removal of the ventilator

from the daughter whose beating heart and warm body were proof to them that she was still alive. Because the physicians at Sarasota Memorial Hospital were unwilling to act without the family's permission, the stalemate went on for some five weeks. All the while, the ICU costs of \$3,240 per day for the uninsured child continued to mount.

The nursing staff in the ICU became increasingly restless with the role they were being asked to perform. The hospital's solution to the situation was to agree to the parents' request that they be allowed to take their daughter home. Because there was no insurance and the family had no other means of providing medical equipment for her, the hospital agreed to pay for the ventilator, hospital bed, intravenous units, and the home healthcare nurses required to "care" for her at home. The child was sent home about two months after hospital admission and was "maintained" there for eight weeks until cardiac failure ended the family's hope for a miracle.

Another case of parental refusal to accept a diagnosis of determination of death by brain criteria occurred in New York City in 1994, when a 16-year-old Orthodox Jewish rabbinic student who was the victim of a gunshot attack on the Brooklyn Bridge was brought to St. Vincent Hospital and pronounced brain-dead.³⁴ Rabbis for the boy's family told the physicians that their religious beliefs dictated that "he be kept on the support systems as long as his heart could beat on its own."³⁵ Faced with a politically charged case that attracted the attention of then-president Bill Clinton and Governor Mario Cuomo, the hospital agreed to continue life support on the brain-dead boy. The issue was rendered moot three days later, when the boy's heart stopped. Similar cases also occurred in Utah in 2004³⁶ and Washington, DC, in 2008.³⁷

If brain death were rapidly followed by cardiac cessation, as happened with the aforementioned young rabbinical student, a delay allowing families a few days to grieve might be a reasonable accommodation. But, as the Theresa Hamilton case illustrates, not all brain-dead bodies succumb quickly to cardiac stillness. Parisi and colleagues give a detailed medical report on a 49-year-old brain-dead man who was "maintained" for 74 days until a court-ordered discontinuation of ventilator support resulted in electrocardiac silence.³⁸ And Shewmon's meta-analysis of 56 patients in a confirmed brain-dead status demonstrates that the bodies of younger brain-dead patients can be maintained with only basic nursing care for several years.³⁹ These cases, along with the bizarre case in Texas of a brain-dead pregnant woman being maintained on life support over her family's objections for two months—to serve as an incubator for a 14-week gestational age fetus⁴⁰—demonstrates the social price of not following widely accepted neurological criteria for determination of death.

Discussion

The Jahi McMath case was the perfect storm. A 13-year-old girl is admitted to Oakland Children's Hospital for what her family described as a routine tonsillectomy. The outcome of the multifaceted surgical procedures to remove the tonsils, adenoids, and uvula and to perform a submucous resection of bilateral inferior turbinates proved anything but routine. Within three days of the surgery, massive bleeding resulted in the girl being diagnosed as brain-dead. The physicians at Oakland Children's Hospital wanted to remove the ventilator that was artificially maintaining her heart and respiration. The parents refused. They sought a court order to block the physicians from removing life support.

The very terms used to describe what was occurring are confused and confusing. How do physicians provide "life support" to a dead body?

The historic mistrust of African Americans toward the medical community was on full display at community-organized demonstrations outside Oakland Children's Hospital. Accusations were made that the hospital disrespected the family, portrayed the parents as "ignorant," and "wanted a quick end to Jahi's life" to limit malpractice costs.⁴¹ The fact that the oxygenated body appeared "warm and alive" rather than "cold and dead" created a problem of perception. If her heart is beating (albeit only by virtue of mechanical assistance from a ventilator), how, asked her tearful mother, can she be dead?

Even without the overlying epistemological problems of determination of death by neurological criteria and the widespread tendency of denial with regard to death and dying,⁴² thrusting the controversy into court is a formula for disaster. In this case, though the statutory criteria for diagnosis of brain death had been met and the trial judge had determined that the patient was legally dead, the judge was still unwilling to authorize the withdrawal of life-supporting medical interventions. This reluctance ought not come as a surprise to those familiar with Dostoevsky's insight that human nature does not want to accept responsibility for difficult, anxiety-producing decisions. As we have earlier written in *CQ*, "the desire of parents and sometimes of physicians to avoid responsibility for the death of a patient . . . can be overwhelming."⁴³ The same proves true of judges. Ambiguity, anxiety, doubt, and guilt, in Dostoevsky's view, are not qualities to be sought but burdens to be shunned. Although the judge in the Jahi McMath case carefully applied the applicable

statute to the fact situation, when faced with responsibility for ordering the termination of life support on a dead body—a responsibility the hospital and the physicians eagerly deferred to the court—the judge balked.

The approaching celebration of Christmas provided the first rationale for postponing the withdrawal of medical interventions. When the post-Christmas deadline approached, the judge extended the deadline another week, thereby providing the family with more hope. This happened in a case in which the judge had already declared the girl dead and the coroner had issued a death certificate.

In a justly renowned essay entitled *The Nature of the Judicial Process*, Judge Benjamin Cardozo commented on the role of a judge. In his words, "He is not a knight-errant, roaming at will in pursuit of his own ideal of beauty or of goodness. He is to draw his inspiration from consecrated principles. He is not to yield to spasmodic sentiment, to vague and unregulated benevolence."⁴⁴ Rather, he noted, a judge is restricted by the "discipline of the system" of law. In a commentary on that statement, Judge Warren Burger, later the chief justice of the United States, observed, "We should heed Cardozo's counsel of restraint and reconcile ourselves to the idea that there are myriads of problems and troubles judges are powerless to solve."⁴⁵

Such fidelity to the rule of law occurred in *Hudson v. Texas Children's Hospital*,⁴⁶ a 2005 Texas case in which a child was born with a severe genetic disorder that resulted in underdeveloped lungs and a small rib cage. The treating physicians believed the ventilator was causing the infant to suffocate. The mother disagreed. She claimed the infant was fine. In her view, he just needed to grow. Then she asserted that her infant was not of human parentage. His father, she told the court, was the sun in the

sky and that as long as the sun shone, her son would thrive.⁴⁷ How were the physicians to accommodate the mother's stance with an appropriate medical response to the child's condition?

Texas has a statute outlining a process for resolving intractable disputes between physicians and families on end-of-life care. The family can seek another facility willing to treat the dying patient as the family requests. If they succeed, the patient is transferred. If the family is unable to achieve a transfer within a statutory limit of ten days, the treating physicians have no further duty to provide the requested medical interventions. In the *Sun Hudson* case, some 42 NICUs were contacted and asked if they would accept the patient on transfer. All refused. The mother then petitioned the court to order Texas Children's Hospital to continue ventilation. The judge declined to order the ventilator continued or disconnected. He informed the parties that if the procedure outlined in the statute had been followed—and if the family had not succeeded within the statutory provisions in finding another facility willing to treat the infant as the mother requested—the present physicians had no further duty to do as she demanded. Because the provisions of the statute had been met and no transfer was available, the physicians at Texas Children's disconnected the ventilator. Moments later they pronounced the infant dead.⁴⁸

It is understandable in the McMath case that no judge, even with a clear finding of brain death, would want to order the ventilator shut off the day before Christmas. What is not comprehensible is a judge authorizing distraught parents to take possession of the dead body of their child, provided they assume "full responsibility for whatever occurs."⁴⁹ As Arthur Caplan, the director of the division of bioethics at New York University's Medical Center,

noted, the decision to allow the brain-dead Jahi McMath's body to be transferred to another facility on artificial life support "makes no medical or moral sense." In his words, "What is being done to her corpse is wrong."⁵⁰ Lawrence McCullough, a professor at the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston, commenting on the same issue, used even stronger language: "What could they be thinking? . . . There is a word for this: crazy."⁵¹

The fundamental problem with this case predates the odd rulings of the trial judge and the corybantic activity of those who, despite the medical evidence and legal findings of brain death, insist that Jahi is not dead. The difficulty began with the physicians at Oakland Children's Hospital who, once the diagnosis of brain death had been made by a qualified neurologist, sought the parents' permission to withdraw the ventilator. It is readily understood that grief-stricken parents might have a difficult time comprehending, let alone processing, what "brain death" means. To ask parents to authorize the removal of what they perceive to be "life support" from their child confuses the parents' need for empathy with the desire to give them unwelcomed decisionmaking authority.

In such a circumstance not only is there no need to ask the family permission to remove a respirator, but to do so is highly inappropriate. It gives a purported choice when, in fact, none exists. Furthermore, it opens the family up to unnecessary feelings of ambivalence and guilt—feelings that may result in moral paralysis or a steadfast denial of death. Those emotions, in turn, may, as happened in this case, result in a decision to continue medical intervention in the hope of a miracle. Once an appeal to a higher authority or divine power has been made, continued discussion of the patient's medical status is nugatory.

An approach more attuned to the reality of the situation was articulated by William Curran, a member of the original Harvard ad hoc committee on brain death, who repeatedly emphasized that the determination of brain death is a technical medical issue, one that does not involve patient consent or family approval. Once the medical staff has made a well-informed determination of brain death, the patient is dead. The only moral issue remaining is the proper disposition of the body. Physicians, it was also suggested, should also avoid using the phrase "brain-dead." Modification of the reality of death not only leads to confusion and false hopes but also, as was demonstrated in this case, sets up the family as well as the hospital and medical staff for seemingly endless misunderstandings and consequent distrust. Such outcomes almost inevitably lead to cumbersome, costly, and needless legal battles.

Informing the parents that a patient who meets the determination of death by neurological standards is "dead" avoids asking them to make a decision to end the family member's life. It also protects them from the guilt of thinking they did not do everything possible to save the patient's life. The death will inevitably occasion grief. But if the approach described here is taken, the family, though mourning the loss of a loved one, will have been spared false hopes, unrealizable expectations, and the seemingly never-ending misadventures that marred this case.

Notes

1. Caplan AL, McCartney JJ, Sisti D. (eds.). *The Case of Terri Schiavo*. Amherst, NY: Prometheus Books; 2006.
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