Ethics and Brain Death in Pediatrics: Recent Controversy and Practical Suggestions

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Abstract

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Who decides when a child is dead? The story of Jahi McMath has brought this question into focus for pediatric intensivists, ethicists, and the American public. In this article, we address this question by arguing that medical professionals do not have an obligation to acquiesce when families insist upon postmortem therapies. To do so may harm the dignity of the child by subjecting him or her to procedures that objectify the body, damage the child's reputation, and violate his or her privacy. Applying this answer to the real world of pediatric intensive care, we suggest practices meant to preserve the dignity of the child while accepting that the family is struggling to understand the tragedy. Muddled communication or an unyielding attitude will fail to help the family understand and cope with the death of their young loved one. Clear and honest communication—in conjunction with an empathetic disposition—can improve pre- and postmortem care for both patient and family.

Introduction

Who decides when a child is dead? The story of Jahi McMath has brought this question into focus for pediatric intensivists, ethicists, and the American public. Some have answered that the medical field has the final authority to separate the living from the dead.¹ Others have argued that the family's conceptions of life and death should take precedence.² Both of these positions harbor notable weaknesses. To insist that medical professionals hold the power to unilaterally determine death runs counter to American medicine's emphasis on medical care informed by patient and family preferences; however, giving the child's family the final say can, in rare cases, lead to a long, drawn-out dying process.

We can see this result, for example, in the story of Oakland teenager Jahi McMath: a 13-year-old girl declared brain dead in December 2013 after suffering an anoxic brain injury related to a tonsillectomy. Her care team at the UCSF Benioff Children's

Hospital in Oakland told her mother Nailah Winkfield that McMath was brain dead; accordingly, they would not grant the mother's requests for continued respiratory and additional nutritional support. Winkfield objected. The family obtained an attorney and petitioned state courts to prevent the hospital from withdrawing her respiratory support. The court granted an extension, and within a few weeks, the family transferred McMath to a Catholic hospital in New Jersey. According to Winkfield, her daughter remains alive, "sleeping," and improving with minimal respiratory support.³

We have no direct knowledge of McMath's case, and do not intend to make judgments about how providers approached this case, the motivations of those involved, or the appropriateness of the case's outcome. Instead, we intend to provide concrete advice for pediatric intensivists who disclose and discuss brain death with family members. This advice will be based on our ethical analysis of the issues involved, as well as our experiences as clinical ethicists. In brief, we will argue that deferral to family preferences must

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be constrained in cases where a child has been found to be dead by neurological criteria. We will show how pediatric intensivists can address the grief and psychological suffering of family members while working in a direct way to move them toward the standard legal, cultural, and religious practices that follow when a child dies.

Conceptual Progression of Brain Death

Many trace roots of the diagnostic category of “brain death” to a 1968 ad hoc committee of the Harvard Medical School. This group sought “to define irreversible coma as a new criterion for death.”⁴ Death occurs when the patient: (1) is unresponsive and unresponsive, (2) is unable to breathe spontaneously and respond to stimuli, and (3) has no brain stem reflexes. These three clinical indicators should be confirmed by a flat electroencephalogram (EEG); if an EEG is unfeasible, the three clinical signatures are sufficient for the designation of death. A decade later in the United Kingdom, the Conference of Medical Royal Colleges associated death with brain death, stating that “brain death means that the patient is dead, whether or not the function of some organs, such as a heartbeat, is still maintained by artificial means.”⁵

In the early 1980s, the Uniform Determination of Death Act codified this standard, defining death as either “(1) [the] irreversible cessation of circulatory and respiratory functions or (2) [the] irreversible cessation of all functions of the entire brain, including the brain stem.”⁶ This act was adopted by all 50 states in the United States in the following years.

It is no secret that these changes to the medical and legal definitions of death were motivated by an interest in increasing the availability of organs for donation and transplantation. The so-called dead donor rule, created by legal and ethical norms, states that organs for transplantation can only be removed from persons who are already dead.⁷ Since cardiopulmonary failure leads rapidly to organ damage, it became useful to identify “a new criterion for death.” Specifically, the neurological criterion for death made it possible for organs to be procured from patients who did not yet meet the conventional, cardiopulmonary criterion.

Although this history is certainly accurate, telling the story in this way has created a significant amount of confusion around the diagnosis of brain death. From this perspective, it appears that brain-dead persons are not “really” dead, but it is convenient to classify them as such so that organ donation can proceed unimpeded by legal or moral objections.⁸ What has been overlooked far too often, however, is that the term “dead,” in its everyday, common sense meaning, has always prioritized neurological function over cardiopulmonary function. That is to say, we experience the life or death of our loved ones in terms of their interaction with us or the world around us, not in terms of their cardiopulmonary function. The cardiopulmonary criterion for death came into use through the clinical practices: pulses and breathing can be easily detected on the surface of a human body, while the technology to directly assess neurological function has only become available in the past century.

Freedom to Define Death

Perhaps because of this muddled history, New Jersey supplemented the Uniform Determination of Death Act with a provision that allows “reasonable accommodation” for families who object to the diagnosis of brain death on behalf of the patient.^{9,10} According to the laws in this state, a person considered brain dead—and whose respiratory and circulatory systems depend on mechanical ventilation—can be considered alive until the patient meets the cardiopulmonary criterion for death. Notably, California (the state where doctors declared McMath dead) allows no exception to the neurological criterion for death.

Ethicists and law makers can justify state-sanctioned objections to brain death (religious or otherwise) by appealing to several tenets, most of them related to what Braswell calls the “freedom to define death.”² The United States is a pluralistic society where we accept that religious values can inform medical care. Perhaps, the most well-known instance: a Jehovah’s Witness can reject blood products—for her or himself—even at the risk of probable exsanguination. The Witness wants to maintain spiritual wellbeing even if the result is the death of his or her body. American medicine accepts this option. In the context of brain death, some Christians and practitioners of Orthodox Judaism use their religious beliefs to inform their conceptions of death. We can imagine an elderly Orthodox Jewish man who believes that death does not occur until the human’s heart had stopped and all respiration has ceased. If he, like McMath, was declared brain death, but his heart continues to beat and his lungs (with assistance) continue to respire, then his family could argue that continuing life support would count as “reasonable accommodation.” Rejecting the neurological criteria for death, the family might say, “He is alive, and he would want to continue living this way.” In this scenario, the benefits that result from respecting a patient’s spiritual beliefs are thought to outweigh the harm that results from continued ventilator support.

However, this argument for reasonable accommodation is significantly weakened in the context of pediatrics. Family requests for reasonable accommodation generally hinge on judgments about how a patient would interpret neurological criteria for death and whether he or she would prefer to remain in this state. However, it is not developmentally appropriate to attribute such conceptions of life and death to infants and children. Providers and parents must instead make decisions on the basis of the child’s interests. The question is not whether the patient would have objected to a diagnosis of brain death, but whether his or her interests would be supported by continued physiological support. Pediatric intensivists, like all pediatricians, are obligated to ensure that children’s interests are protected.

In this case, however, we cannot define the child’s interests in terms of his or her experience of suffering, since a brain-dead child cannot experience physical, psychological, or spiritual suffering. Instead, we must focus on the potential for dignitary harms to the child. Although this term is used with a different meaning in legal discourse, for us a dignitary harm is an unwarranted physical manipulation, objectification, or

denigration of a human body. This type of harm is inflicted when artificial means are used to sustain physiological functioning in a patient who cannot derive benefit from this, and when culturally appropriate death rituals, including burial practices, are inappropriately delayed. In this framing, continued ventilator support of a brain-dead child may confer benefits on a child's family, but it does not benefit the child him or herself. Such a practice, therefore, prioritizes the family's psychological and/or spiritual interests over those of the child. From an ethical perspective, this is not a relevant justification for a "reasonable accommodation."

That said, accepting that families of pediatric patients do not have the ethical authority to determine all aspects of their child's postmortem care is not the end of the story for the pediatric intensive care unit (PICU) care team. Medicine calls upon pediatric intensivists to minimize the harm inflicted upon the child while realizing the child's family is experiencing tragedy. With this in mind, we will spend the remainder of this article proposing ways that pediatric intensivists can bridge the gap between what is ethically preferred and what is practically possible.

Working with Families before and while the Diagnosis Is Made

As noted earlier, the goal of the PICU provider in a time when brain death is a potential diagnosis is twofold: to minimize dignitary harms to the pediatric patient and to minimize the suffering of the patient's family. Beyond the medical expertise required for completing the appropriate assessments and making the brain death determination, these goals press upon the PICU provider to empathically engage with the patient's family throughout their time in the PICU. As ethicist Tia Powell has noted, brain death diagnoses most often arise from unexpected medical events, so family members often have not had time to grieve their loss.¹¹ Recall, for example, that Jahi McMath had undergone an otherwise routine tonsillectomy. Although most PICU visits bring patients and families into a realm of heightened vulnerability, that vulnerability is no doubt magnified when the words "brain death" are uttered to the family of a patient who has had few, if any, previous medical issues. Empathy begins with coordination and consistency among members of the care team. From the attending pediatric intensivist to the health care technician who responds to call lights in the middle of the night, showing an empathetic disposition will minimize the possibility of an adversarial moment casting a shade over subsequent interactions with other team members.

Empathy compels the PICU provider to be an open and understanding presence in the midst of shock, denial, and frequent opportunities for misunderstanding. This does not imply a delicate dance around the words "death" or "brain death," but rather calls for the provider to serve as a guide toward greater clarity by engaging in straightforward, respectful discussions. These discussions may begin with answering basic questions: What is the brain? What functions are performed by the cortex and brain stem? Why might it be impossible for underlying neurologic events to be repaired so

that function is restored? The clinician must be wary of bombarding the family with unfamiliar concepts. This approach carries the risk of cutting off the potential for meaningful conversation. For this reason, it may be helpful to draw a picture of the brain to serve as a visual aid during discussion.

Once the clinician has informed the family of the need for a brain death exam, it will be similarly helpful to clarify what "brain death" entails and how it differs from other commonly heard (but often misunderstood) states such as the persistent vegetative state or the minimally conscious state. Before the brain death exam, the PICU intensivist should explain the three clinical criteria for brain death: the presence of an irreversible coma, failure to initiate spontaneous breathing during an apnea test, and absence of brain stem function. If presented in a respectful, compassionate manner, these explanations should not come across to family members as cold or uncaring. Rather, they can serve as an extension of the provider's empathetic concern by showing that the patient's loved ones are given a small sliver of clarity and understanding in an otherwise foreign, disorienting context. Keeping family members informed and involved throughout the process allows them to feel some sense of control during a time when they have lost all sense of control over what can be done to restore their child.

When family members are present during the exam itself, it is similarly important to explain to them why certain things are being done to their child's body. If necessary, family members should be reminded that the criteria for determining brain death are not provider or patient specific, but have been agreed upon by national organizations of pediatricians and neurologists.¹² Again, these explanations can be an empathic gesture that minimizes the suffering of family members by making them feel a sense of understanding and control in an otherwise disorienting context. For example, the apnea test will require removing the child from mechanical ventilation. For a person who is unfamiliar with the PICU setting and may refer to mechanical ventilation as "life support," the act of removing the ventilator may appear, at best, inconsistent with good clinical care or, at worst, a hostile that kills the patient. An explanation of the purpose of the apnea test and the measures taken to provide oxygen to the body during this time can assuage those potential concerns. Similarly, testing for oculocephalic or oculovestibular reflex, pharyngeal and tracheal reflex, and probing the child's nostrils to provoke facial motor response involve procedures that, for those who are unfamiliar, appear strange and lack clear benefit. If spontaneous spinal reflexes are seen during the exam, they should be acknowledged by the provider and explained in a way that clearly differentiates such reflexes from intentional actions. These real-time explanations about the exam will add time to the process, but the extra time is well worth the sense of understanding and inclusion that family members may feel as a result of being kept up to date about the status of their loved one.

Working with Families after Brain Death Has Been Diagnosed

Once the evaluation for brain death has been completed and the criteria have been confirmed, it is necessary, of course, to

communicate this information to the patient's family. There is little the provider could do to prevent the emotional and psychological suffering that this news will cause for parents and other family members. We know from Kubler-Ross' stages of grief, for example, that denial is a common dimension of persons' reactions to the death of a loved one.¹³ As we argued earlier, however, denial in the context of brain death can have effects that extend far beyond normative grieving. Although providers cannot prevent denial altogether, they should work to prevent manifestations of denial that preclude healthy grieving and healing for family members, or manifestations that delay the entry of a patient's body into a culturally appropriate process of being put to rest.

In the previous section, we argued that allowing family members to observe the process of brain death determination can help provide reassurance that the diagnosis was reached through a careful and diligent evaluation. It is optimal in most circumstances, then, for families to receive the diagnosis of brain death as a part of an ongoing discussion. If the physician has walked the family through the process of determining brain death, this concluding bad news will not come as a surprise, which in turn may help family members respond to denial.

It is also important throughout this process to use language that does not create confusion about the meaning of a diagnosis of brain death. The mechanisms that lead to brain death frequently leave patients appearing otherwise healthy,¹¹ and chest movement caused by mechanical ventilation can create the illusion of spontaneous breathing. Providers should therefore use unambiguous language. For example, instead of using imprecise phrases such as, "There's nothing more we can do," providers should clearly state that the child has died. Ambiguous language can cause confusion for family members, leaving them uncertain as to whether their loved one is dying or already dead. Although this statement can be difficult, the clinician can provide an explanation in a way that is compassionate and supportive. It is a delicate balance to achieve, and so clinicians with limited experience addressing these issues may find it helpful to involve a more experienced colleague, or a social worker, chaplain, or ethics consultant to assist with this conversation. There are also widely utilized protocols for delivering bad news in the medical setting that may provide guidance.¹⁴

The continuation of mechanical ventilation and other interventions that maintain homeostasis can also be a source of confusion. These interventions are frequently continued; therefore, representatives from donor services have the opportunity to approach family members regarding organ procurement and transplantation. However, providers sometimes continue these interventions even when organ donation is not a consideration, such as when family members have already declined donation. Typically, this is because the provider wants to allow time for family members to "say their goodbyes" at a child's bedside. They may even await discontinuation until nonlocal family members have arrived. Although compassion motivates this practice, it may also create confusion for families. To understand why may be so, consider the more common case of a dying child who is unresponsive but still alive. In this circumstance, members of the PICU care team

routinely keep children alive using ventilators and other technologies. Their motivation is that they believe family members should have the opportunity to visit with the unresponsive child while he or she is still alive. By analogy, continuing the use of these same devices after a determination of brain death reinforces the perception that the child is, in some way, still alive until support has been discontinued and the child meets cardiopulmonary criteria for death.

Despite the harm that these implicit messages may cause, compassionate care dictates that providers approach the discontinuation of ventilators and other devices in a manner that helps family members experience the child's death as peacefully as possible. In many circumstances, then, providers will choose to delay the discontinuation of these interventions for the perceived benefit of family members. When this approach is taken, however, it is probably not compassionate to allow this time for goodbyes to become open ended or extended. For some family members, the decision to extend this time may feel like a decision to allow the child to die, which in turn could cause feelings of guilt and responsibility. For this reason, it may be best for providers to set a well-defined period for goodbyes and personally assume responsibility for ending this process at the designated time.

Working with Families Who Are Objecting to the Diagnosis of Brain Death

Although the approaches discussed in the previous section are intended to help families reach closure, there will still be rare occasions when families resist this diagnosis. In many cases, members of the care team may still be able to help family members accept the diagnosis by listening to their concerns and addressing their questions. Also, asking questions such as, "What do you hope to gain by waiting longer?" and "How do you think we can give your child a sense of peace?" may facilitate reflection and understanding.

In the rare cases that these efforts do not lead to a resolution, the PICU team faces an extraordinarily difficult situation. On the one hand, there is no medical indication for continuing ventilation and other artificial support once a determination of death has been made. On the other hand, providers should be hesitant to remove these interventions when family members are actively objecting. Taking this path could easily lead to psychological harm and physical confrontation. Since providers' primary aim is to help family members transition toward recovery and healing, the PICU should take pains to avoid this type of confrontation. It is also untenable, however, to continue such interventions indefinitely. This outcome perpetuates dignitary harm to the patient while threatening the professional integrity of the intensivist. It is probably best, therefore, to inform family members that the hospital cannot continue artificial support without the intervention of the courts, and that the family may pursue legal measures if they so choose. This approach has significant drawbacks, the most notable of which is the tendency for legal confrontation to degrade the provider-family therapeutic relationship. However, this process may provide some psychological, social, or spiritual benefit for the family. After all, parents frequently want to

feel that they have done everything possible for their child; seeing a legal process through to its end may provide reassurance that this goal has been achieved.

If family members express an intention to seek court intervention, it is inadvisable to discontinue medical interventions. However, it is still important to prevent this timeline from becoming open ended. To prevent delays that perpetuate dignitary harms to the child, providers should come to agreement with family on a reasonable timeline for initiating legal action.

Legal proceedings can take time. During this period, the PICU team could be faced with the question of how to appropriately provide physiological support for the body of the brain-dead patient. In this context, it would be imprecise to speak of either a standard of care or medically indicated therapy. During this process, it is likely that the courts will insist that aggressive support continue and additional treatments be added in the event that the patient decompensates. Although these requirements might insult the intensivist's professional integrity, it can be helpful to remember that this therapy maintains trust and transparency during the process of a court challenge, allowing the intensivist to say with veracity that the care team has taken all reasonable measures to maintain physiological functioning during this period.

Conclusion

Who gets to decide when a child is dead? In this article, we have addressed this question by arguing that medical professionals do not have an obligation to acquiesce when families insist upon postmortem therapies. To do so may harm the dignity of the child by subjecting him or her to procedures that objectify the body, damage the child's reputation, and violate his or her privacy. Applying this answer to the real world of pediatric intensive care, we suggest practices meant to preserve the dignity of the child while accepting that the family is struggling to understand tragedy. Muddled communication or an unyielding attitude will fail to help the family understand and cope with the death of their young loved one. We have

shown how clear and honest communication—in conjunction with an empathetic disposition—can improve pre- and post-mortem care for both patient and family.

Conflict of Interest

None.

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