Families and Brain Death

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Abstract

It is necessary to support the family of a patient with a progressively worsening severe acute brain injury, and to do this with the utmost understanding of their ultimate hopelessness. Any conversation starts with an explanation of the catastrophic nature of the illness, but also with establishing the point of no return. When brainstem reflexes are lost and the patient has become apneic, family members should be appropriately informed. In contrast to circulatory death, the relatives of such a patient do not see a deceased person in the traditional sense, and even the neurologic progression may not have been obvious to family members. The conversation about brain death with the close relatives is therefore different, and is more detailed than a conversation about cardiopulmonary death. In this review, a six-phase approach of communication with the relatives is proposed. Insightful snippets of personal conversations with family members are included. Communicating with family members also necessarily involves a discussion on the potential suitability for organ transplantation. Some suggestions on how to approach reluctant family members to accept death of their loved one are included.

Keywords

► brain death
► family-centered care
► communication
► organ transplantation

A major part of care of a patient likely to be declared brain dead is communication with family members. This is no different from a conversation with family members who are suddenly confronted with a progressively—essentially futile—acute catastrophic disease. However, once all brainstem reflexes have disappeared, the patient has no breathing drive, and has developed hypotension requiring vasopressors, the clinical situation changes fundamentally. A declaration of brain death means the person has died and the family must be unequivocally told that their loved one has died. After adequate time has passed, the family is then approached regarding the possibility of organ transplantation. Federal laws in the United States require the physician to contact an organ procurement organization, and in the United States and in many other countries, members of this organization will approach the family separately from the medical team.

Brain death is declared after a comprehensive neurologic examination, and before starting this evaluation families—clinging to hope at the bedside—have to be told the purpose of these tests and also to signal to them the worse possible news. There are justifiable reasons to diagnose patients with irreversible brainstem failure as dead, and in modern medicine it is neurologically, ethically, and legally acceptable “to draw the line” there. Despite the acceptance of the concept of brain death in the United States and many other countries in the world, there is occasionally some unease about this issue. There are for some just too many signs of life, and some may not take the news at face value.1-2

Furthermore, families may notice physicians may continue to actively treat the patient. For some relatives of these patients, it can be befuddling why there is such a concerted effort and certainly before the topic of organ donation is broached. Occasionally, motor movements with finger flexion and foot and leg movement (due to a spinal reflex) may have to be satisfactorily explained because relatives may not believe death has occurred when these movements exist during touch or nursing care.3-5

These sentiments imply that for some a more detailed conversation about brain death is needed. I have heard the following:

Now you tell me he is dead, but an hour ago you told me he was comatose. I see no difference. He is still breathing and his
heart is beating. Why do you tell me he is dead? (Spouse of a 43-year-old brain dead patient).

She is dead, you tell me. But why did the nurse give her a blood transfusion? That does not make sense to me at all. (Father of an 18-year-old brain dead girl).

When you say so. (Daughter of a brain dead patient after the physician had told her that her mother is brain dead, and thus dead).

Research—albeit preliminary, tentative, and possibly seriously biased—has shown that relatives can confuse brain death with other severe neurologic conditions, such as a coma and persistent vegetative state, they may be dissatisfied with the decision to donate organs, they may have a different understanding of brain death as death, they may feel there has been a lack of adequate information about brain death, and some may flatly deny “brain death” as “death.” One study surprisingly claimed that only 52% of relatives felt that they had a good understanding of brain death, even after the physician had explained it. Because relatives who refused organ donation had less understanding of brain death compared with relatives who consented for organ donation, these study results may be clinically relevant. Another study found in a large sample of relatives of brain dead patients that only 28% could “correctly define” brain death when asked at a later time. The question is what can we really expect from nonmedical relatives who have been suddenly shaken up by such an ordeal? One could argue that such studies are flawed.

Popular culture may complicate things even more, and from time to time press reports of “miraculous recoveries” and “misdiagnosis” of brain dead patients are published. This could potentially add to the confusion, mistrust, suspicion, and lack of understanding—if there is such a thing. The international press can also be surprisingly inaccurate. For example, a major newspaper in the United States stated that “The brain dead are candidates for a donation, but the operation generally must be performed before death.” A major news organization recently published an article about a pregnant woman who was declared brain dead. The article said that “A 32-year-old Canadian woman who had been declared brain dead in December and kept alive on life support for six weeks died on Sunday after giving birth to a baby boy.” Experienced journalists may not always be able to carefully describe this condition, and sometimes these inaccuracies slip through. The term “brain death” has a variety of meanings in everyday speech, but one cannot expect lay people to differentiate between the major categories of severe brain injury. It is even questionable if describing brain death in detail to relatives is helpful. Providing information and facts about the patient’s cerebral condition and the irreversibility of the destruction of essential parts of the brain may become easily too technical and perhaps can simply be replaced by saying that the patient has passed away and is not here anymore, with breathing and blood pressure artificially supported, and most importantly that continuing aggressive measures do not make any medical sense.

It should be said that the significance of a beating heart remains important for some relatives. There is a universal acceptance by the public that without a functioning heart, circulation of blood, or breathing, life stops. The centrality of a beating heart has a firm and critical position in our way of thinking, and this point of view is embedded in many cultures. Cardiac arrest and the cessation of breathing imply the death of entire body and human being. Some may have witnessed a person dying a cardiopulmonary death. Probably no family members confronted with a brain dead relative have had a prior experience with brain death.

The universal significance and symbolism of a beating heart is well known. In many cultures and for millennia, the beating heart has been identified as the center of the human body and the seat of life, emotions, and reason. The word heart continues to be used poetically to refer to the soul. Unfulfilled romantic love is often described as a broken heart. This symbolism of a “broken heart” can also reflect a belief that grief can affect the heart.

Removing organs from the body of a loved one whose heart is still beating can be perceived as wrong and unnatural. On the other hand, some feel that to know the loved one’s heart beats in someone else’s body is comforting. (There is a story of a donor family, who after contacting the recipient, actually used a stethoscope to listen to their loved one’s transplanted heart).

Therefore, there may be different sentiments and cultural beliefs. Apart from that, communication with most family members, in our experience and others, is cordial and rational. Relatives typically clearly understand what the physician is talking about and many want to move on and bring closure.

Communication about Brain Death using the Dual Advocacy Approach

For the relatives, the sudden death of the patient is a completely surprising and unexpected event. No one is emotionally prepared. The neurosciences intensive care unit (NICU) staff should help guide them through a process of acceptance; this requires patience. When physicians are “in a hurry” (or are perceived as such), interactions with the family in this early stage of mourning can become confrontational. The main purpose that remains is to prepare for possible organ donation: A problematic rapport with the family will result in anger and refusal of organ donation. In our experience, this situation is the most stressful of all situations because it is sudden, totally unexpected, and often involves a young person with a traumatic brain injury (TBI). The health care staff is also facing a complex situation and sometimes even a “mini crisis” (the most difficult scenario is a pregnant mother with brain death). Often, the NICU staff and family are in agreement as to how to proceed and how to make something good out of this situation. Being able to save the lives of others is very comforting to most family members.

Therefore, the most promising approach for communication with relatives of a possible organ donor is a so-called dual advocacy approach, in which the ICU staff builds rapport with the relatives by acting as an advocate both for the relatives and possible donor organs recipients. 

Trzcinska et al suggested a seven-phase approach for communicating with the relatives of brain dead patients.
based on this concept of dual advocacy. The approach is based on patient- and family-centered care. (The Institute of Patient- and Family-Centered Care states “Patient- and family- centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families”; http://www.ipfcc.org/).

The main concept is to allow an open line of communication and provide information when it becomes available, and not to withhold, distort, or minimize information. Of course, these conversations can only proceed when there is unmistakable certainty about the fatality of the clinical neurologic condition and that there is no perceived benefit of a medical or surgical intervention. Physicians and nursing staff should speak with the same voice. Problems may arise if any of these conversations about organ donation begin prematurely and we think these so-called miracle recoveries of brain death may have much to do with that. The stages of communication are presented herein with some modifications.

Phase 1. Communication with the Relatives about the Patient’s Condition

In this first phase, it should be explained that the patient’s brain is severely injured, outcome is definitively poor, and there is minimal hope for meaningful recovery and little hope for survival. The physician must in all honesty provide the facts, while showing empathy and understanding. The computed tomography scan of the brain can be viewed by the family if requested or one could allow relatives to witness the neurologic examination. Both can be helpful in making the relatives understand the grim situation.

When the doctor showed us the scan of my mother’s brain and explained that the white mass we saw was all blood in her brain, we understood the severity of the situation. (Son of a brain dead 59-year-old woman with an intracerebral hemorrhage).

When the nurse presses her pen on the nail of his finger, and he didn’t move at all, we knew he did not feel pain anymore. (Girlfriend of a 19-year-old trauma victim).

This first encounter is important because it establishes a good understanding of the nature of the catastrophe and it will “set the stage” for any further discussions. Time should be allowed for questions and clarifications. There should be a good understanding of the nature of the injury by family members.

Phase 2. Communicating the Adverse Prognosis

When patients deteriorate further we come to the second phase of communication, which is a reinforcement of the first phase. Possible loss of all brain function may be discussed as a possible outcome. In this phase, the term “clinical brain death” should preferably not be used. Early use of the term brain death may be very inappropriate and may lead to a major conflict if the patient later does not fulfill the criteria.

We knew it doesn’t look good for D. as the doctors and nurses has told us, but when the doctor revealed us that she had suffered a second bleed in the head, we learned from his words that they are losing hope. (Spouse of a 52-year-old woman who was admitted to the ICU with a subarachnoid hemorrhage).

It is also important in this stage to provide a plan of action and next steps (e.g., “It is unlikely that the situation will improve, but we will wait for 2 hours after which we will examine her again and decide what to do”).

If the patient does not worsen further, communication about brain death becomes irrelevant. If early withdrawal of support is specifically requested by the family, physicians may now discuss possible organ donation through a donation after cardiac death (DCD) protocol.

Phase 3. Communicating a High Likelihood of Brain Death

If the patient progresses, the term brain death can be used for the first time. The physician can review the recent events, explain the therapeutic efforts that have been undertaken, describe the progression in deterioration of brain function, and emphasize that it is now an inescapable fact that the patient has died as a result of the severe cerebral damage. The family is told that a more formal examination is going to take place, and this will include testing for breathing capacity.

We understand that R. only breathed by the machine, and that when the doctor turned the machine turn off, there will be no spontaneous breathing and the heart will die. (Spouse of a 63-year-old brain dead patient).

It is common practice in most ICUs for relatives not to be present during the actual neurologic examination. However, it is possible that witnessing the examination can be helpful. In our experience, family members who choose to witness the brain death determination were pleased to have been invited, and many felt that it was helpful in their understanding.

We knew that my mom had died when the intensivist stopped the respirator and when we saw an absence of breathing. (Son of a 43-year-old brain dead patient after witnessing the apnea test).

Whether consent for organ donation increases with such a close participation in brain death remains unknown; perhaps only the disbeliever may wish to see the exam. Witnessing a brain death determination should be an option, and we provide this opportunity. In some instances, it will facilitate communication of brain death when the relatives have witnessed the tests. It will require additional explanation during testing. For some, witnessing these examinations may even be more confusing.

We were shocked when the nurse reconnected the respirator after the apnea test had been performed. For us, she was dead when she was not breathing, but then she breathed again. (Spouse and son of a 51-year-old brain dead patient).

Phase 4. Providing Information about Brain Death as Death of the Person

Here, the family is incontrovertibly told their loved one has passed on. During this phase, the physician may need to explain the significance of the beating heart and all other “signs of life” in the context of brain death.
Phase 5. Allowing Time to Be with the Patient

In this phase, the relatives are offered privacy to be with their loved one. Many relatives need time to cope and others need time for prayers or other rituals.\textsuperscript{22–24} As alluded to earlier, for some, it may be difficult to see a dead person on a ventilator in an ICU environment.\textsuperscript{10,25} Some relatives simply cannot cope with it, and will never accept brain death as death, but most are fine with it and clearly see that the person is gone.\textsuperscript{26}

Phase 6. Requesting Organ Donation

Physicians could ask the relatives to consent to organ donation. In the United States and many other countries, this is delinked from care of the patient and relegated to an organ procurement agency.

If the relatives consent to organ donation, there is a need to fully describe what will happen, what they can expect, and that they can stay with the body of their loved one until it is taken to the operating room.\textsuperscript{26} The family should be assured that the entire cost of the organ donation process is paid for by the organ procurement organization. Generally, this includes all costs from the time of the brain death declaration and consent until the donor’s care is transferred after organ recovery to the medical examiner or funeral home.

Most organ procurement agencies have a presumptive model for consent. That is, families will actively have to state a reason why they would not want to proceed. Many reasons may explain refusal to obtain consent. Sometimes, the objections are of religious nature, but there are many more reasons and much has to do with surgical removal and cutting into the body. If their refusal is final, the physician should explain what will happen next: the disconnection of the ventilator, the withdrawal of vasoactive medication, and other supportive measures that will lead to circulatory arrest.

Phase 7. After Death and Organ Donation

In some cases of brain death and organ donation, confusion and questions about the process of brain death determination do not arise until weeks or months later.

I cannot stop doubting about what I consented to. It all was so horrifying. Often when I am awake at night I see his beautiful warm body with the steadily beating heart. I remember I was lying with my head on his chest in the ICU hearing his heartbeat. And then they say he was dead. My soul mate dead! I was overwhelmed and thought it was good to donate his organs, his heart. But now I have doubts. Was he dead at all? (The girlfriend of a 23-year-old TBI victim)

The relatives should always be offered an opportunity to make later contact with the physician in the ICU, a social worker, or the organ donation agency to discuss the perceived process of brain death determination and organ donation. Guilt may become pathological and excessive, and more bereavement support should be offered.

Refusal to Accept Brain Death

For some family members when a patient is declared dead in intensive care it is not self-evident that the patient has died. Their loved one still feels warm and all vital signs seem intact and may not look that much different from the patient in the adjacent ICU bed. Some relatives may not be convinced that death has occurred. If families fail to accept brain death as death, there are few—mostly unsatisfactory options. First, the physician could consider maintaining full support for several days while trying to resolve this issue with the hospital ethics committee. This group may provide additional insight and sometimes restore lack of trust. In others, the refusal is far more deeply engrained and of a religious nature. Generally, divine intervention creating miracles is an uncommon belief. However, rather than implicitly showing skepticism, continuous communication of the hopeless situation is the best approach. Spiritual council may be sought. Physicians should appreciate these sensitivities and try to help family members come to closure. Spirituality affects a greater part of the American public, but it rarely fully determines the decision to donate organs and tissue. When religious or cultural objections are put forward by the family members, it is important to have families hold a conference with their own minister, priest, or religious leader. Still, it rarely leads to a resolution.

If the family remains intransigent, legal advice should be obtained. A local judge will then decide and can be expected to declare the patient dead, which would allow withdrawal of support. Unfortunately, once it reaches a court these legal cases may become problematic. The courts may magnify the differences and quick resolution cannot be expected (see “Brain Death: Legal Obligations and the Courts” by Pope and Burkle in this issue for specific details).

Conclusions

Families of a patient with an acute catastrophic neurologic illness progressing to brain death are often overwhelmed and off-kilter. There is a great need for support by the NICU staff. When appropriate, discussions on the patient’s futile condition and the possibility of becoming brain dead should start early and progress gradually in less-defined phases of communication. Their support not only includes providing a listening environment, but also providing explanations of the neurologic condition and of the organ donation protocol if so desired.

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