Ethical debate

Brain stem death: managing care when accepted medical guidelines and religious beliefs are in conflict

What should doctors do when a patient in intensive care is declared brain stem dead, but according to their family's religious beliefs is still alive and must continue to be given treatment? Two UK paediatric intensive care specialists describe how they resolved such a difficulty by allowing their patient, an orthodox Jew, to remain on mechanical ventilation until she died from "natural" causes, while a former chief rabbi explains the Jewish position in more detail. However, two Australian intensive care specialists believe that unreasonable delay in stopping treatment serves neither the interests of the patient nor those of society and can be difficult for staff.

Consideration and compromise are possible

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The Right Honourable the Lord Jakobovits died on 31 October 1999

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A young orthodox Jewish girl in our paediatric intensive care unit was declared brain stem dead. However, neither her parents nor their religious advisers accepted that she was dead and refused to countenance withdrawal of care. We describe the ethical dilemmas surrounding her management and suggest strategies for dealing with similar cases in future.

Summary points

- Brain stem death is not recognised by orthodox Jews as death of the individual
- Families should not be pressurised into consenting to withdrawal of care
- Rabbinical authorities should be consulted for moral guidance if an orthodox Jew is declared brain stem dead while being ventilated mechanically
- Compromises that are acceptable to medical and nursing staff are usually possible
- Asystole usually occurs within a few days of brain stem death even if limited supportive care is continued

Case report

A 3 year old Jewish girl was being investigated by a paediatric neurologist at another hospital because of unsteadiness, intermittent tremors, and facial weakness. Magnetic resonance imaging, performed under general anaesthesia, showed a large, right sided, temporal mass extending into the midbrain. The scan was performed as a day case and the child returned home to await urgent neurosurgical referral. The procedure had been undertaken without event, but some hours later the girl suddenly became unresponsive and was taken to her local hospital by emergency ambulance. She was found to have a reduced level of consciousness, posturing consistent with a decorticate state, and unequal pupils. The girl was treated with dexamethasone and mannitol and was referred to our institution for further management. She was assessed by our transport team and was intubated before being transferred to the paediatric intensive care unit.

On arrival at this hospital, the patient was taken to theatre for emergency debulking of the tumour. At craniotomy her intracranial pressure was grossly raised and although some tumour tissue was resected, the procedure had to be abandoned after 7 litres of blood had been lost. The tumour cavity was packed with surgical swabs and the skin was closed. When she returned to the intensive care unit, the child was bradycardic, hypertensive, and had a fixed and dilated right pupil. The parents were told that the prognosis was hopeless and that their daughter had been brought back to the intensive care unit to die. Some hours later, both pupils became fixed and dilated. Formal brain stem testing was performed the next day and the child was certified to be brain stem dead.

The intensive care team advocated withdrawal of care, in line with the recent Royal College of Paediatrics and Child Health guidelines.[1] However, this was in conflict with the family's wishes. They had

consulted their rabbi, who insisted that Jewish law would not allow treatment to be withdrawn. Under Jewish law the child was still alive, and to withdraw or withhold care would be tantamount to murder.

Medical and religious interpretations

Brain stem death has been accepted as death of the individual in the United Kingdom since 1976, when the royal colleges published criteria for making a diagnosis of what was then called brain death.[2] The Royal College of Paediatrics and Child Health and the Department of Health have accepted the criteria as being applicable to term infants and children over 2 months of age. Such is the degree of consensus on the issue that supporting legislation has not been required.

As Jewish law is hundreds if not thousands of years old, it does not deal with the issue of a brain stem dead patient on a ventilator. However, the definition of the moment of death is addressed. In one source, physical decapitation of an animal is said to determine death even if there is some degree of subsequent movement, provided that it is "pirchus be'alma," or like the "severed tail of a lizard that twitches spasmodically."[3] Another source states that in the case of an individual trapped under a fallen building, absence of breathing may determine death even if cessation of the heartbeat is not established.[4] Progressive Jews, who accept brain stem death as a valid determinant of death within the Jewish tradition, argue that it is physiologically equivalent to decapitation—that destruction of the brain stem means inability to breathe spontaneously and that movement of the heart as it beats falls into the category of "pirchus."[5]

The arguments against the latter view are that brain stem death is not the equivalent of anatomical decapitation and that the coordinated beating of the heart and maintenance of circulation cannot be characterised as "pirchus" since it is no different to the beating of the heart in a normal individual. In support of this view, there are also sources which state that death has occurred only when there is neither breathing nor cardiac pulsation.[6 7] Since this is not the case in a brain stem dead patient on a ventilator, these patients are not considered dead. This is the majority view in the orthodox tradition,[8 9] and it is summed up below by the former chief rabbi of the United Kingdom and expert on Jewish medical ethics, Lord Jakobovits.

> So long as the heart still functions and the blood circulates, death has not yet set in. But this does not mean that a lingering life, especially when experiencing great pain, must be prolonged at all costs and in all circumstances. While one may not actively cause or hasten the onset of death, and one may therefore never withhold normal and natural means to sustain life—such as food, drink, blood, or oxygen (or air)—one need not artificially prolong life . . . by administering antibiotics . . . to suppress infection. Thus, one may allow nature to take its course by withholding such treatment. On the responsibility for making such decisions . . . affecting life and death, it should be emphasised that these should, wherever possible, be left to disinterested parties, preferably including experts, including moral specialists such as experienced rabbinic authorities.

The practice of maintaining brain stem dead patients on mechanical ventilation until they become asystolic has largely ceased in the United Kingdom as a result of the clear guidelines of the royal colleges. However, published data show that even if supportive care is continued, asystole occurs within days of brain stem death.[10]

Our care plan

After discussion with the rabbinical authorities, a plan of care was agreed in line with Lord Jakobovits's recommendations. No action was taken to hasten cessation of the heart beat. Ventilation and intravenous fluids were continued. There was, however, limitation of care to allow the heart to stop beating as soon as possible within the limits proposed by Jewish law. Invasive and non-invasive monitoring were stopped and antibiotic treatment was withdrawn. There was to be no resuscitation in the event of an arrhythmia, no endotracheal suction, and no renal support. Asystole occurred four days after the child had been declared brain stem dead.

Conclusion

The aim of intensive care should be to treat the family, not just the patient. Thus, we suggest that when an orthodox Jew is declared brain stem dead while on mechanical ventilation, a death certificate should not be issued. In these unusual circumstances it is more important to respect the cultural traditions of the family than to free a bed in the intensive care unit. Asystole will occur within a few days. It should be possible to reach a compromise with the religious authorities about the level of active care that is required under Jewish law while permitting sufficient limitation of care to allow asystole to occur as rapidly as possible. However alien the belief system of Jewish law is to staff on the intensive care unit and however difficult it is for them to continue supportive treatment, the families concerned should not be asked to become "accessories to murder."

Competing interests: None declared.

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3 Mishna, Oholot 1:6.
4 Talmud, Yoma. 85a.
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6 Teshuvot Chacham Tzvi, no 77.
7 Teshuvot Chatam Sofer, Yoreh De'ah, no 338.
8 HaLevi Wosner S. Heart transplants. In: Roodyn P, ed. *Pathways in medicine.* Jerusalem: Targum Press, 1995.
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Endpiece

Cause of conditions

Notably, there is something extremely arbitrary in the idea of a cause par excellence, as opposed to mere "conditions." "For a doctor," Simiand wrote, "the cause of an epidemic would be the multiplication of a microbe and its conditions the dirt and ill health occasioned by poverty; for the sociologist and the philanthropist, poverty would be the cause, and the biological factors, the conditions."

Marc Bloch, *The Historian's Craft*,
Manchester University Press, 1954

Commentary: Delay in stopping treatment can become unreasonable and unfair

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Death is a common occurrence in most intensive care units. It is thus incumbent on intensive care practitioners to become as skilled in the management of death as they are in managing other complications of critical illness. The management of death requires consideration of the interests of all the people affected—not only the patient and his or her family but also of the medical and paramedical staff caring for the patient and of the community at large. The interests of these diverse groups and individuals may be in conflict, and reconciliation may be difficult or impossible. In the case reported by Inwald and Petros, some, but not all, treatment continued to be given to a patient who was beyond the legal certification of death based on brain stem function. Continuation of treatment was based on compassionate concern for the religious beliefs of the family rather than on the interests of the patient.

Delay in stopping apparently futile treatment is often required where the arrival of a close relative is awaited or the family needs time to adjust to or accept an inevitable, though often sudden, death. In an affluent society, this seems a reasonable compromise between the various interests involved. At some point, however, this delay becomes unreasonable.

Even if one does not accept the concept of brain death it is very difficult to argue that the patient has any interest in continued treatment after brain function has stopped irreversibly. Continued treatment may offend the dignity of the individual, by using him or her as a means to achieve the ends of others. How soon after brain function ceases this becomes an issue is difficult to determine. In these circumstances, four days is a long time. Furthermore, with continued ventilation there is no immediate inevitability about cardiac standstill, and patents have survived (with other interventions not withheld) for up to 64 days.[1 2]

Staff caring for the patient may have difficulty reconciling the apparent misuse of scarce resources or the compromise of the patient's dignity. This will increasingly be an issue the longer treatment continues and is compounded by the apparent inconsistency of continuing some treatments but not others. Though it is usually feasible for practice in the intensive care unit to reflect compassion within a legal and ethical framework, this becomes increasingly difficult when non-standard management regimens preclude access to an intensive care bed for patients with a chance of survival.

Judaism is a mainstream philosophical system. Other, more fringe religions also make demands on the medical system that run counter to usual practice. For example, we have been asked by a small religious group to maintain a (brain) dead patient in order that prayer meetings may be held to effect a resurrection, and a zealous relative requested that we withhold analgesics from a dying patient in severe pain to enable a more favourable afterlife. Man's interpretation of God's law is inconsistent both within and among religious groups. If the requirements of one group are accommodated, does not consistency demand that this courtesy should be extended to all groups, no matter how unreasonable their requests seem?

Non-acceptance of brain stem death precludes beating heart cadaveric organ donation. Where this non-acceptance is systematic to an ethnic group, organ transplantation will become more difficult because histocompatibility genes cluster in these groups. More poignantly, should transplantation be facilitated in groups who, because of their beliefs, cannot participate in organ donation? Furthermore, is it reasonable to offer more expensive treatment options such as dialysis when a cheaper option (renal transplantation) is rejected on non-medical grounds?

The continuation of treatment in the case reported reflects compassionate concern for the religious beliefs of the family. Where these beliefs are at odds with those of society, reflected in legislation, some limitation of this accommodation is certainly justifiable and may become essential.

Competing interests: None declared.

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