Brain death, vegetative state and the RUB

How does one arrive at the decision that a person’s life is no longer worth living?

Grant Gillett

It is common in contemporary clinical practice to be able to keep a person’s body alive after the functions of the brain which animate and give character to that life have been irreversibly destroyed. In many countries there are brain stem death tests which allow us to come to a reliable clinical decision that the brain function required to sustain and animate the body has been lost. The nature of these tests are a matter of clinical neuroscience but the significance of brain death concerns our concept of the person and the value of human life.

Some 200 years ago John Locke, the British philosopher, noted the difference between the death of a person as a being who has consciousness, action, and a thought life and the death of a human body as a mere site of animal functions. But it is even more instructive to go back 2,000 years and examine Aristotle’s idea of the soul or formal principle of life which gives characteristic functions to human beings. He differentiated the vegetative, from the animal, from the distinctively human functions of the soul. The vegetative aspects of the soul gives the human being their vegetative -functions: digestion, excretion, respiration, reproduction. The aspects we have in common with the animals give us sensation and locomotion (and we might say some instrumental intelligence). It is that which gives us rational and social function that, for Aristotle, is characteristically human. Whatever we believe about Aristotle’s ordering of functions it is clear that the organ that integrates and encapsulates these functions in a package that is unique to any given human individual is the brain. Thus, if the function of the brain is irreversibly lost that person as the distinct, integrated functioning being that he or she is has also been lost to us no matter what we do (perhaps by artificial means) to keep some semblance of life in the body. Because of this fact, many countries have thought it right to introduce a brain death standard of death.

We ought to be absolutely clear about this. Once the brain is dead the person as we know them is no longer among us and their body is being sustained in a semblance of life that will no longer manifest the life of that person as the person we love and value. I (and many legislatures throughout the world) have therefore adopted the practice of classifying a person as dead once brain death has been diagnosed.

If the function of the brain is irreversibly lost, that person as the distinct being that he or she is, has also been lost

Our reflections from Aristotle do however raise another possibility that many families and courts have found persuasive. If, after a medical catastrophe (such as stroke or head injury), the only functions that the brain is able to perform are vegetative functions then we are also left with a shell or remnant of the person who used to live among us. This is called persistent Vegetative State (PVS) and it can now be diagnosed with some certainty. Under these circumstances many settings throughout the world have decided that further intervention and life-prolonging measures are completely inappropriate. That being so, such things as naso-gastric tubes and so on can be withdrawn and the biological remnant of what was a person can be allowed to die. PVS is not brain death but once we are sure that it is irreversible it seems that it no longer has the features required for us to value and sustain the human life involved.

One last concept is worth mentioning here. It is the RUB and is also of value in framing ethical questions about decisions to withhold or withdraw life sustaining treatment. RUB is an acronym for the Risk of Unacceptable Badness and it comes from Shakespeare’s Hamlet. Hamlet, in the crucial soliloquy, muses.

“To sleep, perchance to dream, Aye, there’s the rub.” Hamlet thinks about suicide and the eternal sleep that would follow. But then he contemplates the possibility of spending eternity dead but dreaming, and therefore, impotent, but wracked with the moral torments that have provoked his suicidal thoughts. That is the RUB because it would be Unacceptably Bad to him to be in such a state.

There is an analogy in clinical life: some patients have a probabilistic chance of surviving a serious catastrophe but the realities of survival are grim. The person may survive in an unacceptable rather than an acceptable state of living. For instance, consider a patient who has a severe brain injury with a five per cent chance of survival but, if he survives, only a 10 per cent chance of living in an acceptable state and a 90 per cent chance of living in a state he would consider unacceptably bad.
The RUB sets out the three-way split of the probabilities: a five per cent chance of survival of which most of the outcomes would be survival as a person in an unacceptably bad state. Therefore the real probabilities are death 95 per cent; unacceptably bad life 4.5 per cent; and acceptable life 0.5 per cent. The RUB is 19:1. This means that, even if he or she lives, the patient has an overwhelming likelihood of wishing that he or she had not. When we are deciding whether to pursue intensive efforts at resuscitation and life sustaining care that is a very significant ethical consideration. Look at it another way. Relatives will often remark, when facing a life and death decision, “Well, any chance is better than none.” But this is not true; the chance of survival might only be bought at the cost of a very high risk of an unacceptably bad survival. This is a serious wager because we have a responsibility to do what the patient would want if he were able to choose. I would not want to run that risk. The RUB shows us that the “Any chance is better than none” policy has a high risk associated: life to be valued negatively (which in our example is the most likely outcome). We cannot overlook this risk.

The RUB is often there and it is a concept which should inform the ethical advice given by clinicians to patients and their relatives making mortal decisions. Our job is to do the best we can to rescue those patients who are going to have a tolerably good life and realise that we cannot achieve the impossible where that is not the case. It is not the case in brain death because the crucial organ which carries the life of the person is dead. It is arguably not the case in PVS. And it is always a question to be thought about where the damage to the brain is so severe that perhaps no one would want to go on living in the resulting state. These decisions are not easy but if we can achieve clarity about the ethics then we should also be able to achieve consistency in our clinical practice. 

This comment has become particularly relevant in India following legislation defining brain death.

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