Classic cases revisited: Baby Theresa and the definition of death

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Abstract

As our medical knowledge grows the criteria for the diagnosis of death continue to evolve. The criteria tend to be pragmatic, and are designed to serve the needs of the society. They are however, only a set of tools and as such they fail to address the question of what death actually is. More importantly, a question remains as to what does death mean to us, human beings. The historical case of Baby Theresa challenges the way we think about death, life and organ transplantation.

Keywords

Death, anencephaly, transplantation

Introduction

The dead donor rule is a safeguard designed to prevent abuse of vulnerable patients and forms an ethical cornerstone of most, if not all vital organ transplant programs. The rule basically demands that the potential donor is confirmed as dead before any transplant proceedings. However, multiple definitions of death exist, and death from the stand point of modern medicine is a process and the criteria used to establish time of death, while rooted in the current understanding of anatomy and pathophysiology, are arbitrary, changeable and dependent on the technological advances in medicine. The case of Baby Theresa serves to highlight moral uncertainties surrounding diagnosis and definitions of death especially in the context of organ transplantation. In the following article, the problems associated with the concept of death are discussed. All those involved in diagnosing death or referring patients to organ donation services should understand the underlying controversies.

Case history

Theresa Ann Campo-Pearson (who later became known as Baby Theresa) was born with anencephaly. This in its own right is not an unusual event, except that her parents, Laura Campo and Justin Pearson, upon finding out that the condition would be rapidly terminal, and the prospect of any sentient life non-existent, expressed a desire to offer Baby Theresa's organs for transplantation. This act of extreme altruism provoked an ethical and legal debate surrounding

the definition of death. As organs may only be taken from a deceased individual, and Baby Theresa was alive, the case was referred to the courts.

A circuit court judge Estella M Moriarty, ruled 'doctors can take as many transplant organs as possible from the terminally ill 6-day-old infant as long as they don't kill her in the process'. She went on to say, 'I can't authorise someone to take your baby's life, however short, however unsatisfactory, to save another child . . . Death is a fact, not an opinion'.^{1,2} The decision was upheld on appeal, but referred before the Supreme Court of Florida, who sought to address the following question: 'is an anencephalic newborn considered 'dead' for purposes of organ donation solely by reason of its congenital deformity?' Whilst the court deliberated on the definitions of death and life, it eventually decided that these were 'obviously . . . inapplicable to the issues at hand today', and in finding that Baby Theresa was 'a "live birth" and not a "foetal death," at least for the purposes of the collection of vital statistics', the court found that there was enough doubt present concerning both the status of the child (in terms of whether it was alive or dead) and also the utility of actually changing the law (in that the organs would be of limited use and the scenario was rare) that

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they had no mandate to change the law to recognise anencephaly as equivalent to death.³ Whilst this disposed of the issues faced by Baby Theresa's parents and carers, it did not adequately answer the question of whether the child was actually alive; rather it just stated that Baby Theresa was not dead by the criteria used in the state of Florida.

The problem of death

Pertinent to the case of Baby Theresa is the history of the first American heart transplant performed by Dr Adrian Kantrowitz's team. On 6 December 1967, a heart was harvested from an anencephalic baby. The baby was first immersed in freezing cold water in order for the heart to stop, so that death could be declared.⁴ Although this was many years before Baby Theresa was reviewed by the court, it is hard to escape the conclusion that that in order to satisfy the dead donor rule, Dr Kantrowitz's team was responsible for the intentional killing of an infant.

Shortly after this event, in 1968, the Harvard Criteria for determination of brain death were published.⁵ By introducing the concept of 'neurological death' the committee created a parallel set of criteria by which an individual could be declared dead purely due to the presence of a constellation of neurological findings and in the presence of otherwise functioning organ systems. These criteria were welcomed by an intensive care community dealing with a growing number of patients in irreversible coma, but the conceptualisation of Brain Death has created confusion. 'Brain death' has different definitions in different jurisdictions, with some advocating 'whole brain' rather than 'brain stem' death, and using different criteria to diagnose this state. There are also residual issues related to the ethical and philosophical dichotomy between brain death and the more common forms of death that might be recognisable to the man in the street and have existed for millennia. For a concept as universal as death, it is difficult to reconcile these varying definitions.

There have, however, been attempts to do just this. The President's Council on Bioethics Report 'Controversies In The Determination Of Death'⁶ aimed to align neurological death with the more common cardiorespiratory definition under a common final set of criteria which both mechanisms of dying would satisfy. The Council defined death in terms of the loss of the essential functions of a life, which it defined as follows:

1. Openness to the world, that is, receptivity to stimuli and signals from the surrounding environment.
2. The ability to act upon the world to obtain selectively what it needs.
3. The basic felt need that drives the organism to act as it must, to obtain what it needs and what its openness reveals to be available.

Put simply, and reduced to the most basic level, these criteria identify an organism that can sense the oxygen in its environment and the carbon dioxide in its blood stream, and act to effect the exchange of these. An organism that is not responsive to its environment and does not act upon any impulses is dead, whether or not its heart is beating. It is also of note that these criteria adequately describe life that has ended by either neurological or cardiorespiratory criteria.

This concept is now reasonably familiar to UK practitioners. The Academy of Medical Royal College Guidelines⁷ offer a similar unifying concept of death that encompasses neurological, cardiorespiratory and 'somatic' death (e.g. decapitation or incineration). However, whilst the UK and US guidelines have successfully aligned the various modes of dying into a unifying concept, they have done little to answer the question of what actually constitutes death?

Our concept of death in the UK essentially revolves around the brain stem. Loss of brain stem function is incompatible with life and without invasive support there is no doubt that the body would fail. Further, it has been suggested that brain stem death will necessarily lead to biological death through loss of some form of central integrative function native to the brain stem, although this suggestion is refuted to some degree by the observation that a suitably supported 'brain dead' human body is capable of carrying pregnancy to term.⁸

However, these biological definitions of death view the individual as an animal, little more than animated flesh defined by the presence of various coordinated physiological functions. A suitable definition in this context is provided by Becker:

A human organism is dead when, for whatever reason, the system of those reciprocally dependent processes which assimilate oxygen, metabolise food, eliminate wastes, and keep the organism in relative homeostasis are arrested in a way which organism itself cannot reverse. It is a confluence of these and only these conditions which could possibly define organic death, given the nature of human organic function. Loss of consciousness is not death any more than the loss of a limb. The human organism may continue to function as an organic system.⁹

We may feel uncomfortable with this definition. Aside from the fact that many patients potentially could have irreversible organ failures and still be alive, we may note that this definition reduces the individual to a simple organism and neglects our human characteristics. Other theories place greater emphasis on personhood and the higher functions that make us 'human'. These concepts elevate life above mere physiology and suggest that death occurs when the characteristics of the individual are lost.

One such definition has been provided by Robert Veatch—‘Death is the irreversible loss of that which is essentially significant to the nature of humans’.¹⁰

Most of us consider ourselves as more than the sum of the various biochemical processes that keep us alive, and it is not hard therefore to have some sympathy with this position. However, such ‘higher brain’ concepts of death become more difficult when we have to consider those in the persistent vegetative state or with advanced dementia, where higher function is lost but simple biological function is retained.

Acceptance of a higher brain definition might permit organ donation in cases such as Baby Theresa’s, however they remain impractical. It is not easy to define the point beyond which that which is ‘essentially significant to the nature of humans’ is lost. In the absence of a suitable objective threshold such as that provided by the Brain Stem criteria, patients in a persistent vegetative state (PVS) or indeed those with dementia may or may not be deemed ‘dead’ according to subjective assessment and despite being quite clearly ‘alive’.

A full discussion of these concepts is outside the scope of this article, but they are relevant to Baby Theresa, who was born with a functioning brain stem and could not be considered dead by cardiac or neurological criteria. She had a beating heart and breathed, she possessed the necessary functions that preserved life. However, Baby Theresa had no higher brain and she had no capacity for life in anything other than its most basic form. This puts Baby Theresa in a very similar position to PVS patients; however, in contrast to patients in PVS, anencephaly is essentially an unstable condition, and without invasive support all anencephalics will die within days. To examine the status of Baby Theresa and other anencephalics, it may be more useful to consider the concept of ‘brain birth’. This theory postulates that there is a point at which the person comes into being through sufficient development of the brain and is pertinent to discussions about late abortion and the rights of the foetus. This theory could be used to suggest that anencephalics never become alive, as the brain never develops enough for them to attain personhood.

The question of death

It is understandable that we want to know what death is. This need for knowledge is irrespective of religious, scientific, social and philosophical standpoints and death will come to us all. Yet, with the evolving definitions of death and unresolved philosophical questions, it may be better to ask ‘why do we need to determine death?’

Through much of history the point of death was considered to be that at which the spirit left the body; diagnosis of death was a primarily religious concern. However, the recognition in the 17th century of

‘apparent death’, a condition of deep unresponsiveness that mimicked death but was reversible, created a profound fear amongst the public of premature burial, and this in turn prompted greater involvement of medical practitioners and the slow evolution of the physiological criteria used to define death by our current standards.

In the modern world, the fear of premature burial no longer drives the diagnostic criteria for death. The modern world needs death to be defined to permit both disposal of the body and initiation of a number of administrative and legal processes. However, it is impossible to consider death in the context of the modern ICU without reference to organ donation, and whilst a need to provide some form of end point for patients in irreversible coma would persist, it is arguably the organ donation program that has been the major driver for the current definition and criteria for brain stem death in the UK. This was possibly most appositely put in the original publication of the Harvard Criteria: ‘obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation’. Nevertheless, brain stem death is well established and while philosophical and ethical debate continues, most practicing clinicians are accepting of the concept.

Less convincing is the issue of cardiorespiratory death. Questions relating to ‘permanence’, ‘irreversibility’ and ‘timing of death’ given available medical interventions have led some to suggest that contrary to the dead donor rule, organs are being removed from patients who are not convincingly dead.

An in-depth analysis of terminology that describes the process of death has been recently conducted by Bernat.¹¹ Current practice mandates a period of 5 min after cardiac arrest before death is diagnosed. This delay serves two purposes: first, it allows the generation of hypoxic brain stem damage sufficient to meet the neurological criteria and second it ensures ‘irreversibility’. However, the evidence for this is based on little more than case reports and a lack of observed spontaneous reversal after this time. It is clear however, that with support, 5 min is not enough to produce such severe damage to the brain stem that the neurological criteria would be met. Most, if not all, ICU clinicians will have seen effective cardiorespiratory resuscitation commenced after greater than 5 min of full arrest lead to if not a full recovery, then one that would defy the brain stem criteria. One must conclude that death in these circumstances is very much subject to the physician’s volition.

Ultimately, it is difficult to escape the suggestion that current definitions of death have been adjusted at least in part to satisfy the needs of the organ donation program, and this may in itself have damaged that program. Truog and Miller¹² go as far as to say:

It appears that reliance on the dead donor rule has greater potential to undermine trust in the

transplantation enterprise than to preserve it. At worst, this ongoing reliance suggests that the medical profession has been gerrymandering the definition of death to carefully conform with conditions that are most favorable for transplantation. At best, the rule has provided misleading ethical cover that cannot withstand careful scrutiny.

Death considered in this way becomes a utilitarian event focusing on the organs that may potentially be retrieved rather than on the person that is dying and their interests. It should not be forgotten that life has a meaning, irrespective of whether the body after death subserves as a source of organs.

Conclusions

The case of Baby Theresa suggests another option. With the exact moment of death being moot perhaps social acceptance of organ removal from 'dying' patients rather than from a 'dead' patients should be explored, and it is suggested that a public debate on the issue should be initiated, encompassing (but not dictated by) those directly involved with transplantation. The definition of death, contrary to what Judge Estella M Moriarty said, is not a 'matter of fact', but of values. It is perhaps as important to consider what we value in life and how we define life, before tackling what might constitute its absence. Death is not a medical concept, it is a question for society, and in the words of the Florida's Supreme Court: 'In the end, the society as a whole must judge that these technical standards and the opinions they reflect conform to the society's settled values and accepted conceptions of human existence and personal rights'.³

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