Transplants
are the donors really *really* dead?

Is 'brainstem death' diagnostic of death or merely prognostic? And does it matter? *Triple Helix* interviews consultant anaesthetist David Hill

David, tell us about yourself. Give us a brief CV.
I did my preclinicals at King's College and my clinical training at the old Westminster Hospital. I qualified in 1954 and did housejobs with a view to going into general practice, but doing anaesthesia as an SHO I realised I had a particular interest and facility for that. I eventually became a consultant anaesthetist at Addenbrooke's Hospital, Cambridge, but before that I was a senior registrar at King's College Hospital and I mention that because I was there at an early stage of kidney transplantation procedures.

We're going to be talking about organ transplantation and associated issues. Do you accept that transplantation per se is ethical?
Yes I do. I would have no objection myself to my organs being used, particularly corneas and even kidneys, provided they were taken at a time after my death.

Death has obviously got spiritual, philosophical, ethical, legal and medical aspects to it. It's a big subject. Can you tell us how the law in the UK defines death?
There is no legal definition of death. Basically you are dead when a doctor says you're dead.

How then historically have British doctors defined death?
Death has been diagnosed on the basis of there being no respiration and no heartbeat and no circulation and that has been the standard way of assessing death.

When did that change?
It began to change in the late 1960s and early 1970s when intensive care became established and one of the results of that was we found ourselves in the position sometimes of prolonging the deaths of patients rather than prolonging their lives. Decisions had to be made about discontinuing treatment in order to allow a person to die.

So one of the reasons for the development of the new concept of 'brain death' was the inappropriate ventilation of dying people?
I don't know that I'd say 'inappropriate'; we were able to sustain for much longer people who would have died. Of course many of the people in intensive care who would otherwise have died survived, but a proportion of them who would have died still did die, but it turned out in retrospect we were just prolonging the dying process.

Was there any other reason for the development of the concept of brain death?
I think that was initially what it was. At that time there was no question of assuming that the people who were on what is generally called 'life support' were dead - they clearly were not dead but we were maintaining life over and beyond the time for which it seemed reasonable.

What has this new concept of death involved? Tell us about brain death.
It was formalised in this country in 1976 by the Conference of Royal Colleges and their Faculties[1] who determined that, following preconditions and allowing that we knew the cause of a coma, if certain tests were fulfilled then a patient would have no hope of recovery. Those tests were valuable because we had found ourselves having to discontinue treatment and they did formalise that and give one the backing of the Conference. But again there was no question at that stage of saying those patients were dead; it was simply a series of tests to assess whether there was any reasonable chance of the patient ever recovering. It was very much a prognostic test we were carrying out.

When and how did that change?
It changed very suddenly in 1979 and I think we must remember this was the time when organ transplantation was

extending beyond corneas and kidneys to other solid organs and even to lungs and pancreas and bowel. There was a Memorandum[2] in 1979 from the same Committee. They determined that these same tests which they had previously used in prognostic terms (that the patient would not recover) should be used equally as diagnostic terms (that the patient was already dead). Quoting from the Memorandum, this was because by then 'all functions of the brain have permanently and irreversibly ceased'.

Now that's talking about 'all functions of the brain' but haven't we moved on again to use the language of 'brainstem death'?

The tests which were made were of brainstem activity so what was in fact being tested for was brainstem death, but there was a mistake in terminology which was only corrected in 1995[3] that this should not be called 'brain death' but should be called 'brainstem death'. The important point is that the assumption in the 1979 Memorandum equating this condition with death was that all functions of the brain had totally and irreversibly ceased, whereas it has been shown in many papers there is residual brain activity in these patients.

So the language was of 'the whole brain' but in practice it was the brainstem?

Yes. In *ABC of Brainstem Death*[4] Christopher Pallis describes his idiosyncratic view of death, that if 'these few cubic centimetres of tissue' in the brainstem were tested, that was all one needed to establish whether a person was alive or dead, and he disregarded all the activity in the higher parts of the brain[5,6].

Let me pick you up on that word 'idiosyncratic'. Christopher Pallis, who is regarded as Britain's if not the world's leading authority, defines death as 'the irreversible loss of the capacity for consciousness and the capacity to breathe' and he cites the centre of both those capacities as the brainstem. Now, everybody's agreed with him, so why do you call it 'idiosyncratic'?

Consciousness is subjective so there's no external test one can make for consciousness, and there is no way Pallis or anybody else can say there's no consciousness if we can show by electrical or other means that there is brain activity. Also, regarding the capacity to breathe - what he means is the capacity to breathe spontaneously - there are many occasions clinically where people unable to breathe spontaneously can maintain a virtually normal life. I'm thinking of people with polio or paralysis or some demyelinating diseases who are being ventilated.

The 'Further Reading' list cites[1] these various tests for brainstem death which you have criticised, but doesn't the consensus of British medicine regard them as adequate?

I don't think there is a consensus. There is a small group of experts who make the rules and there is a large majority of doctors who really have little understanding of the processes.

Pallis says that any activity in the higher parts of the brain is irrelevant in the presence of brainstem death. How do you respond to that?

I'd like to ask how he knows? Another thing he says is that none of these patients recover, and the only way one could know whether a patient with activity in the higher brain had any consciousness at that time would be by asking them if they recovered. They don't recover, because the only purpose for doing these tests is either to discontinue treatment and allow them to die, or to remove their organs in which case they will die.

But hasn't Pallis in his book got statistics of people maintained on ventilation who die naturally on the ventilator?

He has a phrase which is quite insubstantial and that is that all these patients who have the condition diagnosed as brainstem death 'will die within a matter of hours or days' and this is simply not true. It is based on a retrospective paper in 1981[7] but the patients who died were diagnosed as 'brain dead' on other criteria than the 1976 brainstem tests. There is a recent paper[8] looking at 175 patients who had the diagnosis of brainstem death made and they did not die in common terms for long periods - I think 40% survived a matter of weeks, another 20% survived a matter of months, and one or two survived many months. The other opposing evidence for Pallis' claims that all these patients will die is the number of recorded cases of pregnant women who have suffered some cerebral catastrophe and have been diagnosed as brainstem dead and have been maintained sometimes for many months in order that the fetus may mature and be delivered.

You've commented elsewhere on the extent of responsiveness of brainstem dead people during the process of organ donation. Donors being operated on show a number of physiological responses. What's the significance of that to you?

As an anaesthetist I am horrified that any of these patients are operated on without proper anaesthesia. You would think such an important issue would be well-documented and debated in anaesthetic literature. In fact I've been able to find precious little about it. There are some statements that anaesthesia is not needed but nevertheless should be given[4], there are some statements that it should be given 'just in case'.

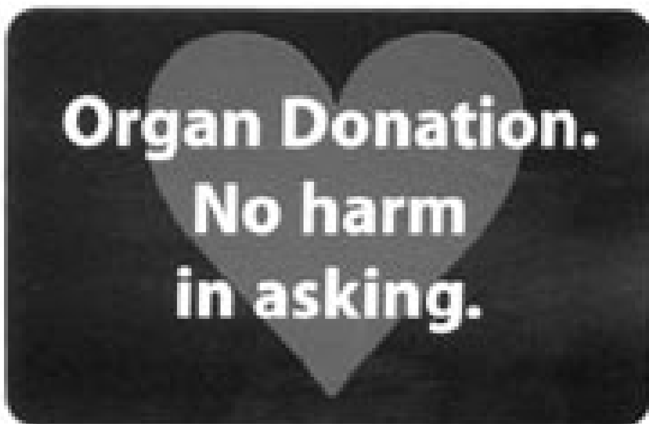
Just in case what?

Just in case, I presume, there is any possibility of residual sensibility or life.

But aren't those physiological responses just a consequence of spinal reflexes below a dead brainstem?
This is what the transplant team will attribute them to, but again there is no evidence in man that an acute transection of the cord (which is what they're referring to) produces these exaggerated responses and nearly all of the patients who are operated on for organ removal without anaesthesia show a rise in pulse and blood pressure at the beginning of surgery, which lasts sometimes 20-25 minutes unless they're given anaesthetics in which case they subside to a normal level[9].

You've also drawn attention to concerns in the literature about removing fears of 'residual sentience'. Do you think it is possible the patients might therefore be feeling something?
I don't think one can exclude that as a possibility[10].

Summing up your concerns so far, you recognise that people who are brainstem dead go on to die eventually by classical criteria but you are saying that 'brainstem death' is talking about a prognosis and not a diagnosis.
Yes.



Moving on from there, please take us through the transplant procedure. The donor is taken down to theatre, the ventilator is turned off, respiration stops, the heartbeat stops, circulation stops, they're dead by anybody's criteria, and the operation begins. Is that right?
That's completely wrong. That is certainly the impression which is given, whether deliberately or not, but that is not the situation. It used to be the situation when we were transplanting only kidneys because the kidneys will survive a period after the person has died. Other organs - heart, lung, liver, pancreas - will not function under those circumstances. The earliest liver transplants were from patients who were treated in the way you describe but they failed, so it became necessary - it was seen to be necessary - to take organs at an earlier stage. It was at that time that the Royal Colleges changed their opinion so that fulfilment of the brainstem tests would diagnose death rather than say that it will happen eventually.

Let's be quite clear. At what point is the ventilator turned off?
The ventilator is not turned off until all the organs that are needed have been removed. The patient comes to the operating theatre with sometimes even more intensive treatment going on than they were receiving in the ICU, they may need blood transfusion, they are treated intensively and they look like any other patient. As I've said, at the beginning of surgery they respond physiologically like any other patient.

What has been your experience of health professionals observing transplant operations? How have they reacted?
The number of people involved is very small and most of them are committed to the procedures. While I was working at Addenbrooke's I did over a period of four years or so see many entries in the Operating Register which gave the time the patient came into the theatre but also recorded the time of death as being some hours after that. Clearly the person filling in the Register, usually a nurse, had not regarded the patient as dead when they came into theatre but had subsequently recorded the time of death when the heart and respiration stopped.

But we've agreed in law you're dead when a doctor says so according to accepted criteria and writes a death certificate, so is that not just a conflict, some confusion, between the two disciplines of medicine and nursing?
No, I don't think so, I think it's a difference between theory and practice, between what we'd like to see and what we actually do see.

The Department of Health has recently had a big campaign encouraging the signing of donor cards, going onto the Register, being willing to have your organs taken after death. The literature they've released to health professionals suggests that relatives don't want to know the sorts of details you were describing earlier. Isn't that fair? Surely the public's ignorance of the detail doesn't matter?
I think it matters tremendously. Relatives are being asked to give consent to a procedure without being given adequate information on which they can base that consent.

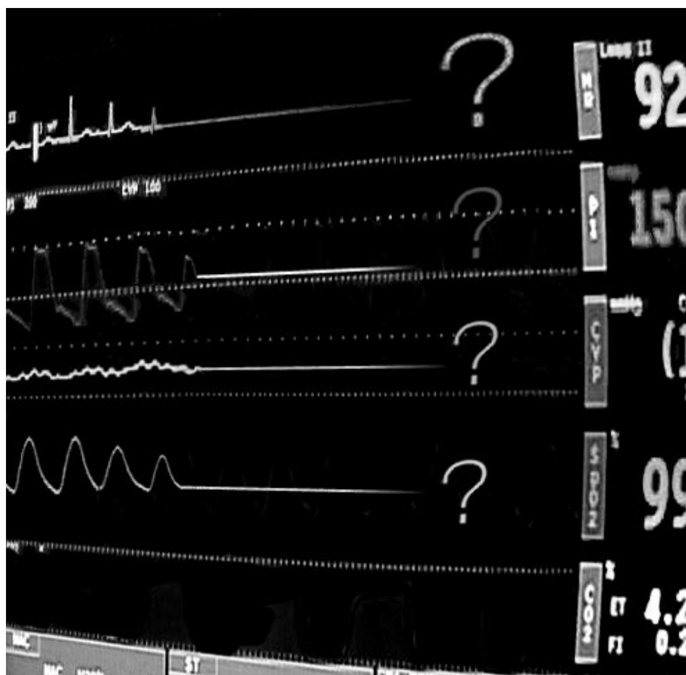
What about relatives' emotional state at that time? Is it fair to burden them emotionally?
Frankly, I think it's not. The condition of mind of relatives at that time is enough in itself to invalidate any consent.

It also says in the DoH promotional literature that 'two doctors working independently' who 'confirm brainstem death . . . are not part of the transplant team and . . . have no connection with organ donation'. Isn't that enough of a safeguard?
No it isn't. Two points: one is that it requires four opinions (two doctors on two occasions) as to whether somebody's dead and that does imply a degree of doubt[11]; secondly, doctors who are asked to confirm death on those criteria are very much part of the transplant team. If the doctors were not willing to confirm death they would not be asked. That was my own observation - I was never asked to confirm death because I would not sign a death certificate under those circumstances.

Aren't you just being semantic? Pallis claims that nobody who repeatedly fulfils UK brainstem death criteria ever survives.

Surely they're as good as dead?

Well, he's right that as far as we can tell they will not survive, but there is a world of difference between being dead and being as good as dead. I'm afraid the perceived urgency for transplanting organs has blurred that difference.



Have your views had any influence on your own career? How did your colleagues at Addenbrooke's react?

I was initially involved with transplants when we did switch off the ventilator before proceeding to remove organs and I was initially involved when we were using beating-heart donors, but I was appalled at that stage at what we were doing. Fortunately, we had a big enough anaesthetics department so that not everybody had to be involved and I was able to withdraw from it without any detriment.

Do you know of doctors with views like your own who've had problems?

I know of doctors who've had to search their consciences about what they're doing but I'm not aware of any anaesthetists who've had their career jeopardised. I do know of one cardiologist who was pressured into early retirement.

Quite recently we've had suggestions that Britain should join several other European countries and have an 'opting-out' system; in other words, somebody whose medical condition following injury or illness makes them a potential organ donor will be presumed to have opted into organ donation unless they're carrying a card confirming they've opted out. What's your reaction to that?

This is even less valid as a consent. Presumed consent is not informed consent under any circumstances.

At the end of the day, deep down aren't you fundamentally opposed to transplantation and just looking for fine print semantic niggles to justify your views?

I've seen the transplant scene develop, I've participated in it at an early stage with as much enthusiasm as everybody else, and it was only when the subsequent change was made that I have been unable to participate. It's not transplantation per se; it's the lack of information and the deceit and increasingly in my mind the lack of anaesthesia for the donors which make me so hostile to current procedures.

So can we sum up your objections?

There are four:

1. We are removing organs from people before we would declare them dead for any other purpose.

2. We are deliberately concealing this from would-be donors and their relatives.

3. We are failing to obtain properly informed consent - the donor card is inadequate.

4. We are failing to offer anaesthesia for the operation.

Thank you, David.

References and Further Reading

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David Hill was a consultant anaesthetist at Addenbrooke's Hospital, Cambridge and since retirement now works for much of each year in Nepal