**EDITORIAL NAGRAL Brain death**

More than fifty years after it was recognised and legalised, the concept of ‘brain’ death as opposed to the traditional ‘cardiac’ death remains enigmatic, complex and lends itself to debate. Starting from questions around its scientific validity and the accuracy of the methods used to diagnose it, to its application in the context of organ donation, brain death has been subjected to intense scientific, ethical and philosophical analysis. It has thus appeared with regularity in the pages of this journal, often in the context of deceased organ donation (1-4) but sometimes in other settings, including the recent bizarre attempt by an Indian researcher to conduct a clinical trial to ‘reverse’ it (6)(5).

By now, in many countries across the globe, brain death (‘brain stem’ death is considered a more precise term though the two are used interchangeably) is legally accepted as death, though the criteria for declaring brain death marginally differ from country to country. If the concept were not accepted, the removal of organs from those brain-dead individuals whose families consent to it would be a criminal act. And the thousands of fortunate patients who have received life-saving transplants would not have got the gift of life.

Deceased organ donations contribute to a larger share of organs available for transplants than live donation in some countries. In these countries even if organ donation is not possible the medical supports which includes a ventilator (brain-dead individuals have no respiratory drive) are switched off.

Historically, the recognition of ‘brain death’ preceded the idea of removal of organs in this state for purposes of transplantation. It must be acknowledged, however, that countries legislated and popularised this concept as it had implications for the availability of organs. These countries also brought together both cardiac and brain death to define death in the same law. Thus, brain death once identified and confirmed, also meant terminating artificial support in case donation was not possible or consented to. It was simple intuition that it was futile to keep the dead hooked indefinitely onto multiple supports including a ventilator.

Shroff and Navin in their commentary in this issue (**8)** highlight the fact that, in India, though brain death was legalised in 1994, brain-dead individuals who are not candidates for donation, or where the family refuses consent for donation, are continued on support. This leads to an alarming scenario wherein family members are approached for organ donation with clear information that their loved one is ‘dead’ but if they refuse and request that the ‘body’ to be handed over, they are informed that ‘life support’ cannot be withdrawn under the law!**(8)** Way back in 2001, this issue was highlighted in the pages of this journal by Sunil Pandya, a neurosurgeon and a plea was made for urgent correction ( [Issues Med Ethics.](https://www.ncbi.nlm.nih.gov/pubmed/16334472" \o "Issues in medical ethics.) 2001 Apr-Jun;9(2):51-2..) The article by Shroff and Navin , who are pioneers in the field of deceased (organ??) donation in India, revisits this issue 17 years later (8)! Meanwhile, deceased donation has increased in numbers and spread across states, but the shadow of this fundamental fault line still looms large. Shroff and Navinrefer to some of the ethically challenging situations on the ground that this leads to, and the potential implications for the future of organ donation.

But this continued ambiguity around withdrawal of organ-sustaining support in the most advanced scenario of futile care which is brain death, now also straddles another emerging public interest area. This is the recent emerging discourse around terminal illness, end of life care and euthanasia in India. This journal has addressed this extensively including in a special theme issue on the subject (11)

It is pertinent to look back at the chronology of some of the history of the passage of the THOA to understand why we may have reached this situation in the first place. The concept of brain death in India was first raised in the public arena, not by those caring for terminally ill patients, but by transplant surgeons who had an opportunity to see deceased donor transplantation in the West. This was in the late 1980’s and early 1990’s when the organ trade was at its peak in India and there was a huge public outcry on the issue of kidney sale rackets. It was thought that the promotion of deceased donation (by creating a larger pool of organs available for transplant) would also counter the organ trade. Thus, a group of surgeons from the All India Institute of Medical Sciences, through a series of public seminars, lobbied with interested parliamentarians to consider enacting a law (12)ref Pande GK, Nundy S). This process resulted in the promulgation of the Transplantation of Human Organs Act of 1994 (13), which combined the definition and criteria for declaring brain death with measures to control commercial trading of organs in the same document. Thus, though not explicitly stated, it seemed as if brain death was being legislated mainly for the purpose of organ donation. In their enthusiasm to push through a legislation which attempted to kill two birds with one stone, policy makers and Parliament perhaps made a fundamental flaw which now haunts us. Several later amendments have been made to THOA, but no effort has been made to address this issue.

The public and judicial discourse on end of life care in India which is now coming of age, was almost nonexistent in the early 1990’s when THOA was passed. Thus, brain death, which is an extreme form of futile care and provides the strongest case for terminating medical support, emerged in isolation from the larger arena of futile care in terminal illnesses. Now, following successive court judgments including the recent landmark judgment of the Supreme Court when we seem to be slowly but surely moving towards recognising some form of euthanasia in terminally ill patients, the fact that we continue to treat brain dead individuals with high end and costly interventions is a travesty of the highest order. Thanks to the focus on donation, care givers in intensive care units who are the first responders to a potential brain death situation, see it in the ‘donation’ paradigm rather than a ‘withdrawal of futile care’ paradigm.

This dichotomous situation also has another hugely problematic fallout which Shroff and Navin also refer to (8). When brain dead individuals in private sector ICU’s continue to receive organ support till cardiac arrest this is associated with huge costs (most intensive care beds in India are in the private sector where payment is largely out-of-pocket) leading to catastrophic expenses. Given the current anger and mistrust that Indian citizens have about the high costs of care, this situation is ripe for a potential conflagration. In fact, it is possible that many intensive care doctors knowing the potential dangers of this problem with the law do not venture into discussing brain death at all; thus, impacting the potential for organ donation and increasing the costs of completely futile care and indirectly reducing the availability of an ICU bed and ventilator which is an extremely scarce resource in India.

It is strange that while on the one hand we have been unable to deal with this fundamental contradiction for decades, periodically there are calls for introducing policies like ‘presumed’ consent wherein all individuals who are brain dead are presumed to have agreed to donation unless they have expressed an explicit wish against this in their lifetime (15)IJME ref). This is yet again a reflection of how the debate around end of life care in India often is informed more by the need for organs from the dead rather than the end of life care paradigm.

Shroff and Navin suggest legal remedies to correct this situation. These include a new version of The Registration of Birth & Deaths Act, 1969, and a modification of the brain death form prescribed under THOA (8). These are important suggestions but the question is who will lobby for them? The transplant community which acted decisively on pushing legislation for and promoting deceased donation will have to partly share the burden. They may have to join forces with the growing movement for dignified end of life care which has successfully fought a prolonged legal battle on the issue. Of course, the State, which promotes deceased donation, can be the key player to take this forward by actively seeking legal sanction on the matter.

There is already a growing discomfort with the fact that due to the domination of the private sector, deceased donations in India are largely serving the interests of the rich and powerful. Thus, almost 25 years after the promulgation of THOA, if we don't correct this fundamental incongruity, the charge that for all the lofty claims about the goodness of deceased donation, we have a narrow, utilitarian interest in the organs of the dead will unfortunately sound true. Thus, Shroff and Navin’s public plea through the pages of this journal to urgently correct this obvious and dangerous dichotomy is critical and long overdue.

**References**