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Ways of dying

SANJAY NAGRAL

How do we die? Is it an event or a process? Does everyone die in the same way or are there different ways of dying? Even with humankind's claims to gigantic strides in knowledge, death still remains one of the great mysteries for the living. And that makes it the subject of profound and perennial philosophical and religious enquiry. Modern medical science, however, had no option but to engage with it in its bodily form and try to define the precise nature of the process of death. Things were rather easy when death was equal to stoppage of the heart. But inevitably, the world of medicine with its keen sense of observation and constant yearning for scientific reasoning, recognised, somewhere in the middle of the last century, that the brains of a set of individuals hooked onto support systems in intensive care units were dying first, inevitably followed by the heart after some time. The tremendous progress in the science of resuscitation, organ support and intensive care while saving many lives resulted in an increasing number of such individuals, who were soon termed "brain dead" but whose hearts were still beating. The damage to the brain was irreversible and complete and inevitably, the heart had to follow within hours, or sometimes days.

More than fifty years after it was recognised and then legalised, the concept of "brain" death as distinct from traditional "cardiac" death remains enigmatic, complicated and still lends itself to doubts. From questions around its scientific validity, to the accuracy of the diagnosis, to its application in the context of organ donation, brain death has been subjected to intense technical, ethical and philosophical analysis. Naturally, it has appeared with regularity in the pages of this journal, often in the context of deceased organ donation (1) but sometimes in other settings, including the recent bizarre and ludicrous attempt by an Indian researcher to conduct a clinical trial to "reverse" it (2).

By now, in many countries across the globe, brain death (or "brain stem" death, considered a more precise term, though the two are used interchangeably) is legally accepted as death, though the criteria for declaring it differ marginally from country to country. Donation of organs in the state of brain death, when the organs are perfused with blood, contributes to a larger proportion of organs available for transplants. In addition, once brain death is declared, if organ donation is not possible, either for medical reasons or lack of consent from the family, the medical supports which include a ventilator (brain-dead individuals have no respiratory drive) are actively withdrawn. It is intuitive that it is futile to keep a dead person hooked indefinitely onto multiple supports including a ventilator.

Shroff and Navin, pioneers in the field of deceased donation in India, in a paper in this issue (3) highlight a serious continuing dilemma concerning the implementation of brain death in India. As they point out, historically, the awareness and recognition of the concept of "brain death" preceded the idea of removal of organs in this state for transplantation. Thus, while the condition was not recognised only for organ donation, it must be acknowledged that countries legislated and popularised this concept

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because of its implications for the availability of organs. If the concept were not accepted legally, the removal of organs from those brain-dead individuals whose families consent to it would be a criminal act, tantamount to murder. And the thousands of fortunate patients who have received life-saving transplants would not have got the gift of life that they have. Most countries first legally recognised brain death by an independent exercise of scientific validation and consensus building. Then, many followed this up by bringing both cardiac death and brain death into the definition of death in the same law. This was a logical step to avoid confusion on the ground. In India, the definition and legal recognition of brain death was first included in a law dealing with organ transplantation which is the Transplantation of Human Organs and Tissues Act, 1994 (THOTA) (4). Following that, there has been no attempt to move towards a uniform definition of death. That, and the resultant problems, are the focus of Shroff and Navin's paper (3).

The specific dilemma they refer to is that brain-dead individuals who are not candidates for donation, or where the family refuses consent, are currently continued on organ support till the heart stops, which may take hours or even days. 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" be handed over, they are informed that "life support" cannot be withdrawn under the Indian law! Way back in 2001, the same issue was highlighted in this journal by Sunil Pandya, a neurosurgeon, who made a plea for urgent correction (1). The current article essentially revisits this plea, but 17 years later! Meanwhile, as Shroff and Navin point out, donation after brain death has substantially increased in numbers across India. They refer to some of the ethically challenging situations on the ground that this leads to, and the potentially explosive implications for the future of organ donation (3).

This continued ambiguity around withdrawal of organ-sustaining support, in what is the most futile care scenario of brain death, also straddles another emerging public interest area in India. This is the emerging discourse around terminal illness, end of life care and euthanasia, which was set in motion by the Aruna Shanbaug case (5). This journal has addressed this area extensively, including in a special theme issue on the subject (6). While acknowledging that brain death is different from a "terminal illness", the debate around brain death and withdrawal of organ support needs to be linked to the larger debate on futile care in terminal illnesses.

It is pertinent to look back at the chronology of the passage of THOTA in 1994 to understand why we have reached this disturbing 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 early 1990's when the organ trade was at its peak and there was a huge public outcry on the issue of kidney sale rackets (7). It was presumed that the promotion of deceased donation (by creating a larger pool of organs available for transplant) would also counter the trade in organs. 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 (8). This process resulted in the promulgation of the Transplantation of Human Organs and Tissues Act of 1994, which combined the definition and criteria for declaring brain death with measures to control commercial trading of organs in the same document (4). 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 may have overlooked a fundamental flaw which now haunts us.

The public and judicial discourse on end of life care in India which is slowly coming of age, was almost non-existent in the early 1990's when THOTA was passed. Thus, the idea of brain death and supporting organ function with artificial means, 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 (5, 9) 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 indeed a travesty of the highest order. Thanks to the historical 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. Transplant coordinators appointed by institutions essentially also work with the narrow focus of identifying brain dead patients and convincing families to donate. As a result intensive care staff often perceive coordinators as organ seekers. The alternative model, which has been implemented in some countries is for the coordinators to assume the larger role of grief counsellors and patient advocates. That naturally gets them to adopt a more holistic end of life care approach including to the brain dead. And it would mean that they would naturally become advocates of withdrawal of futile care.

This anomalous situation has another hugely problematic fallout to which Shroff and Navin also refer (3). When brain dead individuals in private sector ICU's are not candidates for donation, they continue to receive full organ support till cardiac arrest. This is associated with huge costs as 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 citizens feel 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 (3), thus impacting the potential for organ

donation and increasing the costs of futile care. This also indirectly reduces the availability of an ICU bed and ventilator which is an extremely scarce resource in India. From another perspective, it is possible that some families agree to donation mainly as a way to end the high costs of care, as otherwise, in spite of the declaration of brain death, the body of their kin is not going to be handed over till after cardiac arrest. We do not know how the duplicity of asking for organs but not stopping care is affecting the public perception of deceased donation, and in turn, the other group of families who refuse donation.

It is strange that, while on the one hand we have not corrected this dangerous contradiction for decades, there are periodic calls from the highest quarters 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 (10, 11). This is, yet again, a reflection of how the debate around end of life care in India is often informed mainly by the need for organs.

Shroff and Navin suggest specific interventions to correct this situation. Their suggestions include a revision of the Registration of Birth & Deaths Act, 1969 (RBD Act) (12) to include brain death, and a modification of the brain death form prescribed under THOTA by deleting what they call “the offending clause” which is a reference to organ donation (3). It is pertinent to note at this stage, that there is a view that the definition of a “deceased person” in Clause 2 (e) of THOTA which is “a person in whom permanent disappearance of all evidence of life occurs, by reason of brain-stem death or in a cardio-pulmonary sense, at any time after live birth has taken place” actually clearly explains when there is permanent disappearance of all evidence of life (death), ie when there is brain stem death or cardio-pulmonary death and includes both forms (4). And that since neither the RBD Act nor the Indian Penal Code currently explain in clear terms what is meant by permanent disappearance of all evidence of life, the principles of ‘Interpretation of Statutes’ apply *pari materia* (13). These state that when any dispute is dealt with under the provisions of a particular Act, and the definition of a word is not available in that Act, then the definition of the said word can be imported from any other law for the time being in force (13). So, if THOTA has indeed included in its definition both cardiac and brain stem death, it would be legally sound to assume that this is the current definition of death to be interpreted in other laws which do not mention it at all.

So, do we really need to wait for some sort of deliverance from the state or the courts on this issue? And is the reluctance of carers to disconnect the ventilator after brain death is declared based more on an unfounded fear of the unknown, rather than a genuine legal problem? After all, even now when brain dead donors are taken to the operation theatre to harvest organs, the anaesthetist actively stops ventilation and cardiac supports at one stage, even when the heart is beating, during procurement of abdominal organs. This school of thought further argues that by continuing “organ support” to the brain dead, the caregivers may actually be committing a crime and inviting legal action (14)! Put in another way, how would the judiciary look at a scenario where those whose hearts have stopped are kept on a ventilator, pumped with costly drugs and charged by the hour?

However, the majority view as reflected in the Shroff and Navin paper suggests that it may be better to seek judicial clarity on the issue (3). It seems, even by the experience of other countries, that just intuitive and even rational arguments may not be enough and an explicit law or judgment may be necessary.

The questions that Shroff and Navin leave open are: Who will lobby for this move and pursue the matter? And if this hasn’t happened for decades, what will it take for it to happen now? The State, which also promotes deceased donation and hence shares responsibility, should be a key player in quickly taking this forward by actively seeking legal sanction. This could be through the law commission, but will need coordination between various agencies dealing with law and health.

I am afraid though that the transplant community, which acted decisively on pushing legislation for and promoting deceased donation, also has a certain responsibility to lobby for this change. Towards this, we could join hands with a range of forces and build a coalition. One such group is the growing movement for dignified end of life care (5,9), which is successfully fighting a prolonged legal battle. With the highest court of the land recognising the right to abandoning futile care this may be the right time to get an opinion on brain death. The other group of allies is the large number of people’s health movements and patients’ rights groups across the country including those working in palliative care, who are struggling for a more humane and affordable form of care, including at the end of life.

There is already a growing discomfort with the fact that, due to the gross domination of the private sector in performing transplants, deceased donations in India are largely serving the interests of the rich and powerful. Also, doubts have been raised about the motives of hospitals declaring brain death with alleged compromises in testing mechanisms, through a case in the Kerala High Court (15). Thus, as we inch towards completing 25 years of THOTA, if we don’t correct the fundamental incongruity that Shroff and Navin highlight, the charge that for all the lofty claims about the goodness of deceased donation, we have a narrow, utilitarian interest only in the organs of the dead may unfortunately sound true. Thus, this plea through the pages of this journal to urgently correct this dangerous dichotomy though revisiting an old issue is critical and long overdue. We owe it to the hundreds of our fellow citizens who, in acts of astounding magnanimity in a moment of intense sudden grief, are donating organs of someone very close to them.

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