

COMMENT

Will presumed consent make transplantation accessible, ethical and affordable in India?

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Organ transplantation is now a well established life saving procedure for patients suffering from end-stage disease of various organs. In the last four decades, the concept of "brain death", a state where the brain is irreversibly damaged but the heart is beating, has been legalised and accepted in many countries of the world. A majority of transplants are now done with organs retrieved from such brain dead individuals. The need for organs, however, far outweighs their availability and a large number of patients still die waiting for organs.

The form and method of obtaining consent for removal of organs from brain dead individuals has evolved over the years. Generally, two forms of consent are practised. The most common is "informed consent" in which close family members agree to donate organs after brain death has been certified. Often, this means that the treating doctor or a trained counsellor has to communicate with the family and motivate them to agree to organ donation after brain death has been declared. Medical professionals may be reluctant to do so for fear of inviting the wrath of family members in an emotionally charged situation. Besides the trauma of losing a close family member, various cultural, religious and social beliefs may prevent the family from giving such consent. Even in countries with a long history of such organ donation, consent rates have rarely exceeded 50-60% and have plateaued in the last few years.

In order to improve the donation rate, other strategies have been proposed and implemented. In many countries "donor cards" are provided which citizens sign and keep during their lifetime. This makes it easier for family members to take a decision. Some states of the US have what is termed a "required request" which makes it mandatory for the doctor to ask the relatives of a brain dead patient about organ donation. In some European countries such as Austria, Belgium, Denmark, Finland and France, "presumed consent" has now been legalised and is practised. This grants authority to doctors to remove organs from brain dead individuals whenever usable organs are available, in the absence of any objection from the deceased in his or her lifetime, or from family members. Presumed consent places the burden of opting out of organ donation on those who object to this procedure. This form of consent was introduced in these countries after a long history of cadaveric donation as well as public debate on the issue. It must be noted, however, that in spite of such measures, the discrepancy between demand and supply of organs continues to grow.

When the Human Organs Transplant Act was passed by the Indian Parliament in 1994, it had a dual purpose. Besides banning trading in organs, it legalised brain death, making removal of organs from persons declared brain dead permissible after obtaining the consent of the family. The 15 years since the passage of the law have seen negligible activity in cadaveric donation. In many states it has been as good as a non-starter. Even in cities such as Chennai and Mumbai, where there has been some activity, it has not been consistent. It is against this background that attempts are being made to modify the law both to ease the procedure of organ donation and to offer "legitimate" incentives to donor families. States like Tamil Nadu have recently issued directives which put pressure on medical institutions to identify and approach families of brain dead patients. Such measures have seen a marginal rise in donation rates.

Kaushik's paper in this issue gives a well structured historical, judicial, philosophical and social perspective on the need for, and evolution of, the idea of presumed consent (1). It is comprehensive in the ground that it covers and relevant in a country where organ donation has failed to take off 15 years after it was legalised. As a surgeon involved in organ transplantation and hence regularly seeing patients dying while on the waiting list for cadaver donation, I am tempted to support her call for considering the introduction of presumed consent in India.

However, any observer of the social as well as healthcare scenario in contemporary India will inevitably have to first question the relevance of the debate over consent in a country that denies basic healthcare to a large section of society (of course this argument can be extended to the entire field of organ transplantation which is presently beyond the reach of most people). Even if one decides to look at it purely from the viewpoint of those dying while waiting for transplants, societal acceptance of constructs that have their origin in a developed western Anglo Saxon society needs discussion. And, finally, one shudders to think of the Pandora's Box that such legislation would open in a country that has a completely unregulated healthcare system and vast class, caste and regional imbalances.

To be fair, though Kaushik's article largely restricts itself to the US and Europe, where the presumed consent concept has been developed and implemented in various forms, it informs us that

a similar experiment in Brazil did not work. It is silent on Asia and the rest of South America (where organ transplantation is common in many countries and which is culturally closer to India) where such a proposal has not been introduced. Kaushik also alludes to the problem of implementation when she says: "It can be effective only when there is a good infrastructure, for instance an actively involved government agency that coordinates procedures for the removal, distribution, transportation, and transplantation of organs."

The argument of "the greater common good" is indeed a complex and interesting one. At a broader sociological level it throws up many questions beginning with the terminology itself. For example, who constitutes the "greater common"? And how does one decide what is "good"? In the context of healthcare in general, can we use the common good argument to, for example, legislate to stop people in large cities using automobiles and instead use public transport to reduce pollution, which is a major silent killer? Or should we ban smoking and alcohol completely as they not only cause disease but also are health risks for society in general?

After arguing for the implementation of presumed consent, Kaushik admits that "this will be possible only after creating widespread awareness about organ transplantation in the country and addressing the religious and cultural overtones that are associated with it". The history of the last 15 years in India shows that we are far from creating any such awareness. Most large institutions have failed to even set up a basic mechanism for approaching families of brain dead individuals. The lack of progress in cadaver donation is often ascribed to lack of public awareness, but this is not entirely true. In the hospital in Mumbai where I work, a concerted effort was made to increase donations with the appointment of a dedicated transplant co-ordinator and education of staff. As

a result, the consent rate is around 50%, which is close to that of western countries. Recent experiences of armed forces' medical institutions and some institutions in Chennai are similar. It seems that if institutions make efforts to promote organ donation and identification of brain dead donors by ICU personnel, the consent rate is likely to be good. Cadaveric transplants are not being performed not because of lack of awareness and refusal by families to donate, but because of absence of institutional mechanisms to approach families of brain dead individuals. It is the same story as in eye and blood donation which has a much longer history in India. Perhaps this reflects the state of healthcare in India where activities like organ donation suffer because government institutions are grappling with basic problems, and private institutions do not see it translating into profits.

Even in its present limited form, cadaveric donation in India largely benefits the rich. Also, given the cost, transplantation is at present offered to a miniscule minority of patients suffering from end stage disease of organs. In the context of presumed consent, where all sections of society will be involved, it is difficult to see how, in an already lopsided system, one ensures equitable distribution of organs based on those who need it rather than those who can afford it. And do we have the ability to monitor the implementation of such a system in the completely unregulated market of healthcare and protect it from potential abuse? Thus, whilst trying to achieve an increase in organ availability by such a drastic leap, are the proponents of this system willing to go beyond availability and simultaneously look at making transplantation accessible, equitable and ethical?

Reference

1. Kaushik J. Organ transplant and presumed consent: towards an "opting out" system. *Indian J Med Ethics* 2009 Jul-Sep; 6(3): 149-52.

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