

## Editorial

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### Hospital awareness rather than public awareness is key to promote organ donation

Organ transplantation picked up in India during the 1980s and gathered momentum only during the 1990s, especially after the Transplantation of Human Organs Act was passed by Parliament in 1994 and thereafter ratified by most states (except for Andhra Pradesh and Jammu and Kashmir, who passed their own Acts). To start with, it was mostly live donor kidney transplants; live donor liver transplants was a late starter and developed slowly. Deceased donor transplantations (DDTs) took longer to start, primarily because the 1994 Act was silent on who gets the donated organs; each state had to take the initiative to establish the complex networks and systems for organ distribution. As a result, DDTs have gathered momentum only during the past 10 years, slowly nearing 0.8 donors per million population in a year.

While this level of donation after brain death (DBD) is not poor for a developing country, it certainly falls much below what is possible with the present infrastructure of intensive care unit (ICU) beds and specialists and the demand for kidney and liver transplants. However, expertise and demand for heart and lung transplantation are far below the current availability of donated organs; it will take some years to catch up with supply.

A common perception regarding the low rate of DBD in India is that it is due to the low level of public awareness and hence of consent for donation. This perception has led to several civil society organizations and some media houses to take up the cause of promoting organ donation awareness, with support from government agencies. However, there is hardly any religious or community bias in India against organ removal and the communitarian spirit is of a high order.

In this context, if anyone asks for the biggest roadblock to organ donation in India, the answer can only be related to hospital motivation. This reality seems to have dawned on the team at the 350-bed Lakeshore Hospital at Kochi, Kerala, India, which has resulted in a structured programme to involve all key persons in this cooperative effort and improve their levels of knowledge and motivation.<sup>1</sup> The effectiveness of such structured programmes—usually known as Donor Action Program (DAP)—in enlarging the base of donor hospitals and increasing overall organ donation has been well established in many countries.

The outcome of the first 2 years of running this structured programme in that hospital has been lucidly explained in an article by Thomas *et al.*<sup>1</sup> That the programme was planned and executed meticulously and with great energy is clear in its end result. The key takeaways from the success of that hospital are: establishing a dedicated core team, an ICU counsellor apart from the transplant coordinator, and frequent review meetings to evolve a pattern with experience.

Few hospitals in India have initiated similar efforts. The article suggests that hospital administrators are reluctant to do so as it could lead to their 'bad reputation'; elsewhere they cite ethical considerations based on conflicts of interest as another factor. This brings to fore the growing trust gap between public and private healthcare providers. It is true that conflict of interest does exist between profit-seeking and medical ethics.<sup>2</sup> Seeking a second or third opinion for even minor procedures is becoming commonplace.<sup>3</sup> A recent book, *Healers or predators?*<sup>4</sup> is a reflection of increasing societal concern on this issue.<sup>5</sup> Soon after the book was released, a public discussion was held in Chennai by The Hindu Centre for Politics and Public Policy, with two of the editors of the book on the panel. The

takeaway of the discussion was that only a small minority of private practitioners were true predators, an even smaller minority stood up aggressively to uphold ethical standards, while the rest were trapped in conflicts of interest.<sup>5</sup> None can deny that private healthcare costs are market-driven, with rare specialized treatments priced higher than those more commonly available. Transplant surgeries do yield more money per bed occupancy than many others.

This is compounded by the fact that altruistically donated organs come for free, but transplanting them costs substantial sums of money and yields good profits to hospitals. The public perception of conflict of interest in this area—specifically on brain death certification—is a major factor that led to a series of knee-jerk reactions in Kerala, a highly literate state where a steep drop was recorded in deceased donors from 76 in 2015 to 8 in 2018.<sup>6</sup> One can understand the reluctance of hospital managements everywhere to get involved, compounded by needless bureaucratic regulations all over the country, further worsened by an agency of the Central Government being involved in this state subject (states in India have the right to take decisions in the area of health, which comes under the State Subject list in the Seventh Schedule of the Constitution of India).<sup>7</sup>

Another issue that needs to be kept in mind is that the demand for organ transplantation is limited because it is expensive. It is only for kidney transplantation that demand substantially exceeds the availability of donated organs, whereas demand marginally exceeds supply for liver and is substantially lower for heart and lung, with a majority of donated organs being wasted.<sup>8</sup> Hence, promotion of DBD is mainly for kidneys. That too, in less than one-third of states in India that are active in DBD organ distribution.<sup>9</sup> A far bigger need is thus for the Central Government to focus on motivating and helping more states to get involved in promoting infrastructure development for liver, heart and lung transplantations in most states rather than bring in centralized control over operation of the programme in the states that are doing well.

The expense factor also leads to public perception of the reality that organs go from the poor to the rich.<sup>10</sup> The transplant community, which is fully aware of this practice, prefers to ignore it as long as possible. It keeps recommending to the government to address this inequality through public insurance and involvement of public hospitals—solutions that would satisfy those who advocate them, but not the patients who need transplants, as they will still not get it.<sup>11</sup>

Within these constraints, there is an untapped potential for DBD. It is incumbent on those interested in tapping this potential, especially voluntary organizations, to use their scarce resource—quality time—more on motivating and helping hospitals to start DAPs and less on public awareness programmes. Human interest stories in the media highlighting organ donation have more impact on creating public awareness than expensive public programmes and competitions for records in the Guinness Book.<sup>12–14</sup> Experienced transplant coordinators are conscious that there is little difference in consent rates between families that have not heard of organ donation and those that are aware.

The biggest barrier is thus not in obtaining consent, but in seeking it.<sup>15</sup> Global experience shows that mandating certification of all brain deaths as well as required request<sup>16</sup> as a solution to this is beset with many practical issues,<sup>17</sup> whereas nudging is known to work with hospitals. Hence, state agencies should promote DAP in hospitals besides organizing publicity events featuring very important persons (VIPs).

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