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## Review Article

# Cadaveric organ donation: Indian perspective

Bedanta Sarma<sup>1\*</sup>, Shreemanta Kumar Dash<sup>1</sup>, Pankaj Suresh Ghormade<sup>2</sup>,  
Dheeraj Abhaykumar Vinod Kumar<sup>3</sup>

<sup>1</sup>Dept. of FMT, All India Institute of Medical Sciences (AIIMS), Mangalagiri, Andhra Pradesh, India

<sup>2</sup>Dept. of FMT, All India Institute of Medical Sciences, Raipur, Chhattisgarh, India

<sup>3</sup>Dept. of FMT, All India Institute of Medical Sciences, Deoghar, Jharkhand, India



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### ABSTRACT

Cadaveric organ donation in India, although started long back; its present status is not favourable. The percentage gain is very slow in comparison to most of the country even after having proper legislation. There are many reasons for this, lack of awareness being the most common. Most of the people does not know the concept of brain death. Although government and many NGOs are attached with it and are trying their level best to communicate with people for this noble cause, they have not yet reached the expected goal.

To boost up the process of cadaveric organ donation, the hospitals and their staff including doctors must play a vital role. Hence, knowledge and orientation of such potential group is important for further processing because in most of the hospitals even doctors are not well-informed about the legal and ethical aspects of organ donation. If all the weak locus are addressed properly, we can definitely achieve the goals within a short span of time.

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## 1. Introduction

Organ donation and transplantation has been carried out in India as per the legislation, following all government guidelines. However, there is a huge gap between organ demand and actual supply in India.<sup>1</sup> Data from the WHO Global Observatory on Donation and Transplantation (GODT) showed that over 130,000 solid organ transplants are performed worldwide, which is even less than 10% of the global need.<sup>2</sup> In India, there is a need for 258,000 organs/year, which accounts for 185,000 kidneys, 33,000 livers and 50,000 hearts, whereas only 6000 kidneys, 1200 livers and 15 hearts are transplanted annually resulting very low ratio.<sup>3</sup>

\* Corresponding author.

E-mail address: [drbedanta.fmt@aaimsmangalagiri.edu.in](mailto:drbedanta.fmt@aaimsmangalagiri.edu.in) (B. Sarma).

There may be various reasons for this. However, less number of deceased organ donation can be considered to be the most important cause.<sup>1,4</sup> A deceased donor can give up to eight organs saving 8 people's lives, according to the Organ procurement of Transplant Network.<sup>5</sup> In spite of a strong legislation for organ donation and transplantation, deceased organ donation in India has received minimal attention. The cause is multifactorial, which needs to be addressed properly so that statistics can be improved.

The term "cadaver donor" describes donation of solid organs by patients who have been declared brain dead followed by transplantation into patients struggling with end-stage organ failure.<sup>6</sup> Although there is an opt-in system in place, an individual can make his/her wish to donate on their own and the decision to donate or not in the event of brain stem death of an individual rests with the family and

their decisions.<sup>7</sup> Hence, the family plays a major role in deceased organ donation as they must decide if they want to donate the organs of their loved one to save others' life or not.

## 2. Present Status

According to National Organs & Tissue Transplantation Organization (NOTTO), a total of 1028 deceased organ donation was there in 2023 as compared to the previous year statistics. The number could be higher since some states are yet to update their statistics. Telangana continued at the top with 200 donations followed by Karnataka (178), Tamil Nadu (176), Maharashtra (149) and Gujrat (146). Mumbai itself managed a high of 50 cadaveric organ donation in 2023. Each cadaver donor on an average donated three organs, so 2,800-3000 organ failure patients benefited from this in a single year.<sup>6</sup>

However, the US has a 100 times higher deceased organ donation rate than India. It has 41 deceased organ donors per million population which is just 0.4 in India. The rate is 24.7 for France, 19.8 for the UK, 11.1 for Germany and 0.62 for Japan among the advanced countries. Emerging market peers like Brazil (13.8) and China (3.63) also have a higher rate than India. This data is for the year 2021, similar to 2019.<sup>8</sup>

## 3. Addressing the Challenges

The lower implementation of deceased organ donation is multifactorial. Out of all, the most important is poor awareness about deceased organ donation. Converting eligible donors into actual donors are important reason which is linked with awareness for such an organ shortage in India.<sup>9,10</sup> Except a few, in most of the states the awareness programs are conducted; however they failed to reach the mass population.

It cannot certainly be said that if we can achieve higher percentage of reaching people, we will get more number of successful attempt. Even in developed countries like the USA, the conversion rate is half even after proper approach (among the approached family members).<sup>9,10</sup>

Despite having a proper act since 1994, none of the states has shown increased cadaveric donation except a few states. Although, provision of transplant coordinator is there in the act, they are mostly un-trained in most of the hospitals. They are considered as the backbone since they will be constantly in touch with the relatives and fascinate the process. Hence, their proper qualification and training must be ensured.

Another challenge is unacceptability of brain death by family members. They will observe their patient taking breath under support and not ready to accept the fact, may be because of emotional issues and lack of knowledge. There is lack of proper prior discussion about it from the hospital staff so that family members can be oriented. Discussing

organ donation with the relatives of the brain dead itself is never easy.<sup>11</sup>

Most of the physicians are not orientated to the provisions and procedures for implementation of the act in real life scenario. They do have theoretical knowledge about it, however when turn comes to apply it with real life; they become confused. Ultimately, they will try to avoid the situation. This is mostly because of non-inclusion of the topic in curriculum of medical training. Hence, they cannot address brain dead properly in front of family members. Communication strategy must be enhanced, and it must be delivered at appropriate time and place with empathetic tone. Involvement of senior consultant is another value addition.<sup>12</sup>

Challenges with reference to infrastructures are another drawback. There is always lack of ICU care facility and availability of ventilators as per the need in India. Because of non availability of ventilators in every hospital to maintain brain dead cases, we are losing potential donors.

There is always religious sentiment for cadaveric organ donation. Different religions have different perceptions for this. Spiritual belief of life after death plays an important negative role.<sup>13</sup> Superstitions such as being born with a missing organ (that has been donated); and that tampering with the body will not free their dead relatives from the cycle of life–death–rebirth is some of the prevalent superstitions.<sup>14</sup>

Delinking brainstem death condition from organ donation remains a big challenge associated in the current legal scenario. Brainstem death as death is only mentioned in transplantation act and has been linked. However, it is not mentioned in Registration of birth and death act 1969 causing legal and ethical problems while removing ventilatory support in such cases.<sup>12,15</sup>

## 4. Denial by Relatives

Decision-making for deceased organ donation is a complex process involving multiple family members. The most common factors causing difficulties are death circumstances, the coherence of the family members, socio-economic and religious culture and awareness level about the donation, approach of health workers, etc.<sup>16,17</sup> Most relatives remained in a dilemma because of a conflict of values, which is influenced by the disparity between general willingness and actual decisions.<sup>18</sup> There are differential reasons for denial, such as non-willingness to involve in the donation process, lack of decision-making capacity, and overwhelming emotions.<sup>19–21</sup> Among other reasons, desires to reduce the suffering of another or to act according to religious beliefs, social pressures or perceived norms are some of the contributing factors toward the denial.<sup>1,22</sup>

## 5. Addressing the Challenges at Hospital Level

The action of hospitals play a vital role here. There planning and execution can make a huge positive difference for cadaveric organ donation. However, our government hospitals are over-burden of patients, and there is always infra- structural limitations. Hence, most of the hospital does not make additional efforts to pursue the matter.

Criteria for choosing donors are very limited. If it can be extended to non-RTA brain-dead individuals there is possibility of increase in percentage of organs to be retrieved.<sup>23,24</sup> Early detection of potential donor is a must to boost up the procedure. For this there must be a proper protocol which has to be followed strictly by all involved in this process.<sup>25,26</sup>

It is a multidisciplinary approach, requiring a strong and dedicated team. They will ensure precise medical management of donors, mental support of family and relatives, easy and smooth procedure followed by proper dignified handling of body to legal heirs.<sup>25,26</sup> Delayed handover of dead body after organ retrieval is another factor for families to refuse it. This must be dealt seriously.<sup>14</sup>

Physicians are the first contact. They can aware their patients and relatives regarding the noble job of donating organs. Proper training of the health care personals so that they can be oriented not only for the medical procedures but also with legal and ethical issues. Development of proper communication skill must be a core competency into their training.<sup>1,25,27</sup> Discussion about organ donation must be a part of end-of-life care. It can be fascinated by early involvement of Transplant coordinator with sympathetic approach.<sup>1,14,27</sup> The counselling team starts approaching the patient's family at the last stage unlike achiever countries, where the team of counsellors builds an informal rapport with the relatives once patient gets admitted to the hospital. The counsellors' work is to brief about the patient's health progress, in critical cases preparing the relatives about the impossibility of the patient's survival and finally about the option for organ donation.

## 6. Role of Intensivists

Doctors working in ICUs plays an important role in giving care to potential organ donor since all the potential donors are victims of RTA, enter ICU at some point in time.<sup>25,28</sup>

They can make a huge change into this. If 5–10% of all brain-dead patients are considered properly for organ harvesting, there would be no requirement for a living person to donate organs.<sup>28</sup>

Hence, mandatory training sessions can be introduced by Indian society of Critical Care Medicine or National Medical Council for the intensivists. Spain leads the world in deceased organ donation and their success is mainly because of trained intensivists who even plays the role of transplant coordinator in difficult situations.<sup>29</sup>

Declaration of brain deaths must be made a simple, straight-forward and hassle free process for the doctors.<sup>14</sup> In India, even if the family agrees to donate organs of a brain dead patient; the legal formalities takes most of the golden period. Many a times, guidelines from state government are confusing. In this regard, Tamil Nadu followed by Maharashtra have come up with innovative ideas with straight and stringent government orders to make the process smooth for doctor as well as family members.<sup>29</sup>

## 7. Steps at Community Level

1. Awareness: It should be the preliminary effort to spread the message to the public even to the most remote locations of India. For this, they should be funded continuously by central government, and it should be executed in a properly planned and organized manner. PM Modi focused on cadaveric organ donation in his 99th episode of "Mann ki baat". Following this many hospitals have come up with this idea.<sup>6</sup>
2. Media: Media has a big role to reach the people in large scale and consistent manner by advertisement in print and digital platform. All the myths should be addressed and clarified.
3. Movies & shows: They have a dual action. Some movies and shows have been made where the black side of the commercial organ dealing has been showed without much knowledge about it. They can create negative impact on public. Hence, the makers must be very cautious while making such movies so that scientific and legal content is not compromised.<sup>30,31</sup> It should be promoted by government or some nor government bodies with noble intention.
4. Involvement of celebrities: Most of the people follow celebrities. Hence, mega show event with celebrities and renowned persons can attract public for the same. Promotional videos with celebrity faces must be broadcasted through various media.
5. Involvement of spiritual leaders: They must be familiar with present legal provisions of the purpose so that it can be easily percolated at community levels to overcome some religious sentiments.<sup>14</sup>

## 8. Steps at School Level

1. School curriculum: Introducing the topic in high school curriculum which can be added onwards with wide coverage. Students can be given adequate information about the importance of deceased organ donation and the procedure for it. This will help to face real life scenarios once admitted to medical/para-medical field. They can be informed about the process and procedure of pledge for this noble cause.<sup>14</sup>

## 9. Steps by Governments

1. Driving license: Incorporating organ donation pledge in driving license application can be an innovative idea. This was started by few cities like Mumbai, Pune, Bangalore as pilot project. This pilot initiative was a success to create great awareness to increase the number of potential donors.
2. Sensitizing professionals: Police and forensic experts play a major role in deceased organ retrieval procedure. If they can be sensitized properly, loss of vital time during the procedure can be cut short there by increasing the rate. Government has taken up it as “in a health campaign mode”, regularly organizing long programmes and seminars to ensure that every medical and non-medical college is sensitized about the cause.<sup>6</sup>
3. National registry and donor-recipient network: Most of the people has doubt regarding post retrieval commercial trading of the donated organs.<sup>32</sup> Setting up of these centrally managed systems so that donated organs can be shared in a fair and transparent manner will definitely increase faith of public on the system. This has already been initiated in the legislation with a provision for the same.
4. Adaptation of successful models: Maharashtra and Tamil Nadu have done excellent work on this. Hence, such models can be adopted by other states too.
5. Organ transport: Once organs are retrieved they should reach the beneficiary sites in a specific time. To fascinate this, government must arrange for green corridor while transferring by road carrier as and when required. They can also provide financial help by collaborating with air carriers to help in mobilizing the donated organ to different parts of the country and thereby preventing organ wastage.<sup>14,32</sup>
6. Recognition of donor families: Gesture of gratitude must be provided to the family members of donors by conducting various functions, ceremonies, etc.<sup>14</sup>

## 10. Individual Levels

1. Pledging Organs by a living/deceased person: Any person willing to donate his/her organs can do so by filling out the donor consent form available on the Ministry of Health and Family Welfare, Government of India website. However, the organ donor card is not a legal document. At the time of organ donation, the family of the patient will make the final decision on whether to donate organs or not. Newly launched Aadhar-enabled pledged has gain good public response by achieving 1.34 lakhs response within four months of its first launch.<sup>6</sup>
2. Living will: A person can prepare a living will regarding his organ donation. For this the person needs to name an executor (preferably a family member)

in the document who will execute the living-will in his/her absence. It must be attested by the executor, two independent witnesses, and countersigned by a notary or gazetted officer. Organizations such as Aasaan Will, Yellow and estate planning firms can help digitally create a living will.<sup>33</sup>

## 11. Role of Non-government Agencies

MOHAN (Multi Organ Harvesting Aid Network) foundation is working since long mostly in cadaveric organ donation. They are having good network in most of the states. They have given few recommendations to central government like appointing transplant coordinator in all ICUs, mandatory PM examination on the same day of organ retrieval, donor clause in driving license, and many more. They are doing continuous awareness programs in each corner of India.<sup>34</sup>

AORTA (Armed Forces Organ Retrieval and Transplantation Authority) is also conducting various awareness programs extensively. They are involving movie stars and athletes to attract people. They are providing donor cards, arranging functions to express gratitude towards the families who have extended helping hand for the noble cause and also giving recommendation to central government. With the initiative of AORTA, a liver was transported for the first time from new Delhi to Hyderabad and later kidney from new Delhi to Mumbai, Lucknow and Pune (interstate transfer).

ORBO (Organ Retrieval Banking Organization) has been setup by the All India Institute of Medical Sciences (AIIMS) Delhi. They are maintaining donor registration, coordination from retrieval till donation process, information sharing with concerned hospitals alongside awareness. They have a network of 20 hospitals (8 govt and 12 private) in NCR and now moving towards international level with the agenda.<sup>35</sup>

## 12. Conclusion

Awareness of public is the key for the success of cadaveric organ donation in India. It should be started at the community level moving towards school curriculum. Many factors can be addressed by effective and sensitive discussions by immediate household members with successful stories.

Since it is a multidisciplinary approach, all the staff of a hospital including doctors must be sensitized so that they are confident and build interest for this. If it is achieved, they can aware many people directly or indirectly for this noble cause.

Concerned government should come up with new ideas. The retrieval system must be streamlined and hassle-free. Provision for proper and timely handover of dead body must be there. In this aspect, they can issue specific orders time to time.

### 13. Sources of Funding

None.

### 14. Conflict of Interest

None.

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### Author biography

**Bedanta Sarma**, Associate Professor

**Shreemanta Kumar Dash**, Professor & Head

**Pankaj Suresh Ghormade**, Associate Professor

**Dheeraj Abhaykumar Vinod Kumar**, Assistant Professor

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