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*Original article*

## Organ Donation in India: The Organ transplant coordinator's Perspective

Vaishaly Bharambe<sup>1</sup>, Vatsalaswamy Puranam<sup>2</sup>, Vasanti Arole<sup>3</sup> and Manvikar Purushottam Rao<sup>4</sup>

<sup>1</sup>Department of Anatomy, Dr D Y Patil Medical College, Hospital and Research Centre, Pune, India; <sup>2</sup>Academic Director, Dr D Y Patil Medical College, Hospital and Research Centre, Pune, India; <sup>3</sup>Dept of Anatomy, College of Medical Sciences, Bharatpur, Nepal; <sup>4</sup>Head of the Department of Anatomy, Dr D Y Patil Medical College, Hospital and Research Centre, Pune, India

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### Abstract

**Introduction.** The Transplant of Human Organ Act has made appointment of a transplant coordinator as mandatory for every transplant hospital for coordinating all matters related to removal or transplantation of human organs or tissues or both. The present study was undertaken to investigate the challenges of organ donation from the perspective of organ transplant coordinators.

**Methods.** The study consisted of detailed discussion with organ transplant coordinators regarding their experiences related to problems in organ donation activity in Pune. The discussions were analyzed for insights into the organ donation.

**Results.** 14 OTCs participated in the study. The analysis of the discussion revealed that challenges for organ donation in Pune region revolved around themes such as poor awareness about details of organ donor categories and organs each could donate, non declaration of brain death, financial status of the potential recipient, willingness or not to counsel the donor family for organ donation, myths and misconceptions related to organ donation and fear of organ trade, among others.

**Conclusion.** The people of this region needed to be educated about the details of categories of organ donors and the organs each category may donate. The OTCs must be trained in counselling for organ donation. The doctors of the region need to be encouraged to diagnose brain death. There was need to counsel people to help overcome the myths. The police or lawyers who were trained in document verification could be involved in document scrutinisation process to combat problem of organ trade.

**Keywords:** organ donation, organ transplant coordinator, organ trade, transplant of human organs act

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### Introduction

The Transplant of Human Organ or Tissue or both Act

(2011) of India (THO Act 2011) states that no hospital shall be registered under the Act unless the authorities were satisfied that the hospital had appointed a transplant coordinator with requisite qualifications. An organ transplant coordinator (OTC) has been defined by the THO Act as a person appointed by a hospital for coordinating all matters related to removal or transplantation of human organs or tissues or both and for assisting the authorities for removal of human organs in accordance with the related sections of the Law [1].

Organ shortage for purpose of organ transplant surgeries is a universal problem worldwide [2]. However, Asia lags behind the rest of the world in efforts to solve this problem. Authors believe that the way to raise the organ donation rates in Asia, especially in India is to raise ground level awareness, dispel misinformation in the minds of people and encourage people to register for organ donation [3]. An OTC is a person who does all of this besides carrying out grief counselling for the family of the patient and broaching the subject of organ donation with the family of the brain dead patient.

The present study was undertaken to investigate the challenges to organ donation and transplant activity in Pune district of Maharashtra, a state in western Maharashtra, from the perspective of OTCs.

### Aims

The present study was aimed at studying the challenges that impact Organ Donation in India and to find solutions to combat them from point of view of OTCs. After reviewing the findings the study attempted to suggest solutions to improve the rate of organ donation.

### Material and methods

Pune division is one of the 6 divisions of Maharashtra state of India. The present study was carried out in select cities of this Pune division of Maharashtra. All those Cities in the Pune division of Maharashtra which

had registered organ transplant centres or had a non transplant organ retrieval centre (NTORC) were selected in this study. Thus the cities selected were Pune, Karad, Sangli-Miraj, Kolhapur and Solapur cities of Pune district. Institutes Ethical committee clearance was obtained before starting of the study.

This study consisted of detailed discussion with organ transplant coordinators (OTCs) to bring out individual experiences related to organ donation and problems encountered by them as they dealt with recipients and possible donors and their families.

The inclusion criterion for this study population was that all participants had to be OTCs residing in Pune division of Maharashtra. Only those consenting to participate were involved in the study. The exclusion criterion was those who refused to consent to participate in the study. The sampling method used here was convenience sampling.

The OTCs residing and working in each of the cities in Pune division of Maharashtra were requested for time to discuss challenges involved in process of organ donation in Pune division of Maharashtra and they were requested to share their experiences in the field of organ donation. The respondents were assured that confidentiality of identity would be maintained and ethical principles would be followed. The interviews were noted down during the discussion and the suggestions of the OTCs were noted. The discussions were immediately analyzed thereafter, for the themes generated during the discussions and for insights into the organ donation activity. This qualitative research was done till the point of saturation.

## Results

A total of 24 OTCs were approached for participation in the study. 18 agreed to participate in the study. However 4 refused to sign the consent and the discussion with them has not been included in this study. Thus the number of OTCs participating in present study was 14. The themes generated during the discussion are seen in Figure 1.

## Discussion

An OTC is a person appointed by the hospital for coordinating all matters related to removal or transplantation of human organs or tissues or both as per the THO act, 2011 [4]. The OTC may also coordinate between the brain dead patient's relatives and the ZTCC which is a non government organization that maintains the waiting list of registered patients awaiting an organ for transplant in Maharashtra [5]. The OTC must assist the authority in every way to facilitate the organ donation [2].

The OTCs can be doctors, nurses, allied health science graduates or social workers [4]. The success of organ donation and transplant program depends upon effective coordination by trained OTCs. The THO Act- 2011 has made nomination of a transplant coordinator mandatory for any hospital which wishes to be a transplant centre.

<sup>[1]</sup> The OTC needs to coordinate between the related medical, paramedical and non medical personnel to bring about effective organ retrieval and transplant. They are also accorded to the job of raising awareness levels among people of that region regarding organ donation. They are the ones often conducting awareness camps in the locality [2].

The present study reports that while 24 OTCs were approached for participation in the study, 18 agreed to participate in the study out of which only 14 actually signed the consent form for participation in the study. With greatest respect for every participant and non-participant in the present study the researchers would like to state that this non participation shows the fear and curiosity that lurks in the minds of some OTCs regarding organ donation. While there is documentation of fear about organ donation in the minds of people, there is not much literature about fear that medical personnel feel when dealing with the topic of organ donation [6]. The present study finally carried out discussions with 14 OTCs in Pune division of Maharashtra. These were analysed and the discussion is being presented under the themes that emerged from the analysis. At places the discussion on some themes was interrelated and is therefore presented together.

The themes generated during discussion are seen in Figure 1.

### *Awareness about organ donation, Awareness among people about brain death*

The OTCs felt that people of this region though aware of organ donation, lacked understanding of details of the concept of organ donation. They did not know about the different categories of donors and the different organs that could be donated by each category of donor. Some OTCs reported that often elderly persons approached them with doubts regarding organ and body donation process. Balajee *et al.* in a study conducted in Puducherry found that 88% of the participants were aware of organ donation [7]. However, Wig *et al.* studied the awareness of brain death among people in Delhi and found that awareness regarding this definition of death was very poor. Very few respondents in his study were aware of importance of the state of brain death in the organ donation programme [8].

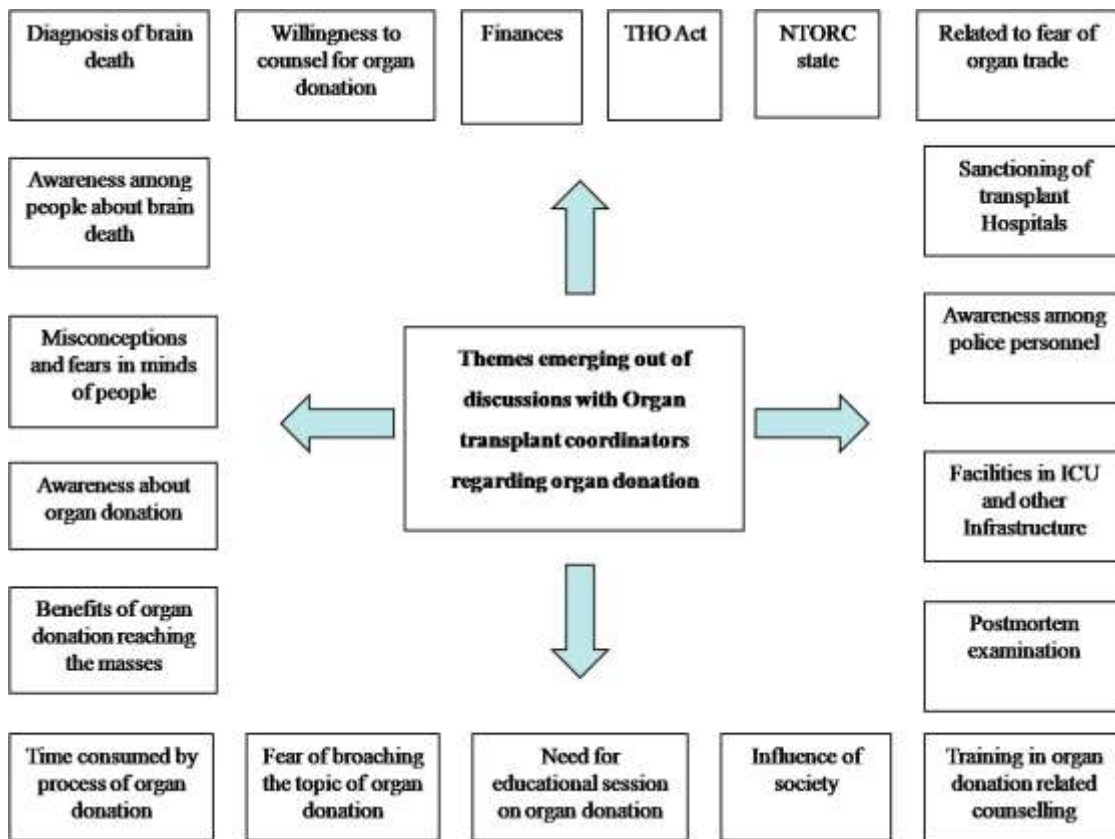


Fig 1. Themes generated during discussion with the organ transplant coordinators

Thus though people may be aware of idea of donating organs, they need to be educated about the details of categories of organ donors and the organs each category may donate.

The OTCs suggested that it was necessary to raise awareness levels about both organ donation and brain death among the people. For this purpose many suggested interesting strategies such as displaying of brochures/posters at key places in the hospital, making pamphlets easily available so that people could read and ask doubts related to organ donation. Some suggested that interesting videos could be played on the television screens of hospitals describing the process of organ donation in the form of small skits, interviews etc. Many OTCs suggested that lectures could be taken in housing societies near their respective hospitals on eye, kidney, liver donation etc, and posters could be displayed in societies for further percolation of knowledge. Some OTCs suggested putting up stalls in fairs held during Ganapati (religious) festivals to promote organ donation and handing out of organ donation related information pamphlets and forms.

#### *Training in Organ donation related counselling, Necessity for educational session on organ donation*

The OTCs felt it was important to build a rapport with the relatives of patients in ICU before declaration of

brain death. Once the relatives began to trust the OTC, the relatives of the brain dead patient would feel confident to discuss their doubts with the OTC. It was important that during the trust building process, the OTC never uttered a word about organ donation. This rule should be strictly followed. Enough time should be given to relatives to accept the calamity and discuss among themselves. Also relatives should not be judged for their reactions related to the patient's health condition. Wojda *et al.* in their review of clinical practices in relation to organ donation at a high-performing health-care organization, state that it is necessary to support the family of the potential donor in the very difficult time when their relative is critically ill in the ICU. There is a set protocol when the coordinator from the organ procurement organization, approaches the family with the possibility of organ donation [9]. The Ramchandra protocol designed at Sri Ramchandra Hospital, Chennai states that it is essential when approaching a grieving family for organs to first make a request for eye donation. If the family agrees to eye donation, then only should a request be made for organs to be donated. If eye donation is refused, efforts for organ donation should be abandoned [10].

One OTC who participated in the present study belonged to rural part of Pune division. The individual was a medical social worker, who was acting as the OTC at the hospital in the rural region of Pune division. He

explained that uneducated people of that region believe that donating any organ means being born without that organ in the next life. The OTC felt that if his own family member was in such a situation (brain dead), he would not be able to give consent for organ donation. He frankly expressed his opinion that "one should not expect from others what one will not be able to do himself/herself". Here the OTC himself was not convinced about cadaver organ donation. There was a dire need to educate the OTC himself regarding organ donation followed by training in organ donation related counselling.

#### *Diagnosis of brain death*

The OTCs stated that one of the biggest challenges in organ donation was the diagnosis of brain death. In Pune division of Maharashtra, doctors were reluctant to diagnose brain death. The OTCs stated that only relatives of a certified brain dead patient could be counselled for organ donation in deceased donor programme. The THO Act of India describes brain stem death as the stage at which all functions of the brain stem have permanently and irreversibly ceased and is so certified.

<sup>[1]</sup> In India as per the THO Act, the brain death is declared by the brain death committee which involves team of four doctors recognized by the Indian Government and who are not part of the transplant [1].

Sheerani *et al.* conducted a study to analyze the knowledge of health professionals in Sindh, Pakistan regarding concept of brain death. The study reported that 54% of the participating health care professionals did not have a clear idea of brain death, 47% would not turn off the ventilator even in a brain dead patient, 26% doctors considered it as euthanasia. The study highlighted the confusion among health care professionals regarding brain death and stressed on including these aspects in medical curricula [11].

In a ruling in 2012 the Public Health Department of Government of Maharashtra observed that Brain-Death was not being declared promptly. Patients who were brain dead were being kept on life support needlessly, delaying organ transplant to needy patients. Following this observation, orders were issued making it mandatory to declare brain-death and certify it, and the certification of the same be conveyed to the ZTCC for distribution of the organs [12].

#### *Misconceptions and fears in the mind of people*

The OTCs observed that there were some misconceptions because of which patients or their relatives refused to give consent for organ donation such as a misbelief that with parts of the body transplanted into different individuals, the soul may not get "mukti". The word "Mukti" means freedom, indicating in this case that with the organs transplanted into various individuals, the soul would remain tethered onto the earth and may

not get release or freedom as is believed happens following any death. There is also a misbelief that the person may be born without those organs in their next birth (related to concept of rebirth in Hinduism).

This situation and related myths was faced by a family in India. After consultation with related priests and pundits in India, they were explained that only the body was considered mortal and not the soul which therefore could not be fractured into bits by the organ donation process and also that it was the soul that moved on into next life and not the body. Therefore any organs donated or otherwise would not affect the next life of that individual (donor) [13].

#### *Time consumed by process of organ donation and Postmortem examination*

The OTCs reported that the relatives of the brain dead organ donor felt that since they had consented to organ donation, the process of organ donation from that patient should be fast and be given preference over other activities of the hospital. They in fact were often very upset with the time consumed during the process of organ retrieval till the final handing over of the body to the family. There is a need to speed up the process of organ donation to bring about early handing over of the body to the relatives to carry out the last rites.

The relatives also often complained that not only did the process of organ donation involve cutting of body (for organ retrieval in the operation theatre) but in a medicolegal case it was followed by tearing and mutilation of the body (their perception) again during post-mortem examination. The OTCs stated that often the relatives would agree to organ donation only if post-mortem examination could be waived off.

Murty in an article on guidelines for post-mortem work in India, stated that medicolegal post-mortem work is done on request of Police/Magistrate or Court. It is not in the power of the Medical officer to waive off post-mortem examination. His role may be that of an advisor at the best, but still the final decision of waiving off the post-mortem examination lies with the Investigating agency [14].

#### *Fear of broaching topic of organ donation, Unwillingness to counsel for organ donation*

The OTCs stated that they often had to face violent reactions from the distraught relatives on broaching the subject of organ donation. The relatives believe that since the patient had a heart beat and the body felt warm, the patient was still alive and feel that the OTCs are requesting for organ donation from a living patient. The OTCs described incidences where police had to intervene to prevent casualty. Hence many OTCs found themselves reluctant to raise the topic of organ donation.

The OTCs suggested that efforts need to be taken to raise the awareness levels among the people to prevent such incidences which lead to unwillingness to counsel for organ donation. Organ donations can only rise if no opportunity is lost to request for organ donation [15].

#### *Awareness levels among the police personnel*

For the process of organ donation to go through, there is need for a no objection certificate (NOC) from the local police. They sometimes refuse this because patient's heart is beating, so he/ she is not dead according to them. OTCs stated that convincing the police personnel takes up precious time and sometimes the opportunity for organ donation is lost.

Recently there were reports that the Maharashtra state organ transplant cell was considering a proposal for a separate organ transplant module for the police during their training sessions, to sensitize them [16].

#### *Related to organ trade/related fears, THO Act [1]*

Some of the OTCs observed that in case of a live organ donation, they (the OTCs) had to be very alert. They observed that many patients would claim that a person was their near relative and would bring necessary documents proving the relationship. The OTCs stated that they found it very difficult to check the authenticity of the documents. The OTCs suggested that a lawyer and representative of police should be involved in verification of documents before the recipient and donor appeared before the approval committee. People also often came trying to misuse the "friend clause" in the THO act. Shroff analysed the legal aspects of organ donation and transplantation, and stated that to a large extent there has been a flawed interpretation of the law by the authorization committee and the registered medical practitioners [17]. The Law states that if any donor authorizes the removal of any of his human organs before his death under subsection [1] of section 3 for transplantation into the body of such recipient, not being near relative as is specified by the donor, by reason of affection or attachment towards the recipient or for any other special reason, such human organ shall not be removed without prior permission of the authorization committee [1]. Shroff states that this clause has been misused or misinterpreted by many over the years since the act was passed. He emphasizes that it is very difficult to judge the affection being claimed. Therefore, every friend, using the deep affection clause in organ donation activity, needs to be considered carefully to avoid legal sale of human organs.

The dilemma of the OTCs was that by doubting the sanctity of the proclaimed relations or friendship, one may be preventing someone from getting a chance at life. At the same time, accepting of an erroneous document could make the OTC party to organ trade.

All OTCs felt that it was crucial that allocation of organs in deceased donor programme be a fair and transparent process and as per the rules set down by the THO act [1].

#### *Finances*

Financial status of recipient affects the outcome of the transplant surgery: The OTCs stated that in case of a poor patient on the waiting list, it is important to inform the recipient about the necessity to take immunosuppressant medicines after the transplant surgery. If the recipient is unable to afford these medicines and doesn't take them, the body will soon reject the transplanted organ. The patient will be back on the waiting list, or worse, may die. Meanwhile the next patient on the waiting list who could have afforded the medicines continues to wait for an organ to become available. The OTCs have to discuss these practical aspects also with the patients and their relatives. Gordon *et al.* have stated that adherence to immunosuppressant therapy is crucial for graft survival in transplant recipients [18].

#### *Influence of society and interpersonal relations*

Many OTCs observed that in case of live donors, majority of the recipients were males and majority of the donors were females. The OTCs stated that they and the examining doctors too, tried to ask the female donors if they were being forced into organ donation. However mostly they were so well rehearsed for these questions that they point blank refused any such suggestion. Doctors often even assured them that if they are being coerced into organ donation, they could be declared unfit preventing the organ donation at the same time helping them to maintain their family relations with the recipient. The OTCs felt that this was a reflection of our social system.

Some gender specific observations were made by Pouti *et al.* in relation to live organ donation. They observed that women seem to have more self-sacrifice and sense of responsibility compared to men and were more predisposed to donate their organs. The gender disparity in living donor transplantation was because of higher proportions of wife to husband donations. This was also observed because of disproportionate female to male donations among biological relatives and also unrelated pairs. A study suggested that men and women donated roughly by the same rate when asked to become organ donors, but women were asked more often, hence the higher incidence of female donors. Today the number of female transplant recipients continues to decline. However, in renal transplantation, female donor kidneys had a worse 5 year survival [19].

#### **Conclusion**

The present study was undertaken to investigate the

challenges for organ donation and transplant activity in Pune district of Maharashtra, a state in western Maharashtra, from the perspective of OTCs and to find solutions to combat these challenges. The study revealed several challenges and solutions, many of which were also suggested by the OTCs participating in the study. The OTCs stated that though people were aware of idea of donating organs, they needed to be educated about the details of categories of organ donors and the organs each category may donate. For this purpose many suggested interesting strategies. The OTCs must be trained in counselling for organ donation. There was a dire need to educate the OTCs themselves regarding organ donation and related counselling.

The OTCs stated that one of the biggest challenges in organ donation was the diagnosis of brain death. People had misconceptions and fears in their minds associated with organ donation. This needed discussions and counselling of the people by respective religious leaders. The process of organ retrieval and final handing over of the body of the brain dead donor was very time consuming. The distraught relatives waiting to receive the body had advised that the process needed to be speeded up and that no post-mortem examination should be conducted of the brain dead donor following organ retrieval (in case of medicolegal cases) as it meant further cutting of the body.

Many times relatives had been known to get violent on broaching the subject of donation of organs. Fearing these reactions, many OTCs were reluctant to broach the topic of organ donation. At times, the police personnel were unaware of concept of brain death and therefore refused to accept the patient as dead, as the heart continued to beat. This lead to delay in the organ donation process or at times the braindead patient's heart stopped beating leading to loss of opportunity for organ donation.

The OTCs reported that they had to be alert to people attempting through falsified documents to pass another person as their relative or as a friend to bring about organ donation. They felt themselves inadequate to detect falsified documents and suggested that police or lawyers who were trained in document verification be involved in document scrutinisation process.

The PTCs observed that more females were donors as compared to males and suggested that it was time for society to change and more number of males should come forward to be organ donors.

Finally the OTCs stated that the financial status of the recipient is an important matter to be considered while planning transplant surgery as the recipient must be able to afford the immunosuppression medicine without which the body would anyway reject the transplanted organ.

*Conflict of interest statement.* None declared.

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