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Editorial

Organ Donation in India from the Point of Liver Specialists

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Abstract

Introduction. Organ transplantation surgeries are best mode of treatment for patients in organ failure. However, acute shortage of organs has deprived thousands of patients of benefits of this surgery. Mortality in case of patients on waiting list for liver transplant is more than in cases of kidney transplant because while kidney failure patient can be supported by dialysis, liver failure patient has no such alternative.

Methods. The study consisted of detailed discussion with liver specialists regarding their experiences related to organ donation in cities in Maharashtra state of India. The discussions were analyzed for insights into the organ donation.

Results. 12 liver specialists participated in the study. The analysis of the discussion revealed themes such as awareness of categories of donors, brain death, and lack of diagnosis of brain death.

Conclusion. The liver specialists suggested that people of this region lacked awareness about categories of organ donors and about concept of brain death. There was lack of diagnosis of brain death by doctors of various hospitals. They suggested that a common brain death committee be created per region to be called upon for brain death diagnose at those hospitals which did not have a brain death committee. There was need for more hospitals to be sanctioned for transplant surgeries and to sensitize the police personnel towards organ donation. They all stated that some form of non-monetary incentive had to be worked into the system to benefit the donor or the family of the donor.

Keywords: organ donation, liver transplant, hepatologists

Introduction

Organ transplantation was one of the greatest technological achievements of modern medicine. The benefits of this achievement are limited by the shortage of transplantable organs [1]. This organ shortage has deprived thousands of patients of a better quality of life as well as increased the expenditure of patients on alternative medical care [2]. World over, there is increasing awareness regarding organ failure and transplantation as a possible treatment option for it. The demand for organs for transplantation is hence rapidly increasing all over the world [3].

In India every year 10^5 people die awaiting an organ for transplant. There is a wide gap between demand for organs and the actual availability of the organs for purpose of transplant [4]. In 2017 when the demand for kidneys in India was estimated to be 200000, about 10000 kidneys became available by process of organ donation. The similar demand for liver transplant in the same year resulted in actual available livers being found to be only 700 [5]. Thus, a huge gap exists between demand and supply of organs for transplant in India [6]. Authors have reported that, mortality in case of patients on waiting list for liver transplant is more than in cases of kidney transplant because while kidney failure patient can be supported by dialysis, liver failure patient has no such alternative. Also, every deceased donor provides two kidneys to be available in the donor pool, while the number of livers contributed by one donor is still single [7].

Hence the present study was undertaken to obtain the perspective regarding organ donation from point of view of liver specialists in Maharashtra, India.

The presented study aimed to assess the experiences of liver specialists from point of view of organ donation. Afterwards the findings were reviewed and possible solutions were suggested to improve the rate of organ donation in India.

Material and methods

The following study was carried out in the cities of Maharashtra, (a State in India) which had registered organ transplant centers or had a non-transplant organ retrieval center (NTORC). Institutes Ethical committee

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clearance was obtained before starting the study. It consisted of discussions with liver specialists regarding their experiences in relation to organ donation. The study also attempted to bring out solutions as suggested by the participants in relation to these challenges. The inclusion criterion for the study population was that all participants had to be liver specialists residing in those cities of Maharashtra which had facility to carry out organ transplant surgeries or which had a non-transplant organ retrieval center. Only those liver specialists consenting to participate were involved in the study. The exclusion criterion was those who declined to participate in the study. The sampling method used here was convenience sampling. The liver specialists were requested for time to discuss challenges involved in process of organ donation and 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 liver specialists were also noted. The discussions were 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 12 hepatic specialists were invited for participation in the study. 5 were hepatologists while 7 were medical professionals trained in liver transplant surgeries. All accepted to participate in the study. The themes generated during the discussion are seen in Figure 1.

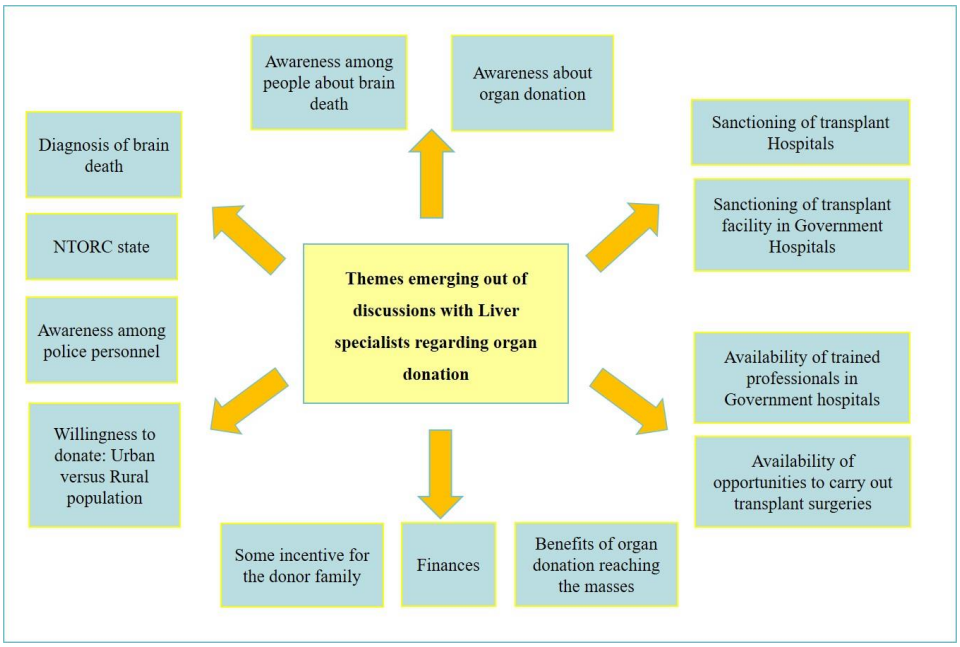

Fig 1. Themes generated during discussion with Liver specialists

Discussion

Organ donation is a process by which a person allows removal of a functioning organ from their body, its surgical transport into another person's body and the organ then serves the function of the new body [8]. The person giving the organ is referred to as the donor and the person receiving the organ is referred to as the recipient [8]. This can occur either with the donor being alive with his or her consent or it can occur with the person being brain dead or cardiac dead with the family member's consent. The recipient is always in organ failure of the organ which is being transplanted [9].

Common organs or tissues being transplanted today are kidneys, liver, heart, lungs, cornea etc. [10]. While few of these organs such as one kidney or a part of liver can be donated while the donor is alive, most of the organs are donated after the donor's death [8].

In the world today millions of people are in organ failure, awaiting an organ for transplant. In USA in 2019, 120000 people were awaiting an organ for transplant [11,12].

Due to significant advances in the techniques of dialysis the patients with end stage renal disease can survive longer than before. Thus, patients awaiting kidneys for transplant keeps increasing.

However, in case of liver failure no such option of dialysis is available today. Hence, mortality in case of patients on waiting list for liver transplant is even more than that in cases of kidney transplant as liver failure has no such alternative of dialysis. Also, while every deceased donor provides two kidneys available

in the donor pool, the number of livers contributed by one donor is still single [13].

The first successful liver transplant was carried out in 1968. Since then liver transplant has become a standard therapeutic option for patients with chronic liver disease and for patients with acute liver failure. Newer surgical techniques and better immunosuppressants have further improved the success rate of this surgery. However, the availability of organs is unable to meet the demand for the organs for transplant [12].

In 1988, split liver transplant was carried out. This allows one liver to be split into two recipients thus providing transplant support to two needy patients [14]. However, this is a technologically challenging procedure.

India has huge number of patients who have liver failure. Today the demand for liver transplant is about 20 per million population. In 2017 the entire country yielded 905 deceased donations resulting in total of 2500 organ transplant surgeries [15]. Thus, the demand is far more than the supply of livers and many patients (almost 50%) die on the waiting list for suitable donor for transplant.

The journey of the ill patient in imminent liver failure usually begins by approaching the hepatologist for health issues. The hepatologists help maintain the health of the patient, often keeping him or her alive while they are on the waiting list for a cadaver organ or till the transplant of liver from a live organ donor is carried out by the liver transplant surgeon. During this period the liver specialists face several challenges in relation to organ donation. Hence the present study was undertaken to get an insight into these challenges from the liver specialist's perspective. The discussion with the liver specialists is being presented as per the themes generated during the discussions. Some of the themes are grouped together for purpose of ease of discussion.

Theme: Awareness among people about organ donation; Awareness among people about brain death

The participants related that the people of this region were aware of organ donation as a concept. However, they lacked understanding of relevant details in this matter which often resulted in poor organ donation rate in this region. A similar finding was reported by Bharambe *et al* in 2018. The authors stated that people of this region lacked understanding about categories of organ donors and the organs that could be donated by each category of donor [16].

In this regard, during the discussion the liver specialists stated that the Maharashtra state of India saw establishment of Zonal transplant coordination center (ZTCC) in the year 2000. This was a nongovernment organization (NGO) set up to promote and facilitate organ donation in every way possible [17]. Initially there was only one ZTCC. Today there are 4 ZTCCs in Maharashtra state i.e. ZTCC of Mumbai, Pune, Nagpur and Aurangabad regions respectively. The ZTCCs began a number of steps which would improve organ donation rates and associated transplants in the area under their jurisdiction.

The ZTCCs planned a number of strategies to promote organ donation. Their primary target was to increase awareness among the masses regarding organ donation and brain death by way of consistent campaigning and public education exercises. They planned to effectively use the media for this purpose [18]. While the media in earlier days gave publicity to the negative side of organ donation and transplants, revealing the various scams related to transplants, the effects of this publicity hurt the transplant programme in India by preventing authentic donors from coming forward fearing misuse of their donated organs. Now the same media was used to promote organ donation, publicizing every successful organ donation and donor [19,20]. The negative publicity was discouraged and positive true stories were regularly published to change the image of organ donation.

Recipients and their family members were encouraged to become spokespersons for the cause of organ donation so that people would be assured that what they gave in the form of organ donation, was benefitting their own people [21].

Films were created and shown to people to further educate the masses about organ donation activity [22].

The liver specialists felt that besides use of media, all hospitals, cinema theatres, malls and other public places should also be used to promote organ donation.

Theme: Diagnosis of brain death

The liver specialists observed that the biggest challenge to organ donation related to deceased donor programme in India is "diagnosis of brain death". The hospitals in Maharashtra, India were not prioritizing identification and maintenance of brain-dead donors.

The Transplant of Human Organs Act (THO Act), India, defines "brain-stem death" as the stage at which all functions of the brain-stem have permanently and irreversibly ceased and has been so certified [23].

Observing that the brain death was not being declared promptly, Public Health Department of Government of Maharashtra issued orders making it mandatory to declare "brain-death" and certify it, and the certification of the same be conveyed to the Zonal Transplantation coordination committee for distribution of the organs [24].

The liver specialists observed that despite the above mandate by which declaration of brain death was made mandatory, brain death was not being diagnosed. They stated that, this was probably because this is a "directive" and is perceived as not punishable. It is not a "law". If it were made into a law, not following which may result in action against the hospital, brain death diagnosis will definitely increase [25].

The participants made several other suggestions to overcome the problem of non-diagnosis of brain death.

They suggested that the hospitals could have an internal audit. If the patient is dead, the case could be discussed. The chances of that patient having been brain dead could to be probed. This could be followed up with a probe into reasons for non-declaration of brain death or for not seeking a neurological opinion in this regard. A study probing into neurological cases admitted in the ICU in Bangladesh have found that there is no dearth of brain dead cases in ICUs but there is a need to promote and popularize the organ donation from the brain dead individual and also to familiarize the faculty with procedure of brain death declaration [26].

The participants discussed that there may be situations wherein the patient was admitted at a hospital that is neither a non-transplant organ retrieval center (NTORC) nor an established center for transplant surgery. In this case, there would be no authorized personnel to declare brain death. Nagral and Amalorpavanathan have discussed this situation and how it acts as a deterrent to diagnosis of brain death. They went on to describe how in such situation cadaver donors had to be shifted to recognized transplant hospitals solely with purpose of organ retrieval. This led to establishment of NTORCs [27].

The participants in the present study suggested that in such cases when the hospital did not have their own established and recognized brain death committee to declare brain death, the committee from a nearby authorized hospital could be asked to examine the patient for diagnosis of brain death. The patient may alternatively be also shifted to an authorized hospital. The interim charge of moving the patient may be borne by the Hospital that finally receives the donated organ. Nagral and Amalorpavnathan discussed this situation as being advantageous to the hospital where the cadaver donor would be transferred as that hospital would now have advantage of allocation of organs on priority as an "in house" donor [27].

The participants suggested that problem of diagnosis of brain death in the absence of brain death committee, could be solved by having a State government recognized brain death committee in every city where there are hospitals sanctioned for organ transplant. This committee could be kept "on-call" for diagnosis of brain death in that region. Just like ZTCC serves a region, coordinating the organ donation activities of that region, similarly this team would respond to the requirement for examining any patient suspected of being brain dead in their respective region or city. This would prevent the necessity to move the patient to another hospital which has a brain death committee approved by ZTCC.

In 1968, United States of America (USA) saw the establishment of organ procurement organizations (OPOs) in different regions and states. They were accorded the job of procuring deceased donor organs for organ transplants in their particular regions. They were to remain in contact with hospitals that were conducting retrieval and transplant surgeries as well as with the family of the deceased person. They were to attend audits regarding patients in USA who could be brain dead but were not tested for brain death or whose family was not approached for organ donation etc. Thus, every death got discussed and missed declaration of brain death got probed [28].

Theme: NTORC

The liver specialists discussed problems regarding Hospitals getting status of non-transplant organ retrieval center (NTORC). They said that, many hospitals were reluctant to apply for this status. The hospital authorities believed that such a status would mean that they would be involved in retrieval of organs with the tag of patient "death" attached to them while the actual transplant surgeries took place at another hospital. Thus, though they were involved in a very positive activity, the resultant publicity and history of subsequent death of the patient may harm the reputation of the hospital by public misconception.

Theme: Awareness levels among the police personnel

The hepatologists reported that to carry out cadaver organ donations, there was a need for no-objection certificate from the police. Untrained police personnel often delayed the nod, leading to delay of organ donation or sometimes loss of the patient and the opportunity for organ donation. They therefore believed that there was a necessity to sensitize them about organ donation and its various aspects in relation to the sphere of activity of the police personnel.

Recently the **Maharashtra State's organ transplant cell** is considering a proposal for a separate organ transplant module for the police during their training sessions, to sensitize them. Discussions will be held with Police personnel educating them about new definition of death i.e. death with a beating heart and the cooperation needed from the police for success of the organ donation activity. They will also be explained the importance of arrangement of the green corridor [29].

Theme: Sanctioning of transplant hospitals

The participants stated that previously, affording patients who were in organ failure, were often going to southern states of India and registering there for liver transplants. It took a long time for the government to sanction the liver transplant facility in hospitals in this region. As stated earlier, a patient with a severe liver ailment does not have much time to wait for the transplant surgery [30]. Hence the participants suggested that more hospitals should be given sanction for carrying out transplant surgeries. A hospital that invests into the set up needed for these surgeries and employs necessary staff on their payroll is under pressure to now carry out the transplant surgeries. They would

therefore promote organ donation in that region. The entire area would benefit by the resultant awareness programs run by the hospital, the brain deaths declared, the organs subsequently retrieved and the transplant surgeries that will be conducted.

Theme: Sanctioning of transplant facility in Government hospitals

The organ donation movement has been perceived as "taking from poor and giving to the affording or rich". It has been observed that the wealthy can leverage their socioeconomic status to gain access to organs [31]. To counter the effect of economic status on the organ donation movement, the participants felt that more government hospitals should apply for a sanction for carrying out transplant surgeries. The government hospitals receive a number of cases which could be brain dead. With these hospitals becoming a part of the transplant surgery group in the region, the number of brain death declarations may increase leading to rise in number of available organs. Thus the poor patients on the waiting list could get benefit of transplant surgeries without the pressure of financial constraints. In 2018, Sassoon Hospital in Pune became the first government hospital to carry out liver transplant on a patient who had been suffering from liver failure but unable to undergo transplant surgery due to the expenses involved. Thus, the facility of liver transplant becoming available at this Hospital directly benefitted the patient of lower economic status [32].

The liver specialists revealed that the ZTCC may be amending their guidelines of organ allocation so that organs from the government hospitals could be given preferentially to government hospitals and be offered to others only thereafter. The final result of this would be easier availability of benefits of transplant surgeries to the poor. In 2006 the Indian Army started the Armed forces organ retrieval and transplantation authority (AORTA). This was responsible for sensitizing the armed forces towards brain death and organ donation. 53 patients underwent liver transplant in the military hospital in New Delhi from 2007 till 2011. This included live and deceased donor transplants. The survival rates as well as the morbidity rates were comparable with the international data [33].

State government and Military hospitals can thus be a solution to the problem of prohibitive expense of liver transplants, thus helping to reach benefits of this procedure to the masses.

Theme: Availability of trained doctors in Government Hospitals

The government hospitals often do not have qualified liver transplant surgeons. The participants described how a medical professional completes training in their specialty in India or abroad and is expected to join the Government at the lowest level of assistant professor often working under persons less qualified than themselves. In these conditions at the kind of salary offered, it was financially not feasible to work in the government sector in this field. They suggested that the government could send their own employees for specializetion in liver related ailments following which they would then develop and successfully run the liver transplant programme in the government hospitals.

Theme: Availability of opportunities to carry out transplant surgeries

The liver transplant surgeons opined that liver transplant surgery is a dependant branch. It depends on the availability of a suitable live donor or on declaration of brain death and existence of the necessary infrastructure for this surgery. Many surgeons who have undergone rigorous training (in India or abroad), have had to subsist by doing general surgery for years after returning to India, awaiting opportunity to carry out the transplant surgeries for which they have trained. This can be very demoralizing, causing many to consider not returning to India and making a career in some other country where there is enough work in their field of choice.

This is an example of "paucity in the midst of plenty", i.e. there is so much transplant related work needed in India, but not enough means of carrying out this work.

In a study conducted in USA, it was observed that out of the total surgeons undergoing fellowship training in transplant surgery, 12% did not find transplant jobs and 14% did not get to transplant the organ of their choice [34]. A rise in the rate of organ donation would increase the number of organs available for transplant and thus would increase the opportunities for these surgeons to carry out transplant surgeries they were trained to conduct.

Theme: Finances

The participants observed that it is the poorer class that agrees to organ donation more easily than the rich and educated. A research in USA has found that when there are equally sick patients, it is more likely that the rich patient will get a transplant compared to the poor. This could be because rich patient can afford to be on multiple waiting lists of different states but this option was not available to the poor patient. Also, not all insurance policies cover the additional testing needed to get a second listing in multiple hospitals and states [35]. Money thus begins to influence organ donation activity in various ways. It can become the driving force behind the organ donation activity in a positive way too. As mentioned earlier, a hospital which is sanctioned for liver transplant has invested a lot in setting up the infrastructure needed for these transplant surgeries and every liver transplant surgery performed would help

recovery of this investment. As a greater number of corporate hospitals get sanction for transplant surgeries, the organ donation activities will increase as these hospitals stand to benefit by the surgeries occurring following the organ donation. Such hospitals set systems in place, prioritizing declaration of brain death with resultant generation of a number of organs some of which are allocated to the parent hospital as per the allocation guidelines. The other hospitals in the region would receive the rest of the organs donated by that brain-dead patient resulting in that many transplant surgeries.
Thus, the facilitative effect of finance and balance sheets cannot be denied and could be used positively to bring about a rise in organ donation rates of that region.

Theme: Willingness to be a donor: Urban versus Rural

The hepatologists observed that large population of our country stays in the rural area and they have observed that the people from rural area are more willing to become donors than those living in urban areas. Alghanim in a study conducted in Saudi Arabia also had a similar observation. The study noted that people in the rural areas were more likely to become donors [36]. Hence the participants felt that it was essential to carry out awareness campaigns in the rural areas.

Theme: Incentive for donor family

The liver specialists felt that there was a need to develop a method of providing some form of incentive to the donor or in case of the brain dead or cardiac dead donor, to the family members of the donor. This may not be in form of payment, but in form of efforts to rehabilitate family members or dependents of the deceased donor. Sympathy is of no use to the dependents of the donor. The participants suggested that this incentive could be in form of providing education for dependents of the donor. However, they clearly stated that incentive should not be in form of money as that would lead to too many ethical dilemmas. Chkhotua stated that though altruism is the main principle of organ donation worldwide, it has been unable to meet the demand for organs. At the same time, it needs to be acknowledged that donors incur many expenses while participating in the transplant process, some of which are unseen as they are not billed expenses [37]. This seems unfair. It may be time to consider the various forms of incentives and discuss these from ethical, economical and legal point of view.

Conclusion

This research was aimed at studying the experiences of liver specialists from point of view of organ donation. The liver specialists suggested that people of this region lacked awareness about categories of organ donors and about concept of brain death. They also stated that one of the challenges to organ donation in this region was lack of diagnosis of brain death by doctors of various hospitals of this region and many hospitals not having an approved brain death committee. They suggested that a common brain death committee could be created per region which could be called upon to diagnose brain death at those hospitals which did not have a brain death committee. The liver specialists also stated that there was need for more hospitals to be sanctioned for transplant surgeries. They stated that not only do these surgeries benefit patients, but the brain death declarations and the awareness campaigns run by such hospitals also benefit the region from point of view of organ donation. The liver specialists were of the opinion that there was a need to sensitize the Police personnel towards organ donation so as to prevent delay from there side for obtaining no objection certificate as well as during arrangement of the green corridor for movement of the harvested organ. They all stated that some form of non-monetary incentive had to be worked into the system to benefit the donor or the family of the donor.

Conflict of interest statement: None declared

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