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ISSUE BRIEF

Organ Donation in India: A Missed Opportunity

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December 2021

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Organ Donation in India: A Missed Opportunity

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ABSTRACT

Organ transplantation has saved and improved the lives of thousands of recipients across the world. According to the Global Observatory on Donation and Transplantation, India performed the third-highest number of transplants in the world in 2019. Despite such a high number of transplants, India faces a massive and chronic shortage of organs. This deficit in turn has led to the exploitation of poor vulnerable sections and gender inequality through illegal organ trade and transplant tourism. This issue brief provides an overview of the legislations governing organ donation and transplantation activities in the country. Further, it explores the complex challenges associated with organ transplantation in India today and highlights some of the ways these challenges can be addressed.

Keywords: Organ transplantation, THOA, organ trafficking, transplant tourism, illegal trade, gender

INTRODUCTION

Organ donation is defined as "giving part of the body (organ) to a person with end stage organ disease who needs a transplant" (National Health Portal n.d.). On 15 November 2021, the Government of India notified a change in the post-mortem protocols (Press Information Bureau 2021). The new protocol allows for post-mortem procedures to be conducted after sunset[1]. Before this, autopsies were conducted before sunset unless the law enforcement agencies had explicitly permitted carrying them out at night. As a result, the organs of many potential donors were not eligible for transplants since the window for organ harvesting and preservation is short. The revised rules are expected to boost organ donations and transplants, facilitating harvest within the required time frame after the post-mortem procedure.

With new protocols and legal amendments, the government has been working towards simplifying and promoting organ donations and transplants in the country. Despite this, a significant amount of organ transplant demand remains unmet, and organ shortages continue to stand in the way of the potential lives that timely transplants can save. At the same time, organ commerce continues to be a massive impediment. Additionally, the legal loopholes that criminalise the donors in illegal organ trade fail to recognise the socio-economic factors at play.

LEGAL OVERVIEW

In India, organ donation and transplantation activities are regulated by the Transplantation of Human Organs Act [THOA] (1994). The act aims to provide a system for removing, storing, and transplanting human organs and bans the commercial trade in human organs and tissues. There are two types of organ donations under the act, Living Donation and Cadaver/Deceased Donations. All Indian states have adopted THOA except the erstwhile state of Jammu and Kashmir and Andhra Pradesh, which have their own organ transplant legislation in place (Ministry of Health and Family Welfare 2021). For the first time in India, this act recognised brain stem death as legal death that could be utilised for organ transplantation. This revolutionised the concept of organ donation after death because unlike natural cardiac deaths, where only a few organs/tissues can be donated, after brain stem death, almost 37 different organs and tissues can be donated, including vital organs such as kidneys, heart, liver, and lungs (ibid.).

Further, an amendment to THOA was passed in 2011, the rules under which were notified in 2014 as the Transplantation of Human Organs and Tissue Rules, 2014. The amendment and rules brought about much-needed changes in streamlining the process of declaration of brain death and organ retrieval, amongst other provisions. The amendment brought tissues along with organs under the ambit of the act, redefined the criteria of 'near relative' to include

[1] The new protocol, however, notes that the cases under categories such as homicide, suicide, rape, decomposed bodies, suspected foul play should not undergo post-mortem procedure at night night unless there is a law and order situation.

grandparents and grandchildren, provided for swap transplantation[2], and permitted organ retrieval from any hospital with an ICU facility registered with the appropriate authority and not just in transplanting hospitals (Directorate General of Health Services 2016). It also provided for the appointment of transplant coordinators in hospitals to facilitate deceased donors' donations. It placed responsibility on medical practitioners to get consent from the prospective donor prior to their death and if not, then make the family aware of the option of authorising the donation of the person's organs (ibid.).

The amendment also provided for the appointment of appropriate authorities and a National Human Organs and Tissues Removal and Storage Network with regional equivalents and the maintenance of a registry of donors and recipients. Thus, with the vision of creating a national networking organisation regulating organ transplantation, the central government established The National Organ and Tissue Transplant Organisation [NOTTO]. NOTTO will have five regional networks called ROTTO [Regional Organ & Tissue Transplant Organization] and each state will have one state-level organisation called SOTTO [State Organ and Tissue Transplant Organisation]. Till now, the government of India has sanctioned 12 SOTTOs (Ministry of Health and Family Welfare 2021).

At the helm, NOTTO aims to facilitate the procurement, allotment, and distribution of organs, set up a country-wide network of Transplant and Retrieval Hospitals and Tissue Banks, and maintain a registry of organ and tissue donation and transplantation. People who wish to become organ donors need to register themselves on online portals, such as NOTTO or ROTTO. However, a study conducted in 2019 shows that only 3% of the population across 12 major cities in the country has registered organ donors (Bhale 2019).

CHALLENGES

The Unmet Demand

As mentioned earlier, there is a massive gap between the demand and supply of human organs and tissues in India (Directorate General of Health Services 2016).

Due to increasing lifespan, there is a correlating rising rates of diabetes, liver diseases, and end-stage kidney diseases, leading to the increase in demand for organ transplants (Levitt 2015). This problem of shortage of organs was further exacerbated by the overburdened healthcare institutions in the wake of the COVID-19 pandemic. In a recent study (Aubert et. al., 2021), based on data from 22 countries, it was found that transplant activity fell in all the countries examined during the pandemic.

The protocols for declaring brainstem death are also unclear and vary from hospital to hospital. This results in confusion and delays. As discussed before, brainstem death has been linked to organ donation in India and is mentioned in the laws governing organ transplants. However, it does not find its place in the Registration of Births and Deaths Act (1969). Therefore, brainstem death

[2] Swap transplantation refers to the exchange of organs between donor and recipient.

is considered a legal death only in THOA. As a result, in a situation where the family of the person who has been declared brainstem dead does not want to donate the organs, the hospitals are unsure about continuing ventilatory support, leading to prolonged ventilation support (Vadi and Shroff 2019: 368). This creates an ethical and legal conundrum where a person is considered dead if the family agrees to donate the organs and their ventilation support is withdrawn. But, if the family does not want to donate the organs, the person continues to be ventilated.

Almost everyone who dies naturally or in an accident is a potential donor. Despite this, a shortage of organs in a country with such a large population highlights the need for policies to raise awareness and address people's apprehensions.

Gender Gap in Organ Donation

Gender plays a role in organ transplants, which is evident while analysing the organ donation data. An analysis done by Dr. Vivek Kute, a professor at the Institute of Kidney Diseases and Research Center-Institute of Transplantation Sciences [IKDRC-ITS], found that 78% of living organ donors in India were women (Shastri 2020). In contrast to their overwhelming representation among organ donors, their share among organ recipients was a dismal 19%. Such disproportion has been observed in global trends as well. According to a study (Sahay 2019), one of the reasons for this disproportion is that the prevalence of end-stage kidney disease is higher in men than women. As a result, more women would be compelled to step up and donate their organs. This may explain women's overrepresentation among the spousal donors. However, this does not explain why women exceed men in donating to other family members as well. The skewed representation of women in the figures for organ donors has its roots in the preconceived gender roles. Care work is often considered to be a woman's primary responsibility and these social conditions put an indirect coercion on women to donate their organs when a family member is in need.

When a country fairs poorly in gender equality, it is reasonable to expect greater gender gaps in organ donation. If women do not have the same economic opportunities as men, they would be expected to be donors. This is because the organ donors would be required to take some time off from work for the surgery and recovery. Therefore, societal pressure, economic conditions, and gender roles put direct and indirect coercion on women, which explains the gender disparity in organ donation data in India.

Illegal Trade

The problem of organ shortage coupled with the fact that, as per the law, only people related to the person in need can donate their organs inevitably make it difficult to find a matching donor. This makes way for the illegal buying and selling of organs.

Despite the legislation curbing the commercial sale and trade of organs, the illegal trade of organs is highly prevalent in India. In a study (Goyal et al. 2002) conducted in Chennai, 305 individuals who had sold a kidney were interviewed, and it was found that 60% of female respondents and 95% of male respondents

worked as labourers or street vendors. Furthermore, 96% of the respondents sold their kidneys to pay off their debts. At the same time, 95% of the participants of the study said that wanting to help a sick person was not a significant factor in their decision to sell.

Illegal organ transplantation rackets are busted every few months in India. One of the main issues with the law governing organ donation and transplant is that it criminalises not just the person buying or facilitating the sale of organs but also the donors. This means that, under the law, victims of trafficking are punished as well. The law fails to consider that victims of trafficking usually belong to poor and marginalised sections of society and sell their organs to meet their pressing financial needs (Mehta, Saksena and Mittal 2017). There is a need to rethink whether organ donors in illegal buying and selling of organs are criminals or the victims of economic coercion. Moreover, the donors become even more vulnerable as organ donation usually requires an invasive surgery that has both physical and psychological impact, and most of the donors receive little to no post-operative care (ibid).

Transplant Tourism

According to the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2008), transplant tourism refers to the "movement of organs, donors, recipients or transplant professionals across jurisdictional borders for the purpose of organ trafficking and transplant commercialism" (Steering Committee of the Istanbul Summit 2008). Even though transplant tourism has raised ethical concerns, it still accounts for 10% of all organ transplants performed worldwide (Adido 2018). The global shortage of organs for transplantation prompts many people in the west to seek transplants abroad, often in developing countries. Along with Pakistan and Colombia, the World Health Organisation identifies India as one of the four leading and commonly-known organ-exporting countries where foreign nationals seek low-cost medical care and relatively easier access to organs. Countries such as the United States, Australia, Canada, Israel, Oman, Japan, and Saudi Arabia are considered the major organ-importing countries (Shimazono 2007). In 2016 alone, more than 4 lakh foreigners visited India for medical purposes (Press Information Bureau 2018).

This international movement of organs is often arranged or facilitated by intermediaries or healthcare providers who travel and recruit donors from third world countries. Organ sellers are recruited through local newspaper advertisements, scouters, or directly through medical facilities (Schennach 2019). Recently, there has been increasing use of the internet to attract foreign donors. Several websites offer all-inclusive 'transplant packages' such as renal transplant packages (Shimazono 2007). A combination of poverty, inequality, illiteracy, and corruption makes India a fertile ground for selling and purchasing organs and the perfect spot for transplant tourism. The poor donors are rarely compensated fairly, and the little amount they do get does not have a lasting economic impact on their lives. In addition to this, medical reports have indicated that even recipients or buyers of organs do not benefit in all cases of this illicit organ trade. Due to substandard medical practices, there is a high frequency of medical complications, including the transmission of HIV and hepatitis viruses, amongst organ buyers (ibid.).

In India, organ transplantation is primarily considered a private sector activity and a significant source of income for hospitals. Some hospitals are known for their large volumes of 'international' transplants (Nagral, Jha, and Gracious 2021). Media reports have highlighted that private hospitals in some states favour transplant recipients over Indian patients on waiting lists for organs (Jha 2018). For instance, it was found that in Tamil Nadu in 2017, foreigners accounted for 25% of heart transplants and 33% of lung transplants (Kumar 2018). Hospitals cite exhaustion of Indians on the waitlist, medical non-fitness of Indian recipients or refusal due to unavailability of a surgeon (Jha 2018) as some of the reasons behind this. Another reason that is often given by state governments is that it helps to promote 'medical tourism' in India. In fact, some states have patted themselves on the back for supplying organs to foreign nationals (ibid.). However, giving foreign citizens priority over Indian citizens is not justifiable when 5 lakh people die each year owing to a lack of organs for transplantation in India (Ahuja 2017). Thus, given our massive population size and the acute shortage of organs in India, these reasons cannot be endorsed.

CONCLUSION

Recently, the Government of India implemented the National Organ Transplant Programme for the promotion of deceased organ donation, in order to reduce the existing gap between the demand and supply of organs in the country. Even though such efforts are widely appreciated, they are not enough to address the complex issue of organ transplantation in India. As discussed above, the consequence of such a massive and chronic shortage of organs in India has led to commercial exploitation of poor and vulnerable sections as well as an unsaid pressure on women to donate their organs. A complex network of intermediaries exists that links the medically desperate recipients with financially desperate donors, which needs to be adequately tackled.

Moreover, the Covid-19 pandemic has only made the situation worse. On the one hand, there has been a significant fall in the number of deceased organ donations due to the fear of infection and the overburdened healthcare system, which has made recipients even more desperate. On the other hand, more and more poor informal labourers who are in severe debt due to loss of livelihood as a result of Covid have been forced to sell their organs to make ends meet. The pandemic presents a perfect opportunity to entice economically vulnerable citizens to sell organs (Nagral, Jha, and Gracious 2021).

Despite stringent legislative measures such as THOA 1994, India remains one of the global epicentres of organ trafficking. The law needs to take into account that victims of organ trafficking rackets are mostly the impoverished and vulnerable sections and decriminalising the victims will enable them to come forward and approach the authorities without fear of prosecution. There is also a need to develop an equitable and transparent system. A robust regulatory mechanism is required to keep healthcare professionals, intermediaries, and administrators of illegal organ trade in check and hold them accountable. Appropriate authorities should continually verify donors and recipients and their relationship to curb false claims. Further, all transplant centres and hospitals should provide preventive and post-operative care to the donors, which should be carefully documented.

Additionally, there is a need for more transparent and effective counselling of prospective donors.

There is also a need for a uniform definition of 'death' to ensure that medical care is consistent regardless of whether or not organ donation takes place (Shroff and Navin 2018). This would involve delinking brain deaths from organ donation and including them as a form of death in The Registration of Births and Deaths Act.

Global inequalities, economic disparity, unequal access to healthcare, and weak regulatory frameworks have encouraged transplant tourism in developing countries such as India, from where organs are supplied to affluent buyers in rich countries. Intergovernmental cooperation and measures are needed to improve transplant oversight and transboundary traceability of donors and recipients (Schennach 2019). Additionally, international cooperation and efforts are required to protect and save victims of organ trafficking and provide them with adequate compensation and assistance.

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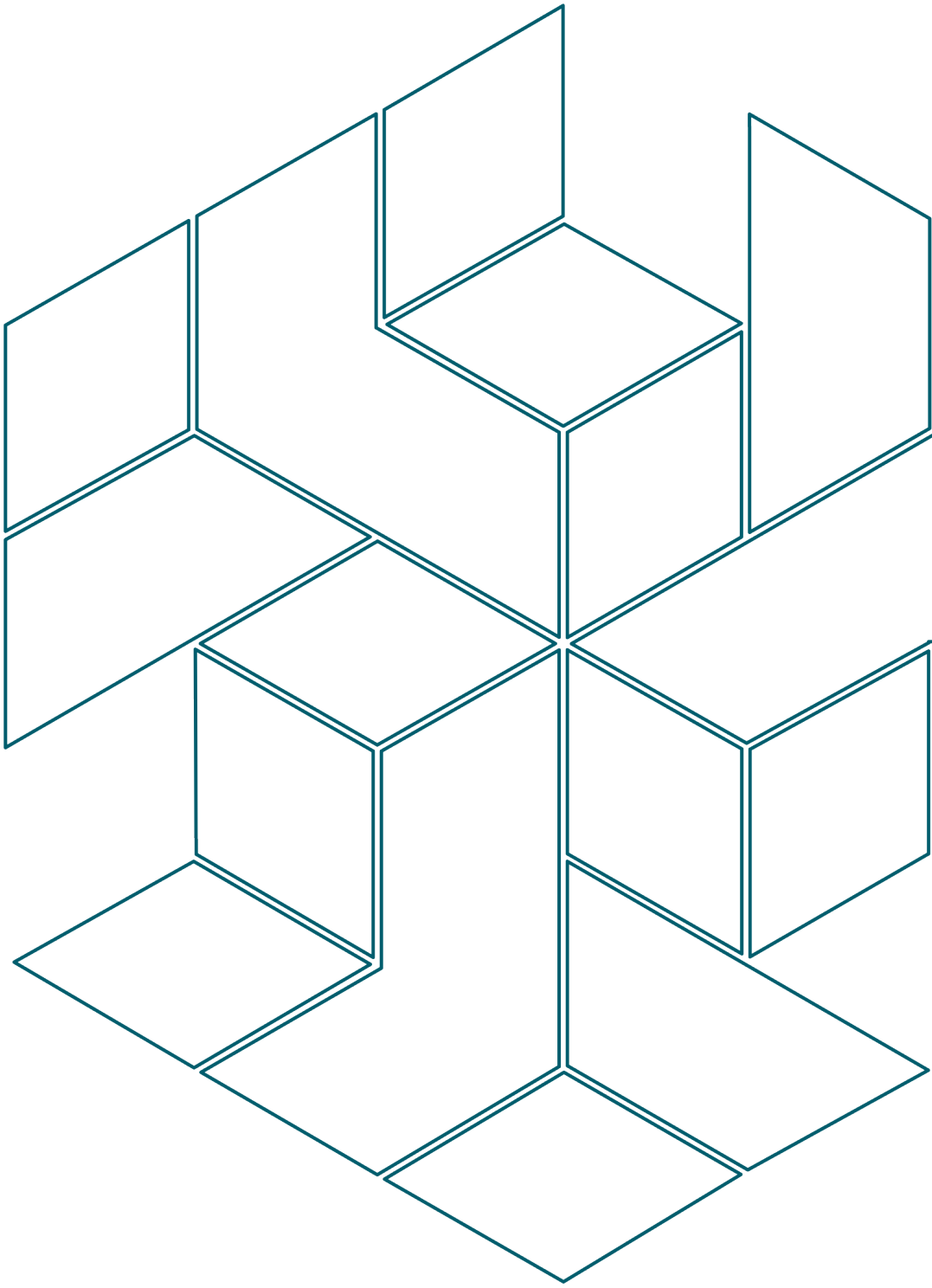

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