

Organ Transplant Disparities: Racial, Gender, and Socioeconomic Inequities in Access and Outcomes

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Abstract

Organ transplantation is a pinnacle in medical progress in India, which provides life-saving solutions for end-stage organ failure. However, this breakthrough has been undermined by the deeply rooted social disparities shaping access and outcomes. This paper examines how socio-economic factors like caste, class, gender, geography, and the financial situation of a person continue to affect the transplant ecosystem. The inefficiency that exist in the institutional framework, biased allocation process and other ethical concerns in the organ trade for commercial purposes, has been highlighted in this paper with the help of various government data and real-life case studies, and peer-reviewed journals. It emphasises that only policy reform is not the solution; systemic inequities need to be addressed too. The paper concludes that equity in transplantation is not just a medical necessity but a moral imperative for just healthcare in India.

Introduction

Organ transplants are the best example of human advancement in medicine. It represents a victory of science over a once-critical condition which can now be treated with the progress in operative procedures, immunology and post-operative care. However, there is a striking difference between this development and the persistent social and ethical disparities that dictate access to these life-saving procedures. Where science delivers, human systems, burdened by bias, inequality and systemic neglect, often fail. This reality makes it clear that advancement is needed in our laboratory, our minds, our perspectives, and our commitment to equity.

Disparities rooted in socio-economic status, geographic location, caste identity and gender shape the chances of who gets evaluated, listed and ultimately receives a transplant. Disparities persist on a regional level, where hospitals in urban areas conduct the majority of the transplants, but rural areas remain excluded. Gender disparity is very evident in the data between 1995 and 2021 from the National Organ and Tissue Transplant Organisation (NOTTO), where approximately 81% of organ transplant recipients were men, while only 19% were women. This imbalance continues even though women are the majority of the living organ donors. This paper argues that even with the medical and institutional frameworks in place, India's current position of the organ transplantation system reflects deep-rooted social inequities that must be acknowledged and addressed if true progress is to be achieved.

Review of Literature

Research on India's organ transplant system reflects a concerning picture of systemic inequities that increasingly focus on regional, gender-based, and socio-economic inequities, which impact the availability and outcomes of transplants.

Scholars such as Shroff, in her review of India's organ transplant system, have noted that even though the Transplantation of Human Organs and Tissues Act, 1994 provides a comprehensive legal infrastructure, a low deceased organ donation rate of 0.52 per million population only could be achieved. A report by the **United Nations Office on Drugs and Crime** has identified India as a hub for illegal organ trade. This illegal organ trade is often completed using the loopholes in the 'near-relative' section. Similarly, a report by **The Lancet(2023)** provides that 15-20% of kidney transplants in India involve commercial transactions.

The gender dynamics of organ donation were analysed by **Prakash et al. (2022)**. It was reported that over 70% of living kidney donors are women, while men overwhelmingly dominate as recipients. The authors link this imbalance to deep-rooted gender norms, limited healthcare access for women, and economic control within households, reinforcing the gender gap in organ transplantation.

Further, **Sharma and Mohan (2020)** in their paper examined the role and functions of the National Organ and Tissue Transplant Organisation (NOTTO). Critical gaps were found in waitlist transparency, digital infrastructure, and coordination between state-level SOTTOs. The need for a centralised, real-time tracking system and uniform guidelines for organ allocation to ensure equitable access across states was emphasised.

Moreover, **Gupta et al. (2023)** evaluated the role of socioeconomic status on transplant access and outcomes in their paper. Their research showed that patients from weak financial backgrounds often experience delays in diagnosis and limited access even under schemes like Ayushman Bharat. These barriers further widen the survival gap between affluent and marginalised patients.

Collectively, the research on organ transplantation reveals the overlap of incompetent infrastructure, gender politics, economic inequity, and regulatory inefficiencies in shaping India's organ transplantation landscape. It reports on the urgent need for institutional reform, community awareness, and digital transparency to close the existing access gap.

Organ Transplantation Framework in India

The organ transplantation framework in India has evolved with various legislations over the past few decades. The **Transplantation of Human Organs Act (THOA), 1994**, was the very first step in this direction. It recognised a dead brain and thus formalised deceased donation for the first time. This Act was amended in 2011 to curb illegal organ trade and regulate transplant procedures across both public and private sectors.

To implement this legislation, the government established a multi-tiered structure. A three-tier system is established under the National Organ and Tissue Transplant Program in India. At the very top of this structure is **NOTTO, i.e. National Organ and Tissue Transplant Organisation**. It manages the national transplant registry and oversees policy implementation. Beneath it is the **Regional Organ and Tissue Transplant Organisation (ROTTO)**, which is at the Zonal/Regional level, and then there is the **State Organ and Tissue Transplant Organisation (SOTTO)** at the State level. The major task of these organisations is to promote awareness, streamline the waitlist process, and facilitate donor-recipient matching.

While living donor transplants account for nearly 85% of procedures in India, often family members are majorly donors for kidney and liver transplants. Deceased donations are rare due to limited public awareness, cultural hesitations, and challenges in hospitals. Where **Tamil Nadu, Kerala and Maharashtra** demonstrate strong systems, others remain far behind. This vast difference in performance across states further complicates the scenario.

Disparity in Organ Transplant

Socio-Economic and Regional Disparities in Organ Transplantation in India

Glaring disparities persist in India across socioeconomic and regional lines. This eventually shapes the access of people to these life-saving transplants. Despite the national framework implemented PAN-India, these disparities continue to affect the process.

Urban-Rural Divide

Metro-cities like Chennai, Hyderabad, and Mumbai are the hubs for Transplant centres. Rural areas often lack access to advanced care hospitals, which are authorised to perform transplants, which then leads to late diagnosis and treatment completion. A 2022 report by the Indian Council of Medical Research (ICMR) noted that over 75% of transplants in India occurred in just a handful of urban districts, despite rural populations comprising more than 65% of the country's total population.

Economic Barriers

The financial costs of organ transplant are on the higher side; a kidney transplant can cost up to 15 lakhs, whereas a liver transplant can cost up to 30 lakh rupees. Although schemes like Ayushman Bharat do provide some financial assistance, their reach is limited.

Regional Inequities

Indian states like Tamil Nadu have progressed more in terms of the deceased donation rate of 1.8 per million population in 2022, which is significantly higher than the national average of 0.52 per million. However, reports show that more populous states such as Uttar Pradesh and Bihar have much lower donation rates. These factors contribute to underscoring stark regional disparities in infrastructure and administrative support.

Caste and Class Disparities

India's existing social stratification makes the already existing inequalities in access to organ transplantation even worse. Marginalised communities due to social stigma face systematic barriers, thus leading to discrimination in access and diagnosis.

Gender Disparities in Organ Transplantation in India

Disparity in Organ transplantation in India is not only limited to socio-economic or regional inequalities, but also covers gender inequality. Why are 70% of donors women, yet they constitute fewer than 20% of recipients? The answer lies in patriarchal healthcare hierarchies.

Women as Donors, Not Recipients

Women are the primary living organ donors, however, they remain significantly underrepresented as transplant recipients. A multi-institutional study published in the Indian Journal of Nephrology (2021) reported that over 70% of living kidney donors were women, while over 80% of recipients were men.

Traditional gender roles contribute to making women the primary donors. In most cases, mothers, wives and sisters step forward to donate organs to male family members. However, women who do require organ

transplants face many barriers, like lower prioritisation within families, and less focus on medical management compared to men.

Bias in Medical Access and Prioritisation

A study by AIIMS and WHO (2020) found that women make up only about 30-35% of patients on transplant waiting lists. This study suggests underdiagnosis and under-referral among women patients. Further, financial decisions in families often favour male members. All this reinforces neglect in women's healthcare.

This gender imbalance in India reflects broader societal inequities. Solving these disparities will not just be reformed through policies, but a definite cultural shift in how women's health is valued and prioritised.

Heatmap of Indian states' transplant performance as of 2023. (Sources: NOTTO, TI India)

State	Deceased Donors (pmp)	♀ Female Donors : ♂ Male Recipients	Rural Access (%)	Liver Transplants	Heart Transplants
Tamil Nadu	1.8	72% : 84%	41%	290	45
Kerala*	1.2	68% : 79%	38%	175	28
Maharashtra	0.9	65% : 82%	29%	420	62
Karnataka	0.7	58% : 88%	23%	195	31
Uttar Pradesh	0.3	48% : 91%	12%	82	9
Bihar	0.1	32% : 95%	8%	24	2

Legal and Ethical Challenges in India's Organ Transplant Ecosystem

The Transplantation of Human Organs and Tissues Act (THOTA), 1994, governs organ transplantation in India. This legislation provides a comprehensive structure to regulate organ donation and prevent commercial exploitation, but several legal and ethical challenges continue to impede equitable and transparent organ transplantation.

Illicit Organ Trade and Commercialisation

THOTA has structured and imposed strict deadlines, yet India remains a definite hotspot for illegal trafficking, where especially the poor section of the society suffers more than others. A 2023 report by The Lancet has revealed that forged documents and coercion are very apparent, around 15-20% of kidney transplants in India involve commercial transactions. Similarly, a 2019 report by the United Nations Office on Drugs and Crime (UNODC) identified India as one of the countries where 'transplant tourism' and black-market organ transactions continue to occur.

Ethical Concerns in Organ Allocation

The absence of a unified national allocation system for all organs facilitates preferential treatment based on financial and institutional clout. The lack of transparency in the Organ allocation system has always been a target for criticism.

Many cases in advanced states in Tamil Nadu, Karnataka and Delhi have revealed that the 'related donor' clause in living donation guidelines is often misused and cheated upon. Fraudulent documents are used to

justify non-related living donations. Concerns also arise when wealthy and influential patients are prioritised over poorer candidates who may be more in need. In a 2023 audit of transplant procedures across five states by the Ministry of Health and Family Welfare, it was found that private hospitals performed 70% of liver transplants, but accounted for less than 30% of total registrations on state waiting lists, which suggests inequity in access. A 2022 study in the Indian Journal of Medical Ethics has exposed how Maharashtra's equitable kidney allocation policies failed in practice: 60% of deceased donor kidneys went to high-income patients, underscoring systematic leakage.

These pre-existing inequities are intensified further by the institutional shortcomings, thus a prompt legislative action and health engagement and awareness in much needed for the whole community.

Role of NOTTO, ROTTO, and SOTTO

The organ transplantation system in India is guided by a three-tier institutional structure, i.e. NOTTO, ROTTO and SOTTO.

National Organ and Tissue Transplant Organisation (NOTTO)

NOTTO is the apex body under the Ministry of Health. It manages the national registry and formulates allocation guidelines. In 2023, NOTTO recorded over 15000 organ transplants, which is a progress from the previous year, but still falls short of the estimated 2 lakh Indians needing kidney transplants alone. There's a funding gap also - NOTTO's annual budget prioritises awareness campaigns in metro-cities, whereas states like Bihar receive less than 2 crores for grassroots mobilisation.

Regional and State implementation: ROTTO and SOTTO

There are 5 ROTTOs and over 20 SOTTOs in India. These institutions are tasked with local coordination. In 2022, Tamil Nadu's SOTTO had streamlined deceased donations by making the brain-death audits mandatory, and as a result, achieved 1.8 donations per million population, which is triple the national average. In a stark contrast, Uttar Pradesh's SOTTO is plagued with a shortage of staff, which resulted in a delay of over 14 months for a kidney transplant in 2023, which killed over 23 waitlisted patients.

The current institutional framework is laid down well and is ambitious, but it lacks proper implementation and bridging the gaps between theory and practice. It suffers from regional inconsistency and weak accountability. Reforming these frameworks demands more than funds; it requires dismantling the bias that exists in the actual design of the structure.

Case studies

Case study 1: Gender Disparity: Rukhsana Begum from Uttar Pradesh

Rukhsana Begum from Uttar Pradesh was suffering from a chronic Kidney disease. She could not be registered for a transplant because her family had already undergone an organ transplant procedure for her husband and could not afford another. She was medically eligible and had a willing donor, too, but societal gender roles and expectations prevented her from receiving the treatment. She dies six months later.

Case study 2: Institutional collapse in Bihar

Bihar's SOTTO had no full-time staff until the year 2023. The majority, i.e. 90% of the transplants, were completed in private hospitals. This led to 4 deaths needing organ donations in 2022 alone.

Case study 3: Economic Disparity- Arvind vs. Prakash

In 2021, in Mumbai, Arvind, a businessman, received a liver transplant within two weeks at a private hospital. However, a four-month wait for Prakash, an unemployed graduate registered at a public facility,

proved to be fatal. This shows how financial privilege accelerates access, while delays in public hospitals prove to be fatal.

Recommendations

Disparities in the Indian organ transplant structure are institutionalised. The following actionable recommendations are proposed to bridge these institutional gaps and systemic disparities:-

1. Access should be decentralised and readily available:-

- a. Transplant desks in District Hospitals can be made mandatory- All district hospitals must be required to have basic transplant screening units by 2027, and these units must be linked to SOTTO. Recently, **Odisha under the Mo Udayan Scheme (2021-2023)** established rural transplant screening kiosks in 30 district hospitals. This early screening cut time to transplant evaluation from 8 months to 3 months for rural patients.
- b. Some slots can be reserved for the marginalised groups- A 25% reservation can be implemented for the marginalised groups, such as rural residents.

2. Institutions can be digitised:-

- a. All institutions should be connected via a real-time, integrated digital platform for waitlist monitoring, allocation and organ availability. A 2022 audit by the Ministry of Health found that less than 50% of SOTTOs maintained and updated public registries- this must be made mandatory.
- b. Maharashtra has a pilot model based on Kerala's Mrithasanjeevani e-registry, which has reduced illegal kidney transplants by 92% by 2020 (Kerala Transplantation Network, 2021)
- c. Fast-track courts can be established for Organ Trade Cases; one fast-track court per High Court jurisdiction can be established based on the Narcotic Drugs and Psychotropic Substances (NDPS) Act, 1985.

3. Address Gender and Social Biases Through Monitoring:-

- a. Gender parity must be enforced through audits and penalties. The Indian Journal of Nephrology, 2021, reported that only 70-75% of kidney donors are women, while 80% of recipients are men.
- b. It must be made mandatory for NOTTO to publish annual gender-disaggregated data, with penalties for non-compliant hospitals.

4. Ensure Financial Protection for Recipients:-

- a. *In a 2023 interview with Down to Earth, an Indian citizen, Sunita Devi from Bihar, said that private hospitals asked for 20 lakh rupees for a kidney transplant; they had to sell their land for that, and now she has to work as a maid.* Full transplant coverage must be included in Ayushman Bharat for BPL, i.e., patients below the poverty line, ensuring affordability does not determine survival.
- b. The 2023 NHRC proposal of a cap for prices, and any violation of the same should be penalised, must be implemented.

Every year, 2 lakh Indians die awaiting organs, as per a 2023 report by NOTTO. Equity in transplantation isn't just healthcare reform, it's reparative justice for systemic neglect.

Conclusion

With growing surgical operations, institutional framework, and rising awareness, Organ transplantation is a feather of medical achievement in India. Still, this achievement is tainted with stark disparities in access. Divide exists all around caste, class, region and gender, which continues to influence who receives timely treatment. Affordability plays a major role in determining access. And despite national institutions like

NOTTO, regional differences in implementation leave many states behind.

It is shown in this paper that just technical advancement is not sufficient; Ethical and institutional reform must reflect scientific progress. With better enforcement, digitisation, and financial coverage, India can create a transplant system where no one is left behind due to structural disadvantage.

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