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The burden of Organ demand

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Organ transplantation for end stage kidney, liver, heart and lung disease is one of the biggest success stories of 20th Century medicine. The year 2017 marked the 50th anniversary of the world's first heart transplant and also marks the same milestone for the world longest surviving liver transplant recipient. Kidney transplantation was already being delivered over a decade earlier. This period of 50 years has seen cadaver organ transplantation being delivered as a routine procedure worldwide, and approximately 140,000 transplant procedures are performed worldwide every year.

In India, awareness about cadaver transplantation has been slow to develop, even though the legal basis for this, the Human Organ Transplant Act, was passed by Parliament in 1994. The last 5 years has seen several Indian states develop and grow their cadaver organ donation programmes, led by Tamil Nadu, Maharashtra, Andhra Pradesh and Kerala with around 700 cadaver organ donations expected in 2017, a figure almost 5 times higher than what was achieved 5 years ago. Despite this growth, we still are only just beginning to address the burden of organ demand, and of the 10,000 transplants performed annually in India, almost 80 % of organs come from living donors, who donate either a single kidney or part of their liver. The figure is reversed in the West, with over 80% of transplanted organs donated from brain dead cadavers. Consequently we are able to offer transplantation to only a small proportion of patients needing this treatment, treating around 3% of the annual total of 300,000 Indians who could benefit from a life-saving transplant, and a vast majority of these Indians will die within a year of being diagnosed with end stage organ failure.

Why then has this been slow to develop? Health is a state matter, and this has resulted in individual states having different approaches to cadaver organ donation and transplantation. The National, Regional and State Organ Transplant and Tissue Organisations (NOTTO, ROTTO and SOTTO) announced by the Ministry of Health in the last 2 years, has yet to have any influence in the delivery of cadaver organ transplantation. There is no structured network of transplant centres, organ donation centres and transplant co-ordinators. The latter are essential to help in identifying and approaching potential donors in the intensive care setting. Currently, apart from Tamil Nadu, all co-ordinators are individuals appointed at their institutions usually to oversee living donor transplantation. In several states where cadaver organ donation has been growing, this growth has been led by initiatives particular to the region, supported by well-meaning NGOs such as the Chennai based multi organ harvesting of organs network (MOHAN) and Maharashtra's zonal transplant co-ordination committees (ZTCC). In many parts of the country, especially in eastern, central and northern India, there is almost no cadaver organ donation activity.

Organ transplantation is still considered as an expensive and complex treatment in India, and is largely delivered in private institutions. Unlike the rest of the world, very little organ transplant activity is undertaken at teaching or University hospitals. Offering transplantation services has been shown to improve levels of care in teaching institutions. This is especially true for the more complex liver, heart and lung transplant procedures, and pancreas and intestinal transplantation are almost non-existent in India. Consequently, little emphasis is given to this field in medical education, so both teachers and students alike have little insight into this treatment option, and as a consequence there is little or no incentive for these institutions to address the need for organ donation. All these factors contribute to India having amongst the lowest organ donation rates in the world, currently at about 1% of what is being achieved by the best performing countries, even though India has very high trauma rates and a limited delivery of emergency neurosurgery. Most potential donors are admitted in public hospitals and almost never have the opportunity to donate, with most cadaver organ donations taking place in private hospitals, where the awareness for organ donation and transplantation is on the increase. Involvement of the public and the teaching hospitals as well as other stakeholders, such as the police authorities for medicolegal cases, in organ donation will be crucial if India is to try to bridge the gap between demand and supply of donor organs.

There is also a huge dearth of data on outcomes after transplantation. Units performing transplants are not required to submit outcomes or be open to audit. The earning potential in transplantation for private hospitals remains large and this financial factor also prevents sharing of outcome data between institutions. This aspect leads individual transplant units to compete with each other, instead of encouraging collaborative practice, so essential for the successful delivery of transplantation. The only outcomes data available is unaudited presentations made by individual units, usually from corporate hospitals, largely performed to help attract new patients to undergo transplantation. This data collection of outcomes is routine worldwide, and is something that could and should be introduced as a matter of priority by the newly designated regulatory authorities, especially for teams currently utilising the few cadaver organs being made available.

The cost burden of transplantation has so far been borne by the patient, limiting this treatment option to a privileged few. The costs of delivering transplantation in India are amongst the lowest in the world, and as activity increases and these treatments become more available, these costs are likely to decrease further. Drug costs in India are amongst the lowest in the world, and some post-transplant medicine regimes cost less than the drugs needed by patients prior to transplantation. Recently, additional funding options are being made available. Recognised governmental and NGO led charities have helped fund patients, innovative web based crowd-funding platforms have helped raise entire transplant and post-transplant costs for some patients, and some state governments and employers are supporting part of the costs for transplants. There also remains the potential to tap into corporate social responsibility (CSR) funds to help bridge the gap between affordability and

cost of transplantation. For transplantation to be widely accepted as a routine treatment, it is essential that this treatment is made available to most members of society, not just the privileged few.

Other practices potentially detrimental to development of good transplant outcomes include delayed referral of patients by managing physicians to transplant centres, by which time the ability to wait for a suitable donor and survive the transplant procedure is compromised, and also further escalates the costs of managing these sicker patients pre and post transplantation. Patients and their families are also habituated to a practice of seeking multiple opinions, a sort of “window shopping”, contributing further to the indecision and delay in accepting transplantation.

In summary, organ transplantation in India is growing, especially from cadaver donors. Adoption of successful practices in realising cadaveric donation by the few groups in some states should be encouraged. Greater involvement by public sector hospitals will make transplantation more accessible to the wider society. Reduction in costs and use of innovative funding will help widen the practice of transplantation. There is an urgent need for the newly designated regulatory authorities to be empowered to regulate delivery of transplantation, and to develop donor co-ordination systems. A uniform organ allocation infrastructure needs to be realised in both the public and private sectors, along with the need for more transparency in availability of outcomes after transplantation.

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