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REFORM CAN ADDRESS INDIA'S KIDNEY TRANSPLANT DEFICIT

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'Reforms of kidney exchange laws have been slow' | Photo Credit: Getty Images/iStockphoto

India's organ shortage when it comes to kidneys is alarming. In 2022, over two lakh patients needed a transplant, but there were only about 7,500 transplants (about 3.4%). Due to the prevalence of diabetes, malnourishment, overcrowding and poor sanitation, there is a high prevalence of Chronic Kidney Disease (CKD) in India, affecting about 17% of the population. CKD often leads to end-stage renal disease (ESRD). A kidney transplant is often the best treatment for ESRD. Specifically, transplant is often better than alternatives on almost all dimensions that matter: quality of life, patient convenience, life expectancy, as well as cost-effectiveness. In contrast to India, the United States and other developed countries could carry out about 20% transplants. Notably, a significant portion of this gap is on account of more stringent regulations in India than a lack of medical facilities.

These are four main ways a patient can obtain a kidney. The first is to get a kidney from a deceased person. This is constrained due to a lack of donations, the particular conditions required on the nature of death, and the infrastructure needed to collect and store kidneys. The second is to request a relative or friend to donate. However, donor and recipient have to be compatible in terms of blood type and tissue type; such relative/friend donors are often incompatible.

Thus, regulations for kidney exchange are needed as kidney exchange must often occur across family units. But we argue that these regulations need urgent reform to unshackle two innovative kidney exchange methods: kidney 'swaps' and kidney 'chains'.

In kidney swap, let us take the example of two strangers, Sunita and Zoya, who need kidneys. Sunita's spouse is incompatible with her, and Zoya has the same problem. However, if Sunita's spouse is compatible with Zoya, and Zoya's spouse is compatible with Sunita, swap donations are possible. In kidney chain, let us look at the case of Sonu who is an altruistic donor donating his kidney with no expectation of a kidney in return. Sonu donates to Sunita (assuming compatibility), Sunita's spouse donates to Zoya, and Zoya's spouse donates to some other compatible person, and so on.

Our research shows that there are barely any swaps and almost no chains in India. This is because of legal roadblocks. And this is a significant opportunity missed with terrible

consequences. Consider swaps. Swap transplants are legally allowed in India with due permission, but only near-relatives are allowed as donor-recipient pairs. Exceptions to this restriction are Kerala, Punjab and Haryana, where High Court judgments have recently allowed non-near-relative donor-recipient pairs after verification. Thus, in most States, if Sunita's donor is not a near relative (such as spouse, parents), she and her donor cannot participate in a swap. By contrast, it is legal for Sunita's non-near-relative to donate to her. These double standards across swaps and direct donations are questionable. Easing the laws for swaps to make them on a par with direct donations is necessary.

Further, unlike national, regional, and State lists for direct transplant from cadavers, there is no national coordinating authority for swaps. This is again a huge lost opportunity, since larger and more diverse pools make it easier to find compatible swaps.

While there are occasional swaps in India, there are almost no kidney chains. First, in all States except Kerala, it is illegal to donate a kidney out of altruism. Thus, one cannot start a chain since one cannot donate without getting a kidney (for a family member) in return. And, kidneys from the deceased or brain dead are only used for direct transplants, not for chains or cycles.

The lack of kidney chains is possibly an even bigger opportunity missed than swaps. While participating in swaps, families demand nearly simultaneous operations of all donors and recipients since no one wants to lose a kidney without gaining one. But in chains, each patient first receives a kidney and only then does their relative donate. Thus, chains, compared to swaps, involve significantly lower hospital resources and uncertainty for participants.

Needlessly harsh laws regulating swaps and chains have contributed to a proliferation of black markets for kidneys. 'Selling a kidney' to relieve financial distress is a mainstream reference. These black markets endanger all their desperate participants since these operations are conducted 'off the books', without due legal and medical safeguards.

Reforms of kidney exchange laws have been slow. The Transplantation of Human Organs and Tissues Act 1994 set the ball rolling by recognising transplant possibility from brain-stem death. In the 2011 amendment, swap transplants were legalised, and a national organ transplant programme was initiated. But the national network remained underdeveloped initially. According to the Transplantation of Human Organs and Tissues Rules 2014, swap transplants are allowed only for near relatives. The government's recent reforms (February 2023) allow more flexibility in age and domicile requirements while registering to obtain an organ. But these reforms leave the fundamental issue of inadequate kidney supply largely unaddressed. This is why it is beneficial to allow and encourage altruistic donation, non-near relative donation for swaps, and to improve the kidney-exchange infrastructure.

India does not need to innovate in order to reform chains and swaps. Sufficient precedents have been set globally. Australia, Canada, Israel, the Netherlands and the United States (among others) now allow altruistic donations. Spain and the United Kingdom have national-level registries for kidney chains and swaps. The U.S. has especially made progress in facilitating thousands of swaps and chains. Spain even has international collaborations for kidney exchange. India's real challenge, therefore, is to learn from and replicate such existing successful regulations to improve the lives of several thousands of citizens.

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