

Pakistan's Kidney Trade: An overview of the 2007 'Transplantation of Human Organs and Human Tissue Ordinance.' To what extent will it curb the trade?

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Abstract

Pakistan has the unenviable reputation for being one of the world's leading 'transplant tourism' destinations, largely the buying and selling of kidneys from its impoverished population to rich international patients. After nearly two decades of pressure to formally prohibit the trade, the Government of Pakistan promulgated the 'Transplantation of Human Organs and Human Tissue Ordinance' (THOTO) in 2007. This was then passed by Senate and enshrined in law in March 2010. This paper gives a brief overview of the organ trade within Pakistan and analyses the criteria of THOTO in banning the widespread practise. It then goes on to answer: 'To what extent will THOTO succeed in curbing Pakistan's kidney trade?' This is aided by the use of a comparative case study looking at India's failed organ trade legislation. This paper concludes THOTO has set a strong basis for curbing Pakistan's kidney trade. However, for this to be successfully achieved, it needs to be implemented with strong and sustained political will, strict and efficient enforcement as well as effective monitoring and evaluation. Efforts are needed to tackle both 'supply' and 'demand' factors of Pakistan's kidney trade, with developed countries also having a responsibility to reduce the flow of citizens travelling to Pakistan to purchase a kidney.

Keywords: Transplant tourism, Human Organs and Human Tissue Ordinance, Organ trade, Pakistan.

Pakistan's Kidney Trade —An overview:

Background:

The milestone that was the first successful kidney transplant in 1951 has since allowed thousands of organ transplants to occur worldwide each year. However, some argue transplantation has 'become a victim of its own success' as the increasing need for transplants has resulted in a worldwide donor shortage.¹ This has led to the development of an illegal trade whereby organs, most often kidneys, are sold by the poorest and most vulnerable of low and middle income countries and bought by wealthy recipients of high income countries.² Long waiting lists and expensive treatment costs have urged many to partake in this 'transplant tourism'.

The WHO has estimated that 10% of the 63,000 kidney transplantations undertaken worldwide involve payment between non-related donors of different nationalities.³

Pakistan emerged as a 'hotspot' for transplant tourism in recent years and was considered 'one of the largest centres for commerce and tourism in renal transplantation'. Prior to 2007, approximately 2000 kidney transplants occurred in Pakistan each year with nearly half being carried out on foreign patients.⁴ Private city hospitals offered all-inclusive transplant packages to patients from around the world.⁵ In 1979, Pakistan undertook its first ever kidney transplant which set the basis for renal transplants to be carried out across the country.⁶ However, Pakistan's kidney trade was a relatively recent emergence. A report from the country's largest public sector transplantation centre, the Sindh Institute of Urology and Transplantation (SIUT), showed that 75% of renal transplantation in 1991 was living-related as opposed to 80% of transplants in 2003 involving living-unrelated donors.⁷ One of the main reasons for this sharp reversal involved India's introduction of prohibitive legislation in 1994 which banned all commercial organ dealings.⁸ Consequently, large numbers of international patients travelled to Pakistan which did not have any organ trade legislation at the time.

Vendor Profile:

The high kidney demand was met with an abundance of supply from Pakistan, where a third of the population lives below the poverty line.⁹ Pakistan has 65% of its 160 million inhabitants living in rural areas.¹⁰ Many are 'bonded labourers' who live and work on landlords' farms often owing large debts accumulated over generations. This is most prevalent in Punjab province and unsurprisingly this was the country's largest source of kidney vendors. Bonded labourers are specifically targeted by organ brokers with the incentive of using the money from the sale to pay off debts and attempt to gain freedom from bondage.

Buyer Profile:

Patients travel to Pakistan from as far as the Middle East, Europe and North America where they pay for and have

the operation arranged in one of Pakistan's abundant private city hospitals.⁵ Transplant waiting lists in developed countries are often long due to a severe lack of kidney supply. In the USA, there are 78,000 candidates on the kidney transplant waiting list of which 3,000 will die each year due to lack of suitable supply.¹¹ The prospect of avoiding tiring and often more expensive dialysis treatment is too enticing for some, who thus travel abroad to purchase a kidney. Prices charged in Pakistan ranged from anywhere between US\$6,000 and \$40,000 depending on the ability and willingness to pay.¹³ This covers payments for the donor, doctors and brokers, medical expenses and follow-up treatment. However, the financial sum finally received by the donor is trivial when compared to amounts allocated to third parties involved.

Health and Socioeconomic effects:

Evidence suggests that the kidney trade was having negative health and socioeconomic effects on Pakistani vendors.

For health, one study compared health status and renal function of living-unrelated kidney vendors with a matched control group of living-related donors.¹² Post-nephrectomy complaints and complications, such as urinary tract symptoms and hypertension, were significantly higher in the vendor group than the control group and the study concluded that vendors were at high risk of developing long-term chronic kidney disease. Another survey showed 98% of Pakistani kidney vendors reporting a deterioration in health status, such as pain and tiredness, up to one year after the operation.⁴ This was supported by similar studies carried out in India.¹³ In addition, a Pakistani ethnographic study looked at the psychosocial consequences of selling a kidney.¹⁴ It concluded there were significant effects to the vendor, such as feelings of emptiness, hopelessness and regret as well as detrimental effects on the vendor's wider family, such as increased pressure to follow suit and stigmatization of communities. As such, most living-unrelated vendors are poorly treated with no proper screening process or follow-up care, resulting in the detrimental physical and mental health costs that come with selling of their kidney.

In terms of socioeconomic effects, the deterioration in health status led to decreased work productivity and consequently a reduced income, frequently putting the vendor and their family in a worse economic situation than before.¹⁵ Selling a kidney provided only temporary income, with 81% of vendors spending the money within 5 months to pay off debts rather than investing in a long-term 'quality of life enhancements'. Another study⁴ showed the average promised payment for a kidney was \$1737, yet the payment received averaged only \$1377. Hence, 85% of the vendors surveyed claimed there was no long-term economic improvement in their lives. Instead of families moving up the

socioeconomic ladder, they remained in the same social strata with the kidney trade only reinforcing and further increasing social and economic inequality within Pakistan's society.

'Transplantation of Human Organs and Tissue Ordinance' (2007):

As the scale of the kidney trade thrived in Pakistan during the 1990's, so too did calls for legislation banning the trade in accordance with prohibitive guidelines from the WHO and other leading medical organisations and national governments. After nearly 15 years since legislation was initially proposed to the government, the 'Transplantation of Human Organs and Tissues Ordinance' (THOTO) was officially promulgated on September 3rd 2007 by former President General Pervez Musharraf.

It specifically prohibits donation of organs or tissues by a living person unless they are genetically or legally related to the patient as a 'close blood relative' (parent, child, sibling or spouse). Importantly, THOTO states that "donation by Pakistani citizens shall not be permissible to citizens of other countries". Any person found to be in violation of this or involved in any commercial organ dealings is subject to 10 years imprisonment and a fine of one million rupees.¹⁶

In addition, the transplantation must be "voluntary, genuinely motivated and without duress or coercion". In cases where there is donor non-availability, THOTO allows donation by a non-close blood relative but only if entirely voluntary. To determine the validity of the claim, THOTO establishes hospital 'Evaluation Committees' to "ensure that no organ or tissue is retrieved from non-related living donors without prior approval". These committees consist of surgical, medical/transplant specialists and social service professionals.

THOTO also creates a monitoring authority, known as the 'Human Organ Transplant Authority' (HOTA), which compiles an official list of institutions recognised to undertake organ transplantations. HOTA inspects and enforces standards in these centres and investigates any allegations of THOTO's provisions being breached.¹⁶

A final stipulation within THOTO is the establishment of a national deceased organ donation programme. Up until THOTO's initiation, there had only been two successfully transplanted deceased donations nationally.¹⁷ To counter the common myth of organ donation being 'un-Islamic', the Pakistani government declared organ donation an act of merit in line with leading Islamic scholars and organisations, such as the 'Organisation of the Islamic Conference'.¹⁸ It is hoped the new programme will address Pakistan's own organ shortage and reduce dependency on living donation as the sole supply.

India Case Study:

India is a useful comparative case study as the country

profile and context of the organ trade share similar characteristics with Pakistan. The vendor profile is again typically an impoverished bonded labourer and the average price of a kidney is similar, ranging between US\$1000 and \$1400.^{4,13}

India's kidney trade thrived during the 1980's with a number of hospitals carrying out transplantations from paid unrelated donors.¹⁹ In 1995, due to growing pressure and negative media attention, the Indian Government enacted the 'Transplantation of Human Organs Act 1994' (THOA). The policy banned payment for organ donation, only allowing donation for immediate family members. However, a loophole within the law allowed non-related donation for reasons of 'affection and attachment' to the recipient. Donors had to convince 'authorisation committees' their donation was purely altruistic and non-commercial. Reports have since emerged of illegal organ brokers recruiting poor vendors, dressing them in new clothes and staging photographs with the recipient to deceive committees into believing they were the recipient's close friend or relative.^{20,21}

THOA did not succeed in eradicating the kidney trade, rather simply shifting it underground. Frequent media reports expose 'transplant rings' such as in India's Punjab province in 2003 and southern India in 2007.²² Current estimates put the figure at 2000 illegal paid kidney transplants occurring in India every year.²³

Various reasons are suggested in explaining THOA's failure. A large factor is the authorities' apparent lack of enforcement. Although some people are arrested and some hospital licences suspended, a few months later 'everything is forgotten'.²¹ Aided by the 'ponderous pace of the judicial system', cases under investigation are often not concluded.²⁴ There is also a lack of enforcement within the very own authorisation committees intended to vet out fake applications. Reports have emerged of committee members being bribed by middle men to turn a blind eye when trying to prove a donation is 'voluntary'.^{24,25}

Overall, India has failed to capitalise on the introduction of THOA due to lack of enforcement, poor regulation and seemingly corruptive practices pervading the system. Encouragingly, the Indian Government is currently modifying the THOA legislation in an attempt to curb the abuses of certain clauses.

'To what extent can THOTO counter Pakistan's existing kidney trade?'

THOTO has set a solid basis for effectively curbing the trade. It is promising to a certain extent but requires full political backing and strong enforcement in order to be largely effective.

In terms of good provisions, THOTO explicitly bans transplants for foreigners and only allows them to be carried out on 'close blood relatives'. In cases of non-availability, evaluation committees assess whether the donation is truly voluntary. Furthermore, HOTA compiles a list of registered and reputable transplant centres and investigates all allegations of organ commercialism. The punishments, including up to 10 years imprisonment and a one million rupee fine should act as an adequate deterrent if enforced.

However, it is necessary to recognise THOTO's potential limitations. For example, instead of totally forbidding non-related organ transplants, this is allowed in cases of non-availability of close blood relatives after evaluation committees satisfy themselves that such donation is 'voluntary'. The threat of manipulation within this clause in non-related donation must be targeted with provisions made to minimise this. The Pakistani government must learn from India's mistakes to minimise the possibility of the trade thriving underground. Lack of enforcement and pervasion of corruption were key factors that hindered India's progress. To this end, THOTO must be strictly enforced with effective disciplinary measures in place to punish violators efficiently. To counter the threat of corruption, leading national scholars insist that THOTO must be "implemented honestly and transparently if it is to work".²¹

How successful has THOTO been so far?

In the relatively short time since the Ordinance's promulgation in 2007, it is difficult to assess how successful THOTO has been.

It is clear that political will in implementing THOTO has been strong, as evidenced by the National Assembly and Senate passing the bill in November 2009 and February 2010 respectively. In addition, President Asif Ali Zardari signalled his support for the bill by signing in March 2010 to officially make it a law.²⁶

There is evidence to suggest that THOTO is being enforced by the authorities. The Supreme Court took action against a number of private hospitals accused of violating the ordinance in June 2009, forcing them to commit to compliance within the law. HOTA is fully operational and has authorized 42 transplantation hospitals, and regularly monitors hospitals throughout the country for evidence of illegal organ trading.²⁶ HOTA recently released figures on the number of related and unrelated kidney transplants carried out from THOTO's introduction (September 2007) to June 2010. In total, 2044 individuals donated their kidneys of which only 127 or 6.2% were living-unrelated. The latter were done voluntarily due to no match within the patient's family. Encouragingly, the report also stated that as of May 2008 there were a total of 4 deceased organ donations since

the legislation's promulgation, thus signalling the start of Pakistan's deceased organ donation programme.²⁷

From the limited media data available, there are conflicting reports on the extent of the illegal organ trade in Pakistan since THOTO's introduction. One report²⁸ claimed the number of kidney tourists visiting Pakistan had decreased from 500 a month to fewer than 10 since the regulations were introduced whilst another quoted a figure of 30 per month.²⁹ Whether these figures are merely showing a temporary decrease due to the 'scare effect' of the recent legislation remains to be seen.

However, other reports suggest illegal operations are still relatively widespread. One article states that an eminent Pakistani transplant surgeon received emails from counterparts in Saudi Arabia, Kuwait, Bahrain and India claiming their patients were still buying and undergoing illegal kidney transplants in Pakistan.³⁰ Newspaper reports of foreign patients visiting Pakistan for illegal transplants and suffering medical complications or even death once returning home have caused concern for the Transplantation Society of Pakistan (TSP). The TSP have understandably appealed to the Government to increase efforts to save Pakistan from becoming the 'cheapest organ bazaar of the world.'³¹

Role of developed countries:

As THOTO is working towards addressing the 'supply' side by prohibiting kidney selling, it is necessary to examine ways to address the 'demand' factors. Two commonly debated strategies include 'ethical incentives' and 'presumed consent'.

Supporters for ethical incentives (for living donors or families of deceased organ donors) claim that because organ donation is voluntary and valuable, the incentives act as a way for society to thank organ donors for their gift without jeopardizing its 'altruistic basis'. Types of incentive could include a 'donor medal of honour' to encourage charitable organ donation and express appreciation on behalf of the society. Others include an intentionally small 'partial reimbursement for funeral expenses', to emphasise appreciation for donation whilst not providing payment for it, as well as 'paid medical leave' which would increase the number of would-be donors who no longer have to worry about the financial and employment risks involved.³²

The controversial concept of 'presumed consent', commonly known as an 'opt-out' system, is where organs are removed after death unless an individual has indicated during their lifetime for this not to be done. In a developed country like the UK, surveys have shown 90% of the population support organ donation.³³ Thus by altering the current 'opt-in' system to a default position of presumed consent, more lives will be saved "while respecting the wishes of those who want

to donate and protecting the rights of those who do not".³⁴ Studies have shown that for countries with consistently implemented presumed consent policies, there was an average 25-30% higher donation rate than those that did not.³⁵ For example, Spain introduced the system in 1989 and in 2005 had the world's highest donor rate at 35.1 donors per million population compared to only 12.8 in the UK.³⁴ However, critics argue it risks breaking the trust between the patient and doctor³⁶ and is unsuitable in societies where 'autonomy is highly prized'.³⁷

Overall, if Pakistan's kidney trade is to be curbed as much as possible, the 'supply' factors should not be the only issue addressed. Instead, 'demand' factors must be targeted within the developed countries from which the international patients are travelling from. National organ supplies must be increased and transplant waiting lists reduced to counter the driving force that urges patients to purchase a kidney abroad and consequently fuel the trade.

Conclusions

THOTO has set a strong basis for curbing Pakistan's kidney trade. For this to be successfully achieved however, THOTO needs to be implemented with strong and sustained political will, strict and efficient enforcement as well as effective monitoring and evaluation. This relies largely on the effectiveness of HOTA in carrying out its intended role and Pakistan's judicial system in delivering on its promises of harsh penalties and punishments for violators. Transparency is also vital and it is the responsibility of healthcare professionals within Pakistan to be vigilant of any signs of illegal organ trading and reporting any suspicions to HOTA. Efforts need to be made to inform those most at risk of organ exploitation, mainly the rural poor, about the illegality of the trade via potential awareness campaigns and education. Ultimately, prevention is better than cure. Hence Pakistan must continue in efforts to improve the living conditions of its poorest inhabitants to reduce the desperation that forces some into selling their own organs to support families, gain freedom from bondage or indeed survive.

Given Pakistan's current political instability, it is necessary to stress the importance of improving its capacity to fully implement the policy and effectively regulate the trade. Without such conditions, THOTO alone will only curb the trade to a small extent and risk repeating the mistakes of India in shifting the trade underground. No law can completely eliminate the organ trade, however with the additional conditions mentioned above, THOTO has a real chance of curbing Pakistan's kidney trade to a large extent. Developed countries must not let the responsibility lie solely with Pakistan. They must look at new ways to address the 'demand' factors with their own deficient organ supply, such as the possibility of implementing 'ethical incentives' or

