The Illegal Kidney Trade: Who Benefits?

Original Article

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Abstract: An illegal trade in organs, primarily kidneys emerged to counter a global scarcity of organs. This paper focuses on the kidney trade in India and primarily discusses a research study undertaken by the author among transplant professionals, commercial donors and buyers of kidneys in India. The study revisit factors sustaining the trade and analyses those who ultimately benefit from it. The transplant professionals argue that a constantly widening gap in demand and supply of organs, a regular availability of impoverished donors, medical malpractice and loopholes in the Transplantation of Human Organs (THO) Act, 1994 perpetuated the trade for decades. However, the study shows that it is not the commercial donors or the buyers of organs who benefit most from the trade. The maximum benefit, which is economic, is for members of the organised crime networks who control the black market of kidneys and who share the maximum profit from the trade. This is the distinct contribution this paper attempts to make. Transplant professionals suggest that a stringent regulatory mechanism, a strong political will to increase the rate of organ donation and early screening of chronic kidney diseases might reduce the demand of organs for transplantation and limit the trade of organs. A legalised market of organs is not favoured by majority of transplant professionals.

Keywords: End-stage renal disease (ESRD); renal transplantation; kidney trade; transplant tourism * Saradamoyee Chatterjee is a Lucy Cavendish College Associate, University of Cambridge and an Academic visitor, Centre of Development Studies, University of Cambridge, United Kingdom. Contact: sc761@cam.ac.uk

Introduction

The kidney trade, like any other business is driven by a basic market principle of “demand and supply”. The present global disease burden of renal failure has reached such a point that almost every country in the world—developed or underdeveloped—is facing the daunting task of supplying an adequate number of kidneys to patients. Renal transplantation today is the most valued treatment for the patients with end-stage renal disease (ESRD). To reach this stage of demand, it took several decades of medical evolution. Understanding these phases of evolution can provide better clarity to the circumstances leading to the emergence of a lucrative kidney trade.

Before the first successful kidney transplantation was performed, the choice for patients with ESRD was either haemodialysis or death. Then in 1954, Murray and his team performed the first successful kidney transplant in identical twins. Gradually, the transplantation procedure was established worldwide (Morris, 2004). However, transplantation was a problem when an identical twin was not available due to negative immunological reaction. Following the discovery of “wonder drug” cyclosporine, the immunosuppressant, in the 1970s, which suppressed the adverse immunological reaction in the patient, the survival rate of transplants significantly increased. With this discovery, the kidney transplant became a much-valued treatment for patients with renal failure. In addition to increasing transplants between living related individuals, this discovery made transplantation between living unrelated individuals a medically successful procedure. This series of medical success increased the demand for transplantations. The scarcity of organs, however, emerged as the major hindrance in reaping the benefit of this phenomenal medical success (Calne, 2006; Barker, James and Markman, 2016). What followed to increase the supply was the emergence of an international black market of organs.

The focus of this paper is the kidney trade - the organ which is bartered most due to its availability as a spare part in the human body. Initiating with a discussion on the global emergence of the trade, the paper then specifically focuses on the kidney trade in India- the emergence, proliferation and the factors underpinning the sustained existence of the trade for decades. This is followed by a deliberation on the ethical aspects of the trade and a discussion on the benefit, if any, of the trade both from the donor’s and recipient’s perspectives. The discussion is based upon newspaper reports and earlier research studies on the illegal trade in India and a research study conducted by this author in India among the transplant professionals, commercial donors, and buyers of organs. The first part of the study revisits the factors underpinning the sustained existence of the trade. The second part of the study aims to provide some distinct insights into the difficulties encountered by both buyer and seller of kidneys in the whole process of trading organs, ultimately leading to the discussion of “who actually benefits from the trade”. This is the unique contribution the paper makes in the study of the illegal kidney trade. At the end, the paper also attempts at exploring alternatives to the illegal trade in kidneys, including an argument on the possible existence of a legalised paid market of kidneys, based on the opinion of the transplant professionals interviewed in the study.

The Emergence of a Global Market in Organs and Transplant Tourism

Data from 54 countries show that at least 80% of cases of end-stage renal disease (ESRD) are caused by diabetes, hypertension or a combination of the two. Over the past decade, the global prevalence (age-standardized) of diabetes has seen an increase from 4.7% to 8.5% (nearly double) in the adult population. An estimated 422 million adults were living with diabetes in 2014, compared to 108 million in 1980. The American Diabetes Association listed diabetes as the primary

cause of renal failure in 44% of all new cases in 2011 (WHO, 2016). The data indicates the propensity of increasing demand of organs for transplantation and even with the best of organ harvesting systems and procedures in countries (such as Spain and the USA), there is likely to be a wide gap in the demand and supply of organs. In Western Europe as a whole 40 000 patients await a kidney but only 10 000 kidneys become available (Erin and Harris, 2003). This gap in demand and supply is ever increasing in most countries, particularly in developing countries such as India and China.

The emergence of the organ black market can be traced back to the 1980s when the number and variety of organ transplantations increased remarkably. The advancement in surgical techniques and immunosuppressive drugs created centres for transplantation in every continent (Harrison, 1999). Gradually, from a few privileged centres in the developed world, kidney transplantation proliferated into the developing world creating a high demand for transplantation and subsequently a global ‘scarcity’ of organs for transplantation (Schepher-Hughes, 2003). An international black market of organs emerged in response to this worldwide organ crisis. An increase in transplantations from unrelated living donors (after the discovery of cyclosporine) opened the door of a huge transplantation industry, a global traffic in organs.

This international traffic of organs is also a product of “transplant tourism” in a globalised world. The disparities in the cost and access to health care between nations and different regulatory mechanisms, generated “transplant tourism”, which in certain circumstances is akin to the illegal organ trade. It is considered a relatively easy way to trade organs. The patients i.e. the potential recipients of organs travel to another country to obtain an organ for transplantation. The international movement of potential recipients is often arranged or facilitated by intermediaries and health-care providers who arrange the travel and recruit donors (Shimazono, 2007). Despite efforts to boost altruistic donation and resolutions to curb transplant tourism, the implementation is not effective (Jafar, 2009). As the demand for kidney transplantations increased, a few needy patients chose to explore the possibility of transplantation in a foreign country. The risks of this practice is assessed in a single centre study in the United States. 33 patients who underwent transplantation abroad and returned to the centre for follow up were evaluated over a 10-year period for post-operative outcomes. Although, the patient survival rate was not significantly inferior, the rate of acute rejection in the first year after transplantation, and incidence of severe infections among them were higher in comparison to local patients (Gill et al., 2008). Similar infectious complications such as Hepatitis B or C and pulmonary tuberculosis were present in 69 Canadian commercial transplant recipients (Prasad et al.,2016). Different countries have varying infectious diseases profiles and the medical history of organ vendors are often not examined properly. These factors, in addition to country-specific limitations in the whole transplantation process, make these patients unintended bearers of different infections post-transplantation (Gill et al., 2008). Irrespective of general advantage of transplant tourism i.e. a patient is able to receive a kidney, the risks of transplant tourism are higher, particularly if it involves countries where a black market of kidneys exists (Turner, 2008).

This illicit trafficking of organs brings strangers from different ethnic groups, classes, regions, religious backgrounds, political affiliations and nations into intimate contact for the procurement and transfer of tissues and organs. The popular trajectory of this traffic is from South to North, from East to West, from poor, low-status men to more affluent men. The trade has led to the identification of a source of organs in the bodies of the poor, the medically illiterate, the displaced and the desperate. These transactions might range from consensual contracts (formal and informal), to coerced deals, to criminal trafficking verging on transnational kidnapping by local and international brokers involved in a multi-million-dollar business. The difference in economy, health care and regulatory policies have created organ donor vs organ recipient nations (SchepherHughes, 1998).

For several years, organized programs carried affluent patients from Israel, Saudi Arabia, Oman and Kuwait initially to India for transplant. Later these patients went to Turkey, Iran and Iraq, Russia, Romania, Moldova and Georgia and more recently to Brazil and South Africa, where kidney sellers were recruited from army barracks, jails and prisons, unemployment offices, flea markets, shopping malls and bars (Schepher-Hughes, 2003). Recently, Syrian refugees were found to be regular commercial donors of organs in absence of sustained livelihood options and mounting debt (BBC news, April 2017).

A Market in Organs in India

The World Health Organisation (WHO) identifies India among a few other countries (such as Colombia, Pakistan and Philippines) with a black market in organs (Turner, 2008). The trade also exists in Bangladesh (Islam and Gasper, 2017). In this section, the emergence, proliferation and sustained existence of the organ trade in India are discussed in below, proceeding to the ethical aspects thereafter. The first section is a commentary on the emergence of a legal market in organs, the subsequent prohibition by the Government of India on the organ market and the re-emergence of the trade illegally. The commentary is based on secondary data from newspaper reports and available studies on the organ trade in India and an empirical study undertaken by the author on the illegal trade in organs in India.

The Existence of a Legal Organ Market in India (1970-1994)

Renal transplantation started in India in the 1970s. The country progressed from one stage to the next to become the leading country in renal transplantation in the Asian subcontinent (Shroff, 2009). The number of renal transplantations increased phenomenally when the anti-rejection drug cyclosporine was introduced in 1983 and transplantations from unrelated donors became a feasible option. Thus, a combination of factors i.e. the mastery of surgical techniques, the use of powerful

immunosuppressant drugs, lack of medical regulations and ethics indirectly encouraged a kidney transplant industry dominated by living unrelated transplants (Acharya, 1994; Jha, 2004). The availability of low-cost, commercial organ donors was no challenge in a country where a vast section of the population lived below the poverty line. A class of touts and middlemen grew to dupe innocent people to be exploited for kidney donation (Acharya, 1994). The modus operandi of the trade involved scouting small towns and city slums and lure people in need of money. The touts particularly preferred the slums, a goldmine for the organ traders, where the underprivileged surviving in appalling living conditions hoped to uplift themselves by selling their kidneys (Schmitt, 2007). A centre of supply was typically a pocket of concentrated poverty and indebtedness, from where an initial few desperate people would have sold their kidneys. These donors returned home with a small “fortune”, as the people of a poverty-ridden community viewed it and gave the necessary motivation to others to engage in the same trade. Some of the initial donors acted as collection agents for city brokers and doctors in renal transplant centres, and brought many others with similar interests to the centre (Frontline, 1997). These poor people would sell their kidneys to pay for a daughter’s dowry or to repay a debt, to build a small house or to feed their families (Cohen, 1999). Thus, for years, India was known as a “warehouse for kidneys” or a “great organ bazaar”, offering kidneys at nominal cost and ensuring almost immediate availability (Acharya, 1994). The pockets of kidney supply and sales grew in various parts of India. Many people between the late 1980s and 1995, travelled to and within India to receive kidney transplants from living donors who were in most of cases compensated financially, although rarely receiving the actual money they were promised for the donated kidney. The countries from where people requiring kidney transplants most typically came to India for surgery were Middle Eastern countries such as Oman, Saudi Arabia, Bahrain, Kuwait, and the United Arab Emirates. Additionally, may also came from Canada, Malaysia, Singapore, the United Kingdom and the United States (Scheper-Hughes 2000; Goyal et al., 2002).

This unscrupulous trading continued unabated until 1994 developing a successful legal market in organ trading in India. A number of complaints from the donors such as unpaid compensations, uninformed kidney transplantations in which people were unaware that a kidney transplant procedure had taken place, prompted the Government of India in 1994 to enact the Transplantation of Human Organs (THO) Act which prohibited commercial dealings in human organs (Shroff, 2009). This Act involuntarily changed the profile of a live unrelated organ donor in India—“legal” or “illegal”.

Emergence of the Illegal Trade in Organs in India (1995 Onwards)

Immediately after the THO Act was enforced, fear of the law drove brokers out of the business and forced many hospitals to withdraw from active involvement in the trade. However, the prohibition did not cease the demand of organs. To keep up with the pace of demand, the country witnessed the emergence of an illegal market of organs. Consequently, there were reports of reactivation of

the trade in some areas as soon as 1997. For example, since the late 1980s, two places in the southern part of India grew into virtual kidney farms. Kidney sales in these towns were associated with the fortunes of the power loom industry, for it is from the power loom workforce that kidney sales were prolific. Indebtedness was very high among this poorly paid workforce and they sold their kidneys to clear debt. After the enforcement of the Act, the brokers remained inactive for some time, then resumed the trade activity again, this time illegally, once they became conversant of taking advantage of the loopholes in the law (Frontline, 1997). The loopholes in the THO Act, 1994 are discussed below.

The Limitations in the THO Act (1994)

There is one major loophole in the law which indirectly encouraged the illegal trade in organs in India. The Section 9(3) of the Act permits an unrelated person to donate an organ out of affection or attachment. There has been a gross misuse of this section as there are large number of unrelated transplantations in India claiming to be out of affection. Mani (2002), a nephrologist in India argued that it is inconceivable that hundreds of slum dwellers would have sufficient affection or attachment to millionaires they had not met two weeks earlier to donate a vital organ to them.

Section 9(1) allowed donation only from “near relatives”. The Act defined near relatives as “spouse, son, daughter, father, mother, brother, sister and excludes uncles, aunts, grandparents, nephews who are often ready to donate organs in the extended Indian family”. Therefore, the act restricted the scope of live related transplantation encouraging needy patients to seek an organ commercially.

The low level of punishment in the Act for the perpetrators was another limiting factor. The nature of the offence i.e. selling an organ is non-cognizable and the level of punishment was also not stringent enough to deter people in committing the illegal act. The Act was also not successful in establishing an active deceased donation programme in India which could have reduced demand on live organ donors. The Act was amended in 2011 to plug these loopholes, which is discussed later.

The Incidents of the Illegal Trade in Organs in India (2003-2016)

The illegal black market of organs thrived and took a substantially firm hold over the years, in a scenario of unfulfilled demand of kidneys and active operation of organised crime networks driving the trade. In absence of a proper renal registry in India, it is not possible to estimate the actual demand of kidneys in recent years. Approximately, there was a demand for 175,000 kidneys in the country in 2010, but only 5,000 patients received kidneys to undergo transplant (Sinha, 2010). Due to the persistent increase in end-stage renal disease, the demand has increased annually, and the supply of organs has trailed far behind. Shroff (2016) estimates the prevalence of ESRD between 151 and 232 per million population in India. The rate of organ donation has been dismally low in the country at 0.08 donors per million populations, compared with countries like Spain (35.1),

Britain (27) and USA (26) (Sinha, 2010). Public apathy and a lack of public awareness, an absence of proper infrastructure across the country to retrieve organs, and myths and misconceptions surrounding organ donation, restrict optimum organ donation in India. Otherwise, with a history of a high rate of road accidents in India, a large part of the problem could have been solved even if organs from 50% of the road accident victims could be retrieved (Sodhi, 2011; Shroff, 2016; Rosail, 2016).

That the THO Act, 1994 was unable to give a boost to organ donation and was unsuccessful in restricting the illegal organ trade, is evident from the fact that even a decade after the enactment of the Act, the Indian media frequently reported incidences of kidney trade being dismantled by the police, which are primarily run by the organised crime networks. Some of the cases year 2003 onwards, are briefly described in **Table 1** to provide an insight into the nature and extent of the illegal trade prevalent in India. The nature of the trade being clandestine, it is hard to find detailed reports of the incidences of trade. The cases listed below are result of an electronic search on the newspaper reports and journal articles. The list is not exhaustive. Cases from different states are selected to show that the trade is active in all the regions of the country.

Table 1. A Few Incidents of the Illegal Trade in Kidneys in India (2003-2016)

Source: author’s own.

It is evident from the above table that the illicit organ trade is prevalent in all regions of the country. The organised trade networks involving middlemen and allegedly surgeons run the trade and the donors are usually those who are deeply entrenched in poverty. A few earlier research studies conducted among the commercial kidney donors in India, looked at the modus operandi of the trade and the factors, which compelled the poor to sell an organ, discussed below.

Is Selling a Kidney a Preferred Option for Donors?

Cohen (1999), conducted a study in Chennai on 30 kidney donors and revealed that “kidney zones” in India (where kidneys are sold in large numbers) emerge through interactions between surgical entrepreneurs, persons facing extraordinary debt and medical brokers. He conducted a study in Chennai on kidney donors and found that most people sold their kidneys to get out of severe debt, but they were back in debt within a very short period of time. A study few years later by Goyal et al. (2002) found widespread evidence of the sale of kidneys by poor people of India despite a legal ban on such sales. During a month, they were able identify and interview more than 300 commercial kidney donors in Chennai alone. They found that 96% of the participants had sold their kidneys to pay off their debts. Three-fourths of the participants who sold their kidneys were still in debt at the time of the survey. About 86% of the participants reported deterioration in their health after nephrectomy. The sale of kidneys by these poor people did not benefit them either socially or economically. The donors often received less money than promised and that nephrectomy was associated with a decline in both health and income status. 79% of such participants would not recommend that others sell their kidneys. Haagen (2005) in his case study on the trade in kidneys in the South Indian state Karnataka found that due to the existence of a high rate of poverty and inequality, selling a kidney becomes a necessity. However, he also argued that in India, poverty may be the primary reason behind people selling their organs, but selling an organ is the last, not the preferred option, for earning money. He argues that it happens only in an emergency—it is a reflection of the limited possibilities that these people have.

Similar factors such as poverty, debt and weak enforcement policies encouraged the illegal trade in kidneys in Bangladesh and Pakistan, the two countries which are geographically and socio-economically closer to India. Pakistan has been a hub of kidney trade for long time. Poverty, ineffective enforcement policies, and the limited supply of organs encouraged the affluent to routinely exploit its millions of poor with the help of organ trade mafias. Kidneys can be bought so cheaply in Pakistan that overseas buyers largely from the Gulf, Africa and the United Kingdom visit the country (The Express Tribune, 2017). A study among the commercial kidney sellers of Bangladesh reiterated the theory of poverty and debt behind kidney sale, as discussed in the studies above. The kidney was sold to repay the microcredit NGOs and informal money lenders (Islam and Gasper, 2017).

The Illegal Trade in Organs in India: An Empirical Study

The existence of the trade in organs in India for decades is an irrefutable reality. The media reports on the illegal trade in organs from different parts of the country show a widespread existence of the trade since the 1980s (Frontline report on pg.7) to until very recently (2016). The enforcement of the THO Act 1994, was not able to control the trade. This sustained existence of the trade prompted a study by this author to revisit the factors behind and explore the principal “beneficiary” of the trade that causes the long-term existence of the trade in India.

The study was undertaken during 2012-14, under a research project entitled, Illicit Trade in Organs Research Programme (ITORP), of the Von Hügel Institute (VHI), St. Edmund’s College, University of Cambridge. The first section of the study aimed at seeking opinion of the medical community i.e. the transplant surgeons and nephrologists on the probable factors and probable solutions including deliberation on the existence of a regulated legal market in organs in India.

In the second section of the study two commercial donors and two buyers/receivers of organs were interviewed to re-examine the factors driving to sale of organs and the difficulties encountered in the whole process of the organ trade. Due permission was obtained from the ethical committee of the VHI for interviewing the participants of the study. The study did not endeavour to study a large group of commercial donors as other research studies in India, such as by Cohen and Goyal et al. discussed earlier, have attempted that before.

Methods

The scope of this study was limited to four cities in India. One metropolitan city from each geographical region of India viz. Delhi, Mumbai, Kolkata and Chennai were selected for the study. These cities have well-established transplantation services.

The first section of the study was primarily quantitative; a self-devised structured interview schedule was used to collect the data. The questions were both closed and openended. During the interview, after the personal details, the question related to the major cause and the factors which fuel the illegal trade was discussed. The question was a multiple-response one. Therefore, the respondents could express their opinion on more than one factor. At the end of the interview, the opinion of the transplant professionals was sought on measures to control the illegal trade including a possible existence of a legalised market in organs in India. The data was analysed using SPSS.

The second section of the study is qualitative. Two commercial organ donors and two buyers of organs were interviewed with the help of an interview guide.

Participants

A review of the literature revealed that the nephrologists and renal transplant surgeons are the medical professionals responsible for the treatment of patients with renal failure and they closely encounter issues related to organ scarcity during the course of treatment. In addition, they also play an important role in policy level recommendations on organ donation and countering the organ trade. Therefore, it was considered appropriate to seek the view of these professionals on the perpetual existence of the kidney trade in India and explore means to counter it. The sample was drawn through non-probability purposive sampling (judgmental/selective sampling) method. At first, a list of 70 transplant professionals from prominent hospitals of the above mentioned four cities was prepared. Subsequently, they were contacted by email and telephone to explain the purpose of the research and seek permission for interviewing. It was emphasised that the study was purely academic and complete anonymity will be maintained on their response. A personal interview was preferred rather than sending questionnaires to elicit better and more authentic response. The renal transplant surgeons and nephrologists with more than five years of experience in the field were included in the study. Five years of experience was thought essential to discuss the subject of the study. Liver, pancreas or heart transplant surgeons are excluded from the study. From the 70 professionals initially contacted, 42 (N=42) agreed to participate in the research in which 32 were nephrologists and 11 were transplant surgeons. The rest were either not available or were not interested in participating in the study.

The two commercial kidney donors and receivers were selected with the help of snowball sampling. The two donors were from the same village in Chennai. The village was known for commercial organ donations. The first donor led to the second. The two buyers of organs were from Kolkata selected with the same method.

Results

A majority of these medical professionals had more than 10 years of experience in renal replacement therapy. In a multiple-response question, the opinion of forty-two transplant professionals was sought on the dominant factor and the fuelling factors behind the sustained existence of the trade (Fig. 1), the results of which are discussed below:

The Opinion of the Transplant Professionals on the Factors Contributing to the Illegal Organ Trade

(1) 72% of the respondents emphasised that the gap in demand and supply of organs as the major cause responsible for the trade i.e. there is a continuous increase in the demand for organs against an inadequate supply. Both the live and deceased organ donation programmes are not able to meet the demand of kidneys in the country. They explained that there are limitations to live related donations. In a substantial number of cases there is no one suitable in the family to donate due to factors such as ABO (blood group) or HLA (antigen) incompatibility, aging or deceased parents, and the absence of siblings due to shrinking family size. The deceased donation programmes are

underdeveloped in most of the states, which compounds the problem of organ shortage in the country. This chronic organ scarcity has created space for an alternate black market for organs. Furthermore, the factors, which help to fuel the illegal trade, were discussed with the respondents: (2) the gap between the have and have-nots i.e. the rich have the purchasing capacity to buy an organ and there are very poor people, who are compelled to sell their organs to earn money (62% of the respondents), (3) easy availability of poor donors as a the vast section of the population in India live in poverty (53% of the respondents), (4) loopholes in the THO Act, 1994 (41% of the respondents), (5) the poor enforcement of the THO Act, 1994 (36% of the respondents), (6) medical malpractice aimed at easy money (36% of the respondents) and, finally (7) 14% of the respondents were of the opinion that the level of punishment within the Act is insufficient to deter people from committing such offenses.

A confluence of all the factors projected in Figure 1 perpetuated the trade for decades in India. The opinion of the transplant professionals supports the facts discussed earlier that there is a sustained huge gap in demand and supply of organs in the country which is the major cause to perpetuate the trade. Poverty is still endemic in the country which regularly supplies the poor donors, in addition the poor enforcement and loopholes in THO Act, 1994 fuel the trade and a section of the medical community is also responsible in perpetuating the trade.

Figure 1. Factors Contributing to the Illegal Organ Trade in India (N=42).

Source: author’s own.

From here, we proceed to the second part of the research study, discussing that although the trade of organs is prevalent in all the regions of India, it is pertinent to understand who actually benefits the most in each transaction- the commercial donors or the receivers or another third party. The discussion is primarily based on qualitative case studies.

The Illegal Trade in Organs: Who Benefits?

Several international declarations prohibit sale of organs. The guiding principles of the World Health Organisation on human organ transplantation (1991), states that the commercialisation of human organs is “a violation of human rights and human dignity”. The Declaration of Istanbul (2008) also prohibits organ trafficking and transplant tourism as both violate the principles of equity, justice and respect for human dignity. Putting a market price on body parts exploits the desperation of the poor, the mentally weak and dependent classes (Scheper-Hughes, 2000). Phadke and Anand (2001) argue that the growing waiting list of organs for transplantation has created an acceptability of commercial dealing in organs especially in developing countries such as India. However, such a market exploits the poor, deters altruism in the society, negatively affects the livingrelated and deceased transplant programmes, commercialises the human body and debilitates human dignity. It puts organ sale in the same category of paid human body transactions such as sex work and slavery. Potter (2015) claims that inequality is the defining factor of the organ market as this market always operates under the condition where “the globally rich would be pitted against the globally poor”. For the poor it is a choice between “sell or suffer”. For the poor, therefore, it is a choice between “sell or suffer”. Four qualitative case studies below shed light on the nature of transactions in the illegal kidney trade.

Do the Commercial Donors Actually Benefit from Selling Organs?

The incidences of organ trade given in Table 1 shows that it is the poor debt-ridden farmers of Palnadu, the potters of Kolkata, the poor, illiterate workers of Punjab, Tsunami-affected fishermen, the poor labourers in the Gurgaon incident and the poor workers of the power loom industry in Tamilnadu who sold their organs to relieve themselves from debt and poverty. The research studies by Cohen, Goyal et al. and Haagen, discussed earlier, projected the similar coercive circumstances, which drove the poor to selling kidneys. Two case studies[1] conducted by this author in Chennai, also showed similar compelling situations among the donors for selling kidneys.

A 52-year-old woman sold kidney in 1988 (when the organ sale was legal in India) to save her

family of six becoming homeless. She did not receive any post-operative care and received only half the amount of promised compensation with which she built a small house to live with her family. Although she saved her family from homelessness, she could not save them from future financial crises. Therefore, at the time of this study, she was still struggling to survive due to economic severity.

Another 37-year-old woman sold her kidney to save her husband's life from a local money lender. Her family of four was high in debt on account of the money borrowed from the money lender. She sold her kidney in 2007 to repay the debt as well as to pay for her daughter's marriage. However, similar to the previous narrative, she did not receive any post-operative care and the compensation paid to her was half of the promised amount. With hardly any residual money left after paying off the debt, and a diminished physical ability to work due to deterioration in her overall health status, the family was in a similar state of financial crisis at the time of this study.

In addition to showing the compelling, coercive situations which drove a poor to sell kidney, the above two narratives as well as studies by Cohen and Goyal et al. suggest that although they sold kidneys to overcome an urgent financial crisis, this had no significant impact on their overall, poor financial condition. On the contrary, their financial situation worsened, as the compensation money is quickly spent and their ability to work is adversely affected due to poor health post-surgery.

Acharya (1994), who was an eminent nephrologist of India, discussed that as most of these donors come from a stratum of society where their health and nutrition are already compromised due to economic stringency, removal of organs from them further impairs their health and functional integrity. The research studies by Cohen and Goyal et al. also discussed a weaker physical health of the donors, post-transplantation. Additionally, studies have shown that when the motive of donation is purely altruistic, the physical and psychological recovery of the patient is much better as the donor makes an informed decision with a clear understanding of the risks and benefits, receives post-operative care and the notion of altruistic giving provides a psychological boost to the donor (Phadke and Anandh, 2002). However, when the donation is purely commercial, the donors are more prone to ill-health in the post-operative period (Shroff, 2009). The two women in the above narratives individually commented, "I will not recommend any other person to sell a kidney". As discussed earlier, the majority of the respondents in the study by Goyal et al. also recommended the same.

When a female commercial donor in Tamil Nadu was asked whether she regretted selling her kidney, her response was in the negative as she received the money in return. But she expressed her sadness about the fact that nobody was concerned about her after the kidney was taken away. She felt that **"**after all, she saved a life" (Frontline, 1997).

Therefore, it is evident that in this unjust and unequal market of illicit organs, the poor donors hardly benefit as they are paid only a fraction. In a global market, a kidney can be bought from a donor for $1,000-3,000 and can be sold for up to $40,000 (Hudson, 2008). The maximum share of

profit, which is between $37000-$39,000 is then primarily shared between the members of the crime network who run the market.

This discussion leads to another important question whether the buyers or the recipient of organs benefit from all of these transactions.

Does the Recipient or Buyers of Organs Always Benefit?

The dominant argument against the commercialisation of organs favours the donors- their exploitation, and potential health risks, a no-win status post-organ sale as it fails to bring any noticeable change in their socio-economic status. However, the recipients of the organs from these commercial donors are also not immune to any negative impact of the trade. Two other case studies[2] conducted in India describe the problems encountered by the recipients and their families in this illegal trade.

In the first case, a 36-year-old woman discussed her negative experience with a middleman in the attempt to save her husband's life (a severely ill ESRD patient). She was not successful in her effort due to deception by a middleman. Wife of an ESRD patient said:

Everyone is concerned about the exploitation of donors. No one empathises with the harassment the organ recipients or their families undergo at the hands of these middlemen.

In this case, the middleman who responded to her advertisement in the newspaper promised to arrange a suitable donor for her husband. The woman belonged to a middleincome family. The compensation money demanded by the middleman was unaffordable for her. She eventually agreed to save her husband's life. However, the transplantation did not take place as just two days before the transplantation, the commercial donor ran away from the hospital and her husband died due to pulmonary oedema. She felt that

The organ trade does not benefit anyone, instead the society and the government should make sincere effort to increase the supply of organs in legal ways.

In another case, a twenty-year old woman's initial attempt to transplant a kidney in her husband also failed because of a middleman. She also belonged to a middle-income family. The middleman who promised to arrange a suitable donor for her husband with ESRD, in return for the demanded compensation, deceived her after receiving the money in advance of the transplantation. Contrary to his claim, the donor he arranged turned out to be unsuitable for her husband and therefore, the transplantation did not take place. The wife of another ESRD patient suggested that:

With the money, which I arranged with great difficulty (borrowed from relatives) to pay the middleman, I also lost hope of saving my husband.

She later purchased a kidney for her husband from an independent commercial donor. Her husband eventually did not survive due to post-operative complications.

The above two narratives show that for the families of an ESRD patient, whether affluent, middle-income or poor, buying a kidney becomes a matter of urgency in absence of a suitable related or a deceased donor. The middlemen take advantage of the desperate situation of these families—for whom the “kidney” is essential for survival. Although, for some families, the money demanded by the middlemen is unaffordable, they try to arrange it by all possible means to save the life of a family member.

If not death, the adverse impact on the life of organ recipients and their families is aggravated in some cases, if the patient contract any additional transmissible infections from these commercial donors such as hepatitis, AIDS, malaria and other infectious diseases prevailing in India (Acharya, 1994).

Therefore, an illegal market for organs largely does not benefit the donors and in some cases does not even benefit the buyers. As these markets are operated by organised crime networks, the major benefit, which is economic, accrues to the members of these networks. Therefore, controlling these illegal markets of organs is a unanimous opinion shared across the world and some of the plausible measures to achieve that are discussed below.

Is Legalisation a Solution?

When altruism has failed to supply the adequate number of organs, time and again an argument for a legitimate, ethically acceptable market of organs is offered by a few to increase the supply of organs, avert the risk of endangering the health of millions, and limit the exploitation of donors. A possibility of a legalised market of organs has been debated for long and become more polarised. On the one hand, globally, over 200,000 individuals worldwide are on the kidney transplant waiting list (World Health Organization, 2007). Therefore, a favoured argument towards the existence of a legalised market is that it will reduce the global demand for kidneys and organ trafficking (Potter, 2015). Several international declarations condemn organ trafficking, which is defined as:

…. the recruitment, transport, transfer, harbouring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation (The Declaration of Istanbul 2008).

Article 3(a) of the United Nations, “Protocol to Prevent, Suppress and Punish Trafficking in Persons Especially Women and Children” includes trafficking for the removal of organs in the definition of “trafficking in persons”. Trafficking in persons for organ removal is also defined and

prohibited under The Council of Europe (CoE) Convention on Action against Trafficking in Human Beings.

As trafficking for organs involves coercion and abuse, it violates a vital guiding principle of the WHO on organ removal i.e. informed consent. The proponents of a paid organ market believe that a state regulated market could reduce this heinous form of abuse (Potter, 2015). Erin and Harris (2003), consequently propose a strictly regulated and highly ethical market in live donor organs. They argue that such a market would do proper justice to the donors as they would be appropriately compensated for their risk and time. As the market would be state regulated, there will be no scope of exploitation of poor donors from low-income countries. Only a government medical institute such as National Health Service (NHS) in the UK, would have the authority to buy and distribute the organs. The risk to the health of the recipients will also be minimised as the organ donors would be tested for HIV and other infectious diseases. However, they emphasise that without all these pre-requisites, a legalised market of organs cannot succeed.

On the other hand, Phadke and Anand (2001) argue that a legalised organ market is an “easy way out” to counter the organ scarcity or poverty without considering the implication on society as a whole. They argue that a paid system of organ donation can enthuse a deliberate conflict between altruism and self-interest, a gift and a commodity. Their views support the arguments of Shroff (2009) that the value of using short-term financial gains for donors to increase the supply of organs for transplantation is not a cure for poverty. As long as there are people who can be exploited for money in society, certain evils are likely to perpetuate and legalizing the organ donation process will add another dimension to that evil and further weaken the social fabric. Iran has a legalised compensated paid donation system since 1990s. Although, the country claims various benefits of the system such as elimination of organ trafficking and exploitation of the donors by middle men, data reveals 84% of the kidney donors are poor and additionally, many donors felt stigmatised and socially isolated for donating kidneys for compensation as the act was considered inhuman (Potter 2015 and Koplin 2014).

The argument on “legalisation of organ market’ is akin to the long-standing debate on “legalisation of drug use”, which is another worldwide demand-led unregulated market. To eliminate exploitation by the drug mafias, a legalised market of addictive drugs has been advocated by some. However, the critiques of this view argue that legalisation of drug trade would only worsen the drug problem—by increasing addiction, making the drugs accessible to underage individuals who would be less aware about the risks of these drugs. Further, legalisation of drug use would relegate its sale to profit-hungry people and corporations or governments and would significantly cheapen the price of addictive drugs such as cocaine and heroin, making them more accessible (Wheeler, 2013).

Can a legalised market of organs exist in India? To proceed with this argument, the author now discusses the results of interviews with the forty-two transplant professionals in India on the subject of legalisation, as mentioned earlier[3].

Opinion of the Transplant Professionals in India on Legalisation of the Trade in Organs

To the question on legalisation of the trade, the respondents were given three choices to respond i.e. agree, disagree or agree to some extent. More than half of the respondents (55%) disagreed with the idea of legalisation of the trade. The reasons they cited are: 1) Legalisation would reduce the number of live related transplantations, which are more likely to be successful. It would open the path for people to buy an organ instead of encouraging live donation. 2) Legalisation would organise the illicit trade more instead of curbing it, encourage touting for organs and defeat the purpose of serving justice to the poor due to ensuing corruption and the continued presence of middle men. 3) The poor person may ultimately have no long term benefit as it is likely that they will spend all the money quickly and revert to the same state of poverty again. 4) Selling organs would entail the same stigma in Indian society as the notion of selling blood. 5) Lastly, even after legalisation there is no certainty that the country would meet the required demand for organs.

23% of the respondents agreed only to some extent to the idea. They recognised the benefit of such a market in reducing the organ shortage, but sceptical of the fact whether such a market will be regulated properly in a country with high level of corruption. In addition, ultimately the market will exploit the poverty of a certain section of population, as it is very unlikely that any rich or affluent will be willing to sell a kidney.

16% of the respondents were in favour of the argument. The reasons they cited were 1) This policy would be beneficial for the patients with ESRD who would require organs for survival. The policy would increase the availability of organs to them. In particular, it would benefit the patients from those families in which there is no one to donate. 2) Legalising the trade would protect the interests of the poor donors because they would be more likely to receive post-operative care and compensation commensurate with their risk and sacrifice. However, the poor would fully benefit only if the measure was implemented centrally, including a fixed amount for compensation, middlemen were eliminated, and a clear agreement on post-operative care.

The remaining 6 respondents refused to comment on the subject.

The above responses show that there is no unanimous agreement among the transplant professionals on legalisation of the organ trade in India, which is in line with the polarised view on the subject worldwide.

Are There Alternative Answers to the Illegal Kidney Trade in India?

To an open-ended question, the transplant professionals suggested a few alternative measures to reduce the illicit trade in organs in India. As the demand-supply gap of organs is the major factor

behind the sustained existence of the trade, escalating the rate of organ donation in India is the most appropriate measure and the essential step to be taken to control the illegal trade. Especially, establishing an active deceased donation programme throughout the country would curtail the demand of live donated organs. Improving the dialysis facility in the country can further reduce the demand of live organ donors. The Government of India (GOI) recently introduced a few significant amendments in the THO act, 1994, which aimed to reform the system of organ donation and transplantation in the country and control the illicit trade in organs. The new amended act is now known as the Transplantation of Human Organs (Amendment) Act, 2011. One of the amendments aims to broaden the scope of organ donation from the near relatives as it included the grandparents and grandchildren in addition to the first-degree relatives such as parents, siblings and spouse. By another section of amendment, the level of punishment for engaging in the illicit trade of organs was increased. Largely, through these amendments, the GOI has attempted to plug the loopholes in the earlier Act. As well as these amendments, the GOI has taken systematic measures to establish the appropriate infrastructure in the country in order to give a fillip to deceased organ donation. Different states are also taking state- specific measures to promote deceased donation programmes. Additionally, the transplant professionals suggested that early screening of the patients with chronic kidney diseases (CKD) would halt the progression to ESRD and subsequently reduce the demand of organ transplantation. With strong political will and awareness among the people, India can make substantial progress in reducing the demand-supply gap in organs and curtail the incidences of illegal organ trade.

Conclusion

To conclude, the trade of organs emerged in response to a global organ crisis. Economic disparity and unequal access to health care encouraged transplant tourism in which the developing countries such as India supplied organs to the affluent buyers from rich countries. This paper was primarily focused on the kidney trade in India, but the discussion on the factors sustaining the trade can be generalised to other countries with similar socioeconomic conditions such as Bangladesh and Pakistan where this trade exists.

In India, the trade was made illegal after the enactment of the THO Act, 1994. However, the trade re-emerged after the act, albeit, illegally. The current study discussed the opinion of transplant professionals of India on the illegal trade. The results confirm that the widening gap in demand and supply of organs, the sustained poverty in India, which ensures an uninterrupted supply of commercial donors, loopholes in the THO Act, 1994, and medical malpractice perpetuated the trade for decades. Similar factors such as poverty, debt and weak regulatory mechanisms perpetuated the trade in Pakistan and Bangladesh. However, ethically the trade is against the WHO principles and other international declarations because the trade survives and flourishes on the exploitation of the poor and in some cases may not benefit the receiver or buyer of organs.

This study confirmed the findings from earlier studies that poor donors have no long-term benefit from the trade. They are rarely compensated appropriately and are denied post-operative care. The meagre amount of money they receive is spent in haste without significantly changing their poor financial condition and the impact of the nephrectomy negatively affects their overall health. The recipients or buyers of organs also may not benefit in all cases of this illicit trade. Earlier studies suggest that they are at risk of contracting an additional infection such as HIV or hepatitis as in those clandestine transplantations, the donors' health status is not properly investigated.

This study shows that the middlemen exploits the crisis situation of the patients either by demanding more money or absconding after receiving the money, depriving a needy patient of an organ and recovery, although there are not enough research studies to confirm and generalise this aspect. Therefore, in this illegal trade, the commercial donors and the buyers of organs may not benefit eventually. It is the middlemen and other members of the organised crime networks who operate these illegal markets, benefit most by retaining a maximum share of the profit. Legalising the organ market is not fully supported by the majority of transplant professionals interviewed, and may not even succeed in benefitting either the donor or the recipient in countries such as India where corruption derails major development programmes.

A rigorous effort by the government, public and private health care service providers and civil society organisations to improve the supply of organs and reduce the demand of organs by early screening of chronic kidney diseases, combined with a strict law and regulatory mechanism to control medical malpractice in these countries can significantly minimise the incidences of the trade. The recent action of the Indian government cancelling the license of popular Apollo Hospital of Delhi (Table 1) shows that the country is escalating measures to control the illegal trade. Haagen (2005) suggests providing other options like micro-finance loans, better salaries, more employment opportunities as part of the long-term solution to the existing organ trade in India.

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[1] The two case studies are part of the same study, ITORP, mentioned above. They are also part of a chapter by this author entitled, “The illegal trade in organs and poverty in India: A comparative analysis with Brazil and China”, in a forthcoming Anand, Comim, Fennel (ed) Oxford University Press book entitled, *Oxford Handbook of BRICS and Emerging Economies*.

[2] The case studies are part of the same research project ITORP discussed above.

[3] The views expressed by the transplant professionals are part of the same study under ITORP mentioned above..