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Saurabh Sardana

Intern

Centre for Civil Society

Cell: +91-9818146431

Email: saurabhsardana@gmail.com

### 1. Introduction

# A story worth reading..

"Three years ago, Ravi Yadav left his home in Dehradun for Punjab, in a last-ditch attempt to raise money for the medical treatment of his father. He did not find the work he was looking for, but another opportunity came his way. Yadav was offered Rs.70, 000 for one of his kidneys. There was no risk to his life; an operator in the organ trade whom he knew as Tinku assured him. He would not have to appear before the Authorisation Committee in Amritsar charged with approving transplant surgeries, he was told. He did not even read the affidavit in English that stated that he was donating his kidney purely because of love and affection for a person - a person whom he had never met. When Yadav left the hospital and asked for the money that he had been promised, Tinku, now identified as Yogesh Kumar, turned down his request. The man from Dehradun was arrested after he approached the police, charged with filing a false affidavit, and is now serving a two-year prison term. No action was taken against Kumar, the organ recipient, or the hospital that performed the procedure. Ravi Yadav's aged father meanwhile died." (www.hinduonnet.com)

Welcome to India!! Welcome to the organ market.

The concept of organ donation dates back to the year 1954, in which Dr Joseph Murray carried out the first ever-successful kidney transplant operation on identical 23 year old twins Richard and Ronald Herrick in U.S.A. Since then medical fraternity (http://www.bbc.co.uk/health/donation/factfilesod\_history.shtml). Extensive research and development in this field has enabled doctors to transplant human organs, thus saving the lives of thousands across the globe. But the demand for the same has been soaring up with little supply to match. The result is acute shortage that has fuelled growth in "transplant tourism" to developing nations where organs can be bought (Scheper-Hughes, 2000). Is there a way in which the equilibrium can be met? Can there be a free market for organs trade? Does law require radical change? Will the Indian society accept it? The text below will attempt to answer aforementioned questions and a few more.

### 2. Literature Review

"India probably ranks in the top among countries that are becoming great organ bazaars of the world."(http://www.wtopnews.com/?nid=106&sid=1102863) K.C. Reddy, an urologist, "described the kidney market as a marriage bureau of sorts, bringing together desperately ill buyers and desperately poor sellers in temporary alliance against the wolves at their doors."(http://www.american.edu/TED/body.htm). Though organ trade is illegal in most of countries including India, but still an illegal market prevails where organs like kidneys, livers are being sold for cash. Before we proceed further it is imperative to understand the legalities pertaining to the current problem:

### 2.1 What is an organ?

As defined by Dr. Arun Arora, a General Physician based in New Delhi, "An organ is an integral part of our body which may not only perform the role assigned to it but also performs two or three other functions. For instance: Primary function of tongue is to taste. However it also helps in speech." However there is an ongoing debate among anthropologist and bioethicists in regards to the aforementioned question.

They have posed questions like "Is the transplant surgeon's kidney seen as redundancy, "a spare part," equivalent to the Indian textile worker's kidney, seen as an "organ of last resort"?" (Scheper-Hughes, 2000) Where bioethicists focus is on organs as unique property of individuals, anthropologists infuse the cultural relativism in it (Scheper-Hughes, 2000). For instance: The chronically hungry sugar plantation workers in Northeast Brazil, for example, frequently state with conviction, "We are not even the owners of our own bodies" (Scheper-Hughes, 2000).

From donation point of view an individual can pledge nine organs ranging from eyes, heart, lung and kidneys to liver, pancreas, bones, cartilages and tissues. For the purpose of this research more emphasis will be on the kidneys than any other organ due to its acute shortage, which is established later in the paper.

### 2.2 The flaw 'less' Law - THOA, 1994

In India, Transplantation of Human Organ Act (THOA) came into existence on 8<sup>th</sup> July 1994. This is primarily meant to "provide for the regulation of removal, storage, and transplantation of human organs for therapeutic purposes and for the prevention of commercial dealings in human organs. The central act illegalises the buying and selling of human organs and makes cash-for-kidney transactions a criminal offence" (Frontline 2002). However, reports by human right activists, journalists, and medical anthropologists indicate that new law has produced an ever larger domestic black market in kidneys, controlled by organized crime expanding out from the heroin trade (in some cases with the backing of local political leaders)" (Scheper-Hughes, 2000). The act was formed to achieve the below mentioned objectives:

- → To curb the commercial purchase of organs from live donors.
- → To protect the donors who are usually from the low socio-economic status from being exploited by the middlemen.
- → To restrain the removal of organ from patients without their knowledge.
- → To recognize the concept of brain death in order to encourage cadaveric donation.

# 2.2.1 Salient Features of THOA, 1994

The Act is applicable only for transplantation of human organs for therapeutic purposes and for prevention of commercial dealings in human organs.

There are two regulatory bodies established under this act: (i) Appropriate Authority for licensing the hospitals to conduct transplant operations; (ii) Authorisation Committee to "prevent" commercial transaction between donors and recipients.

(http://www.hefp.lshtm.ac.uk/publications/downloads/working\_papers/08\_03.pdf)
People intending to donate their organs after their death may do so by giving their written consent, attested by two witnesses at least one of whom is a near relative. Similarly, person in lawful possession of the dead body may also give authority for removal of human organs. The persons in lawful possession are near relatives, authorities such as hospital authorities, prison authorities.

### 2.2.2 Defining 'Donor'

As per the Act, 'Donor' means any person, not less than eighteen years of age, who voluntarily authorises, the removal of any of his human organs for therapeutic purposes. Also Donor can be 'a live near relative'; 'live unrelated' or 'deceased' which are explained below in detail.

(http://www.hefp.lshtm.ac.uk/publications/downloads/working\_papers/08\_03.pdf).

# a) Live near related donor: -

The "near relative" means spouse, son, daughter, father, mother, brother or sister. In no country, other than India, which has an Act to regulate organ transplant, has the spouse been included as "near relative". In some of the countries the definition of "near relative" is wide enough to include half brother or half sister, uncle or aunt, niece or nephew, or first cousin, provided there is a direct blood link, but the spouse is not considered as a near relative.

### b) Live unrelated donor:

The Act permits, an unrelated donor to donate his/her organs if he/she could establish before the Authorisation Committee an "affection or attachment" towards the recipient. The live unrelated donor cannot donate in many countries.

### c) Cadaver/deceased donor

The organs of deceased person, who consent to removal of organs after death, can also be transplanted to the recipient.

In fact, THOA has recognized the concept of Brain Death in India. Brain stem death indicates that the brain stem has permanently and irreversibly stopped to function, and this needs to be certified by a medical board comprising the head of the hospital in which the death has taken place, an independent doctor, a neurologist or neurosurgeon, and the patient's doctor.

(http://www.hefp.lshtm.ac.uk/publications/downloads/working\_papers/08\_03.pdf).

The Act specifically excludes minors from being live donors. This is a very important provision as it keeps check on the minors being exploited. However, the parents of the

minor can authorise the removal of organs from the minor in case of a brain stem death of the minor.

#### 2.2.3 Offences and Penalties

Under the THOA, Any person or hospital that carries out removal or transplantation without authority is punishable with jail for up to five years and a fine up to Rs. 10,000. The name of medical practitioner may get struck off from the register of council for first two years and permanently for any subsequent offence.

# 2.2.4 Compendium of Organ Trafficking Laws in Key Countries

#### Brazil

"A 1997 law makes it illegal to sell organs and tissue and forbids anyone from soliciting them." (Frenkel S., 2004). Brazil's new law of presumed consent was enacted on 4<sup>th</sup> February 1997 (Scheper-Hughes, 2000) with the objective of establishing equilibrium between demand and supply, equitable distribution of organs and to end commerce of organs. But presumed consent, which makes all Brazilian adults an organ donor at death, was excoriated by the critics and popular class and was consequently, amended a year later to require consent of relatives (Frenkel S., 2004). Anybody found breaching the law would have to serve three to eight years of imprisonment and fine equal to as much as 360 days of minimum wage.

### Government and Efficiency: Cannot go hand in hand!!!

Head nurse of the largest private transplant centre in Sao Paulo, Brazil explained:

The government wanted the population to believe that the real problem was the family's refusal to donate. The truth is that the national health care system does not have the technical capacity to maintain the donor's body, and so we loose most donors. When we have found a perfect donor, a 25 year old man who suffered a car accident, who is brain-dead otherwise perfect, it is a weekend and there is no public surgeon available, and the perfect heart goes into the garbage. (Scheper-Hughes, 2000)

#### **South Africa**

"The Human Tissue Act of 1983 says that no one can receive payment for the transfer of any tissue, including flesh, bone, organ or body fluid. Violators are subject to a maximum of fine of \$ 300 or imprisonment of no more than one year." (Frenkel S., 2004).m However medical practitioners were able to identify a loophole whereby they had the authority to remove the organs without the consent of kin. Moreover, because the organs have to be removed within a stipulated time period after death, they removed the prized organs without thinking about their emotions, if nobody came forward to claim the dead body.

#### China

As found in above two countries it is illegal to sell and buy organs in China. "But a 1984 law allows organs to be transplanted from a executed prisoner if family member doesn't claim the body right away" (Frenkel S., 2004). In the year 1996 at least 6,100 death sentences were handed down and atleast 4,367 confirmed executions took place (Scheper-Hughes, 2000).

"While some organs are used to reward politically well connected Chinese, others are sold to transplant patients from Hong Kong, Taiwan, Singapore, and mainly other Asian nations (Scheper-Hughes, 2000)." Recent reports allege Japanese to be the new member in the international organ trafficking where a large number of them travel across to China for transplantation surgeries. A patient named Mr. Hokamura said, "I was on dialysis for four years. I was tired of waiting." (McNeill D & Coonan Clifford, 2006)

#### Wretched Prisoners in deplorable state!!!

Harry Wu, the director of the Laogai Foundation in California, said in the 1996 Berkeley conference on traffic in human organs,

In 1992 I interviewed a doctor who routinely participated in removing kidneys from condemned prisoners. In one case, she said, breaking down in the telling, that she had even participated in a surgery in which two kidneys were removed from a living, anesthetised prisoner late at night. The following morning the prisoner was executed by a bullet to the head. (Scheper-Hughes, 2000)

#### **United States of America**

"President Bush signed the Organ Donation and Recovery Improvement Act on April 5. While it is still illegal to sell or pay for organs, the act authorises the federal government to reimburse living donors for expenses and to offer project grants aimed at increasing donations and improving organ preservation and compatibility. And this year Wisconsin became the first state to give living donors a tax deduction of up to \$10,000 for medical costs, travel and lost salary." (Frenkel S., 2004).

#### Israel

It is illegal to sell organs in Israel. However if the bill gets passed brokers could be fined and could be sentenced to three years of imprisonment. In another proposal it would start paying live donors.

#### **Iran**

Iranian Model is by far the 'most successful' model one may come across. It has been commended by the World Health Organisation for eliminating the disparity between the demand and supply of organs. The so-called 'Compensated Kidney Donation Model' proposed to suitably reward the unrelated donors and thus enabled them to catch up on the demand as quickly as possible. "The Charity Foundation of Special Diseases, a non governmental organization is responsible for providing monetary compensation as a social gift to unrelated donors" (Bagheri A., 2006). (For details refer to discussion section)

# 2.3 Organs: Are they a commodity?

For long now organ trade has created a 'catastrophic situation' both in domestic and international markets. Stories and news concerning illegal organ trade are in abundance. Time and again many people globally, especially in India, have used their organs as a commodity to fulfil or satisfy their basic needs and requirements. The question of treating organs as commodity or merchandise is one that a lot of authors have attempted to answer. This is one of those questions, answer of which oscillates between the economics of demand and supply and ethical dilemmas of different societies and cultures.

# 2.3.1 Economics of Demand and Supply

Economics is all about actualising gains. The rationale is to create an environment where buyer as well as seller can beamishly walk away. But we all seem to have qualms about this logic. For instance: We all have two kidneys and just by donating one we won't loose much. On the contrary the recipient of the same will gain a lot. But people are apprehensive about organ donations, which decrease their willingness and leads to acute shortage of organs. Therefore, black markets for organs exist and function because they work on fundamental logic of economics that says that there should be a cash price at which both the parties are satisfied. (Harford T., 2007)

Scarcity is the backbone of all economic theories. All through history, economists have developed theories based on production and consumption, seemingly ignoring the role of scarcity in all economic choice. After all, what is economics, but the science of making choice, and without scarcity, there is no need to make a choice. Dr Christopher Lingle, Professor in Economics, has gone to the extent of remarking, "If there wouldn't be scarcity, economists wouldn't exist". It is this scarcity, which has led to blatant commercialisation, and scramble of organs and tissues has led to gross human rights violations in intensive care units and morgues (Scheper-Hughes, 2000).

"If it was just another product, the markets would work its usual magic: supply would respond to high prices and rise to meet surging demand. But human kidneys are no ordinary commodities. Trading them is banned in most countries. So supply depends largely on the charity of individuals: some are willing to donate one of their healthy kidneys while they are still alive (at very little risk to their health); others agree to let their kidneys be used when they die. Unsurprisingly, with altruism the only incentive, not enough people to offer." (Economist, 2006)

Furthermore ascertaining the grimness of situation is an arduous task. Most challenging is to determine the number of people who are waiting for transplant because of unavailability of exact figures. But it can be rest assured that figures are appalling and tip-off towards the severity of the situation. As per 2004 figures about 150,000 patients are diagnosed with end stage kidney disease in India each year. But number of kidney

transplants has fallen from an estimated 3600 in the year 2002 to 2800 in 2003, and around 2000 in 2004 (Mudur G, 2003). Figures are even scandalizing in 2007 where CNN IBN (a reputed news channel) reports every year 300,000 people are diagnosed with end stage kidney diseases. Only about 4,000 patients receive transplants. In Mumbai, the commercial capital of India, alone 850 people are waiting for transplants (http://www.ibnlive.com/news/kidney-transplants-to-be-made-easy/42584-3.html).

# Let your nerves 'unnerve' (ibnlive.com)

Forty one-year old Nozer Canteenwalla, who works as an insurance officer, doesn't even wince when the needle goes into his arm. Having endured over 300 dialysis procedures since his kidneys stopped working, life for him is lived in moments spent waiting for a transplant from a deceased donor. "There isn't anything I can plan for. All the time I'm dependent on dialysis itself," says Nozer.

This grave situation can be traced in the other parts of the world as well. For instance: an estimated by United States Department of Health and Human Services: '17 people die each day waiting for transplants that can't take place because of the shortage of donated organs.'(Friedman E., Friedman A. 2006) To add to these figures, in early September, 2005, sixty five thousand candidates were listed in the United States by the Organs Procurement and Transplant Network as waiting for a deceased donor kidney (Friedman E., Friedman A. 2006) with numbers soaring up to ninety six thousand nine hundred ninety five in 2007 (www.unos.org). Around 90% Americans say that they endorse organ donations, but only 30% have actually signed up to part their organs after they die (Kingsbury, 2007). The condition is even worse in United Kingdom with 5,615 people still awaiting a transplant (Harris J., Erin C 2003).

As per Dr. Sudhir Chadha, Senior Urologist and Kidney Transplant Surgeon in Sir Ganga Ram Hospital, every year there are ten new kidney failures per year per lac in India. He further adds to that by averring transplant to be the cheapest cure available for Chronic Kidney Disease. (According to rough estimates given by doctors of Sir Ganga Ram Hospital a kidney transplant would cost around Rs 5-6 lac and a liver transplant costs Rs 16-17 lac for an adult in India.)

This scarcity in the market leads to black-marketing and illegal trade seeks to transform everything into a commodity. In developing nations, like India, poor is the worst affected as he/she will sell their organs to free him/her from the debt peonage. For instance: It is estimated that of US\$ 2,000-2,500 paid by the recipient of kidney, only about \$1000-1,200 reaches the donor in South Asian nations (Jha V, Chugh K, 2006.) The very rich in society would even acquire organs from an unrelated donor by bribing the middlemen and authorisation committees.

As correctly quoted by Nancy Sweeper Hughes Footnote? , "Though fathers and brothers talk about selling kidneys to rescue dowry-less daughters or sisters, in fact most kidney sellers are women trying to rescue a husband, whether a bad one who has prejudiced the family by his drinking and unemployment or a good one who has gotten trapped in the debt cycle.

#### 2.3.1.1 The Process Unveiled

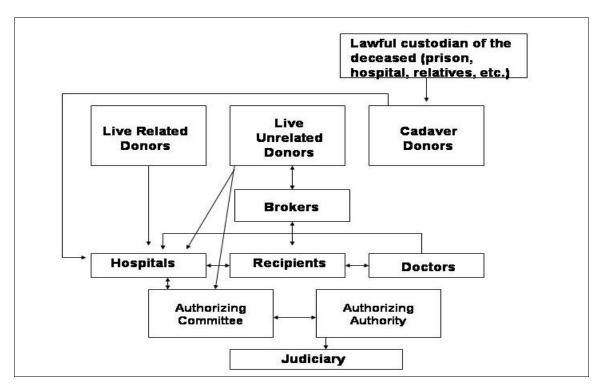


Figure 1, Source: Murlidharan V., Prasad S., A Study of the Implementation of Transplantation of Human Organs Act (THOA) 1994, and Consumer Protection Act (CPA) 1986. 2003. Accessed on 5<sup>th</sup> June 2007 at <a href="http://www.hefp.lshtm.ac.uk/publications/downloads/working\_papers/08\_03.pdf">http://www.hefp.lshtm.ac.uk/publications/downloads/working\_papers/08\_03.pdf</a>

The patient with organ failure is advised by the practitioner to go through a transplantation surgery. If the patient can find a 'near relative' donor, the donor undergoes medical tests to ensure proper tissue matching with the recipients. On the contrary, if the recipient is unable to find the donor, then the patient may set out to find an 'unrelated donor'. The search often culminates upon finding a middlemen or broker in the market. He acts as linchpin between donors and recipients. He introduces recipients to the donor and medical team after negotiating a price. Sometimes hospital officials may help recipients to find a potential donor. The medical team after carrying out series of tests on donors and recipients directs them to Authorising Committee to get the desired approval.

The Authorising Committee summons the potential donor and recipient. Both are interviewed separately. The objective is to ascertain if their intentions are not to receive any financial benefits and is purely out of love, affection or attachment.

"Typically, the committee members ask donors the following questions: "What motivates you to donate your kidney? How are you related to the recipient? Has the recipient assured you that he/she will take care of your health after donation? Has the doctor fully explained to you the possible after-effects of donating your kidney?" (Murlidharan V., Prasad S., 2003)

"Typical, donors' answers to these questions would be: "I donate my kidney out of affection or attachment, not for any financial reasons. The recipient is related to me. I am confident that the recipient will take care of my needs in future. I am fully aware of the possible consequences of donating my kidney." (Murlidharan V., Prasad S., 2003).

Middlemen/Agent is often familiar with the functioning of Authorising Committee. He usually instructs and tutors the donor and recipient with the responses, which cannot be argued upon. "For example, a donor may claim to be an aunt of the recipient. Yet, there is no proof (other than oral evidence) that the Authorising Committee can insist upon to establish this relationship. Only the so-called "not near relatives" are required to appear before the Authorising committee and orally assure the Authorising Committee that they did not receive any money for donating their kidney."

### **Inside 'Kidneyville': Rani's Story**

Rani's daughter Jaya poisoned herself with a pesticide and had to be hospitalised. She needed an intensive care for more than a week. The hospital administration refused to proceed further as Rani's family could not afford the cost of the treatment. Rani knew where to arrange money.

Ernnavoor, a slum in northern Chennai, is popularly known as *Kidneyvekkam* or Kidneyville is the epicenter of this whole trade. The fact became conspicuous when 90 Tsunami survivors alleged that ravening middlemen/agents took their kidneys, sold it to the highest bidders and swindled them out of promised payment. The aftermath was – one of the widest police investigations yet into illegal organ sales (www.wired.com).

Rani was directed by her friends, who had already sold their kidneys, to a broker named Dhanalakshmi who ran a teashop outside Devika hospital in Chennai. He gave Rani \$900 upfront and promised to pay rest \$2600 once operation is done. She was supposed to donate her organs to a wealthy woman from Chennai. He even threatened Rani that if she backed out the payment made would be sorted out with violence.

The Authorising Committee also entrusted her with the task of passing the review. "The committee routinely approves illegal transplants through brokers. Its members are meticulous about covering their tracks, and give the procedures every appearance of legality. Rani's brokers coached her to speak only when spoken to, to hand over a packet of forged papers, and to leave as quickly as [possible. Rani says that sometime before the meeting, *Dhanalakshmi* most likely paid a 2,000 rupee bribe to ensure everything went smoothly." (www.wired.com)

The operation went on smoothly and when Rani returned to the hospital a week later for check up doctors refused to recognize her. Moreover her broker vanished and when she saw his vacant tea stall, she understood that she has been cheated. She is still unable to work as a laborer because of pain in her side.

"When asked whether or not it was worth it she replied: "The brokers should be stopped. My real problem is poverty – I shouldn't have to sell my kidney to save my daughter's life."

# 2.3.1.2 Purchasing Power of an organ

"Paying people to donate kidneys is often proposed or justified as a way to increase the supply of organs and help the seller. However legal issues as well as concerns about weakening altruism and exploiting poor families have so far prevented these proposals from being implemented." (Goyal M, et al. 2002)

Reason	Number	Percentage*
Pay off debts	292	96
Food/household expenses	160	55
Rent	71	24
Marriage Expenses	65	22
Medical Expenses	54	18
Funeral Expenses	23	8
Business Expenses	23	8
Other Debts	49	17
Future Marriage Expense for Daughters	10	3
Extra Cash	4	1
Start Business	2	1
Other Reason	3	1

 $Table \ 1: \ \% \ do \ not \ add \ up \ to \ 100\% \ because \ some \ participants \ had \ more \ than \ 1 reason \ for \ selling \ or \ more \ than \ 1 \ source \ of \ debt.$ 

Findings of Goyal M, et al, ascertain the economic and health effects of selling a kidney. A survey was carried out among 305 individuals in Chennai. Table 1 depicts all the findings. It can be seen that 96% of the people sold off their kidneys to pay back their debts. Food and household expenses, rent and marriage expenses were among the major reasons.

Moreover it can be observed from the above case studies that people have sold off their organs to save lives of their family members. They exactly know how to milk the cow and envision it to be the easier way to make money.

2.1.3.3 Organ Market: Maximum Retail Price (In Dollars)

	Kidney	Lung	Liver	Pancreas	Heart
Pakistan	15,000-40,000	NA	25,000	NA	NA
Iraq	20,000	NA	NA	NA	NA
Russia	25,000	NA	NA	NA	NA
Philippines	35,000-85,000	NA	100,000	NA	NA
China	65,000	150,000-70,000	60,000-130,000	110,000	130,000-160,000
Columbia	80,000	NA	100,000	NA	90,000
South Africa	120,000	290,000	290,000	140,000	290,000
Turkey	145,000	NA	NA	NA	NA
Singapore	NA	290,000	290,000	140,000	290,000
South Korea	NA	290,000	290,000	140,000	290,000
Taiwan	NA	290,000	290,000	140,000	290,000
Egypt	NA	NA	25,000	NA	NA

Source: http://www.wired.com/wired/archive/15.04/start\_page7.html

#### 2.3.2 Ethical Dilemmas

Ethics can be defined as philosophical study of moral values and rules. As established by the rule of demand and supply, acute shortage has caused dearth of organs hence loss of lives. So the organ procurement method should be ethically supportable and transparent to build safeguards against wrongful exploitation. But then how do we define 'Ethics' per se Indian socio context. With people coming from varied backgrounds and cultures, it becomes even more challenging to generalise norms which will be readily accepted by the society and will stand the test of time.

"To complicate the issue further, some commentators cast the debate in philosophical terms, pitting personal autonomy (the right for individuals to make their own choices) against paternalism (which obliges third parties to protect people from themselves)" (Rothman D, 2002). To further crystallise this ambiguity let's take an example:

Abortions in India were illegal before Medical Termination of Pregnancy Act, 1971. It led to loss of hundreds and thousands of lives, if not millions. But post 1971 period, India became the most liberal country and granted abortions on demand. So the issue, which was unethical for many, became ethical after 1971 Act. It was primarily because of the alteration in the law that changed the mind set of Indian population.

So, ethical questions and concerns may remain complex and unresolved (Flarey, Dominick L, 1991). These ethical conflicts have great potential to create a surge of anxiety not amongst the health care providers but general population as well (Flarey, Dominick L, 1991). Different authors have suggested wide range of ethical questions listed below-: (Curtin, Leah L, 1993)

- 1. How do we determine who, among the potential recipients, shall receive an available organ? On need basis (sickest patients first); On first come first serve basis; On income basis i.e. whoever pays a premium price goes first.
- 2. Should we have standard criteria or hit-or-miss system (no system)?
- 3. What methods ought to be used to procure organs? Should there be a market, regulated body or incentivisation technique for procurement of organs?
- 4. Should any one person receive more than one transplant, particularly, when others are anxiously waiting for their first one?

(The list of questions given above is inclusive and not exhaustive.)

Another significant ethical question for which many are seeking answer is "How does one attach 'value to life'?" For instance: According to J Savulescu 'When people go to war voluntarily, risking their lives for their country, they are herald as hero. If we allow people to die for their country, it seems to me we should allow them to risk death or injury for the chance to improve the quality of their lives or their children's lives or for anything else they value.'

Moreover David J Rothman's findings on kidney sellers in a slum in Chennai concluded that "decisions to sell kidney appear to have less to do with raising cash toward some

current or future goal than with paying off a high interest debt to local moneylenders. Sellers are frequently back in debt within a few years."

### The Big Donor Show!!!

Remarkably, even the corporate sector has not remained untouched by this lethal predicament. June 29, 2007 sparked a worldwide polemic debate when Dutch broadcaster BNN herald its intentions to air 'The Big Donor Show' (Dutch de Gronte Donor Show) where a terminally ill 37 year old women will donate her organs to one of the three patients suffering from kidney problems (Times of India, 2007).

"She will choose among three patients based on contestant's history, profile and conversations with their families and friends." (Times of India, 2007) The show comes from Endemol, the makers of controversial programme Big Brother in which there was a nationwide racism dustup involving Bollywood actress Shilpa Shetty.

The show turned out to be a hoax and was an attempt to draw attention to the global scope of this problem (Kingsbury, 2007). The idea was conceived to demonstrate the severity of the problem and was a tribute to BNN founder Bart de Graaff. However, the concept was objurgated by legislator Joop Atsma of Christian Democrats and called it "morally wrong and reprehensible".

# 3. Research Objectives

With rapid advances in medical technology, it is becoming easier to transport organs across human beings. This has created an underground market for human organs since no country allows a legal market in organs except a few. How do we bring the suppliers and demanders of organs together without violating the norms of the Indian Society?

# 4. Research Design and Methodology

### 4.1 Research Approach

In the given study, exploratory qualitative research in the form of four in-depth interviews was conducted in order to gain more background information. The researcher interviewed the following people:-

- Dr. Sudhir Chadha, Senior Kidney Transplant Surgeon, Sir Ganga Ram Hospital, New Delhi
- 2) Dr. Poonam Gulati, Senior Urologist, Max Hospital Saket, New Delhi.
- 3) Dr. Arun Arora, Physician, New Rajinder Nagar, New Delhi.
- 4) Mr. Baldev Sharma, Kidney Transplant Patient.

The interviews were based on the following components of research objective:-

- 1) What are the views of different stakeholders involved in this process regarding the scarcity of organs?
- 2) What is the feasibility of transplant surgeries in India?
- 3) What is the best method to procure organs considering the norms in the Indian society?
- 4) How effective Transplantation of Human Organ Act, 1994 has been?
- 5) How to deal with the ethical dilemma, if faced any?

In order to find out the answers to above question a questionnaire consisting of 14 questions was prepared Due to confidentiality no surgeon/physician revealed the exact figures of transplant surgeries done in a year. But according to unofficial sources last

year 66 liver transplant surgeries were done out of which 62 of them were successful in Sir Ganga Ram Hospital, New Delhi.

### 4.2 Methodology

## **4.2.1 Secondary Research**

General information about organ trade such as the THOA Act, illegal trade, news stories, articles were used as secondary data in order to understand the current situation clearly. The information was primarily acquired from websites, journals, and news articles. The secondary research helps in redefining the research problem as a part of exploratory research. In addition it provides useful information related organ trade in order to support our findings.

### 4.2.2 Primary Research

As far as exploratory research was concerned researcher conducted four in-depth interviews. Researcher chose in-depth interviews over focus group discussions because in-depth interviews can uncover greater depth of insights. Researcher wanted free exchange of information and attributed responses directly to the respondent. By doing it, researcher would get a profound understanding of the problem and would experience how different stakeholders feel about the aforementioned issue.

On the basis of secondary and primary research, a model is proposed where the researcher has attempted to eliminate redundancies in the present Transplantation of Human Organ Act, 1994. Initially a pilot model was prepared and was discussed with senior researcher and a journalist. Their valuable critiques were appreciated and accordingly accommodated in the existing model before researcher came up with final interpretation.

#### 5. Results and Discussion

The subject of 'Organ Market' is receptive and has attracted different views and suggestions from several authors across the globe. Though nearly everybody acknowledges the fact that India is considered to be the organ bazaar, still they hold varied outlook towards the same problem.

### **5.1 Incentives for Donors**

Professor John Harris and Charles A Erin have tried to dispel hypocrisy about ethics and buying and selling of organs. They support the view that donors should be rewarded suitably. Incentivisation would encourage more people like them to donate kidney or any other organ. "These rewards shouldn't be misinterpreted as a commercial transaction but should be perceived as the badge of recognition" adds Dr Sudhir Chadha. Incentives are imperative because everyone is paid, in this process, except the donor. "The surgeons and medical team are paid, transplant coordinator does not go unremunerated and the recipient receives an important benefit in kind. Only the unfortunate and heroic donor is supposed to put up with the insult of no reward, to add to the injury of the operation." (Erin C., Harris J., 2003)

Also recent evidence suggests live donations to be better than cadaver donation as the donor is fit, healthy and free from disease (Erin C., Harris J., 2003)

The solution given above may or may not hold true for Indian society, as there is a large divide between rich and poor. A rich may not find incentives attractive enough that motivates them to donate an organ. For this Dr Sudhir Chadha suggested rewards to commensurate social standing. He compared the compensation, which a victim of airplane crash receives to what a victim in railway accidents gets. He further added by saying that incentives like a rich getting tax rebates or a poor getting a permanent employment or railway concession pass would actuate them to donate their organs.

Moreover Dr. Poonam Gulati said that many doctors in India were skeptical of performing transplant surgeries. He added to it by saying 'whoever has performed these surgeries has gone to jail at least once.' It is because there have been instances where people make false affidavit to show blood relation and once operation is performed donor sue doctors accusing them for taking out their organs. Moreover recipient sues them because the organ transplanted may or may not function.

The fact was affirmed by a well-known doctor who even told the researcher that 'To hell with patients. I don't care if they live or die. Hospital, my boss and I are sick of this system. We will only do what's written in the law.' He was reluctant to give any advice

to his patients, as they are the ones who would turn back and accuse him of giving incorrect suggestions.

"Doctors say that dishonest recipients and donors have exploited a loophole in India's decade old Human Organ Transplant Act. "For the police, doctors have become the soft targets," said Umesh Oza, a urologist at Bombay Hospital and Medical Research Centre." (Mudur G., 2003)

Furthermore Dr Arun Arora advocates that the whole system should be transparent. He said, "Whatever method Indian government adopts, it has to be transparent".

However patient Baldev Sharma is a proponent of opening up a market for organs. He found it very difficult to search for a kidney and suggested that there should be enough organ banks in the city to readily provide an organ, when needed.

#### **5.2 Stern Governance**

This school of thought supports government regulation in this issue is imperative. John Harris and Charles A Erin in their article 'An Ethical Market in Human Organs' have suggested that there should be one purchaser of organs in the market like NHS in United Kingdom, which would buy all the organs and would distribute it as per the medical priority. But effective governance in developing countries can be challenging task. As stated by Vishal Thappar defence correspondent for CNN IBN, the news channel in an interview, "efficiency and the government cannot go together."

Some donors might indicate that they are donating organs purely out of sympathy, altruism and sense of pity. However a few suspect monetary payments are the prime motivations.

### The pursuit of life!!!!

I was waiting in Dr Sudhir Chadha's clinic for an interview with him while he was examining a few patients. One patient (whose name is kept anonymous) entered the room with all his reports. He knew that he had 70% kidney failure and immediately told

doctor that he has arranged the donor. Though doctor refused transplant and told him that he would only operate in case there is 90-95% failure and suggested him a few medicines. He walked out of the clinic and I followed him. I tried to strike conversation with him from whom I got to know that a distant relative was donating his kidney and had demanded an amount in lac.

"It is hard to imagine that in societies where there is a combination of desperate individuals, greedy, and unscrupulous facilitators and poorly developed justice system, transplantation would remain untouched by all-pervasive corruption." (Jha V, Chugh K, 2006)

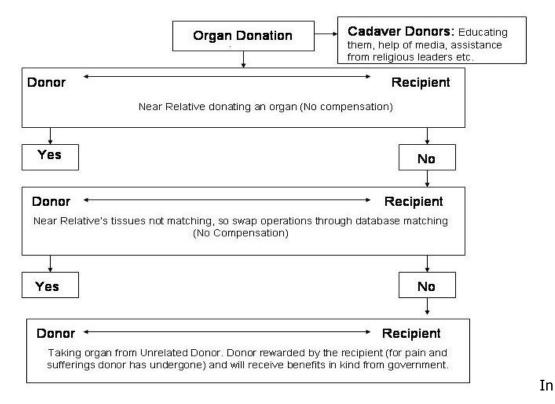
#### 5.3 Free Market

Some commentators have suggested that there should be a free market where prices of organs should be fixed by the market forces. But such kind of methodology can have serious repercussions on the Indian society. It can lead to more exploitation and if it does not function judiciously society may have to bear ill effects of it.

# **5.4 Contract in and Contract Out Policy**

These policies are used in countries like U.S.A, Singapore etc. In the Contract-in policy (also known as opting-in) human organs or tissues can be removed only with the consent of the decedent or his/her next of kin (Borna S, Mantripragada K., 1987). Under contract out policy (also known as opting-out or presumed consent), unless a person or his/her next of kin explicitly states that the organs are not to be donated, the person is assumed to donate them (Borna S, Mantripragada K., 1987)

# 5.5 The Proposed Indian Model of Organ Donation



the quest to make the organ donation policy transparent and solve the inequalities in demand and supply it is imperative to revisit the Transplantation of Human Organ Act, 1994 and revise it taking present circumstances into consideration. The proposed model is the blend of Iran's Compensated Kidney Donation Model and recommendations made in the 'Report of Transplant of Human Organs Act Review Committee', Ministry of Health & Family Welfare, and Government of India.

The attempt is to identify, classify and treat different donors differently. For instance: Strategies adopted for unrelated donors might differ from those of cadaver or related donors. The key points of the model are highlighted below: -

### Why Iranian Model?

WHO Assistant Director-General for Health Technology and Pharmaceutical wrote in a letter dated 11<sup>th</sup> February 2005: "I have the honour to refer to the original system that

has been built by the Islamic Republic of of Iran to ensure that end stage renal disease patients have access to kidneys from living unrelated kidney donors. With this approach Islamic Republic of Iran has been able to avoid the waiting list for transplantation, which exists in almost all other countries... On the international scene, the current Iranian approach is praised for its efficacy for the recipients... The Islamic Republic of Iran, in particular through their Management Centre for Transplantation and Special Diseases, could become an international model for governmental concern for well being and long term follow up of citizens accepting to become a living unrelated kidney donor..."(Bagheri A., 2006)

#### 5.5.1 Cadaver Donor

Bai Koichi, a legal scholar, states: "the family of the deceased has a certain voice in the disposal of any part of his body even during his life, although their voice is secondary to his own while he is alive. After his death, their voice becomes predominant" (Feldman, 1994). This especially holds true for countries like India and Pakistan where high levels of collectivisms can be witnessed. Colonel Avinash Seth, Liver Transplant Surgeon in R & R Army Hospital, affirmed to the fact cadaver donations need to be promoted for cardiac surgeries. The objectives can be achieved in the following ways:-

- a. "It is the need of the hour that a special public health programme for creating awareness and generating encouragement for organ donations should be launched through mass-media" ('Report of Transplant of Human Organs Act Review Committee', Ministry of Health & Family Welfare, Government of India)
- b. The masses should be educated to prevent maladies, such as chronic kidney diseases, which will lead to decrease in demand for organs.
- c. To alleviate poverty and enlighten the masses against the ill effects of illegal donation.
- d. "Religious leaders should also be approached and requested for their help in disseminating their help in cadaver organ donation, keeping in view that at times these issues are related to religious restrictions and prohibitions by a large number

of ill informed individuals, who avoid or oppose human organ donation on religious grounds or other general or superstitious misgivings/misbelieves." (Report by MHRD)

e. A national level database needs to be maintained whereby donors and recipients could be brought together, whenever a need arise. The central body should maintain the database responsible for organ donation. All states need to submit their transplantation figures as well as the people currently on waiting list to gauge the current situation.

#### 5.5.2 Live Unrelated Donors

Present law allows an unrelated donor to donate his organs if he/she can establish before the Authorising Committee that donation to be made is purely out of affection or attachment. The suggested Indian model for unrelated donors is based on the Iranian system which corroborates the fact that denying legitimate compensation because of understandable fear of organ trade is morally not justifiable (Bagheri A., 2006), and the unrelated donors should be suitably rewarded. Daar, Abdallah S. in 1992, coined the term 'rewarded gifting'.

However Robert Veatch considers 'rewarded gifting' as conspicuous term for corruption, which is prevalent in all putrid systems and believes more in non-monetary rewards such as bonus point system etc. (Bagheri A., 2006). Moreover, there is a remarkably thin line between making payments and being compensated. A lot of *pundits* in organ trade envisage that compensatory models might lead to further exploitations of poor as it might induce desperate people to offer their organs (Bagheri A., 2006).

Therefore, Indian model for unrelated donor will clearly state that donors are being financially rewarded not for the organ donated but for the moral reasons where he/she gave up their time, underwent pain and suffering and to ensure that they do not suffer economic deprivations. Moreover, the compensated model for unrelated donor will hold valid only when donor and recipient are the same nationalities.

The process will be regulated by the Ministry of Health, Central Government, and will pay fix amount to the donor. The amount fixed at Rs. 60,000 and the recipient for the hardships will pay the entire amount and pain donor has undergone. The process of remuneration will be made hassle free with minimal formalities to be fulfilled to encourage donation. The rate of compensation is decided on the basis of black market rates found in secondary research.

To ensure that there is transparency in the system, database (without personal details) will be made public so that media and other agencies can keep strict checks on it and make certain that people on waiting lists are getting transplants serially.

Doctors will not be involved in the process and there will be special clauses to protect them from any allegations, if made, so that they can act as a *messiah* for organ donation and educate and inform masses about it. Also complete check for donors will be undertaken prior to transplantation and potential donors will be communicated about the precautions and medicines need to be taken after the process.

Following additional benefits mentioned in the Review Committee Report can be accrued to live unrelated donors along with the compensation:-

- a. Security of donors against any post operative mortality risk due to organ donation related reasons, a custom made life insurance policy of Rs. 2 Lac for 3 years with one time premium to be paid by recipient will be offered.
- b. A donor card to be issued to donors to avail such benefits and concessions. It should notably display a slogan such as "Thank you for saving a life" as a badge of recognition.
- c. Life long free checks ups in the hospital where organ donation has taken place.
- d. 100% Tax rebate for any expenses/loss of income incurred.
- e. 50% concession in  $2^{nd}$  class by Indian Railways.

Donors who want to donate with an altruistic motive may waive off the compensation and additional benefits. They may do so by giving it in writing to the central body responsible for organ donations.

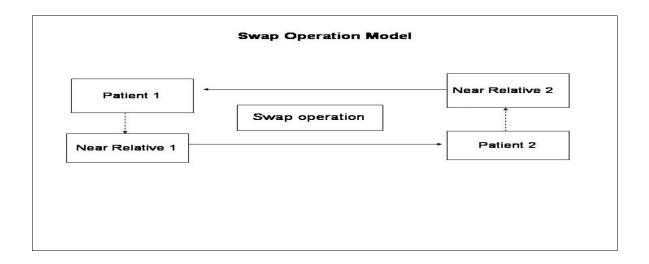
#### 5.5.3 Live Related Donors

One of the major criticisms of Iranian Model is that there was a significant decrease in the willingness of family members to donate their organs to loved ones (Bagheri A., 2006). Family members were reluctant to donate because of the availability of Live Unrelated Donors for transplantation (Ghods, Savaj, and Khosravani, 2000)

In order to avoid such a problem 'Swap Operation' strategy, recommended by review report committee, is used whereby 'near relative' donors are permitted to donate their organs in exchange without any commercial interest and only due to the reason that despite willingness, their organ was not found medically compatible for their intended recipients. "This would greatly help patients who have 'near relatives' willing to donate but incompatible or the recipient" (Ministry of Health and welfare, 2004).

"Most people think this is morally acceptable." (Harford T., 2007) Their respective matches can be found on the national database maintained. Inter-state donations may also take place leaving up to the donor and recipients who will travel for donation.

"Moreover economists Al Roth, Tayfun Sonmez and Utku Unver have been working with transplant surgeons in New England to design a kidney exchange programme." (Harford T., 2007)



#### 6. Recommendations and Conclusions

To alleviate the shortage of organs new model, which is the fusion of Iranian Model and Ministry of Health committee report, is proposed. But implementation of that model, without contravening the norms of society, becomes critical as factors like corruption; religion etc can act as obstructive forces. Dr. Samiran Nundy, a senior gastrointestinal surgeon who had helped frame India's Human Organ Act said, "There is nothing wrong with the existing law. We will not have any trade today if authorisation committee did their job honestly and efficiently." Furthermore transparency will be the key in deciding the success and failure of such model. This life threatening issue should be given proper consideration and should be taken up as a priority agenda by government and non-government organizations.

#### 7. Limitations

Organ Donation is a niche subject for Indian society as still a lot of people are unaware about its dynamics. Moreover, the issue of organ trade is highly sensitive and doctors/surgeons reserve their comments for the same. It was challenging to get interview appointments fixed and probe for the required answers from the doctors/surgeons. Moreover they were skeptical of discussing about arguable subjects and reserved their comments on the same.

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