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Indian Organ Trade: The Public and Private Sphere

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ABSTRACT

*The theme of this study was **Indian Organ Trade: Public and Private Sector**. It was believed that research literature on this subject is dominated by Human Rights Discourse (HRD), which prohibits analysis. The aim was to check whether thinking outside human resource development and asanas in weak cultural relativity could create a better understanding of the underlying causes of Indian organ trade. Using discourse analysis, Indian reality was incorporated and conceptualized as inequality poverty **discourse** and discussed human resource development and organ trade. The objective was to help in creating a diverse basis to solve the problem of organ trade. Using empirical evidence from Lucknow and Bangalore, it was shown that literature was banned by the Ministry of Human Resource Development. The study concluded that organ trade cannot be supported by law based on human rights, but can be combated by scientific medical studies, by providing organ sale options and strengthening the media.*

I. INTRODUCTION

Due to advances in medicine and surgery, organ and tissue transplantation has been transformed over the last 30 years from an experimental procedure performed only in highly developed countries to being a mitigate intervention carried out in hospitals and clinics around the world². The shortage of available organs has created a flourishing global organ market in which kidneys are the most traded commodity. A combination of poverty, a significant level of inequality and a global corruption makes India a fertile ground for this trade. At one end, there is an abundance of desperately poor people who see the sale of a kidney as a possibility to raise cash and at the other end, there are rich patients in need of a kidney and some of the world's best medical facilities to perform the actual operations. The trade in organs was prohibited in 1995 by law in India, but trade, having gone underground, continues to flourish³. This study arose in answering the question: Why do poor people sell their kidneys for some

¹ Author is a PhD Scholar in India.

² For a thorough historical analysis of the commodification of the body: Sharp 2000

³ See for the instance Ghose:2005

money? However, when the situation in the area changed in class study direction. It became clear that literature, without exception, proposed only one solution for organ trade: that is, a ban on violation of universal human rights. Literature was found to be influenced by the Ministry of Human Resource Development, which adopts the idea that human rights are universal and fundamental in nature and not based in a particular culture, and which organ trade is in violation⁴.

Throughout the region, in Lucknow and some other cities, I was confronted with a completely opposite solution, namely, legalization of organ trade. I found that inequality poverty discourse (IPD) is very powerful in India. It became clear that universal human rights referred to by the Ministry of Human Resource Development did not creep into Indian society to any extent. The components that create IPDs are high levels of isolation, inequality, poverty and corruption. Unlike HRD, the view on human life in IPD is relative; Humans are not equal, but exist within a pyramid order, with the rights and duties of the steps. The problem arises when the solution to the ban on proposed trade based on human rights is short due to the situation souring questions in the society. Moreover, research literature lacks practical guidelines on how total restrictions can cause real stops for the trade of kidneys or any other organs. I believed that when solutions are practically tested, deep-rooted weaknesses become apparent. The fact that the organ market continues to grow is proof that the law is not enough to prevent trade. We should start thinking circumstantially and consider the socio-economic and cultural characteristics of societies in which trade takes place.

(A) Assumption and Research Questions

I suggest that literature fails to create practical solutions, because it is dominated by the Ministry of Human Resource Development and does not consider the forces of IPD. I believe that in order to create practical solutions to complex events, it is necessary to have a full understanding of various factors that contribute to the problem as much as possible. Therefore, the purpose of this study is to examine the thinking outside human resource development, by taking a seat in weak cultural relativity, including cultural and socio-economic conditions under which trade takes place, can create a complete understanding of the root causes of organ trade. The research questions are as following: -

1. How does the HRD influence research literature on the Indian Organ Trade?

⁴ Bellagio Task Force: 1997; Cohen: 1999 and Schaefer-Hughes and Wacquant Ed. 2002; MD Goyal:2002

2. What other causes and explanations can a posture in weak cultural relativism unveil and which alternative solutions can be contributed to the problem of organ trade?

(B) Description

The phenomenon of organ and tissue trade is global in nature. Since it is a case study of kidney trade in India, as a result analysis is limited to this. The study does not claim to reach the distribution of discourses in Lucknow and other cities but only demonstrates human resource development and the existence of IPDs and gives some examples of how these discourses have influenced practices at various levels in important ways. Further, it should be noted that the work of the area was done in an urban setting and consequently limited to it.

(C) Design of The Study

To find out the two discourses and effects on Indian society, I have chosen to do qualitative studies using case study methods. The empirical base was built in Lucknow and Bangalore which is the high-tech capital of India. Bangalore and Lucknow were chosen because I wanted to find out that a stance in weak cultural relativity could unveil underlying causes for organ trade, apart from those found in literature. That's why I followed in step the feet of the writers of current research literature on organ trade. Case study method is used because it is well suited for the study of complex phenomena and processes such as human rights and organ trades. In addition, the methods of case study and the use of two sources of evidence in qualitative interviews are:

1. direct observation,
2. Systematic interview.

(D) Empirical Base: Liability and Validity of Data

My primary data consists of interviews with: -

- Doctors from the **nephrology** department at two hospitals,
- A journalist from **The Hindu** newspaper,
- A law professor,
- A government official,
- 8 related donors⁵- (5 women and 3 men),
- 18 women living in the slum⁶.

⁵ A related donor under the Indian legislation is defined as spouse, son, daughter, father, brother and sister.

⁶ I must here emphasize that having only used female respondents naturally has implications for the generalization

In addition to interviews, I used the following written sources: -

- The legislation on organ and tissue transplant,
- Two court transcripts from Madras High Court,
- Various newspapers,
- Journals⁷

Contact slots were received from doctors, government officials and law professors through Dr Rajesh Verma, Assistant Professor, SRMU Lucknow (Institute of Legal Studies). SGPGI, KGMU and KANTI Hospitals in Karnataka in Lucknow were selected based on both **Cohen (1999 and 2002)** and newspaper and journal articles covering organ trade.⁸ The journalist was selected based on a team covering **the "kidney scam"** in the national newspaper The Hindu and Journal Frontline.

Contacts were received from the concerned donors with the help of directors and staff of the hospitals. The basis of the selection was that he lived in or just outside Lucknow and Bangalore and was English-speaking. One problem with this selection is that I did not have access to the **patient list** and therefore I cannot verify that my data is representative for the hospital as well. However, from interviews with doctors in hospitals, I am understood that they portrayed themselves as highly winsome and successful. So, I believe the reason is that they interview me to choose the most positive, reflective and informed donors.

The slum area of Sugamau and Indra Bridge was selected based on newspaper articles and proximity to hospitals as I hoped to trace those who sold a kidney. It has not been successful. The initial contact of the respondents was obtained with the help of a local NGO, and then expanded to the district.

To increase the underlying problems with representation. However, since neither the press nor the government officials; I was able to trace kidney vendors for interviews because hospital records were false, it was only possible to trace donors. One can claim that it limits validity and to what extent normalization from empirical material is possible in the final analysis.

of the constructed data because in so many cases women are the donors who donate their organ for some money.
⁷ The articles were selected based on an open internet search using the words "organ, kidney and trade". Articles from The Hindu and Frontline were the ones covering the trade most extensively in Lucknow and Karnataka and are also the ones referred to in the literature. Extensive notes were taken during all interviews and as a rule they were written up immediately after the interview was over. Due to the very sensitive nature of organ trade all interviews were guaranteed anonymity and I only give their gender and age. In addition some of the respondents wanted to remain anonymous; in these cases I only give the title. The interviews were semi-structured with both open ended questions to closed questions such as age, housing, etc.

⁸ From 1997-2005. Please refer to the bibliography for those involved in this study.

However, as the main points out, the concept of generalization in the case study is not related to population but in principle proposal (in 1984). Moreover, I argue that many empirical grounds are valid because my analysis is based on discourse analysis. This form of analysis enhances the validity of the empirical basis as it focuses on rebuilding discourses and relating them to other discourses. Therefore, no attempt is being made to reveal any underlying truth.

The focus of analysis in the discourse is precisely what is presented as truth, why is it presented, and how is it accepted? Therefore, the empirical basis of this study, which is problematic, is that the example attempted analysis in examatic; Reliable and recovers because different interviews and respondents eagerly portray different images according to their orientation.

(E) Theoretical Stance

Contemporary debates on human rights focus on either one or both of two sets of division: -

1. Universalism versus particularism,
2. Individualism versus collectivism.

My focus is on the First Division. On the one hand of partition, we have an **evolutionary** approach to modernization, that is, once all societies have achieved a certain degree of development, culture will also develop and a better alliance with the liberal principle of human rights will be formed. Proponents of evolutionary approach believe that human rights are based in human nature and are such universal in nature and thus apply to all societies.

Critics on the other hand are - modernist, cultural relativist and subaltern studies - which deny the evolutionary view of modernization. According to critics, human rights are an ethnocentric creation and thus they are specific in nature and have limited⁹applicability.

I follow the view of critics to some extent. I believed that human nature is relative and somewhat culture - bound and culture - defined. Therefore, the claim that human rights are universal is, I think, a major weakness in human rights because it fails to accept the need to consider cultural and socio-economic aspects.

Adopting an understanding of human rights will provide for a more constructive basis for ending organ trade. It is inadequate to address organ trade based on universal understanding of human rights. Indians¹⁰ are active participants in negotiating their lives, not silent observers. Therefore, if we end organ trade, we need to think beyond more constructive and clear answers - try to understand poverty and exploitation and other factors within Indian society and justify

⁹ Under the influence of amputation, globalization and modernism, the concept of culture as a homogeneous, integral and coherent unity has been gradually abandoned or softened.

¹⁰ Here I used the word plural to indicate that India is crowded with different cultures and people.

trade.¹¹

(F) Model of Analysis

With a posture in weak cultural relativism, I propose to use discourse analysis in order to incorporate the Indian society into the analysis. I operate with two discourses: -

1. The human right discourse, which dominates the research literature.
2. The Inequality/ Poverty discourse, which dominates the Indian society.

My model of analysis is inspired by **Patrik Hall** (2003)¹². Hall draws on Foucault¹³ and develops a two-phase model: -

1. Describing the discourse is strictly structuralism and concentrated on identifying the discourse and its parts.
2. The practical meaning of the discourse is concerned with relating the discourse to the reality in which it exists.

Hall follows Foucault quite closely by starting that a discourse is built up by relations between different discourses. Thus, a discourse is an open system of representations, which is defined through its relations to something else. Hall states that discourses are both representations of reality as well as reality creating, and they are successful when they have been elevated to an ontological truth. Revealing the underlying factors of what seems to be ontological truths or primordial notions is precisely the overall objective of discourse analysis. Hall understand the discourses as connected representations of reality which regulate what can and cannot be said about this reality.

The weighting of the two phases in Hall`s model is not quite clear, but he states that only going through phase one is possible but not advisable because the actual analysis takes place in the second phase and would consequently be missed¹⁴. My focus is on phase two, but in order to have a basis for doing this, I will begin by briefly going through phase one and describing the discourses. Phase two is where I use my empirical material to trace how the discourses manifest themselves in Indian society.

Hence my model of analysis is as follows: -

1. Describing the discourses in relation to the organ trade and to each other.

¹¹ Please see a 'Nan: 2003.'

¹² Discourse analysis of National Identity.

¹³ Discourse, as defined by Foucault, refers to: ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations with inhere in such knowledge and relations between them. Discourses are more than ways of thinking and producing meaning.

¹⁴ For a more through description of Hall`s analysis model see Hall: 2003.

2. Tracing the discourses in the empirical evidence.

(G) Disposition

In chapter two I go through phase one of the analysis in respect to both HRD and IPD and show how the influence of the discourses from the conceptualization of organ trade. In chapter three I begin phase two of the analysis using empirical evidence from the public sphere in Indian society. I analyze the legislation regarding organ and tissue donation and show how IPD had a power to transform the human right intention of the law to effectively making the poor more vulnerable. I analyze how organ trade is portrayed in the written media and show how sensationalism affects the media's role as the public's guard dog. My interviews with the doctors show how IPD influences the medical conduct and opinion of organ trade and give examples of causes of organ trade not found in the research literature. Finally, I discuss how the Indian gender inequality is mirrored in Indian society. Chapter four applies phase two to the empirical material from the private sphere represented by a group of related middle-class donors and a group of residents of a slum. Through data from these interviews, I broaden the understanding of both why buying a kidney can be attractive and why selling a kidney may be an appealing choice. Additionally, I expand the understanding of why there is gender inequality within related organ donation. Chapter five presents the final discussion and conclusion.

II. ANALYSIS: PHASE ONE

This chapter contains phase one of the analysis: Describing the discourses in relation to the organ trade and to each other.

(A) Human Right Discourses

The main academic research center into organ trade is situated at **Berkeley University**. In 1997 a working group. The Bellagio Task Force wrote report on **Transplantation, Bodily Integrity and The International Traffic in Organs**, which addressed the commercialization of organs from paid donors and the use of organs taken from living or dead prisoners¹⁵. The WHO is a recognized articulators of the HRD as it recommends “**commercialization of organs should continue to be declared illegal and unethical**”¹⁶. The WHO acknowledges that organ trade is permitted or not punished in many countries and that some philosophers, patients and clinicians would allow the payment of organs and therefore calls for further work are needed in order to understand the ramification of programs that permit payment of organs¹⁷.

¹⁵ The Bellagio Task Force: 1997

¹⁶ WHO (2003): Human Organ and Tissue Transplantation Report by the Secretariat. EB113/14.

¹⁷ The WHO thereby fails to acknowledge that a proportion of the kidney sellers should also be included in this

Academic research on organ trade in India is limited to the above reports and studies conducted by Lawrence **Cohen: 1999 and 2002; MD Goyal: 2002**. Additionally, the finding of this academic research has generated a multitude of discussions in various medical journals¹⁸. **Cohen`s** and **Goyal`s** research in India includes socio-economic aspects in the analysis, but only in terms of the negative effects of organ sale. Socio-economic aspects are not a part of the final analysis or proposed solution. The solution proposed by the researchers in unison and based on human rights values is a ban of the trade. This common solution is I believe a strong indicator that the research is dominated by the HRD, which is so powerful that it prevents the researchers from thinking outside it.

Example: Cohen (1999), who narrates a story of a woman who has sold a kidney in the clinic of **Dr. K.C. Reddy**. The story of the woman is of a positive experience of selling with adequate follow up care and report of post-operative pain or negative impact on family income. As such their experience is in stark opposition to the conclusion of both Cohen and Goyal, but in accordance with reports from related donors in the west. Cohen could have taken up the positive experiences of the women in an open discussion, addressing the reality of the woman and very limited possibilities they have for raising cash and thereby providing a full understanding of why this choice appeals to them. However, Cohen keeps within the HRD using the example to enter an academic discussion of the ethics of the trade and of the agency of the sellers and reject that this story can be used to advocate kidney trade. Cohen claims that because poverty motivates the women to sell their organ, but the transaction cannot be deemed ethical. The problem here is that Cohen takes human right for granted and applies general western ethics to a specific Indian example.

Ethics like human rights are not universal and thus Cohen discusses from the western academic standpoint. He fails to acknowledge that these women circumstances are as per the IPD and that their possibilities for raising money are very limited. Selling an organ and getting the required aftercare may be an attractive option for them in their current circumstances. Reducing these women`s positive experience to an academic discussion as Cohen does is to exclude the Indian reality from the discussion.

Firstly, we need to acknowledge that organ sale can be an appealing choice within Indian reality,

Secondly, we need to include Indian reality into the discussion in order to understand why it is

category.

¹⁸ Specially British Medical Journal: 2001

appealing.

I will do this below by elaborating on the characteristics of the IPD.

(B) Poverty Discourse

Indian society is characterized by a high degree of inequality, poverty, corruption and a highly segregating caste system. According to **Stig Toft Madsen (1996)** “means that some segments may maintain a high degree of self determination or autonomy. This has implications for any project to promote citizenship rights and human rights in the subcontinent”

Furthermore, the caste system, which traditionally categories people into four overall hierarchically organized groups with distinct duties and rights has served to make Indian concepts of duties and rights particularistic¹⁹. In short this mean that Hinduism by far the largest religion in India is fundamentally unequal.

The caste system is instrumental in a creating a high level of inequality. In 1999/2000 according to the Human Development Index²⁰. India scored 32. In my analysis, IPD is premised on segregation, corruption and widespread poverty. As such IPD stands in direct opposition to HRD and thus serves to articulate resistance to HRD in the case of Indian society. The Indian state is characterized by corruption and rent seeking and there is an overlap between of the civil society and the state²¹. As I will show in the following chapter, elite groups are able to pressure the state into making legislations that is favorable to them.

Gender difference is another side of IPD. it's several expressions; Reverse sex quantitative relation, dower deaths, terribly low feminine adult acquirement to call some. This inequality is mirrored in each organ trade and organ donation. Over eightieth of organs are given by ladies whereas sixty fifth of recipients are male. One in all the reasons for this can be that one in all the elements of IPD is patriarchal system underneath that husband is that the main bread winner of the family and thus wife's financial gain is considered supplementary. Moreover, women's work is considered as being easier, less economical and fewer necessary. Understanding women's work as secondary for men maintains patriarchal family structure. Additionally, the impact of organ trade and organ donation on the feminine body, in terms of the danger of

¹⁹ Post-modernists have shown that prior to the arrival of the British the caste system was more fluent than today. The divide and rule policies of the British and the academic discipline orientalism commented a relatively fluent social system into a fixed law. Especially the surveys of the colonial government and the interpretations of indigenous laws were instrumental in this. For more on this subject see for instance said, Edward W: 1978; Breckenridge, Carol A. and Van der Veer, Peter eds. 1993.

²⁰ The HDI is a summary composite index that measures a country`s average achievements in three basic aspects of human development: longevity, knowledge and a descent standard of living.
<http://hdr.undp.org/en/data>

²¹ see for instance Evans: 1995

surgery and the loss of ability to figure later, that is considered minor compared thereto of a person. Within the second section of study, I'll discuss however gender difference is mirrored in organ trade and organ donation.

(C) Discussion and Summary

Figure 1: position and themes within the discourses below show the recurring themes in the inter-discursive dialogue and illustrates how the orientation and conceptualization serve to create not only opposing solutions to organ trade but also gives examples of how facts are reformulated differently depending on the discourse under which they are used²². I use the model as a point of departure to illustrate features of the two discourses.

Figure 1: Position and Themes Within the Discourses-

SR. NO.	Themes	Human Rights Discourse	Inequality Poverty Discourse
1	Orientation	Sellers	Recipients
2	Politically Correct	Yes	No
3	Attitude towards health hazards of donation	Serious health hazards for poor people	None, the donors claim that just to get more money
4	Effect on sellers	Negative	Positive
5	Attitude towards cadaver-based transplant system	Possible	Not possible
6	Success rate of live vs. cadaver transplant	Almost the same	Significantly lower
7	Dialysis as a solution	Yes	No
8	Attitude towards the Act,1995	Negative, it exploits the poor as it enables them to sell but give them no protection or	Negative, it prevents people in need of a kidney gaining access to one

²² I must emphasize that by setting up this dichotomy I exclude the standpoints that are between the discourses. Therefore, the figure should not be perceived as being exhaustive, but rather illustrative of the extremes within the two discourses.

		anywhere to complain	
9	Attitude towards the exploitation element	They are forced to sell due to the socio-economic reality and inequality	No one force them to sell
10	Attitude towards middlemen	Negative, they exploit the poor. Kidney sale is always exploitation	Negative, they should be eliminated, and the role taken over by the Authorization Committee
11	Major argument	The sale of any body part is unethical and should always be rejected	No one should die of kidney failure if someone else can benefit from selling a kidney
12	Human rights issue	To buy an organ from the person is a violation of that person`s human rights	The ban is a violation of the individuals right to do with his body what he wants
13	Solution	To stop the trade and develop a cadaver-based transplant system and give the poor alternatives	To legalize and control the trade

I find it especially interesting that facts are bent in different ways within the two discourses. If we consider number 4, ‘Effects of the sellers’, we have the postulate from the HRD that the effects are negative and from the IPD that it is positive or neutral. I believed that this is an expression not only of the discourse’s orientation but also of the fact that currently there are no scientific studies on the effects of removing an organ from a poor body²³. I believe that scientific studies will facilitate a more informed discussion within and between the two discourses.

Another example is no. 6, ‘Success rate of living vs. Cadaver transplant’, which within the HRD is claimed to be almost the same, whereas within the IPD it is significantly lower.

²³ Where appropriate medical care is available, the risk associated with live nephrectomy are low but not negligible in addition to operative complications; they include long term risks of failure of the remaining kidney. No reliable data are available on the risks to living donors in low-quality facilities with poor clinical services. WHO: 2003

According to WHO live kidney transplant do produce better results, but cadaver transplants are preferred because inherent risk for the donor are avoided²⁴. Here we see a manifestation of the orientation of the two discourses: within the HRD concerned for the donor is included and consequently a positive phrasing is used; within the IPD this concern is excluded and hence the phrasing is negative. This in turn has a impact on number 13, 'The solution', where the cadaver based transplant system is proposed within the HRD but a legalization of the trade within the IPD. Number 8, 'The attitude towards the act 1995' is negative within both discourses but again the orientation within the discourses determines the reasons.

Human rights orientation gives literature an orientation towards the organ seller while the relativistic perception of the IPD of human beings gives orientation to recipients. The broad impact of this orientation is how the problem of organ trade is conceived. The problem of organ trade within human resource development is conceived as exploitation and violation of human rights of the poor. It demands complete rejection of trade. The concept within IPD revolves around the problem of organ deficiency and therefore acts as a justifying of trade. It is important to recognize this fundamental difference between the orientation of two discourses because it is one of the main reasons why it is inadequate to enact a law against organ trade. Orientation towards recipients and boycott of poverty-stricken vendors is an expression of the relative perception of human rights within IPD. Therefore, the desire to perform kidney transplant with the purchased kidney is not established on the desire for monetary benefits as it is claimed within human resource development.

I will now turn to phase two of the analysis 'Tracing the discourses in the empirical evidence' and elaborate on how a foundation in 'Weak Cultural Relativism' can create a broader understanding of the causes of the continued trade in organs.

III. ANALYSIS: PHASE TWO-THE PUBLIC SPHERE

In this chapter I will focus on the public sphere of Indian society, as represented by the legal framework, the media and the medical society.

(A) The Legal Framework

In 1995 **The Transplantation of Human Organ Act,1994** (The Act)²⁵ and The Authorization Committee (AC) was setup to administer the law. The law was drafted because India did not

²⁴ According to WHO, in case of kidney transplantation, the use of organs from live donors produces better results medically than material from deceased donors (ibid). However WHO recommends the use of deceased donors because a broader range of human material can be obtained and because the risks and burdens inherent on a living donor are avoided (ibid).

²⁵ The transplantation of Human Organ Act,1994

have a comprehensive legislation to regulate organ removal. The main objective of the law is “to enact a comprehensive law for regulating the removal and transplantation of human organ by providing punishment for such dealings”²⁶. The objective is consistent with the HRD, but the many loopholes in the law, makes it open to implementation which are consistent with the IPD.

Section 9.3 of the Act permits unrelated organ donation and is often referred to as the major problem of the law. According to member of the AC, The National Human Right Commission and according to various articles in Frontline²⁷ section 9.3 has been widely abused to facilitate organ trade. The recipient and the seller get the approval of the AC by fabricating a story of close relationship when it is a trade²⁸.

Interview with Dr. Sudarshan on October 11,2004; he recognized that there has been a problem with corruption and a bias towards the recipients in the AC but even when The Act is administered properly and dubious transplant applications are dismissed, pressure from the political system can also be a problem:

“We get so much pressure. The patients and the doctors go to the Chief Minister to complain. Therefore, Karnataka Lokayukta has educated the Chief Ministers so that they know that no one dies from renal failure; dialysis is a perfectly safe option. There is also a lot of pressure from the ministers, and it is a question of educating them- People with a lot of influence also need to be educated”²⁹”

The Act which has a clear human rights orientation is being transformed within the IPD because of corruption and the connections of elites group. This is supported by **Professor Nagaraj** from the **National Law School** of India, who states that **“The holes in the law have been built in one purpose in order to serve the interests of elites”³⁰**.

A further problem is that the Act is non-cognizable (The Act: Section-22). This means that the police cannot launch an independent investigation into a claim of organ trade but must wait for action to be taken by the appropriate committee³¹. According to Professor Nagaraj³², a law is made non-cognizable when either-

- a) There is no urgency

²⁶ The act 1994: p3

²⁷ Frontline vol. 19: no.7, March 30-April 12, 2002 Features in the act 1994

²⁸ See how this section is misused in the quotation from the Madras High Court

²⁹ Interview of Dr.Sudarshan on October 11, 2004

³⁰ Interview of Prof. Nagaraj October 25, 2004

³¹ This is the another regulative institution set up by the state government under this law

³² From the National Law School of India

b) When the legislators want the juridical magistrate to control the investigation.

Normally, when a law is non-cognizable a private person and the police can go directly to the Judicial Magistrate, who can launch an investigation but under this law, the Judicial Magistrate must wait 60 days for the appropriate committee to do its own investigation. This impedes swift investigation of complaint of organ trade, thereby weakening enforcement of the law.

The Act is also problematic from the point of view of gender inequality. Due to the very weak position of women in Indian society, "**concerned donors**"(who do not require permission from the Authority Committee) including spouses in the category³³are very problematic. It should be remembered that organ transplant in India is done by private health care center and hence, it is available only for middle and upper class. Therefore, this discussion is only related to this group of women. According to the PhD thesis conducted by **Anju Wali Tikku, lecturer** at Delhi University, there is a wrong balance of gender in the³⁴data of Delhi hospitals. More than 80% of organs are donated by women while 65% of recipients are male. The proposed solution excludes the spouse from the "concerned donors" category, but in my opinion this solution is inadequate. The Act says that any decision of organ donation should be taken without any pressure. This pressure has been mentioned to come from family, friends and medical personnel but fails to consider the reality of Indian society, the reality which I considered referring to as IPD. Middle class women in India are generally in a live-in dependency relationship with their husbands.³⁵ As a result, it is in the best interest of the wife to ensure the income of the future family from charity. He cannot be forced into such a way by his surroundings, but his common position within Indian society is weak and therefore he is not much of a choice. Therefore, even if the spasal donation is approved by AC, I don't believe it will change the figures considerably.³⁶

The last major problem with the law is that since there is a ban on organ trade (Act: Section 19) the poor are unable to complain anywhere if they cheat doctors and middle-aged persons, as **selling a kidney is a violation of the law** and it has imprisonment of **2-7 years and fine ranging from Rs 10,000 to Rs 50,000**. The Madras High Court has given an example of³⁷ this. In a 2003 case where a kidney seller contacted the State Human Rights Commission to

³³ Apart from husband, the category includes son, daughter, father, brother and sister.

³⁴Organ Transplant: Women are the leading donors New Delhi, October 14, 2004.

³⁵ See Kibria, Nasli: 1995 to discuss how the income of a wife in the lower middle class is considered as a supplementary under patriarchal dominance. To discuss the liberation of poor women through work in any State of India.

³⁶ To discuss concern spasal donations. See also Bhowmik, Dipankar et.al.: 1999

³⁷ Tamil Nadu has passed the Human Organ Transplant Act, 1994

receive the balance of money he has promised for his kidney:

The State Human Right Commission has no jurisdiction to entertain the complaint of M.R. Balasubramanian (donor). Since section 19 of the act makes it clear that no donor of his kidney can claim payment of money. Further, in his affidavit dated 13/12/2001 sworn in the presence of the XXI Metropolitan Magistrate, Egmore, Chennai-8, the donor has specially stated that “there was no monetary consideration”. He also points out that since the complainant – Mr. M.R. Balasubramanian (donor) has prayed for payment of the balance amount of Rs.105000/- which is prohibited under section 19 of the act, the same cannot be taken note of and enforced by the State Human Rights Commission³⁸.

Based on finding of M.D. Goyal (2002) which shows that kidney sellers on an average are given 1/3 less of the price that was agreed upon, this is likely to be a true complaint. However, as the transaction is illegal the court can only dismiss the claim. In this way the HRD has indirectly served to weaken the position of the poor. One might object that the law is for all to follow- also the poor but the situation is now the poor are forced out of poverty to sell their one kidney, so if the conditions of the poor are not alleviated, there is no need to talk about values, such as it is wrong to sell a kidney.

“This is an expression of the debate of conflicting systems of value within the human rights debate, which in relation to organ trade is expressed by the fact that the right to economic security conflicts with the right to bodily integrity³⁹”.

(B) Media

The media has been instrumental in creating awareness of kidney trade theft in states. In 2002 reporters from the Hindu, Karnataka launched an investigation into the kidney trade because there were reports about organ trade continuing despite being banned in 1995 and about widespread corruption in the Authorization Committee⁴⁰.

The series of articles from Frontline and The Hindu⁴¹ can be divided into two overall groups both of which have a clear human rights orientation-

1. Focused on analyzing problems with the law, corruption in the AC and the underlying reasons for the very weak cadaver program. The articles **Features of the Act 1994**,

³⁸ Writ petition Nos.40101 and 41806 of 2002, W.P.M.P. Nos. 59587 and 61806/2002 and Wv MP No. 393/2003, section 4 and 11

³⁹ See Schech & Haggis: 2000 for a discussion of conflicting systems of value within human rights.

⁴⁰ The Authorization Committee is a regulative body set up under the 1995 act to ensure that all unrelated kidney donations are in accordance with the law.

⁴¹ See the bibliography for a list of the articles I have used in this study.

Popularizing the Program and Options before Kidney Patients are illustrative of this group.

2. It consists of exposé stories covering the element of scandals.

Examples – Murder and Kidney Commerce, A case of Organ Theft.

According to N.V. Anand Raman (in C.J. Nirmal Ed. 2000), who has made a case study of Tamil newspapers, most newspapers are interested in sensationalism⁴². The impact of these two groups on public debate differs. Whereas the first group of articles has served to create awareness of the problem, the second group has created fear and mistrust among the poor towards the medical society⁴³.

The attitude towards the Act is clearly negative in the articles. The solution to the problems with the legislation is to pressure the government to making the law cognizable and to make data from the AC publicly accessible. This would function as a counterweight to the political pressure on the AC to approve dubious applications. The media does not live up to its role as the public's guard dog public and does not utilize its power to pressure the government.

(C) Medical Society

Karnataka Nephrology and Transplant Institute (KANTI) is one of 8 centers that provide nephrectomy (kidney transplant) in Bangalore⁴⁴. According to evidence from Frontline there are strong indications that KANTI has performed transplants on patients who gave the Authorization Committee (A.C.) false information regarding the relationship with donors⁴⁵. Like Doctor K.C. Reddy, the directors⁴⁶ openly advocate organ trade as a win-win scenario in the context of local conditions and claim that if a donation is approved of by the Authorization Committee, then they have no right to refuse the donation.

KANTI is a medically well-reputed center and have very clear information on kidney transplant both on the internet⁴⁷ and in the form of an information brochure: **what you should know about kidneys and kidney diseases**, which is given to all recipients. The brochure consists of 39 questions/answers. Out of these only 5 concerns the donor and 2 are official disclaimers that

⁴² Even though I am not using vernacular language newspapers, I believe that especially the element of scandal evident in the Hindu are similarly found in the newspapers read by the poor segment of the population.

⁴³ The poor do not read English language newspapers, but it is clear from my interviews with the poor that the stories printed in vernacular language newspapers are like the ones published in the Hindu.

⁴⁴ I also talked to Doctors at Chinmaya Hospital, and they were much more cautious talking about organ trade but there was a similar orientation towards the recipients.

⁴⁵ See for instance Vidya Rama Data Sources and Insights, Frontline, volume.19, issue 7, 2002

⁴⁶ In the following I refer to the directors in unison as opposed to naming everyone specifically because they all participated in the discussion and voiced the same opinions and attitudes as well as substantiated and supplemented each other's stories.

⁴⁷ www.kanti.com

it is possible to buy a kidney. The brochure gives a good description of the procedure for the recipient, but the procedure for the donor is completely absent. This is puzzling because the operation on the donor is comparatively much larger than the one on the recipient. According to the directors, **“It is a major surgery; we must remove one rib, which will not be reinserted and to cut open a muscle. The donor is in this way made into a patient”**⁴⁸. As I will discuss below, the acknowledgement that the donor is transformed from a healthy person to a patient is interesting because this conflicts with the director’s non-commitment to the checking up on donors.

Regarding the effects donor’s health, the brochure states that **“Several scientific studies conducted world-wide have proved that kidney donation is safe, if performed at a reputable center”**. One problem with this statement is of course that the scientific studies are not specified and that it is only a true statement if adequate post-donation care is provided for. The brochure states that donors should be followed up annually for the rest of their lives. In addition to the brochure the recipients are given an additional paper, which emphasizes that they have a responsibility for the donor’s follow-ups. It is stated that KANTI can reject recipients if that they do not observe follow-up of their donors. It is quite unlikely that any recipients have been or will be rejected on this basis because KANTI’s directors deny having any responsibilities for these follow-ups. When asked if donors are contacted when they are due for checkups, I got the answer: **“No we only contact the recipients. They are the ones who brought the donors, so they know where they live”**⁴⁹. There is a striking difference in between the care provided for the recipients and donors.

KANTI is oriented solely towards the recipients. When I asked about the stories that donors have become ill after donating, the directors became very agitated.

First, there is the anger/frustration towards the scholar Cohen, which can be seen as a clash between the I.P.D. represented by the directors and the H.R.D. represented by Cohen. According to Cohen (1999), he conducted a series of interviews with the directors in 1998 wherein they constantly deflected his questions regarding donors. In discussing the director’s non-commitment to donors; Cohen refers to information obtain from Dr. K.C. Reddy who accuses the directors of having served as procurers of organs in Chennai. Cohen thus constructs the directors are being motivated solely by economic gain. By doing this, Cohen shows how HRD limits his understanding. If we return to the last sentence in the above quote “You forget

⁴⁸ In comparison the operation on the recipient only involves a small incision through which the new kidney is inserted. The failed kidneys are left in the abdomen.

⁴⁹ Ibid

the recipients in all this” and in another statement by the directors “When you deal with patients everyday it makes you change your mind about organ trade”. This motivation should not be overlooked as it forms part of the directors, positive attitude towards the organ trade and contribute a part of the solution. The suggested decision should instead be based solely on written documentation because seeing the ill recipients put **“Enormous pressure on them to clear the applications”**⁵⁰. The problem is that, at present there are no scientific studies into the effects of organ donation on the bodies of the poor⁵¹. I believe that scientific studies will generate less bendable facts and thereby provide the opponents and proponents a common ground for the discussion of organ trade. **M.D. Goyal’s** study is the largest study on organ sellers in India and does not include any medical test on the kidney sellers.

The last element of the bid is that I want to discuss "When donors complain later only because they want more money - so they say there have been complications. It is exploited by the poor. It is interesting to note how the directors here take the main argument from the Ministry of Human Resource Development "organ trade is exploitation of the poor" and reverses it by claiming that it is poor who are exploiters. It again shows directors the only concern for the recipients and is also an insult to the poor.

(D) Discussion and Summary

In this chapter I have shown that in having a basis in weak cultural relativism, I have been able to identify causes and explanations for the organ trade other than the ones found in the human rights influenced literature. I have shown that the IPD has been so strongly manifested in the drafting of the law that it has served to weaken the position of the poor while at the same time facilitating organ trade for the elites. I have found that the general gender inequality with in IPD is mirrored in the legislation, but I have also shown that this feature is not unique to India thereby opening the discussion on why there is gender inequality within organ transplantation⁵². Within the media I have identified two groups of articles and found that there is a clear human rights orientation, but that sensationalism has caused the media to neglect its role as the public’s watchdog.

I have shown that the research literature on organ trade by being dominated by the HRD, constructs a perception of the doctors who advocate kidney trade as being solely motivated by monetary gain. Accordingly, one of the components of the positive attitude towards organ trade namely the concern for the recipient is excluded and the basis for constructing workable

⁵⁰ Parvathi Menon “Against the Organ Trade” in *Frontline* Vol.19, issue on 10/2002

⁵¹ See for instance WHO: 2003

⁵² Unfortunately, it is beyond the scope of this paper to undertake this task.

solutions to organ trade is weakened. I have shown that the doctors under the IPD demonstrate a fundamental disregard for not only potential poor sellers but also of related donors.

IV. ANALYSIS PHASE THREE-THE PRIVATE SPHERE

I will now move to the private sphere beginning with interviews with the related donors and finishing with the interviews with residents of the slum. These two groups come from the middle and the bottom of Indian society respectively. In related to organ trade the first group comprises the potential buyers and the second group the potential sellers.

(A) Related Donors

The group of respondents consists of 8 related donors- 4 wives, 2 mothers and 2 husbands with family income of Rs. 16000/- per month on average.

As I discussed above in Sections 3.1 and 3.3, related organ donation is characteristic of gender inequality. In both cases where husbands donated to their wives, there were objections from their families and friends, and it added to the tension felt by their **wives- "I am very happy that my husband is fine. If something had happened to him, I would have had to answer to his family."**⁵³ This concern was not expressed by any of the recipient husbands. In all the instances where a woman donated, she was the first choice - "the first choice was **clearly mother, brother and then father**".⁵⁴ It was believed that there is a **natural** option for women to donate based on being a mother or wife and hence grateful.⁵⁵ Love for the recipient was also a cause and this factor should be taken in analysis as it forms a part of the motivation for organ donation. Nevertheless, this love does not account for gender inequality in donations. This natural **alternative** can be seen as an expression of IPD an ontological has become true and therefore women have not questioned themselves. In a case where a wife donated to her husband the family objected because of her husband's illness. She had become the only bread winner of the family. It indicates that he had achieved the same status as one of the male donors through work.

Three of the 8 families admitted having tried to buy a kidney and their motivation was to protect their immediate family from the risk of surgery. To translate this concern into a disregard for the bodies of the poor will only give us part of the explanation.

⁵³ 42-year-old wife gets kidney from husband

⁵⁴ 63-year-old mother

⁵⁵ However, these women may be interested in preserving a positive self-image by claiming that they have decided to donate themselves and therefore will not volunteer information about pressure for me.

1. The element of love which I gain must stress must be included as it constitutes the major reason for wanting to buy a kidney.
2. I believe that the issue of buying a kidney is complicated by the fact that it is possible to donate a kidney safely and that doctor repeatedly assure families of this.

In this understanding the potential risks associated with the kidney sale can be compensated for with money and thus a win-win situation is created.

(B) Residents of Slums

The group of respondents consists of 18 women and 3 men. Average family income amongst the respondents has Rs.2800/- per month.

In the interviews two concepts regarding the kidney surfaced a holistic energy centered body concept, *“If you give your kidney, you will not have energy to work. It is like half your life has been taken away”*⁵⁶ and an ownership concept, *“It is your kidney. Why should you give it? It is different with blood- that you can give when it is needed urgently. The kidney we should not sell”*⁵⁷. That the two concepts coexist in Indian society can be seen as an expression of a society in the phase of modernization. The ownership concept was also an expression of a **reversed** human right namely the right to decide over one’s own body. For the Indian poor the body constitutes the main means of raising money. Selling an organ is therefore an extension of a normal way of utilizing the body for survival.

Only 2 of the respondents claimed that they would sell a kidney- **“If there is a situation and it is the last resort then you can sell it”**⁵⁸. Thus, selling a kidney is not a first option but within the IPD selling a kidney is a possibility for raising money in an emergency. It is reflection of the limited possibilities these people have. It may not be a first choice, but it is an option when there are no others. This we must include in the analysis because it constitutes the reason for why poor people sell their organs. Providing other options such as micro-finance loans, better salaries and more employment opportunities comprise a segment of a constructive way of eliminating organ trade.

The high awareness regarding the negative health effects of selling an organ came primarily from television and newspapers. This information was not neutral but was closely connected to scandals. This kind of media coverage spread fear among the respondents- **“You know when I was in the hospital I was put to sleep and when I was falling asleep the doctors showed**

⁵⁶ 30-year-old woman

⁵⁷ 32-year-old woman

⁵⁸ 42-year-old woman

my mother the kidney tray – that is what they call this tray because of the shape but I thought they will take my kidney. I got so scared. When I woke up in the morning I was crying and crying and shouting - you have taken my kidney”⁵⁹. The situation of needing hospitalization and the fear of having an organ stolen are further expression of the insecurity that characterizes the lives of these people. Theft of organs is the most resent expression of the exploitation of the deprived section of the Indian society and is also in their own reversed human rights understanding a grave violation because they are robbed of an essential part of their most valuable asset- the body.

(C) Discussion and Summary

In this chapter I have shown that love is an aspect of organ trade and organ donation that must be included in the analysis. With regards to the gender aspect of related donation I have shown that love is the major motivation of donation, but I have also shown that gender inequality can be seen as a manifestation of the IPD which is so strong that the women themselves do not question being the **natural first choice**. I have given one example of a woman who was no longer the first choice because of her status as she is only one earning member of her family. Therefore, in order to correct the gender inequality within Indian society needs to be addressed. Furthermore, I have shown that the wish to buy a kidney is motivated by love and justified by the belief that it is a win-win situation which is since organ donation is safe. Therefore, the wish of buying a kidney into disregard of poor bodies will give a partial explanation.

I have shown that the kidney is understood under two concepts: -

1. A holistic energy centered body concept.
2. An ownership concepts.

I have interpreted the ownership concept as having a reversed human right understanding i.e., the right to decide over one's own body and I have shown that this body is the main asset of the poor. Further I have explained that under the IPD selling a kidney may be the sole option for raising money and can be understood as an extension of a normal way of utilizing the body for survival. I have shown that the fact that poor people are deprived of options for raising money under the IPD must be given consideration as it is the major motivation for wanting to sell a kidney. Further this understanding opens for a more constructive approach to solving the problem of kidney trade as alternatives to selling a kidney can be implanted.

I have shown that the sensational orientation of the media has added to the insecurity under

⁵⁹ 27-year-old woman

which the poor people live thereby intensify their existence under the IPD and failed in utilizing its power to pressure the government.

V. CONCLUSION

In this study I have taken a stance in weak cultural relativism and used discourses analysis and case study method to examine **How the HRD influence research literature on the Indian organ trade**. I examined whether this approach could unveil other causes and explanations for the organ trade and thereby provide alternative solutions. I included **cultural** and **socio-economic** factors by conceptualizing them as the IPD and I compared the **attitudes towards organ trade** under this discourse to those under the HRD. My study revealed that the opposing orientation of the discourses determines how organ trade is conceptualized and determines the solutions proposed.

I found that the influence of the HRD on the research literature has restricted the understanding of the causes of organ trade because cultural and socio-economic factors have been excluded. These constitute part of the explanation as to why selling an organ can be an appealing choice in the Indian context. The study has shown that selling an organ is a last and not a preferred option for raising money but that the sale of an organ constitutes a much-needed option for raising money. Thus, it is an extension for the normal way of utilizing the body for survival by the poor and legislating against organ trade can be perceived as a violation of the reversed human right to decide over one's own body. Therefore, providing the poor with alternatives to organ sale constitutes part of the long-term solution to organ trade.

I have shown that the doctors under the HRD are perceived as being solely motivated by monetary gain. Using empirical evidence, I have broadened the understanding of doctor's motivation for advocating organ trade. I showed that in addition to a non-commitment to donors and a rejection of claims concerning negative effects of selling a kidney doctors have a great concern for the recipients that serves to justify the trade. Similarly, this study has shown that the wish to buy a kidney cannot only be translated into a disregard for the bodies of the poor but must also be understood in the context of love for one's own family and that the fact that organ donation can be safe serves to create a win-win scenario wherein the potential hazards of organ selling can be compensated for by money. I have proposed that scientific medical studies into the effects of selling an organ in the Indian context: -

1. Create the basis for a common ground between the discourses and thereby facilitate a more constructive debate than the current one.
2. Challenge perceptions of organ trade as a win-win scenario.

Furthermore, the study has shown that the media need to take its role as the public's guard dog more seriously. Doing this the IPD can be countered, and the government pressured into dealing with organ trade more thoroughly.

It has been found that the gender inequality within related donations reflects the general gender inequality in Indian society. Therefore, dealing with the root causes of the Indian gender inequality is the solution to the gender inequality within organ donation. This study has only dealt with domestic Indian organ trade. However, the organ market is not restricted to India but forms part of an international network of organ and tissue trade. Therefore, I would like to encourage the reader to consider how his/her own country participates in the organ trade.

In my country organ trade is prohibited by law. Nevertheless, when patient travels to another country and buy a kidney the Danish State (Denmark) provides the necessary after carefree of cost. Is it not a problem that Denmark and many of the other countries which pride themselves of complying with the Universal Declaration of Human Rights (UDHR) in this way facilitate organ trade? Do we not have a responsibility?

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