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Bodies, "Love" and Kidneys: The Regulation of Living Donor Donation in India and its Social Repercussions

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WATER FOOD ***DIABETES*** AYURVEDA ***GENETICS*** POVERTY ***YOGA*** STDS ***HISTORY*** SEX ***SOCIETY*** FAMILY PLANNING ***CASTE*** GENDER ***RIOTS*** RELIGION ***HEALTH*** DEMOCRACY ***FLOODING*** WASTE-MANAGEMENT ***UNANI*** PSYCHOLOGY ***FOLK MEDICINE*** AFFIRMATIVE ACTION ***GLOBALISATION*** BIOCHEMISTRY ***OLD AGE*** REPRODUCTIVE HEALTH ***MALARIA*** POLICY ***HIV AIDS*** WHO ***MEDICOSCAPES*** COLONIALISM ***PHARMACY*** RELIGION ***LEPROSY*** BOTOX ***DEHYDRATION*** NGOs ***AYUSH…***

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Table of contents

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Abbreviations

BC: Before Christ

ESRD: End Stage Renal Disease

ICU: Intensive Care Unit

IPC: Indian Penal Code

IRODaT: International Registry on Organ donation &Transplantation

NGO: Non-Government Organization

NOC: Non-Objection Certificate

NOTTO: National Organ & Tissue Transplant Organization

OTP: One Time Pass

PGI: Post Graduate Institute of Medical Sciences and Research

RBDA: Registration of Births and Deaths Act

THOA: Transplantation of Human Organs Act (1994)

USA: United States of America

WHO: World Health Organization

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Mandeep Kaur, 27th April 2022

Abstract

Organ transplantation touches upon existential questions of life and death, the self and the other, and the gift and the commodity. It uniquely challenges social norms and ideas and necessitates a close analysis of cultural concepts and differences. In India, the regulation of organ donation has led to social repercussions and consequences that highlight Indian approaches to these existential questions of life, death, bodies, and social relations.

The concept of brain death was introduced into the Indian legal and medical systems in 1994 with the Transplantation of Human Organs Act (THOA, 1994). The major aims of THOA were the regulation of living donor donations to prevent illegal markets and to increase deceased donations as a solution for organ scarcity.

Organ donations, while usually beneficial to the individuals who receive them, raise several ethical concerns about social justice and equality, such as where organs come from and to whom the organs should be given, as well as the concept of distributive justice. It also highlights how biomedical technologies are adapted and understood differently in diverse cultural settings, especially those that touch upon sensitive and significant topics such as death and body ownership. This thesis will analyze how THOA and its regulations pertaining to human organs have changed and shaped Indian societal norms. It will analyze how Hindu concepts of death relate and connect to transplantation and show attempts at reconciliation and integration of transplantation into Hindu belief, but also friction between the understanding of death as a process and the instantaneous "declaration" of brain death. The complexities of organ transplantation in India extend to the ethical dimension of gendered donations, in which women are far more often the donors than the recipients, but also to the logistical and bureaucratic shortcomings of the Indian medical system.

Introduction

Advancements in medical technology have far-reaching impacts on our lives, our relationships with each other and with our own bodies. A particularly interesting case is organ transplantation, which has become increasingly prevalent in recent decades. The idea of transporting body parts from one body to another is not new and features in the myths of many ancient civilizations and traditional or religious texts (Hamilton, 2012; B. Parry, 2012, p. 215; Shayan, 2001). In Indian ancient legends, Lord Ganesh, the elder son of Goddess Parvati and Lord Shiva of the Hindu pantheon, was the very first 'transplant patient' in India since Lord Shiva performed surgery on him using the head of an elephant (Hamilton, 2012, p. 3). Apart from the stories of mythology, evidence of transplantation can be found in ancient Indian Ayurvedic texts, e.g., in the second century BC text *Sushruta Samhita*. Sushruta, an ancient Indian surgeon, described the surgical concept of transplantation by utilizing skin autografts for rhinoplasty (Hamilton, 2012, pp. 11–12).

The modern era of transplantation began with the first successful[1] kidney transplant on identical 23-year-old twins Richard and Ronald Herrick, performed by Joseph Murray at Boston's Peter Bent Brigham Hospital in 1954[2] (Caplan, 1983, p. 23; Langer, 2019, p. 31). Murray received the 1990 Nobel Prize in Physiology or Medicine for his groundbreaking work on human organ transplantation (Tan & Merchant, 2019). In the 1950s, Dr. P. K. Sen and his team from Mumbai's King Edward VII Memorial Hospital performed the first experimental kidney and liver transplants on dogs in India. In May 1965, the first cadaver donor kidney transplant was tried on a non-renal failure patient with hypernephroma[3] at King Edward Memorial Hospital in Bombay.

Organ transplantation is now commonplace in many parts of the world and is frequently shown in popular media in various circumstances. The invention of immunosuppressants[4], e.g.,

[1] In 1933, the Ukrainian surgeon Yurii Voronoy attempted the first human kidney allotransplant/deceased-donor transplant. However, his first patients died 2 days later from blood group incompatibility (Matevossian et al. (2009, p. 23)

[2] Richard's life was extended by eight years because of this procedure. At the Royal Infirmary of Edinburgh, Sir Michael Woodruff performed the first kidney transplants in the United Kingdom on twin brothers in 1960. They both survived for another six years before succumbing to an illness unrelated to their prior transplants (Langer (2019, p. 31).

[3] The same team performed a second kidney transplant in April 1966, this time using a cadaver donor to treat a patient with chronic renal failure. Following an acute myocardial infarction, the first patient died on the 11th postoperative day, with a functional graft. On the third postoperative day, the second patient died from bilateral pneumonic consolidation, which was the cause of his death (Acharya (1994)).

[4] A medicine capable of adequately suppressing the recipient's immunological reactivity to foreign organs without the need for dangerously high combinations of steroids.

the development of Cyclosporine in the 1980s, led to major improvements in graft and patient survival rates. Patients previously deemed unsuitable for transplantation began receiving transplants even from unrelated donors (Kahan, 1999). As the quality of life after kidney transplantation is generally much better than being dependent on dialysis, transplantation is becoming more and more attractive for dialysis patients (Axelrod et al., 2018; Nemati, Einollahi, Lesan Pezeshki, Porfarziani, & Fattahi, 2014). However, with a large pool of possible recipients, the demand for transplantable organs soon outweighed the supply and created an organ scarcity. The waiting list for transplant organs is longer than that of available donations, and people often die before receiving a life-saving organ ("Transplant waiting list," 12-Aug-21).

Several initiatives have been made to increase the organ pool. One of them was the enactment of the Uniform Anatomical Gift Act in the United States in 1968, which was an important step toward establishing a new system for distributing organs for transplantation (Sadler, Sadler, & Stason, 1968, p. 120). Other countries around the world have also introduced laws and national programs to promote it. These laws detail the rights of individuals to designate their organs for donation after death and the conditions under which a living donor transplant is permissible. However, the same laws prohibit the buying and selling of organs. Therefore, while organ donation has been promoted around the world, the trade in organs is illegal in almost all countries except Iran.

Initially, organ donation began as an altruistic and humanitarian act. This approach is used by many public health organizations that attempt to encourage people to donate voluntarily. Despite efforts to raise awareness of organ donation worldwide, there are still not enough people who are willing to donate their organs.

Organ scarcity is often presented as a concern[5], and there has been significant discussion about how to solve this. Some scholars are promoting organ markets as a solution to this scarcity (Brooks, 2003; Caulfield, Nelson, Goldfeldt, & Klarenbach, 2014; Reddy et al., 1990; Shaw & Bell, 2015; Taylor, 2006a). However, in order to meet the need for organs, human body parts are frequently presented and reduced to scarce commodities (Engelhardt Jr, 1984; Svenaeus, 2010). Because of this unavailability of kidneys and the increasing demand, wealthy patients find other ways to obtain a kidney for transplantation. As a result, in many

[5] Veena Das calls it a created notion of a 'crisis' and much debate has recently taken place on how to solve this ''crisis'' Veena Das (2000, p. 265)

parts of the world, the trade of organs from a living donor has become a lucrative, albeit illegal, business for clinics serving wealthy nations and foreign patients (Scheper-Hughes, 2002; Scheper-Hughes, 2000).

The repercussions of organ scarcity in various areas of the world are fundamentally different. For example, in the United States, the crisis is mostly focused on motivating more people to register as organ donors, so their organs can be donated upon their death, whereas in developing nations such as India, the need for organs has led to the development of illegal markets (Margret Lock, Allan Young, & Alberto Cambrosio, p. 266). Anthropologists have provided critical commentaries on the devastating ramifications of organ donation and organ trafficking and analyzed the way in which they connect problems of exploitation, obligation, and bodily autonomy to one another and to the public (Cohen, 1999; Hogle, 1996; Kaufman, 2013; Lock, 2002; Lock, Young, & Cambrosio, 2000; Scheper-Hughes, 2001b). Biological knowledge and medical imperatives impact and remold intergenerational ties, personal responsibilities to family members, and strangers in need of organs (Kaufman et al. 2006,84). Donors and recipients, bioethics, and medical practice are all impacted by the practice of transplanting body parts.

Transplant professionals and researchers are inspired by the plight of patients to broaden the criteria for organs that can be transplanted; affected families are motivated to travel the world in search of donors; and novel solutions like xenotransplantation, and artificial organs are being developed in laboratories. However, international professional codes and/or local moral values are violated by some of these practices (e.g., using executed prisoners as donors, allowing commercial transactions between donors and recipients, and transplant tourism). The medical and technical achievements of transplantation, the commercialization of health care, and the growing division between the rich and the poor have created the circumstances for an illicit but booming human body parts trade. These lead to frequently cited issues of human rights concerns and violations. Other concerns surrounding organ transplantation are social, cultural, and religious. As these are country-specific, they will have to be addressed in a way that is unique to each country because people's views and acceptance of organ donation can change in different places (Crowley-Matoka & Lock, 2006). The expanding prevalence of organ and tissue transplantation necessitates a closer look at how these biomedical advances change human relationships with their bodies and each other (Cohen, 1999, p. 141). The ethical questions that need to be addressed include ethnic/racial disparities in rates of donation, cultural barriers to the wider adoption of the concept of brain death, the gendering notion of organ

donation, and international variations in the relative proportion of living to cadaveric transplants.

The scarcity of organs affects developed and underdeveloped nations differently, and this dichotomy grew to a crisis point in India in the 1980s and 1990s (Chengappa, 1990). Foreigners from wealthy nations flocked to the country to 'purchase' organs from poor locals, turning the country into what was termed a 'warehouse of kidneys' (Puri, Singh, & Yashik, 2010, p. 18). The large scale of the trade led to growing national and international concern and to political and legal consequences in 1994 when India introduced the Transplantation of Human Organs and Tissue Act (THOA). THOA introduced 'brain death' into the Indian legal and medical system. It also banned the organ trade and made organ transplantation from living donors permissible only among close family members and friends after the approval of a special authorization committee ("Act and Rules of THOA: NOTTO"). Although the Indian government and public health organizations put a lot of efforts towards encouraging people to donate organs after death, 90.7% of organs in India still come from living donors ("IRODaT - International Registry on Organ Donation and Transplantation," 07-Feb-22). With an extremely limited supply of cadaveric donations and strict legal regulations, the illegal organ trade still occurs on a regular basis in India and involves a complex system of organ recipients, 'sellers,' hospitals, doctors, and middlemen.

I will analyze the process of organ transplantation from both deceased donors and living donors in India, to reveal common themes regarding social repercussions, injustice, and inequalities related to this biomedical technology. The chapter "The Body of the Dead: Deceased Organ Donation" discusses organ transplantation, its practice, as well as the social life around this technology in India, along with the social ramifications of brain death after it was introduced through THOA in 1994. India is home to 1.3 billion people from twenty-nine states and seven union territories spread across four distinct geographical regions. It is a diverse country, where language, dress, and cultures change every few hundred kilometers. Some authors have argued that religious beliefs can make people reluctant towards accepting organ donation (Panwer et al. 2016; Seth et al. 2009; Chakradahar et.al 2016), a suggestion that warrants closer analysis. The majority of people in India follow Hinduism, but Muslims, Christians, Sikhs, Buddhists, and Jains comprise significant religious minorities. A discussion on the view on transplantation by all major religions in India is beyond the reach of this thesis. Instead, this thesis will focus on the Hindu perspective, particularly on the way Hinduism is practiced in Punjab in Northern India, where Hinduism, Sikhism, Islam, and Christianity often

intermingle and interact in complex ways. In this cultural context, the Hindu view on death, the concept of brain death, and cadaver donations will be investigated. The concept of *dharma*[6] and *dāna* is looked into to understand the ethical perspective on organ transplantation in Hindu belief.

The second part of the thesis explores how THOA, and its subsequent modifications regulate the field of organ donations and transplants in India. The question of who gives and who gets organs also reveals problems of injustice, exploitation and excessive pressure on disadvantaged populations and reveals social hierarchies. While the law was a welcomed move to put an end to the organ trade that was prevalent, what was beyond anticipation was that the onus would now come to immediate family members, especially the women of the family, to be the suppliers of organs.

Often, organ donation is portrayed as a "gift of life," an "act of altruism," and affection towards family and other humans. I will discuss the intricate social networks through which organ donations and transplants are negotiated and the normality of kinship hierarchies assumed within medical protocols and testing. I will also discuss how and why THOA's classification of "near relatives" puts women at odds with the social systems that underpin such contributions, resulting in a regulatory failure and a gendering of living donations.

[6] Dharma illustrates duties in a moral and ethical sense, but it also means "divine law... way of righteousness, religion, duty... [and] virtue, justice, goodness, and truth" (Subramuniyaswami, 1993, p.710). For more details see: Satguru Sivaya Subramuniyaswami's, Dancing with Siva: Hinduism's contemporary catechism.

1 Literature review

A substantial amount of medical anthropology and social science research has emerged around the topic of exchanging this finite supply of tissues and organs between donors and recipients—conceptualized as gifts, commodities, or both. The idea of a gift was fraught with other kinds of tension in the field of transplantation. Deceased donation in the United States is often referred to as the "gift of life". However, Leslie Sharp states that this metaphor obscures the real process of obtaining organs from deceased donors (2001), which leads to the commodification of organs. Several studies[7] on organ trading and on organ trafficking have focused on ethical issues, such as moral dilemmas and human rights violations in the exploitation of donors. Reflecting the same line of thought, other scholars empirically support the idea that globalization aids in the international human organ trafficking trade (Cho, Zhang, & Tansuhaj, 2009; Ignatieff et al., 2011).

Organ transplantation has long been a source of concern for medical anthropologists (Cohen, 1999; Hogle, 1996; Joralemon, 1995; Rainhorn & Boudamoussi, 2017; Scheper-Hughes, 2001a, 2001b), who are concerned that it could lead to severe forms of objectification and commodification of bodies. Scheper-Hughes' work is mainly focused on organ markets in developing nations, including India. Objectification of human bodies results in what Scheper-Hughes bombastically dubbed a kind of "neo-cannibalism" (Scheper-Hughes, 2015). Amahazion outlined how the medical epistemic community played a major role in shaping, guiding, and influencing the norms and approaches to organ transplantation by providing policy initiatives, recommending practices, giving statements, and recommending model legislation in organ transplantation (Amahazion, 2016). Cohen's work has focused on the illegal organ trade in India, the underlying cultural phenomena that allowed it to flourish, and the ethical implications for the country's medical establishment. His work is an investigation into where the standard of informed consent lapsed. He focuses on deceased donations in India to reduce commercial organ donation. In the context of increasing commercial living donations, he cites the THOA model's limitations, a lack of infrastructure, and a "mentality that won't support it" (Cohen, 1999).

[7] See for more details: Cohen (1999); Crepelle (2016); Garwood (2007); Haagen (2005); Jafar (2009); J. Koplin (2014); J. J. Koplin (2017); Scheper-Hughes (2009, 2001b); Scheper-Hughes and Wacquant (2002); Rothman et al. (1997).

The debate over how to increase the supply of transplantable organs reveals two opposing sets of values: those of altruism, or gift-giving, and those of individual rights, or property rights (Joralemon, 1995). Both can be considered forms of objectification of the body and its parts. Joralemon compares these to immunosuppressant drugs, which are used to prevent cultural rejection of transplantation and its view of the body. Sharp writes that the ideological focus on benevolence is explicitly aimed at encouraging recipients to objectify their new organs as gifts. Recipients are desensitized to the idea that these gifts bear any emotional attachments or other qualities associated with their donors (L. A. Sharp, 1995, p. 369). Sharp argues that these activities indicate ideological conflicts. "Procure" and "gift of life" are employed in the transplant procedure as euphemisms to depersonalize the operation and avoid implying the commodification of human parts.

Most materials released on the problem of organ trade highlight the human rights perspective (Ignatieff et al., 2011; Jafar, 2009). In contrast to this position, some scholars argue that commercial organ transplantation or legalizing the organ trade is a viable solution to both the lack of organs and the problem of organ trafficking (Brooks, 2003; Bryan, 2009; Howard, 2007; Taylor, 2006a), however, this has been often rejected on human rights grounds. While Scheper Hughes criticizes these markets stating that people who defend organ markets presume that they can buy life at any cost based on the idea of assumed universal desire to live long (Scheper-Hughes, 2005). James Stacey Taylor defends his view of organ markets by stating that it is purely based on the right of personal autonomy and concern for human wellbeing to save lives (Taylor, 2006b). Scholars who support commercial markets justify it as a win-win situation for both recipients and donors, since the organ will save a life and the payment of the organ will help poor donors in gaining financial and economic benefits (Brooks, 2003; Kennedy et al., 1998; Taylor, 2006b). However, this view has been challenged, because after receiving financial compensation for selling their kidney, donors are usually not better off economically but instead face additional health deterioration that puts them at risk of long-term income loss (Cohen, 1999; Goyal, Mehta, Schneiderman, & Sehgal, 2002; Kumar, 2020).

On the other hand, the literature on the critique of biomedicine also discusses the virtues of technological imperatives and criticizes the assumption that biomedicine is universally practiced, i.e., the implicit assumption that biomedical technologies can be readily introduced across cultures without expecting major differences in their acceptance or application in different societies. However, not considering social and cultural differences when introducing biomedical technologies to a different setting can prove to be disastrous. Ultrasonography is a tragic example of this: in countries where male offspring are more valued than females,

ultrasound imaging was not used to simply detect anomalous developments of unborn children, but to detect the biological sex of the unborn child, which led to a high rate of abortions of female fetuses (Akbulut-Yuksel & Rosenblum, 2012). In contrast to the assumption of easy "translatability" of any form of biotechnology, scholarship in anthropology, science, and technology studies has amply demonstrated that cultural context matters (Brodwin, 2000; Hogle, 1995; Lock, 2002; Marshall & Koenig, 2004).

Ethnographic studies on organ donation and transplantation, e.g. in the USA, Canada, Japan, Mexico, Europe, and India, offer specific insight into the impacts on the social life around these technologies as well as the manner in which the practice of transplantation across borders shapes the bodies of the living and of 'brain–dead' people[3] (see, for example, Cohen, 1998, 2002, 2005; Crowley-Matoka, 2005, in press; Fox & Swazey, 1974, 1992; Hogle, 1995; Lock, 2002; Mukherjee, 2018; Scheper-Hughes, 2000, 2004; Sharp, 2006). In addition to shedding light on the potential benefits and dangers of organ transplantation, these studies serve as a helpful reminder that there is no right approach to implementing this particular biomedical technology in any given case. Margret Lock's work on the reinvention of death and transplant medicine in North America and Japan made important interjections in shaping our understanding of how technology tends to follow disparate trajectories in distinct cultures.

The source of transplantable organs is a severe ethical dilemma. Recently, options have become available that do not require human donors, such as xenografts (organs from animals), and artificial organs. However, these alternatives are still limited in their current application, and so far, living, and deceased donations from humans are the most common sources for organ retrieval. Plough (1986), and Koenig (1988) were among the first to raise the alarm about the technological imperative. These authors point out that physicians who research new therapeutic techniques travel along the experimental-therapeutic continuum to improve medicine and treatment. Initially, they have to evaluate whether the experiment is worth the risk to the patient. If the early trials are successful, the drug, device, or intervention is gradually introduced to more patients until, at some point, it becomes standard treatment. Both the biomedical and the wider public cultures believe that there is a technological cure for every ailment and that every patient should be offered the latest treatment (Ikels, 2012). The mere availability of treatment makes its use inevitable (Kaufman, 2013; Kaufman, Russ, & Shim, 2006).

S. R. Kaufman claims that in the United States, people in their 70s felt a “mandate to live” and their adult children or even spouses of similar age would donate kidneys. Kaufman questions the right to life and health and asserts that due to limited and expensive medical services, shifting demographics, and growing social demands, the “right to live at any cost” for older people should be questioned if it comes at high risk for young lives (Kaufman, 2013). Hogle has investigated the processes by which bodily materials are processed and turned into therapeutic tools that are subsequently used to prolong life (1996). Western literature talks about an aging population relying on the bodies of the young children and grandchildren as donors. Kaufman asserts that failure to resist these interventions is due to individuals' or families' inability or unwillingness to accept life's finiteness (Kaufmann, 2005). She calls it the “tyranny of opportunity” in the face of shifting altruism, duty, accounting, and market forces (Kaufman, 2013, S56). Writing about India, Sinjini Mukherjee states that transplantation to elderly people is rare, and that they are regarded as "unworthy recipients" by doctors and the elderly themselves, however the elderly may donate organs to younger relatives (Mukherjee, 2018, p. 25). This illustrates how two different settings adopt the same technology differently.

Disparities in disease prevalence and outcomes can vary due to treatment availability and accessibility. Crowley-Matoka and Lock (2006) explain why these services are scarce, expensive, or too far away for most people, as well as how differences between countries can be easily understood (Crowley-Matoka & Lock, 2006). Hogle was one of the earliest anthropologists to pursue cross-cultural comparisons of these practices explicitly. After studying organ procurement in the US, she turned her attention to Germany. Hogle points out that the donor evaluation process differs between Germany and the US. Compared to Americans, Germans paid less attention to the donor's social history. Recollections of Nazi-era medical experiences make it difficult to talk about "donating your body so that others may live" or ensuring that organs “will not go to waste” (Hogle, 1996, p. 679).

Hogle states that a European trend toward "presumed consent" was resisted in Germany in 1997 by requiring permission through the written will of the deceased, and in the absence of it, the assumption of the next of kin of what the will of the deceased might have been (Hogle, 1995, 1996, 1999). Because of the medical community's need to develop and adhere to standard guidelines for uncommon cases, brain–dead organ transplantation is fraught with controversy. Multiple medical team actions result in the creation of brain-dead donor bodies. For instance,

after performing tests[8] that confirm the brain-dead state of a body, the brain-dead bodies are actively maintained, their heart is beating while the ventilator delivers oxygen to the lungs to keep the organs healthy for the transplant process. According to Hogle, standard protocols must be implemented at the local level, otherwise the attempts to mold bodies into precise standardized tools were often met with opposition (Hogle, 1995, p. 484).

Margret Lock argues that the western genesis of the brain-dead cadaveric organ donor bodies holds the assumption that 'brain death' should be universally accepted as 'death' by everyone involved, including the grieving families. However, she shows the difference between this Western understanding via a comparison with Japan (2002). In Japan brain death and organ transplantation were considered controversial and viewed with skepticism until 1997 and even after then it was limited only to individuals who had previously stated their desire to become organ donors and who had their family's support (Lock, 2002). According to Sherine Hamdy, there is a variety of approaches to the concept of brain death and deceased donation in Muslim countries. For example, deceased donation was legalized in Saudi Arabia, Jordan, Kuwait, and Iran much earlier than in Egypt that only started acknowledging brain death in 2010 (Hamdy, 2012b). However, this may not merely be the effect of religious conservatism. Anthropologists have drawn attention to the broader political and economic circumstances that contribute to a greater acceptance of living donations than deceased donations in these countries, and particularly to the unofficial tolerance of illegal payment to (unrelated) living donors (Budiani, 2007; Hamdy, 2010, 2012b; Aslihan Sanal, 2004; Aslıhan Sanal, 2011; Tober, 2007). These studies made significant contributions to our understanding of how technologies tend to follow divergent paths in diverse cultural contexts.

[8] Guidelines for Determining Brain Death
https://www.health.ny.gov/professionals/hospital_administrator/letters/2011/brain_death_guidelines.htm#:~:text=Generally%2C%20the%20apnea%20test%20is,the%20absence%20of%20brainstem%20reflexes.

2 Methodology

Because of the current coronavirus pandemic, I was unable to conduct field research in Punjab. Therefore, online interviews were conducted with medical professionals to get their views on the current legal situation of organ transplantation and what improvements they think can be made to ease the limitations of THOA and to prevent exploitation of the poor. Along with it, extensive literature research on existing anthropological literature was conducted.

2.1 Open or Semi-structured Digital Interviews

Audio interviews were conducted with two medical professionals who are working in the field of kidney transplantation and nephrology in Jalandhar (Punjab, India). They were asked for their views on the current legal situation of organ transplantation in India and Punjab and if there should be a legal market for organs to prevent the exploitation of the poor in illegal markets, and what they think this market should look like. The interviews were conducted in Punjabi (my mother language) and English, and afterwards transcribed after being translated into English when necessary. The motive for this was to capture the viewpoints, narratives and experiences of professional people directly involved in transplantation and the possible ethical conflicts they experience. Family members were also interviewed for information on funeral rites of my own community in Punjab. The language used for the interviews was Punjabi.

2.2 Literature Research

Documents examined include academic articles and books, written laws, websites, newsletters, press releases or statements, summaries and reports, and countless news articles available from the Google database or general online searches. The literature research focused on three main topics: (1) the current legal situation due to THOA and its social repercussions; (2) Indian religious Hindu beliefs around the body and death and how they affect people's decisions on organ donation; and (3) the bioethics of organ trade and suggestions for regulated markets. The synthesis and intersection of these topics then formed the central research for this thesis. Apart from anthropological perspectives and bioethical discussions, websites included in the research about organ donation in India include NOTTO, MOHAN[9] foundation, OrganIndia.org, and Dadhichi Deh Dan Samiti. Academic articles are covered from a wide range of perspectives

[9] Mohan Foundation is a nonprofit NGO that promotes organ donation. It was started in 1997 in Chennai by philanthropists and medical professionals led by Dr. Sunil Shroff. The NGO's mission is to provide a "gift of life" to every Indian suffering from ESRD (End Stage Renal Disease). https://www.mohanfoundation.org/who.asp

and are accessible in English through online database services that include PubMed, Scopus, Web of Science, Research Gate and Google Scholar. Citavi software was used to manage references for this thesis.

2.3 Qualitative Observations

Despite not being able to travel to India due to the ongoing pandemic, I was able to use personal experiences of death rites and rituals practiced in my own family that I experienced while I was living in India. My family is from a rural village in Punjab, where many different religions are practiced and is therefore a perfect illustration of the complex religious interactions that happen in multireligious India. I interviewed several family members and asked them about the significance of the rituals that were practiced and their own beliefs.

3 The Body of the Dead: Deceased Donation

Death marks the inevitable endpoint of every human life. Since time immemorial, the relationship between the dead and the living has been of crucial importance to many human societies. Defining death, or what exactly constitutes a 'dead body' is therefore far more than a medical necessity or a simple biological reality: it is a complex task that touches upon many spheres of human activity, from medicine, anthropology, and sociology, to religion, law, philosophy, and lived culture.

Finding a universally applicable definition of death is complicated by the diverse ways in which death is viewed and perceived across cultures. The disparities in the perceptions of death do not only extend to what happens when someone dies and what rites are followed, but also to the question of when life ends, and death begins.

Understanding the challenge of defining death can help us grasp the difficulty of having a single vision of death or the death experience. From a biomedical perspective, it has been more than a century since the cessation of a heartbeat, breathing, and blood circulation, referred to as "clinical death[10]" was solely used to determine the death of a person. Advances in technology allow machines to maintain vital signs. With the invention of ventilators in the 1950s, clinicians were able to artificially maintain the respiration and heartbeat of a patient with severe brain damage that could otherwise lead to respiratory and circulatory arrest. Death was no longer a singular event after cardiopulmonary arrest but appeared to be dissociated into the failure of single vital organ systems. As respiration and heartbeat can be maintained indefinitely, this raises the question if patients on ventilators without brain activity should be regarded as alive, dead, or in the process of dying (Pernick, 1999; President's Commission for the Study of Ethical Problems in Medicine, 1981).

How can life-sustaining organs like the heart, lungs, kidneys, and the liver be removed, while maintaining the body viable enough to allow extraction of as many organs as necessary? These practical questions also connect with traditional medical ethics: How can doctors remove vital organs while bound to the Hippocratic oath, which prohibits them from intentionally harming a patient[11]? In order for a transplant program to be successful in any country, the boundaries between life and death need to be redefined (Lock et al., 2000, p. 268), which led

[10] "The reversible period following cessation of respiration and pulse as 'clinical death' and the irreversible as 'biological death'" (Parish, Goyal, and Dane (2018)

[11] The principle of "First do no harm" is also known by its Latin form primum non nocere.

to a new definition of death as "whole-brain death[12]". This allowed to terminate ventilation of patients in an irreversible coma with no chance of recovery and freed up hospitals beds and ventilators for other patients and it made it possible to obtain viable organs from people with beating hearts (Truog, 1997). Since then, the initial draft of the Harvard Brain Death Committee's proposals on how to define death, the "whole-brain" concept of death has been adopted by many countries worldwide, making it an official legal definition. However, despite widespread agreement among policymakers, using neurological parameters to define death is still problematic.

The new definition of death as 'brain death' has caused widespread misunderstanding among individuals of many cultures and religions. Japan did not embrace this clinical and legal definition of death until a revision of the Organ Transplantation Law in 2009, but socially it remained widely unaccepted (Aita, 2009). Before the revision, the law employed a double standard in which a person could only be declared brain dead if the person had agreed to be a donor and the family gave their consent. Otherwise, the person would not be declared dead and remain on the ventilator till cardiac death occurred. This led to the absurd situation that families could 'choose' whether their loved one was to be considered dead or not, and also led to incredibly low donation rates as most families withheld consent. Under the revised law, brain death is now declared independent of the organ donation decision (Aita, 2009). People frequently raise doubts about whether brain death truly signifies death. Will organs be extracted from someone who isn't 'really' dead yet? For instance, although being certified brain dead, patients appear to be alive because they feel warm to the touch (Pernick, 1999, p. 230; President's Commission for the Study of Ethical Problems in Medicine, 1981, p. 83). Declaration of brain death has been generally accepted and routinely practiced in the United States and other Western countries since the middle of the twentieth century, in accordance with attempts to obtain organs for donation (Gardiner, Shemie, Manara, & Opdam, 2012; Wijdicks, 2002).

Brain death definitions have changed throughout time, and the basic objections they raise are still not settled (Verheijde et al. 2018). A patient may be declared brain dead in one country or region but not in another because of regional and national differences in how brain death is diagnosed (Smith 2020). Anthropologists have long emphasized that death is always

[12] "The "whole brain" standard of death defines death as the irreversible cessation of whole brain function including the brainstem, due to primary brain damage without any chance for recovery (President's Commission for the Study of Ethical Problems in Medicine (1981), ("A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death," 1968).

culturally defined, even though it may be expressed in biological terms. Cross-cultural research from countries like Japan, Mexico, and India highlights the critical importance of the larger social context in which organ transfer takes place. This has revealed that the meanings with which it is imbued and the actions that it authorizes are not the same everywhere (Cohen, 2001; Crowley, 2001; Lock, 2002; Lesley Alexandra Sharp, 2006; Swazey, 2017).

3.1 Introduction of THOA, 1994

In 1989, surgeons who attended a global meeting on transplantation in Canada[13] stated that "in India, the commerce in organs seems to be getting out of hand and there is a need for it to be regulated immediately" (India Today, 1990) (Chengappa 1990). The WHO also warned in the early 1990s that "the [organ trade] was approaching dangerous proportions in the third world, especially as modern medical technology proliferates," (Hedges, 23-Sep-91). During the 1980s and 1990s, India was derided as an "organ bazaar" since numerous foreigners flocked to the country to purchase organs from destitute locals (Chengappa, 1990). It was estimated that in the year 1988 alone, over 2,000 kidneys were sold and transplanted to foreign kidney patients who had traveled to India for transplantation (Abouna et al. 1991: 164). With numerous media reports in the 1980s revealing the practice of organ trade, and surgeons publicly calling for a prohibition (with few exceptions[14]), public pressure for a political and legal response arose (Nundy 1996, Chengappa 1990, Wallace 1992).

In 1989 and 1990, India announced plans to implement comprehensive legislation recognizing brain stem death and barring commercial trading in human organs. In 1991, partly as a response to the kidney scams, the central government constituted a committee to prepare a report which could form the basis for an India-wide new law (De Cruz 2001: 591).

On the 20th of August 1992, the Lok Sabha introduced the Transplantation of Human Organs Bill. On the 21st of December 1993, after a select committee had completed its investigation, it presented a detailed report that recommended banning the sale of human organs. With India desperately hoping to improve its poor global reputation as a 'warehouse of

[13] Health and Welfare Canada and The Transplantation Society cohosted the event, The First International Congress on Ethics, Justice, and Commerce in Transplantation: A Global View took place in Ottawa, Canada between August 20 and 24, 1989.

[14] Such as Dr. KC Reddy, who was an ardent advocate of commercial transplantation and had established a commercial transplant clinic. In stark contrast to most reports regarding commercialism in India, Reddy's practice was allegedly "exemplary" and lacked many of the negative features traditionally associated with commercialism, such as coercion, lack of follow-up care, fraud, etc. (Cohen 2003, p. 664)

kidneys,' the government finally took legislative action (Agarwal et al. 2012; Chengappa 1990; Kakodkar, Soin, and Nundy 2007). Following the select committee's recommendation, the bill was debated again in both Houses of Parliament. The bill was passed by both Houses of Parliament and obtained presidential assent on July 8, 1994, becoming the "Transplantation of Human Organs Act, 1994 (42 of 1994)".

There is no doubt that the law has made some significant contributions to medical practice and transplant therapy. One of the major contributions was that it clearly defined "brain death" and made it a legally and medically acceptable category, allowing deceased organ donations in the country.

THOA aimed to establish deceased donation as a morally acceptable form of social good and tried to establish donation as a "gift of life," modeled on the approach to transplantation common in Western countries like the USA. The goal was to establish deceased donation as the more usual form of transplantation, with living donation as the exception, and only permissible among close family and friends, which required authorization by a committee. However, the success of this approach is questionable, as living donation outnumbers deceased donation and the illegal organ trade, which THOA tried to overcome, still persists.

3.2 Giving and Receiving the "Gift of Life"

The pioneering work of Marcel Mauss on the subject of gifting and exchanging has had a significant influence on current sociologists. According to Mauss, gift giving is part of a larger cultural relationship based on reciprocity between the donor and the recipient (Mauss, 1925). Organs as "gift-giving" was an idea that was proposed to highlight the eventual importance of donation, while simultaneously maintaining the moral ideal that a body cannot be owned and traded as a property (Sque & Payne, 2006, p. 119). Donating organs is viewed as an extremely valuable offering by the organ transplant community[15], which employs the construct of a "gift" and its derivative expression, the "gift of life," to convey the value of this offering. The term "gift" appears frequently on websites, booklets, and media portrayals aimed at encouraging organ donation and transplantation. However, calling organ donation a "gift of life" overlooks the nuanced emotional and interpersonal ramifications of giving a physical part of one's body.

[15] "Transplant community include donors, both brain–dead and living; donors' families and friends; patients with life-threatening chronic illness; patients' families and friends; and doctors, nurses, social workers, and other members of medical teams on various hospital units" (Heinemann, 2008).

It also ignores the differences in meaning that gift giving can have in different cultures, making a universal approach to organ donation as "gift giving" dubious.

As of April 2022, over 100,000 people were waiting for a transplant organ in the USA (OPTN data 2022), despite the country having a deceased organ donation (DOD) rate of 38.03 people per million (ppm), which is moderately high globally ("IRODaT - International Registry on Organ Donation and Transplantation," 07-Feb-22). Nineteen countries in total have high DOD rates of above 20 ppm ("IRODaT - International Registry on Organ Donation and Transplantation," 07-Feb-22). Spain leads the list with a DOD rate of 48.9 ppm. Despite the numerous efforts undertaken by several countries, it appears that meeting the growing demand for organs will be difficult in the foreseeable future (Kessler & Roth, 2014). According to Sharp, "the phrase 'gift of life' is intended to evoke the values of humanitarianism, compassion, and selflessness in potential donors" (Sharp, 1995: p. 370). In principle, the existence and widespread use of transplantation as a means of avoiding death make nearly everyone a possible source of life-saving body parts, which Cohen refers to as "bioavailability" (Lawrence, 2005).

The capacity of transplantation to function is contingent on public engagement and acceptance of organ donation. Organ donation (especially deceased donation) has been promoted around the world and organs come from both living and deceased donors. The concept of donating and receiving organs is based on moral attitudes and perceived obligations for ethical behavior among people and their close relatives (Howard, 2007).

Lack of awareness, education, generosity, and religious obligations are frequently cited as reasons for low donation rates. Comparative studies on the development and implementation of organ transplantation throughout the world illustrate that it is critical to consider how local cultural values, politics, medical and commercial interests contribute to variance in the local forms of this technique and to the "gift of life" idea. In societies like Japan, individuals may fear being the recipient of a large and impressive gift. Such a gift can humiliate the receiver, who has no way of repaying it in societies where the demands of gift giving are very elaborate (Lock, 2002). Renée C. Fox and Judith P. Swazey have called this "the tyranny of the gift" (1992:40). A truly extraordinary gift is "inherently unreciprocal," as there is nothing the recipient can give back to the donor that has approximately similar value and therefore remains in debt indefinitely. Japanese transplant receivers therefore may feel a burden of responsibility towards the living related donors: "If the donor falls ill, or if the transplant is rejected, even

years later, the recipients experience overwhelming remorse and a sense of failure" (Lock, 2002:334).

With the introduction of THOA, India tried to establish the western approach to organ transplants as a "gift of life" within the country (Sharp 2006). However, this concept is often promoted and presented with Indic conceptions of the gift as 'Dāna' to increase the organ donor pool (Ibrahim, 2014). Farhana Ibrahim asserts that the organ transplant laws in India find an "elective affinity" with Hindu and Jain debates on death, which makes it possible to successfully integrate the "gift of life" concept. In her ethnographic research in Gujrat state (a Hindu majority state), she emphasizes the successful translation of the global discourse surrounding organ donation into "culturally significant idioms within India", especially in the case of deceased donations (Ibrahim, 2014).

However, if the Indian government's strategy to promote organ donation is geared towards a Hindu discourse of gift-giving in the form of *dāna*, other religious groups who do not subscribe to the concept are automatically excluded. It is also questionable how successful this strategy is in addressing the over 960 million Hindus[16], as deceased donation rates remain exceptionally low. India ranks second in the world in terms of live donor transplants after the United States, but the rate of deceased donation is so low, that it is absent from the global list of deceased donor transplants[17]. In India, as estimated in 2017, 115 million people suffer from chronic kidney disease and 220,000 people die each year because of end stage chronic renal diseases without receiving transplant kidneys (Bikbov et al., 2020; Jha, 2013). Every year, the country requires 258,000 organs, including 185,000 kidneys, 33,000 livers, and 50,000 hearts, yet only 6,000 kidneys, 1,200 livers, and fifteen hearts are transplanted (National Organ Transplant Program). These figures show that the elective affinity of Indian Transplantation law and advertisement of organ donation as *dāna* has not been successful in increasing deceased donation, which was one of the key purposes of THOA.

[16] 2011 Census of India, https://censusindia.gov.in/census_and_you/religion.aspx
[17] Tamil Nadu, on the other hand, has performed admirably in organ donation, with 1.4 donor pmp (Abraham et al. (2012)).

4 Concepts of Death

The conceptions of death and the body that accompany transplantation still face substantial cultural resistance both nationally and internationally (Joralemon, 1995). In many cultures, death is viewed as a social process, particularly among non-Western societies, in which elements of a person continue to exist after they pass away. Culturally identified signs of death such as cessation of heartbeat and the gradual decrease of body temperature allow grieving friends and family to observe the "process" rather than the "moment" of death (Ohnuki-Tierney et al., 1994, p. 235). However, the concept of brain death has created an altogether different type of death. Medical professionals are the ones who make "death" happen, preventing the family from experiencing it as a gradual process. The introduction of brain death changed the traditional definition of death from being heartbeat/respiration-based to being based on brain function, allowing some previously alive patients to be labeled dead. This new definition makes it medically and ethically acceptable to consider deceased people potential sources of viable organs for transplantation.

The body of the deceased is of critical importance for social death in some societies. People's decisions to donate the organs of deceased family members may be influenced by sociocultural belief and conventions concerning the disposition of the corpse. If it is believed that one's ancestors live on after death, mutilating the body will disrupt a tranquil existence beyond death for both the departed and the living. This is a view shared by both the Japanese and Chinese communities, but for varied reasons. Many individuals in Japan are opposed to organ donation because it contradicts Japanese Buddhist ancestor worship beliefs (lock 2002). Buddhists believe that departed family members become ancestral spirits who must be acknowledged and appeased (Lock 2002).

Some cultures in Europe (e.g., Italy) and the United States, have an open casket in a traditional funeral, which involves public "viewing" of the dead. Modern American and European funeral practices sterilize and commercialize death. Morticians will prepare the body by washing, dressing up, and using make-up to make the person look alive, to make the last image of the deceased beautiful for the family. This, to some degree, distances people from death and changes the image of their loved one as being asleep and not as a dead body (Varisco, 2011). The commercialization has been successful because of the cultural significance of the dead body for the social process of dying and funeral rites (Ohnuki-Tierney et al., 1994). There are also examples of the mummification of bodies in some cultures to preserve them after death, and veneration of their body parts. Praying to relics of saints for example is a common practice

in Catholic Christianity (Kiong & Schiller, 1993). Therefore, in the perception of some people, the removal of organs from the brain dead constitutes an act of transgression that deprives the deceased of the final process that enables them to leave this world with dignity and as persons – a social and cultural death.

But does this also mean that Hindu religious beliefs about death and bodies make people reluctant to donate organs in India? In India, dominant liberal discourses describe organ donation as a generalized social good. This is due in part to legislation that restricts the circumstances under which human organs may be transplanted. As a result, the law establishes a distinction between tangible, commercial transactions and donations motivated by emotion, attachment, charity, or love. Subsequent parts examine mainstream Hindu conceptions of death and the body and their relationship with organ donation.

4.1 Death in Hinduism

Hinduism, Islam, Sikhism, and Christianity are the four major faiths practiced on the Indian subcontinent, and customs, beliefs, and perceptions of death differ among them. In many cultures, death has a purely negative connotation (Kübler-Ross & Byock, 2019), but in the Hindu religion, it has a positive facet as well as significance for life, as Hindus believe that a person can attain liberation from the cycle of rebirth only after death. Death is seen as the end of a journey; mortuary rituals are as much a tribute to the departed and their lives as they are intended for the survivors. It is worth noting that Hindus believe in *karma*[18], reincarnation, and liberation – that the sum of a person's actions in the present state of existence affects their future fate and rebirth, while Abrahamic religions postulate a single life for the soul, followed by a reward or punishment on the Day of Judgement (Mannan, 1995).

The word 'death' in Sanskrit, written as "*dehanta*," derives from the two words "*deh*" (body) and "*anta*" (end), literally meaning "the end of the physical body". However, physical death may not "necessarily mark the end of that person's social life" (Bergstrom, 2017). According to Hindu philosophy, there is a distinction between the body and the soul; when a person dies, they will be reborn with a new identity; thus, death can be defined as "the departure of the soul from the body" (Setta & Shemie, 2015). On the other hand, some religious gurus

[18] Karma is "one of the most important principles in Hindu thought,"... And it refers to 1) any act or deed; 2) the principle of cause and effect; and 3) a result or "fruit of action" (karmaphala) or "after effect" (uttaraphala) that returns to the doer sooner or later. We will reap what we sow in this life or future lives. Much as gravity is an impersonal law of the outer cosmos, Karma is a neutral, self-perpetuating law of the inner cosmos. Desai (1989, p. 32).

may not be reborn after their physical death but instead maintain important social roles in the community as spiritual advisers and religious authorities, communicating with community members through a medium [19].

To illustrate the significant role of family and community and how the dead are intricately linked to the living in Hindu death rituals, I will describe the death rites I experienced in one particular community in India. The rituals practiced there are an example of Hindu death rites in general, although their particular expression differs among communities and regions. The traditions I describe are of my own community and took place on the occasion of my paternal great-grandfather's death. They illustrate the death rituals of a predominately Hindu[20] family in the village of Haripur, which is part of the Jalandhar administrative district, in the Doaba region[21] in Punjab, Northern India. Haripur is a small, historically agricultural village of about five thousand people. Residents are split between a "*basu*" (native) group, whose ancestors had already inhabited the land, and a "*baria*" (outsider) population, who migrated from Pakistan during the division of India. Most of the population is SC[22] (scheduled caste). My family are of the Valmiki caste (also known as Balmiki, Chura, or Bhangi) and belong to the "*baria*" (outsider) population. Most of my family members identify as Hindu, but often follow Sikh and occasionally Muslim customs. However, death rituals are predominantly Hindu.

When my great grandfather was gravely ill, his children were called and told that their father was nearing the end of his life, so that they could all join him in his final days. His daughter was spooning holy water[23] into his mouth while sitting next to him. At one point, he stopped moving his lips. His daughter checked his breath by moving two fingers in front of his

[19] When my family's guru died in 2015, his body was not cremated but buried in the temple he used to serve. His followers still communicate with him for advice through a medium that is my father. The final disposition of one's body after cessation of life is usually by donating it to fire by way of cremation and in certain sects, children, and sanyasis, by burial directly in the soil.

[20] Religious identity is complicated and religious traditions are sometimes not followed exclusively. The same family may follow Hindu, Muslim, and Sikh customs, and in family homes religious figures of multiple traditions may be displayed and venerated. In practice, describing a family as "Hindu," "Sikh," or "Muslim" can be difficult because people's religious lives frequently take place outside of these strict divisions.

[21] The Doaba region lies between the Beas River and the Sutlej River, and includes the districts of Jalandhar, Kapurthala, Hoshiarpur, and Nawanshahr.

[22] The Simon Commission (1927) coined the phrase "Scheduled Caste," which was used in the Government of India Act, 1935, following the Commission's recommendations. The Government of India decree, published in April 1936, designated some castes on the list of oppressed classes as Scheduled Castes. 'Scheduled Caste' refers to castes, races, or tribes, as well as sections or groups within those castes, races, or tribes, as defined under clause (1) Article 341 of the Indian Constitution.
https://web.archive.org/web/20120829160224/http://socialjustice.nic.in/scorder1950.php .

[23] Ganges water is considered holy and it is an important death ritual to pour water drops into the mouth of a person before their last breaths(Purnell and Fenkl (2019)).

nose and his heartbeat by placing an ear on his chest. With tears in her eyes, she finally said "*Bapa*[24] is gone."

As in previous generations, the halting of the heartbeat and breath defined the moment of death of my great grandfather. In every society, the culturally defined death of an individual must be acknowledged as the social death of a member of that society (see Metcalf and Huntington 1991). In most societies, a death initiates a prolonged, institutionalized series of rituals, often involving considerable financial and human costs. Before the funeral, the body was washed and dressed. During an interview with my mother (Surjit Kaur), she explained that there are three important showers in a person's life:

> "There is *pehla naun dai da* (the first shower by the midwife after birth), *dooja mai da* (second shower by the mother upon marriage), and *te teeja char bhai da* (last shower by four brothers or male relatives after death)."

The shower thereby signifies important transitions in life. With the shower, the old life is washed away, and the next part of life is entered. Following that, his bed, where he lay after showering, was decked with flowers, balloons, and decorations. This signified the celebration of his "good death." There was no great outpouring of grief and emotion like I had witnessed at other funerals in the community, even though everyone was sad. Instead, some suggested that he had ascended a golden staircase, implying that he had seen and loved and achieved everything in life, and died surrounded by his children, grandchildren, and great-grandchildren.

There might be regional differences between Hindu death rituals, however all strata of Hindu society share the distinction between "good death" and "bad death." A "good death" is only possible for people who die a peaceful, natural death of old age, with no lingering hopes or dreams (Christof Heyns & Viljoen, 2001). "Bad deaths" are violent and premature, or from visible diseases (Justice, 1997, p. 229).

After the shower, my great-grandfather was carefully set on a chair and a picture was taken with him surrounded by the children of the family who touched his feet as a final gesture of respect. Touching and seeing the dead body (and even taking family pictures with it), is an interesting contrast to funeral rites and attitudes towards death and dead bodies in many European societies. In Germany for example, public viewing of the dead body is outlawed[25].

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[24] The title used for father in Punjab.

[25] See for example *Bestattungsverordnung of Baden-Württemberg*, § 13 "Verstorbene dürfen nicht öffentlich ausgestellt werden." (The public display of the deceased is forbidden.) https://www.landesrecht-bw.de/jportal/;jsessionid=F44CE686804A63F94B3A18A033A8B5AA.jp91?quelle=jlink&query=BestattV+BW&psml=bsbawueprod.psml&max=true&aiz=true#jlr-BestattVBW2015pP13

Private viewing of the dead is possible, but many people show great aversion and fear towards the dead and handling deceased bodies is usually done by funeral houses, instead of the families themselves.

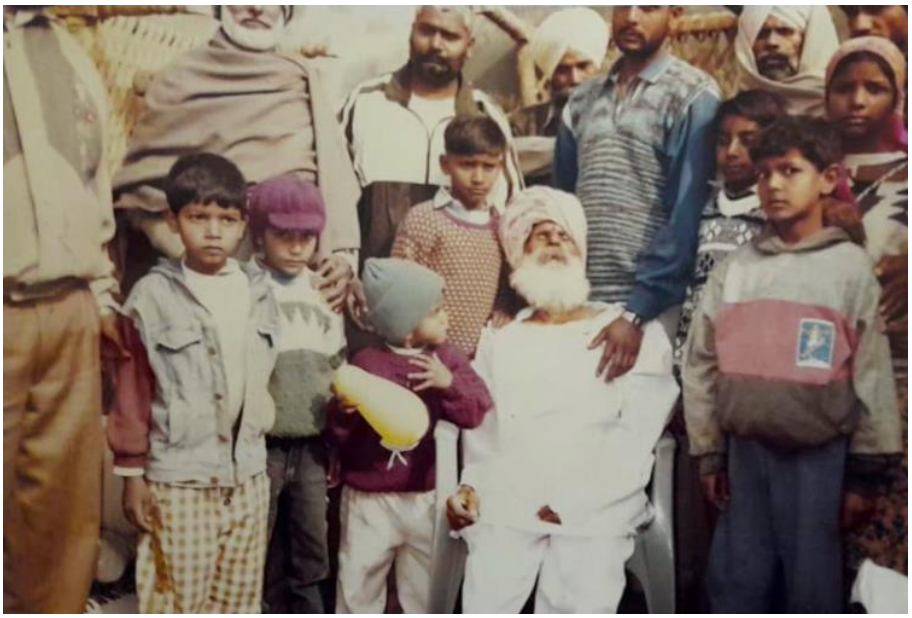

Figure 1 The body of my great grandfather, surrounded by his children, grandchildren, and great grandchildren during his funeral rites. Some of the children are holding balloons, signifying that his "good death" is a joyous occasion. My uncle and my brother placed their hands on his body to express affection. The physical touch also illustrates that there is no reluctance to touch the body of the dead, and he is still treated in a manner similar to when he was alive.

After the picture was taken, he was placed on a funeral bier called *arthi*. A pot with burning coals was set by his feet, and everyone came to pour ghee into it and pay him tribute. He was getting prepared for *Antim Sanskar*, the final rite of passage.

When four men, typically close relatives, carried him on their shoulders, s*hawaras* (dried dates) and money were tossed over the *arthi* in the hope that a relative would collect them and experience the same type of life and death as him. The coins that were tossed over the dead body were then placed around the necks of babies to protect and bless them. The coins carry with them the good fortune of the deceased person who lived a happy and full life, and the hope is that the coins will carry this good fortune to the new generation (Surjit Kaur, Satnam Singh, 25/01/2022). Symbolically, the rite connects the departed with the living, creating a circular vision of life and death. The blessed babies may live long lives themselves, and after they die, their blessings may be passed on again. Throughout the funeral rite, life and death are continuously connected, and death marks not only the end of a good life but also contains the seed for a good life for others.

The four men, including his sons and grandsons, carried his body on the *arthi* toward the cremation place on foot. Before entering the cremation place, they placed the body on a

concrete slab a few hundred meters away from the cremation site. The eldest son, who was carrying a water pot[26] on his left shoulder, walked around the body three times counterclockwise and stood south-facing, throwing the pot backwards next to the head so it broke into pieces. The water and the pot represent life. The breaking of the pot was a very emotional moment for the family, as it is a symbol of the end of this life and the beginning of the next stage for the deceased. As Jonathan Parry describes, it suggests the end of the bond between the departed and the family (J. Parry, 1994, p. 177). After the pot-breaking ritual, they picked up the *arthi* again and continued towards the cremation place, where the *arthi* was carefully placed to the side, and the procession joined in building the funeral pyre that other family members had already started building. The pyre was made of wood and straw with a platform on top, where the dead body was placed, after which more wood was placed on the top. Then the chief mourner, in this case, my grandfather, lit the pyre: the ritual is known as *dag dena* (to set on fire).

In some communities, a ritual *kapal kirya*[27] (breaking the skull) is performed when the body is almost burned. The eldest son breaks the skull with a pole, the intention is to release the deceased's "vital breath" as well as to enable relatives and friends to comprehend that the spirit has already begun its journey to a new destination (J. Parry, 1994, p. 6). However, this ritual is not performed in my community. After placing the body on the pyre, another ritual called *khopri thorna* (to knock or hammer the head gently) was performed, in which the head is touched with a pole, then circled with the pole, after which the pole is placed on the earth. This process was repeated seven times (Raj Rani, 30/01/2022). Interestingly, none of my interview partners knew the meaning behind this ritual, although they all agreed on the importance of it. One could speculate however that it is a symbolic rendition of the more violent *kapal kirya* ritual. The pyre burned throughout the night, guarded by a night watch. The next morning, the ashes were gathered by the family, which is called *Phul chugna* (collecting of the flowers). They were then brought to Kiratpur, a town 100km west of Haripur that is of religious significance to both Sikhs and Muslims, where the ashes of my great-grandfather were distributed in the Satluj river.

The death of a prominent member of the family also begins a cycle of shifting responsibilities among family members. Four days after the cremation, it is time for the *antim*

[26] Jonathan Parry in his book Death in Banaras relates the breaking of the water pot as a symbolic representation of “Kapal Kriya” breaking skull ritual J. Parry (1994)

[27] "In fact, Kapal kriya consists of a general breaking up of the partly incinerated corpse and a stoking of the fire so that it is more completely consumed” J. Parry (1994, p. 177)

ardass, the last prayers. Another custom that follows, known as *rasam pagri* or "ritual of turban", implies the transfer of responsibility as head of the family, in which the turban of the deceased male is put on the head of his eldest son. This signifies that he now carries the honor and responsibility as head of the family (Copeman, 2009, p. 60).

In Hinduism, the belief is that the body merely serves as a transitory receptacle for an immortal soul in this world. The soul is immortal and immutable. Life after death is a fundamental tenet in Hinduism, and it is part of a continuous cycle of rebirth that occurs after death. The next life of a soul is determined by the rule of *karma*. When a person dies, his or her particular soul departs from the physical body and, depending on one's past actions (*karma*), either permanently gains liberation (*moksha*)—completely merging with the universal soul—or takes another birth in a different physical body.

In Hindu philosophy, humans were conceived by the gods and the body was encased in a sanctum of air, water, land, sky, and fire, the five elements of creation. They transform from one form to another form, from one body to another body, or from one place to another place, when the soul leaves the body (B. Parry, 2012, p. 17). Although many people regard the physical integrity of the deceased body as vital, it is not thought to be necessary for reincarnation. In the *Bhagavad Gita*, the relationship of a mortal body with the immortal soul is compared to that of clothes and a body: "As a person discards worn-out clothes, he or she replaces them with new ones, so the embodied soul, casting off worn-out bodies, enters into new ones[28] (Fosse, 2007, p. 16)". The body's perception as a vessel also implies that the physical integrity of the body post-death is not crucial. These principles, therefore, are often used to argue that Hinduism lends itself easily to the idea of deceased donation and organ transplantation (Copeman, 2006). Copeman argues that prominent Hindu reformists and revisionists see cremation as outdated and wasteful and encourage organ and body donation (Copeman, 2006, p. 104).

4.2 Reformed Ideologies: 'Organ Dāna'

Dadhichi Deh Dan Samiti (Dadhichi Body Donation Society; henceforth, the Samiti) is a Delhi-based organization that advocates body donation (*deh-dan*) for dissection and organ transplantation. The Samiti leadership has links to Hindutva organizations. The name of the organization is based on the story of the sage Dadhichi, as told in the *Brahmana Purana* and

28 "Vasamsi jirnani yatha vihaya navani grhnati naro parani, Tatha sharirani vihaya jirnan nyanyani samyati navani dehi" (Bhagavad Gita chapter 2:22).

the hymns of the *Rig Veda*, which is the inspiration for the organization. The sage Dadhichi is a Sanskritic emblem for bodily donation, asceticism, and selflessness, and he is honored by the organization. According to the mythological story, Vritrasur, the demon king, threatened the world and could not be defeated by ordinary weapons. Therefore, Indra asked Dadhichi[29], who had transformed his body into a state of pureness by ascetic practice and continual penance, to sacrifice himself, so a weapon could be made out of his bones to defeat the demon king. Dadhichi's sacrifice follows an ideal of ascetic practice, in which penance is not performed for personal gain, but ultimately for the welfare of society (Copeman, 2006)(Prakash 1999 p. 151).

According to Copeman, religious leaders are frequently at the forefront of advancing knowledge of socio-medical issues in their communities. He states that "effluent bio-spiritual medical creativity" is promoted in India most often through the usage of guru figures, which showcases a tight relationship between medicine and religion (2009: 132). The *Samiti* arranges annual festivities during which wills are carried out and various speeches are delivered by religious dignitaries. They portray the stories of ancient mythologies and relate them to organ donation to support the use of body parts.

> "Of all the things that it is possible to donate, to donate your own body is infinitely more worthwhile," (The Manusmruti) (Venkata Siva Sai, 2014, p. 148).

The above-mentioned quote appears frequently in various pamphlets and websites[30] used to encourage people to do organ *dāna* (donation). *Dāna*[31], (donation or the unselfish giving of aid), is an essential concept of Hinduism, Buddhism, Jainism, and Sikhism (Coles, Das, Lahaie, & Szymanski, 2012, p. xv; J. Parry, 1986, p. 461). Gift giving as *dāna* is described in great length in *Dharmaśāstra* literature, a significant branch of Indian philosophy that is concerned with the ethics of righteous living. Within *Dharmaśāstra* is a synopsis called *dāna-nibandhas*, which describes *dāna* as one category of the moral and religious responsibilities of a person (Heim, 2004). To be a good human being, one must be willing to give and assist those in need. This is an inalienable and obligatory virtue of every person.

The *dāna* ideology offers an interesting contrast with gift-giving based on the work of Marcel Mauss. His research had a significant impact on western ideas of gift-giving: He states

29 See Copeman (2006) for a fuller account of the samiti's activities. Myths surrounding Dadhichi are analyzed by Babb (2004). See also Heim (2004:138) on bloody gifts of the body (deh-dan) as discussed in Hindu and Buddhist sacred texts, and Reddy (2007) on Indians in Houston looking to mythical examples of bodily gift-giving as templates of a kind for their own giving of blood for genetic research.

30 https://www.giftoflife.on.ca/resources/pdf/Hindu%20Brochure%20EN%202019.pdf, ("Hinduism and organ donation - NBTA," 2019-04-14BST15:05:20+01:00, p. 26), https://beadonor.ca/campaign/hss-canada.

31 There is no single logic of *dāna* shared by all participants and present throughout the whole of Indian society (Laidlaw, Riches and Renunciation, pp. 294-295).

that a gift always contains an obligation of reciprocity. It may appear free and gratuitous; however, it actually elicits a counter gift from the recipient (Heim, 2004). Gift reciprocity, according to Mauss, builds social peace by fostering balance and mutuality. The gift thus is unilateral while building bonds of exchange and mutuality. It is claimed that Hindu philosophers disagree with the reciprocity theory and that *dāna* is asymmetrical and is a gift for which no return can be countenanced unreciprocated (Copeman, 2009, p. 27; Heim, 2004, p. xviii). Similarly, Jonathan Parry's 'The Gift, the Indian Gift and the "Indian Gift"' (1986) also claimed to overturn the classic treatise of Mauss on the gift as foregrounding reciprocal social relations, by arguing that market societies idealize the distinction between gifts and commodities, and that classical notions of *dāna* in Hinduism do not necessarily subscribe to the idea of reciprocity (J. Parry, 1986).

Dāna is claimed to be a positively valued, one-way gift. It is supposed to purify the donor by enabling riddance of accumulated sin or impurity (Heim, 2004). However, Parry argues that in this formulation, the gift as *dāna* also 'comprises the sins of the donor, whom it rids of evil by transferring the dangerous and demeaning burden of death and impurity to the recipient' (Parry 1986: 459). This transference of inauspiciousness to a "worthy" recipient is what Raheja (1988) calls the 'poison in the gift'.

Some argue that even though the donation of organs might be one way for donor individuals and their families to acquire spiritual merit, it is not seen as the transference of evil. Considering this aspect of the gift as *dāna*, one does not pass on evil in an expiatory act by the giver (Heim, 2004). Laidlaw describes the conditions necessary for dan as a free gift: no reciprocity from the receiver and a de-personalized gift exchange. There is no special recognition or thanksgiving from the side of the recipient. If the *dāna* is food for example, it would not be specifically cooked for the recipient, but would be left-overs from the family meal (Laidlaw, 2000). Thus, the *dāna* is not given with the intention of receiving merit from the receiver and does not establish a special relationship between giver and receiver. Laidlaw concludes that "a good gift is given 'without desire.' It is un-premeditated and prompted by either reverence (bhakti) or compassion (daya) for the recipient" (Laidlaw, 2000, p. 624).

An array of humanitarian and philanthropic groups, and the government most notably, aim to use *dāna* as an instrument to promote a public "giving culture" by utilizing it for organ donations. This seems to make organ donation acceptable as a mode of medical altruism that would otherwise be culturally alien to most people (Ibrahim, 2014). There are many illustrations of how the idea of 'gift of life' in relation to *dāna* dominates official speeches,

organ donation promotional societies, websites, and published materials. In India, corneal donation (*netradaan*) and blood donation (*raktdaan*) programs are well developed, and directly linked with the notion of *dāna* (Copeman, 2009). In order to increase potential organ donors, the state expended enormous effort in promoting greater acceptability of the most contentious aspect of deceased donation. The government of India often uses religious merits: for instance, in a promotional tweet about organ donation on National Organ Donation Day on November 30, 2021, the Ministry of Health tweeted:

> "Don't take your organs to heaven with you. God knows we need them here" (https://twitter.com/mohfw_india/status/1332199177871183873).

Figure 2 Tweet from the Ministry of Health, India

The Indian government's organ donation website (NOTTO[32]), and two NGO's websites named "Organ India" and *Dadhichi Deh Dan Samiti* are other examples where the language of *dāna*, immortality, and religious merits are being used. The promotional advertisement on the first page of the NOTTO website says "अंगदान जीवनदान जीवन दान महादान" *Angdaan Jivandaan*

[32] National Organ and Tissue Transplant Organization https://notto.gov.in/

Jivandaan Mahadaan ("Donating body parts is giving life, and giving life is the greatest donation[33]").

Figure 3: NOTTO Homepage with the promotional slogan prominently featured.

Figure 4: Illustration of the "One Time Pass to Heaven" in the Organ India advertisement brochure https://www.organindia.org/MTVOrganDaan/

Another example of the use of religious ideas to promote donation is from an NGO called "Organ India," also representing organ donation as *dāna* (see Fig. 4). It is marketed as *"#MTVOrganDaan, #YourOTPtoHeaven*." OTP means "One Time Pass," implying that after

[33] Translation by author.

organ *dāna* the donor will be removed from the cycle of life and birth, will attain *moksha*, and remain in heaven[34].

The Sanskritic Hindi used by the NGO websites and Indian government websites is replete with copious allusions to Hindu scriptural precedents for donation and 'renunciation' of the body. They are appealing specifically to the Hindu community, which excludes other religious communities that do not relate to this ideology (Ibrahim, 2014). This strategy can be culturally significant to people and succeeded to some extent, as the *Dadhichi Deh Dan Samiti* claimed to have encouraged 1150 people to donate their bodies (https://dehdan.org/). These initiatives urge people to donate their organs considering it as a *dāna* for the betterment of another human being.

Promoting organ donation as *dāna* suggests that it is an attempt to popularize organ giving as a common good. Organ *dāna* is presented as a shortcut to salvation to people by linking it to religious ideologies; when promoted as an act that allows people to breathe life into another, it simultaneously generates the rebirth of the other body and achieves immortality (Copeman, 2006, p. 119). However, Laidlaw states that making a *dāna* is meritorious, an act of *punya* or good *karma*, so the donor will profit from being the giver of the gift. No one, however, can have an impact on the nature of the reward. It could happen at any time or even in a future life (Laidlaw, 2000, p. 624). One can argue that there is reciprocity and self-interest involved when donating a body or organs as *dāna*, although not in the form of reciprocity from the receiver, but instead from a higher power. When someone is appealed to donate something which is "just a vessel," but promised to receive salvation, liberation, immortality, and a ticket to heaven, it could be considered a "return gift" for organ *dāna*. There is also a strange paradox at work that emerges out of this entanglement of Hindu philosophy and organ transplantation: The recipients of organ *dāna* experience a life-changing and longed for "rebirth." However, the donors are promised to be released from the cycle of rebirth and achieve *moksha*, the ultimate goal of Hindu salvation. But through their organs, they are presented to still remain on Earth and live on in another, which is a source of comfort for their grieving families – and as a motivation for families to agree to the donation of a beloved's organs. Is rebirth through organ donation therefore a blessing, made possible through the selfless *dāna* of another? Or is this selfless *dāna* the ultimate way to escape the dreaded cycle of rebirth forever? These complex interactions of religious philosophy and organ donation, where rebirth is presented as

[34] It is interesting to note here, that the image used to promote the OTP is a stock image depicting the "Pearly Gates of Heaven" from Christianity (https://www.shutterstock.com/image-illustration/concept-depicting-majestic-pearly-gates-heaven-580634539).

both desirable and undesirable, are worth a closer analysis, which goes however beyond the scope of this thesis.

Cadaveric donations, which are presented to resonate with *dāna*, must resolve the inherent tensions of brain death and be incorporated into meaningful cultural norms[35]. However, despite culturally and religiously significant ideologies, massive publicity, awareness campaigns, and educational efforts, even after three decades, the number of deceased donations remains low. In the 24 years between 1995 and 2019, there were only 2,475 deceased donations, while the number of living donations was 29,386 ("NOTTO: National Organ & Tissue Transplant Organisation," 19-Jan-22). This calls into question the success of this promotional strategy and where the reasons behind its failure may lie.

[35] Farhana Ibrahim explains in detail about Gujrati society and its resonance with the notion of dan because of Hinduism. Gujrat is considered a very religious Hindu state and the donation rate is far higher than the rest of India (Ibrahim (2014)).

5 Between Life and Death: Ground Realities in Transplantation

Today, 28 years after brain death was first introduced into Indian law, there is ample evidence that the (re)definition of death based on brain activity is still fraught with uncertainty. THOA explains brain-stem death as the stage at which all functions of the brainstem have permanently and irreversibly ceased and is certified under sub-section (6) of section 3. It defines a person as 'deceased' at the moment of the "permanent disappearance of all evidence of life, by reason of brain-stem death or in a cardio-pulmonary sense, at any time after live birth has taken place" ("THOTA 1994"). However, death is currently also a significant aspect of two other laws in India: The Indian penal code (1862) (Section 46) describes death as "the death of a human being unless the contrary appears from the context" ("IPC_186045," p. 21). Section 29(B) of the Registration of Births and Deaths Act (RBDA 1969), describes death as "the permanent disappearance of all evidence of life at any time after live-birth has taken place" (Government of India, Ministry of Law and Justice, 1969, p. 3). There is no mention of brain death in RBDA and IPC as they were established before THOA. Thus, there is no 'uniform' definition of death in the legal framework of India, which can lead to contradictions and considerable confusion (Nundy, 1996). For instance, a person who is brain-dead (according to THOTA), but whose breathing is supported by a ventilator and whose heart is still beating could be considered alive under the RBDA, as not "all evidence of life" has been lost. RBDA, therefore, appears to be in contradiction with THOA, as transplantation of organs such as the heart and liver requires a brain-dead donor with a beating heart (Shroff & Navin, 2018). Even medical staff, such as physicians and nurses may be confused by these contradictory definitions of death and in the absence of a conclusive definition may have their own personal views on death (Shroff and Navin 2018) (McGough and Chopek 1990; Youngneret al. 1989).

5.1 Structural challenges

The diagnosis of brain death and subsequent donation is only possible in hospitals with Level 3 intensive care units (ICUs) for keeping a brain-dead patient's organs working. Such ICUs are rare and are available only in big hospitals in major cities. For instance, in the state of Punjab, procedures involving donations after cardiac death are conducted in just one location, the Post Graduate Institute of Medical Education and Research (PGI) Chandigarh. It is the only authorized hospital to declare and proceed with brain dead patients. When asked about organ donation awareness in Punjab during the interview, Dr Bhutani stated:

> "Punjabis usually don't believe in donation of organs. Religiously the body is pious, so they believe in giving it to the fire than to give it to someone else. That is why – that is why where there is Christianity, where there is literacy like in Bangalore and Chennai there's a lot of organ donation", (Dr Bhutani, 16/01/2022).

The rate of organ donation in Punjab is almost zero and people often travel to the south or west of India for organ transplantation (The Tribune, 01-Dec-19). According to data from NOTTO, Punjab had only 226 live donations and 2 cadaver donations in the years 2017 and 2018 ("NOTTO: National Organ & Tissue Transplant Organisation," 19-Jan-22). However, as the NOTTO data does not cover all hospitals, some donations may be missed.

This scarcity is due to hospitals in Punjab waiting for a 'No Objection Certificate' (NOC) from the Punjab Department of Health which is required for a brain stem death declaration[36]. Only then can families be asked for permission to donate their loved one's organs. This is also one of the reasons Punjab is not contributing to the national organ registry (The Tribune, 01-Dec-19).

"There is no team or facility even in the tertiary level government medical colleges of Amritsar and Jalandhar," said Dr Sanjay Mittal during my interview with him (Dr. Mittal, 13/01/2022). Dr Bhutani agreed and added that "PGI is the only nodal center for Punjab, so wherever the organ donation has to happen they decide who is going to get organ as per the pipeline, but the organ registrations are so slow that you cannot get to it because the line is so long, and the donation is so less. So, it takes years for someone to come into that pipeline" (Dr. Bhutani, 16/01/2022). The few available hospitals with all the necessities are often overloaded and understaffed and lack a central command structure (Shroff & Navin, 2018). In a country where intensive care unit beds and ventilators are scarce, this creates a dilemma for institutes to either keep brain dead patients on ventilators or free their beds to make the ventilators available to other patients with serious illnesses (Pandya 2001).

The law identified only certain hospitals performing the transplant operation as recognized institutions where brain death could be declared. Thus, in the substantial number of institutions where transplantation is not being performed, declaration of brain death was not possible. This led to bizarre situations where the brain-dead cadaver donor had to be shifted to another recognized institution only for the purpose of brain-death declaration and organ retrieval. Recent amendments to the Act in 2011 and 2014 created a category of institutions

[36] As stated by Dr H. R. S. Girin, head of the SPS Liver and Pancreas Institute in an interview with *The Tribune* in December 2019 (https://www.tribuneindia.com/news/archive/ludhiana/-organ-donation-a-dream-in-punjab-even-in-2019-868591).

called “non-transplant organ retrieval centers” where suitable cadaver donors can be identified and consent from families obtained, after which the body will be transported to a hospital where the transplantation surgery is performed.

In Punjab, facilities to maintain brain-dead patients exist exclusively in private hospitals[37], and the cost of their maintenance is another issue. Private institutes face a dilemma in determining how to bill a family for ventilation costs after they agree to donate organs from a brain-dead family member. During our interview, Dr Mittal described a hypothetical situation in a private hospital that highlights this dilemma:

> “The expenses for maintenance of brain-dead patient can go up to six lakhs and no donor family will agree on paying that much fee. As they will argue that we lost our loved one and, on your request, we agree to donate the organs, so, at least our bill should be waived, or the receiver should pay that bill. As if the bill should be waived, at what point in the illness should it be done? And waiving off the entire bill in the private sector can be seen as an incentive which is illegal according to THOA and can create problems for the doctor and the institute.” (Dr Mittal, 13/01/2022)

To solve this dilemma, Dr. Mittal proposes a system in which prospective recipients of organs already agree to pay a certain amount of medical bills for the brain-dead donor upon signing up for the waiting list. In this way, the legal problem of apparently “paying for an organ” can be avoided, without leaving the donor family to pay the bills, while guaranteeing transparency for all involved parties.

Other reasons why family members refuse consent for organ donation are lack of awareness (80.1%) and lack of faith in the healthcare system (40.3%) (Panwer et.al 2016, Seth et. Al 2009). Intensive care nurses testify to the difficulty of explaining to relatives why a patient with a heartbeat, who is warm to the touch, retains their normal skin color and looks like they are sleeping, is dead. It is difficult to start a conversation regarding organ donation when the family is grieving, and the beating heart can create a wrong impression that there is still hope for recovery. Dr. Mittal added that there is little understanding of the distinction between reversible and irreversible coma, and belief in medical miracles and a sudden awakening of comatose patients is common (Dr. Mittal, 13/01/2022). Families may be suspicious of doctors who suggest organ donation for their family members and may assume malicious intentions of organ harvesting (Srivastava and Mani 2018).

[37] https://indianexpress.com/article/cities/chandigarh/in-punjab-17-districts-without-icu-beds-in-government-hospitals-7302653/

Dr Bhutani confirmed that people often lack an understanding of brain-death and at the same time are frequently suspicious of medical staff, alerted by ongoing criminal activity in the context of organ transplantation:

> "To tell someone that the person has died and is right to donate the organ is very difficult. People are not ready to believe it. They even sometimes doubt that the doctors are telling lies to them, they just want to sell their kidneys off, so they don't agree to it" (Dr Bhutani, 16/01/2022).

The scams related to organ transplants play a critical role for people's suspicions towards medical professionals (Mahajan, 2010). Dr Bhutani said: "Media always paints doctors as thieves. Then whatever the stigma they put on, even the courts are affected by the media. Once the media is showing this whole the people believe all doctors are fraud" (Dr Bhutani16/01/2022). Dr. Mittal agreed that doctors accused of being involved in kidney rackets are already portrayed as criminals in the media, even before the trial is concluded. He may be speaking from personal experience: It appears that in 2016 he himself was accused of being involved in criminal activity surrounding illegal kidney transplants. He was arrested and released on interim relief[38]. Currently, no update on the status of the trial can be found. In India, the general mistrust towards medical professionals spurred on by criminal activity has led to a change in the relationship between doctors and patients. In ancient times, doctors in India were held in the highest esteem and were labelled as "next to the Gods" (Paul & Bhatia, 2016). Asked about the changing image of medical professionals in India, Dr. Bhutani replied:

> "Definitely once we have put medical practice in equivalent with consumer court as a consumer and once you are a consumer and I can be sued in a consumer court law or anyone so that relationship definitely changed."

This deterioration of the doctor-patient relationship is one more factor that makes it difficult to establish deceased donation as the de-facto standard form of transplantation, as THOA intended.

5.2 Consent and Organ Donation

Across the world, the form and method of obtaining consent for the removal of organs from brain-dead individuals have evolved over the years. In cadaver donation, the consent of the deceased before his death is a pre-requisite for the removal of his or her organs upon death.

[38] Newspaper articles that reported on this: https://www.hindustantimes.com/punjab/kidney-racket-police-arrest-doctor-couple-grant-bail/story-7zJ0TnIYXZ8jM8x2v5GrOK.html , https://www.tribuneindia.com/news/archive/jalandhar/three-more-doctors-made-accused-in-kidney-racket-case-191352

There are three processes through which consent may be given: The first is ‘opt-in’ consent (informed), the second is “opt-out,” and the third is “mandated choice.” The most common is "opt-in," through which close family members agree to donate organs after brain death has been certified. This is the form of consent that has been practiced in India.

Section 3(1) of THOA allows any donor to prescribe the conditions and procedure for donating any of his or her organs or tissues for therapeutic purposes[39]. Under the act, even if the individual has opted in or has given their consent for organ donation, their wish to donate organs cannot come true if their family is not ready for the donation. According to Section 3(3) of the Act, consent for organ donation can also be given by the family of the deceased, provided that the deceased did not object to the donation during their lifetime. The inclusion of the notion of "brain death" in Indian law and "opt-in" consent for cadaver donation were supposed to increase the deceased donor pool and combat illicit organ trade through THOA, 1994.

Unlike other countries where the will of the deceased is of primary importance (e.g., Germany and the USA), the family plays an important and authoritative role in deceased donation in India. This raises ethical questions about body ownership and bodily autonomy. Medical personnel are not allowed to remove organs from a deceased without the consent of the family, even if the donor had explicitly donated the organs in his or her will (Act and Rules of THOA: NOTTO, p.41 4a). Obtaining explicit consent for organ donation from the grieving family of a deceased donor is a critical issue that impacts the success of transplantation (Vathsala 2004).

According to THOA, organ donation is not morally acceptable even if an individual has opted-in or provided their approval for organ donation, if after their death the family does not explicitly consent[40]. Unlike in some countries, "family consent" seems to be a vague term in Indian law where no hierarchy of relatives has been specified in the rules. In another less common case, the family could decide that a deceased member becomes an organ donor, even if the person made no such statement during their lifetime. Only if the person explicitly objected to becoming an organ donor in written form before their death, the decision cannot be ruled over by the family. Therefore, the will of the deceased and the right to autonomy are inconsequential and may only have a small emotional effect on the family’s decision. The

[39] See Section 3 (1) of the Transplantation of Human Organs and Tissues Act, 1994, available at: http://lawmin.nic.in/ld/PACT/1994/The%20Transplantation%20of%20Human%20Organs%20and%20Tissues%20Act,%201994.pdf

[40] FAQ’s, "Deceased donor related transplants," Answer to Question No. 15, available at http://notto.nic.in/faqs.htm

family's decision therefore ranks higher than medical professionals, the state, and even the will of the deceased. This problem is also addressed in the FAQs on NOTTO's website under "Deceased Donor Related Transplants" [41]:

> "What if I had pledged to donate organs, but my family refuses?
>
> In most situations, families agree to donate if they know that was their loved one's wish. If the family, or those closest to the person who has died, object to the donation when the person who has died has given their explicit permission, either by telling relatives, close friends, or clinical staff or by carrying a donor card or registering their wishes on the NOTTO website, healthcare professionals will discuss the matter sensitively with them. They will be encouraged to accept the dead person's wishes. However, if families still object, then the donation process will not go further, and donation will not materialize"

The deceased has therefore no guarantee that their wishes will be respected after their death, as the ownership of their body is transferred to the family, who are able to make decisions over it that can even directly contradict the deceased's wishes. Many cultural norms and settings in India undercut or simply ignore the Western concept and ideal of individual rights in organ donation decisions. If and to what extent a person's wishes are respected after their death is an interesting cultural difference.

The law defined brain death only in the context of organ transplantation, setting the stage for a peculiar situation. A frequent interpretation of the law by the medical community in India is that if brain death is diagnosed and the family refuses consent for donation, there is no legal permission for removing life support. This means that the family is informed that their relative is "dead," but that the body will not be handed over to them and remains connected to the ventilator. This paradox occurs because medical professionals fear legal consequences and this has led to major ethical dilemmas in hospitals (Nagral & Amalorpavanathan, 2014a).

How the exchange of organs and tissues regulated by THOA reified existing hierarchical social structures, where those with less social and economic power bore the burden of these technologies is discussed in the next chapter.

[41] answer to question no. 20, available at http://notto.nic.in/faqs.htm

6 The Body of the Living: Living Donors

Apart from making deceased donations a possibility, THOA also allowed living donations but restricted it to "near relatives". Section 9(1) requires that it be only permissible for a spouse, son, daughter, father, mother, brother, or sister to be living donors. Later, the amendments act modified and accommodated grandfathers, grandmothers, and grandchildren, consanguine kin from the extended family as well as affinal relatives, on the condition of sufficient proof of relationality. THOA prohibited the sale or donation of an organ to anybody who was not "near family" ("Act and Rules of THOA: NOTTO").

Since the legislation requires donors to be immediate family members, the responsibility of meeting organ needs was made to squarely rest within the family. However, the question of who gives and who gets organs also reveals problems of injustice, inequalities, and excessive pressure on disadvantaged populations and reveals social hierarchies.

Literature encouraging organ donation extols the virtues of saving someone's life by donating a body part as a gift. However, the physical and psychological strains, upheavals, and disappointments that people have to deal with as a result of these gifting ties are often overlooked. Kidney donation advocacy organizations and kidney recipients frequently express how receiving a kidney has changed their lives and prospects. Recipients' accounts of receiving a lifesaving organ are understandably emotional, as demonstrated by many "stories of hope" on the website https://www.organindia.org [42]. One of the examples is 'I am Vartika Raghuvanshi. I am one year old,' in which a young girl expresses her experience of receiving an organ and referring to her age as one-year old, alluding to the transplantation as a "rebirth"[43]. She is aging herself from the day she received a new organ. Many more touching stories exist of people referring to themselves as six-month-old, one-year-old, or two-year-old[44]. Organ transplantation has undoubtedly revolutionized and saved innumerable lives, earning it the title of a "miracle of medical science" (Plough, 1986) because of its efficacy in extending life and

[42] ORGAN (The Organ Receiving and Giving Awareness Network) India launched in March 2013. It is an initiative of the Parashar Foundation, an NGO based in Delhi. The foundation was set up by the late Shri Ashok Parashar. His wife, Mrs. Kirti Parashar, former chairperson of the organization, also underwent heart transplantation in December 2013 (died in November 2018). The foundation has focused on creating awareness about organ donation in India (www.organindia.org).

[43] Rebirth is also used to remind mothers of their duties of motherhood by providing organs for their diseased children. As they gave them birth once, they are (or should be) obliged to give them a rebirth once again by donating their organs (Mukherjee (2018)

[44] https://www.organindia.org/films/stories-of-hope-transplant-recipients/

restoring health. As some have pointed out, however, “the miracle was not an unalloyed grace” (Jonsen, 1998, p. 197).

On the other end of the spectrum are cases like that of 23-year-old Sundar Singh Jatav, who sold his kidney to pay off his family's debts. The family was more than $10,000 in debt, and Jatav was the only hope. “I was the only son who my parents thought could make some money for them,” he said. “With my health, what options do I have now?” (Los Angeles Times, Sept. 15, 2016). Sundar never received the promised payment for his organ “donation” and suffered adverse health outcomes after surgery, which left him in an even worse position to provide for his family. The stories of Vartika, who received a "rebirth" after a kidney transplant, and Sundar who sold his kidney to get money for his family's financial necessities, illustrate the life-changing consequences and ethical complexities of organ transplantation in India: Lives saved via transplantation are next to terrifying depictions of exploitation and commodification of human organs in the illegal market.

The lower supply of deceased donations and the enormous demand for organs has resulted in their commodification, particularly in developing countries where there is a substantial population base below the poverty line[45] and weak regulatory authorities, such as India. The introduction of THOA was somewhat successful in curbing the previously thriving organ trade in India. However, it did not eradicate it altogether as the activity has since moved underground. There have been many reported cases of organ scams, kidney rackets, and scandals in different parts of the country (Jha 2014).

It has also been asserted that THOA is flawed, and its provisions have been abused by donors and clinicians (Landau, 2017; Nagral & Amalorpavanathan, 2014b; Shroff, 2009). "Every transplant practitioner in India knows that commercial transplants continue in the country," notwithstanding the modifications (Jha, 2004). Cases of organ trafficking have also been reported to be prevalent and described as "dark figure crime" or following "the iceberg of crime theory" – where the largest proportion of crime remains hidden and only a small proportion becomes visible (Manzano, Monaghan, Potrata, & Clayton, 2014). The existing organ commerce and recurrent organ scandals show that India is still one of the most well-known examples of bodily commodification in transplantation, despite the introduction of

[45] According to the Indian government, 6.7 percent of the population lives below the country's official poverty line in 2019.
https://web.archive.org/web/20140407102043/http://www.rbi.org.in/scripts/PublicationsView.aspx?id=15283

legislation designed to prevent it. The vast majority of these transplants have been performed with the approval of authorization committees, which are tasked with the obligation of ensuring that no commercial transaction is taking place during the procedure. However, corruption among authorization committees, hospitals, and physicians is a major enabler of this trade (Haagen, 2005; Mathiharan, 2011; Mukherjee, 2018). The law which was supposed to make business deals in human organs illegal and end the organ trade now effectively protects the same commercial dealings (Haagen, 2005; Mani, 2007).

6.1 **Illegal Organ Markets**

Illegal markets exist because of the shortage of available organs along with an increasing number of patients with kidney failure. The shortage of organs for transplantation leads to a long waiting time for patients. At present, the waiting list to receive an organ transplant increases faster than the legal supply of donors: In the United States in 2019 for instance, only 7,400 living donors donated their organs, but as of today, 112,555 kidney patients are on waiting lists for transplantation (Organ Procurement and Transplantation Network, 2020). In India, the waiting list for organs shows that only 15,000 of India's almost 220,000 kidney transplant candidates receive a transplant each year (NDTV-Fortis More to Give: Be an Organ Donor, 2017), and approximately 50,000 individuals die each year while awaiting an organ transplant (The New Indian Express, 29-Nov-21). Because of this unavailability of kidneys, along with increasing demand, wealthy patients find other ways to get a kidney for transplantation. As a result, in many parts of the world payment of organ recipients for an organ from a living donor has become a lucrative, albeit illegal business for clinics serving wealthy nations and foreign patients (Scheper-Hughes, 2002; Scheper-Hughes, 2000). The WHO estimates that 10% of all transplantations were to patients from developed countries who traveled to developing nations to buy organs under so-called “transplant tourism” (Lancet, 2007; Scheper-Hughes, 2002, p. 68). “Transplant tourism” is a common way to obtain an organ from a living donor in which recipients, donors, or both travels abroad for organ transplantation. India became a destination for transplant tourism since a significant part of the population lives in poverty and a lot of people are willing to sell organs out of desperation. At the same time, the country has first-class medical facilities with low surgery costs (Cohen, 2003, p. 139; Mendoza, 2010, p. 379).

THOA allows organ donation from friends and unrelated individuals if they donate the organ out of love and affection. THOA’s chapter 2 clause nine stipulates that if a donor is not an immediate family member, but still consents to the removal of an organ from his or her

body, such transplants cannot be performed until the donor has obtained no-objection certificates from the state police officials and authorization committee. Farhana Ibrahim argues that when the state rules out the commercial market, oversees organ procurement, and keeps the power to determine the flow of organs from one body to another, the state becomes the arbitrator of the individual. One could argue that a friend cannot donate a kidney as the term "near relatives" is defined so narrowly that only members of the biological family are considered "near." In order to avoid the use of intimidation in organ procurement, potential donors are required to undergo psychological examinations and appear before an authorization committee. The committee, ironically, determines the extent to which "affection or connection" are sufficient conditions to allow organ transplants between living donors. The state reserves the power to designate permissible states of exception, just as it reserves the right to govern the passage of body material across individual bodies. The state has assumed the right to regulate its citizens' bodies by distinguishing between the “desirable” donors (close family members and unrelated brain-dead people) and the “un-desirable” donors (any healthy individual willing to donate an organ for love or money) (Ibrahim, 2014).

On the other hand, authorization committees were formed to protect people from exploitation and any illegal unrelated organ donation. However, due to corruption, it is not uncommon for authorization committees, doctors, and hospitals to be involved in illegal kidney scams (Haagen, 2005; Mathiharan, 2011; Mukherjee, 2018). There have been several incidences of kidney rackets[46]; on June 5, 2016, Delhi police had broken a kidney racket that included the personal staff and physicians of the Apollo Group of Hospitals. An accused of the scandal mentioned above involving the same network of hospitals was allegedly apprehended in Kolkata the same week (Raghavan, 11-Jun-16). The revelation of such rackets proves that cases of illegal organ trade are still prevalent.

Almost all donors sell their kidneys out of financial desperation. Marginalized populations and women are especially at risk and likely to become sellers (Cohen, 2003). According to the World Development Report 2010, half the population of developing nations lives in poverty, surviving on less than $2 per day (“World Development Report 2010,” 2009, p. 41). People in poverty are often vulnerable in several aspects of their life: they can easily

[46] A whole list of Kidney scams has been published in the media across the nation. “Kidney Thefts Shock India” as reported by Amelia Gentleman in the New York times; “Stolen kidneys in India” as reported by Jason Overdof in the News Week. Apart from International media reports, National and regional media and publications have continued to report and record such crimes. Examples are Murder and Kidney Commerce, A Case of Organ ‘Theft’, A Racket in Karnataka, Gurgaon Kidney Scandal, Case of fake donors in Punjab reported in the Tribune, The Hindu, The express and several Television Media/News channels between 2000 to now. Haagen 2005

lose their employment, have little access to medical care, no health insurance, a limited social safety net to fall back on in emergencies, and are sometimes subjected to inherited debt. This makes them more susceptible to enticing offers by brokers to escape their situation by the promise of significant payment through organ sales (Moazam, Zaman, & Jafarey, 2009, p. 41). Promises by brokers to entice possible donors into selling their organs rarely come true and long-term health consequences are downplayed: After surgery, donors may find themselves with less than the agreed upon amount, and with long-term health consequences that can affect their subsequent employment and therefore also their income. Instead of improving the donor's situation, kidney sales in most cases further worsen it.

Organs purchased in illegal markets might indeed be a "gift of life" for the recipient, but the donors are the ones with little power. Without being controlled by an official system to protect them and with little interest in their well-being post-surgery, their "gift of life" can put them at the risk of exploitation and long-lasting health problems (Hamdy, 2012a; Scheper-Hughes, 2002). Poor people consider their kidneys a commodity and sell their organs due to family and particularly financial pressure (Cohen, 2003). Kidney sellers in developing countries are often not given proper post-surgery care and have no access to long-term health care. The transplant surgeries are performed at private for-profit hospitals in larger cities, and often neglect proper post-surgery care for the sellers. Moreover, a high rate of graft loss and transmission of infections (including HIV and Hepatitis) has been observed after kidney transplantation. This provides a clear indication that safety standards are seriously compromised (Budiani-Saberi & Mostafa, 2011, p. 322; Yosuke Shimazono, 2007, pp. 958–959). The health status of donors considerably and consistently deteriorates after paid kidney donation with a high prevalence of depression, kidney insufficiency, and psychosomatic reactions (Goyal et al., 2002; Scheper-Hughes, 2002, p. 77). Apart from physical and psychological harm, donors also face financial damage and therefore the assumption that money from selling kidneys can improve their financial status is questionable. The family income of donors decreases after the sale as the impaired physical health affects their employment (Budiani-Saberi & Mostafa, 2011, p. 318; Goyal et al., 2002). The amount of money kidney sellers receive is often much lower than initially promised by brokers, and donors consistently remain in debt even after selling their kidneys (Cohen, 2003; Goyal et al., 2002).

Apart from the illegal markets, the regulation of THOA has also changed how individuals relate to themselves and to one another and has established new roles and duties

(Mukherjee 2018, p. 178). "Near relatives' donation" taps into conventional kinship obligations and duties, rather than altruism[47]. The reduction of choice of donors from within the family puts women at risk of being pressured to become organ donors and be exploited through donation (Bal & Saikia, 2007; Bloembergen, Port, Mauger, Briggs, & Leichtman, 1996; Cohen, 2003).

6.2 Gendered Organ Donation

Gender inequality can be seen in various strata of Indian society, starting from the male-female sex ratio, crime against females and dowry, to lower literacy rates among women. This inequality is also visible in organ donation and the organ trade. Women, in general, are more likely than men to be living donors and are less likely to receive organs (Crowley-Matoka & Hamdy, 2016; Dar, Sunil, & Dar, 2015; Rasmussen, Paneru, Shrestha, & Shrestha, 2016). In the United States, 24,334 (62.3%) men and 14,702 (37.7%) women were receivers of organs in 2020 ("National Data - OPTN," 11-Aug-21). In India, the gender gap is even wider: according to data from the National Organ Transplantation and Tissue Organization, 53,987 (90.2%) men and 5,874 (9.8%) women received organ transplants ("Organ Report," 10-Aug-21). Data provided in 2017 by the Directorate of Medical Research, Maharashtra, states that 63% of all live organs transplanted in Maharashtra in 2016 were obtained from female donors (Debroy, 07-Mar-17). Similar figures are shown by information gathered from top hospitals in India that perform organ transplants (Dar et al., 2015). Organs derived from female bodies dominate the commercial organ market (Bal & Saikia, 2007; Cohen, 2003; Scheper-Hughes, 2007).

This gendered difference is more pronounced in spousal donations: in 98.4% of spousal donations, wives donated to their husbands (Sakhuja & Kumar, 2014). It is also a widespread practice for ESRD patients to marry a woman for their kidney and then divorce them after getting approval from the authorization committee (Mathiharan 2011). However, to safeguard against this practice, it has been suggested that only married couples who have been married for more than seven years be allowed donations within their marriages (Mathiharan, 2011, p. 135). The hierarchy goes from mothers being the first ones to donate an organ to the family followed by wives, sisters, and daughters. However, in the case of a married sister and daughter, there is again the requirement of consent from the in-laws. Mothers (32.1%) and wives (22.1%)

[47] There are no additional clauses added to altruism, such as restricting it within close relatives. In other countries, like the USA, anyone can donate organs regardless of their biological relationship.

formed the most common group of donors (Bal & Saikia, 2007). Dr Mittal confirmed that it is a general trend in Punjab as well as in India that mothers and wives tend to donate organs more frequently than their male counterparts (Dr Mittal 13/01/2022). There are some exceptions where a husband donates a kidney to his wife, or a son donates a kidney to his father. Dr. Mittal gave an example of a male colleague who was diagnosed with kidney cancer and his son donated a kidney to him. But he emphasized that these cases were more prevalent in high-income educated families. He mentioned that although women are often the donors, they are rarely the recipients of transplants. In the few cases they receive organs, other female relatives usually donate them, usually either a sister or the mother. Dr Mittal also mentioned that kidney failure is more common among men, due to risk factors such as diabetes, hypertension, and extensive use of painkillers (Dr Mittal 13/01/2022)

Women rarely get a chance to consider their options or make donation decisions alone as they are frequently influenced by prominent figures in their families (Klinge & Wiesemann, 2010; Mukherjee, 2018; Schicktanz, Schweda, & Wöhlke, 2010). Factors accountable for women to donate their organs reveal a substantial effect of subtle but powerful socioeconomic constraints, socio-cultural conventions, sociological positioning, commercialization of female body parts, and undervaluation of women's domestic labor (Hanson et al., 2017; McGrath & Holewa, 2012; Mukherjee, 2018). Because of each of these reasons, women are persuaded to donate their organs in exchange for significant socioeconomic and emotional benefits (Hanson et al., 2017; McGrath & Holewa, 2012). The norms and values affecting Indian women today have their roots in the past. In Indian society, mothers and wives are portrayed as self-sacrificing caregivers for the sake of the family. For many women, the willingness to carry the responsibility of family caregiving extends to their position as kidney donors (Mukherjee, 2018, p. 203).

Another common motivation for women to consider kidney donation is to avoid widowhood and the repercussions of poverty (Mukherjee, 2018; Rasmussen et al., 2016, p. 41). A woman in India who donates one of her kidneys to her husband is saving both her husband's and her own life from the dangers of a social existence without a husband, where a widow's life is even worse than that of a woman with only one kidney (Mukherjee, 2018, p. 203). Men's tacit refusal to donate organs, sociological norms that sort to define women's roles within their families, and the economic value of their bodies have all combined to create a common culture in which a woman's bodily parts are interchangeable and available to compensate for their limited economic role in society.

Economic disparity is another reason organ donation from men is uncommon. Women's employment rate is 27.2%, while for men it is 78.8%, and women are paid less than men. Thus, men are more likely to be able to pay for and undergo transplantation surgery than women. At the same time, man's absence from work as a result of donor surgery is deemed to be more expensive (Rasmussen et al., 2016, pp. 39–40). Some males are exempt from donating organs due to alcoholism or cigarette usage; both habits are usually avoided by women due to their distinct socialization (Wilsnack, 2012). Others contend that ideological discourses that portray males as primary producers of material resources within families may encourage women to donate (Øien et al., 2005; Rasmussen et al., 2016).

Organ donation in India becomes another complication in an already complex social structure rampant with gender inequalities. Women's place in the social order and conventional perceptions[48] in the private sphere of the home have frequently worked as an additional impetus for them to take on the obligation of organ donation for family members. Not only among altruistic donations but also in the illegal organ market, women make up a disproportionately large percentage, selling portions of their bodies to repay their husbands' debts and sustain their families, although most of them end up in debt again after a short period (Cohen, 1999). However, the women who sell their organs for money do it usually out of profound altruism and care for their families, not for the recipient (Cohen; Cohen, 2003). Therefore, the distinction of "altruistic" donation to relatives and of "non-altruistic" donation on illegal markets for financial gain appears crude, as in both cases love and affection for family members and fears over a deteriorating economic situation are usually the motivation.

Gender systems, as a structure of societies based on privilege and power relations, lead to an uneven access to economic, social, and symbolic resources. When women give parts of their bodies in response to socioeconomic demands, their organs take on the characteristics of tradable or exchangeable goods that may be traded or swapped for economic efficiency, financial stability, social acceptability, and cultural conformity. This trade-off, which is unseen since it corresponds to acceptable societal norms of filial obligation, affection, and female

[48] In Hinduism, Stridharma '(स्त्रीधर्म)' refers to the "duties of women" as daughters, wives, and mothers, mentioned in ancient Indian philosophies, e.g., in the Śivapurāṇa 2.2.23. Stridhrama: Woman's duty: "Traditional conduct, observances, vocational and spiritual patterns which bring spiritual fulfillment and societal stability. Characterized by modesty, quiet strength, religiousness, dignity and nurturing of family. Notably she is most needed and irreplaceable as the maker of the home and the educator of their children as noble citizens of tomorrow" Subramuniya, 1993 p.711

sacrifice, has economic overtones. This exemplifies the commercialization and collateralization of women's organs (Teubner, 1986).

The introduction of THOA inadvertently precipitated an uneven distribution of care-giving responsibilities among family members. The emphasis on altruistic donation under the theme of “gift of life” shifts among female family members from "gift" to "duty", "responsibility" and "sacrifice" (Mukherjee, 2018, p. 197; Sque, Payne, & Macleod Clark, 2006). The act of altruism becomes an obligation for women (Das 2015). It invokes a sense of duty and self-sacrifice that leads women to bear the burden of supplying organs for diseased and weak members of the family (Mukherjee 2018, p. 197). Cutting-edge medical technologies have reconfigured roles and responsibilities within the existing kinship structures. This gendered tendency in organ donation demonstrates that motives for organ donation or sale are affected by several social variables. The law's inability to fulfill its intended objectives may be due to a lack of structural coupling between the legal and social systems.

Conclusion

Organ transplantation has opened new avenues for scientific advancement in society. The discussions over the manner and intention of transplantation, and the plethora of information collected from the diverse experiences of people around the world, are invaluable resources for understanding transplantation in all its facets, present, and future. We must keep up with the ever-changing social repercussions of our ability to control the human body as organ transplantation and other biotechnologies advances. Organ transplantation touches upon and interconnects the topics of death, body ownership, social hierarchies, exploitation, and gift-giving. Cultural and regional differences in what constitutes death, how we conceptualize the relationship between body and self, and the numerous ways in which we might monetize our bodies go far beyond the realm of the quaint and exotic.

The concept of 'brain-death' was introduced into Indian medical law by implementing THOA, to make brain-dead persons available for donation and to eliminate illegal organ markets. After three decades of its introduction, THOA showed partial success in achieving its goals but caused various social ramifications. Indian law only permits donation if the consent of the deceased person's family is given, which is often refused, which results in low deceased donation rates. The Indian government has aimed to increase donation rates by using religious language and metaphors, directed towards the Hindu community. However, so far, this strategy has not made a significant impact to encourage people to opt for deceased donations. Some movements within Hinduism such as the *Dadichi deh daan Samiti* also promote deceased donation as a new ascetic ideal among devout Hindus. They use the compatibility of Hindu religious philosophy with the idea of organ donation. It could be argued that Hinduism lends itself particularly well to the idea of transplantation, as ascetic ideals encourage selflessness and penance. The Hindu view of the body as a "transitory vessel" that loses significance after death contrasts with Catholic Christianity for example. Catholics also believe that the soul leaves the body after death to then return to the body on the Last Day, during the resurrection of the dead. One might therefore expect that Catholics would be more skeptical towards donation, as a donated organ would be absent from the body for resurrection. Surprisingly, the Catholic Church officially embraces and encourages organ donation.

Bodily integrity after death is not as important in Hinduism since the body is "just a vessel." The deceased slowly transitions from personhood to non-personhood. In the beginning, the corpse is still treated with the dignity and respect the person received during

their lifetime, signified by joint family pictures and the reverential touching of the feet. But as the rituals progress, the deceased becomes more and more "body" and less "person", culminating in the burning of the remains on the funeral pyre.

The religious concept of *dāna* as an impersonal gift that is given without the want for reciprocity from the recipient, but instead with the hope for achieving good *karma*, is also frequently employed in Hindu adaptions of organ donation as an act with religious merit. Based on its religious philosophy, Hinduism has several concepts that resonate well with the idea of deceased donation and that have also been employed in both the public and private sphere. However, Hinduism has not one central "holy book" or one central religious authority, and therefore a wide variety of religious practices and beliefs exist. Therefore, the sometimes-stated view that people refuse organ donation on the basis of "religion" has to be considered oversimplified and has to be looked at with considerable nuance.

There is little doubt that the structural limitations of medical facilities, legal complexities of defining death, lack of understanding and awareness of brain death, and suspicion towards medical staff play huge roles in the lower rate of deceased donation. However, brain death as a new definition of death requires the mourning families to accept the non-personhood of the deceased instantaneously after the declaration of brain death. A person has to become "merely a body" first to make the removal of vital organs morally acceptable and is therefore at odds with the view of death as a gradual, social, transitional process.

Similarly, India's legislative efforts to combat the illegal organ trade through THOA were not a success either. Illegal organ trade and exploitation persist. Unlike other countries which successfully established deceased donation based upon the "gift of life" ideology, India's living donation rate far exceeds the deceased one. Inequalities and poverty influence structural problems such as the high degree of segregation, corruption, and economic disparity in India. Due to the corruption in authorization committees and medical professionals, the clauses of THOA have been misused, which weakens the position of the poor and facilitates organ trade.

In India, people live in social hierarchies with specific rights and duties. The social norms of Indian society dictate that women are supposed to be the nurturers of the whole family, which made them also the main victims of transplantation technology, as they are much more often donors than recipients. These gender inequalities within related donations reflect the general gender inequality in Indian society. Therefore, dealing with the root causes of

India's gender inequality could be the solution to the gender inequality within organ donations (Haagen, 2005). Similarly, the end of extreme poverty would be the end of exploitation in the illegal organ trade. All this proves that the assumption that technologies and inventions are universal and can be implemented with similar effects in culturally different settings is flawed, especially when it touches upon such sensitive topics like death and body ownership.

We should be more concerned about the global rise in kidney failure than with how to find more kidneys for these patients: Environmental pollutants and renal disease have a close association, according to Hamdy and others (Hamdy, 2012). Rather than preparing for more renal patients in the future, efforts should be directed toward preventing kidney failure. If we care about the well-being of both potential kidney donors and ESRD patients, we should prioritize eradicating extreme poverty and environmental pollution over legalizing trade: People should never be so desperate that they have to consider commodifying their own organs or commodifying the organs of another.

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Appendix

Table 1: Interview partners

Name	*Gender*	*Profession*	*Date*	*Language*
Dr Sanjay Mittal	Male	Nephrologist at Sarvodya Hospital, Jalandhar	13/01/2022	English and Punjabi
Dr H. S. Bhutani	Male	Urologist and Medical Superintendent at Ghai Hospital, Jalandhar	16/01/2022	English
Surjit Kaur *(Mother of author)*	Female	Housewife from Haripur	25/01/2022	Punjabi
Satnam Singh *(Father of author)*	Male	Religious leader and healer from Haripur	25/01/2022	Punjabi
Raj Rani *(Paternal aunt of author)*	Female	Housewife from Nakodar	30/01/2022	Punjabi

Declaration of authorship

– Include the following statutory statement at the end of your thesis –

I hereby declare that my thesis with the title:

Bodies, “Love” and kidneys: The regulation of living donor donation in India and its social repercussions.

1. is the result of my own independent work,
2. makes use of no sources or materials other than those referenced,
3. that quotations and paraphrases obtained from the work of others are indicated as such,
4. and that I have followed the rules and recommendations stated in Heidelberg University's guidelines on „Verantwortung in der Wissenschaft (Responsibility in Science) “.

Heidelberg: 27 April 2022 Signature: Mandeep Kaur