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Reluctant to Give: Exploring Youth Attitudes Towards Organ Donation in Delhi

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ABSTRACT

Introduction

India continues to grapple with a notable imbalance between the demand for and their actual availability of transplant organs, despite of concerted efforts in creating public awareness through mass campaigns and policy driven initiatives. While biomedical solution to this problem asks for more efforts for cadaveric or living donors as a viable way for addressing this challenge, the persistence shortage indicate existence of deeper and complex interrelationship between medical and socio cultural factors.

Aim

This paper critically examines the socio-cultural factors influencing the reluctance to organ donation among youth in Delhi, the capital city of India.

Material and Methods

Using online surveys and telephonic interviews this study has identified four thematic frameworks that converge together and shape the youth reluctance regarding organ donation.

Result

By examining the ways in which youth today navigate in between the complex moral framework and societal values, this paper reframes the organ donation refusal not as a simple irrational act of the youth but as a conscious and contextually grounded act of resistance that are often been shaped by their cultural norms and institutional structure.

Conclusion

Organ donation reluctance among the youth must be viewed as a culturally embedded decision-making process rather than a lack of awareness, calling for approaches that engage with the socio-cultural realities of contemporary youth.

Keywords: Organ donation, youth, values and attitudes, cultural beliefs, transplantation

Introduction

There is an established tradition of empirical research in sociological and anthropological literature on organ donation and transplantation, arguing that it goes well beyond medical technology and is reflective of the psycho-social wellbeing of donors, families, recipients that is deeply interwoven in their socio-cultural specificities.1 In other words organs, viewed from a social life approach appear to be having a social life of their own.[2] Understanding the reasons behind either the eagerness or reluctance requires examining the social and cultural factors that influence it.

While there has been scholarly empirical researches on this topic in India from a biomedical or health perspective, relatively scanty literature exists in India taking into account its cultural and social concerns baring few.[3] Biomedical perspective to organ donation rests on the organ transplantation ethos of ‘saving life at any cost’ is a problematic affair owing to the fact that it emphasises too much on the market logic, individual choice while ignoring the socio-cultural insights about the importance of understanding death, bereavement, the body, organs and its transfer to others , claim scholarly studies.[4-7] Ben-David[8] emphasizes the social and emotional dimensions of organ exchange are frequently dismissed when organs are viewed merely as commodities governed by supply and demand. He argues it is necessary to define what constitutes the body and its parts in the context of organ transplantation.

Studies that recognise socio cultural dimensions of organ donation are extensively present in international domain. For instance Lock and Crowley-Makota[9] in a comparative analysis of the United States, Mexico, and Japan, noted that both donating and receiving organs should not be understood as the "autonomous choice" of an individual but rather as based on moral positions and obligations again reiterates the socio cultural dimension of organ donation and transplantation. The metaphor of the 'gift' or reciprocity is frequently emphasized in organ transplantation discussion , but this is to some scholars an oversimplifies the concept. For many involved, this 'gift' can evoke feelings of coercion, extending beyond simple health implications and healing, as noted by Scheper-Hughes[10,] Siminoff and Chilag[11] and Margaret Lock[2] explored the contrasting cultural and historical reasons for organ donation across countries. In the United States, organs retrieved from post-mortem donors are generally accepted without hesitation, while in Japan, the practice faces significant obstacles due to deeply rooted beliefs about death. Lock pointed out that definitions of death are culturally constructed within modern medicine. Hogle[12] discusses how

medieval beliefs about the diffusion of life essence throughout the human body complicate organ donation in multicultural Germany. Despite the state's political narrative of 'solidarity' being used as a powerful metaphor in East Germany, and Christian notions of 'charity' being employed to encourage organ donation at the state level, the process remains fraught with difficulties.

Additionally, based on extensive fieldwork, Crowley-Matoka[9] illustrates how organ transplantation in Mexico is often viewed as a family matter, particularly concerning kidney donations among living relatives, contrasting with the practice of seeking donations from strangers that is more common elsewhere. These broader discourse under the socio cultural perspective therefore acknowledges that organ transplant discourse is a complex socio cultural matter and cannot therefore only be understood with the overused concept of 'gift' metaphor alone which many see as a 'politically loaded and non-neutral concept' to make sense of this act.[1] This is so because the gifts entail a complex and contradictory meaning in itself and if taken into account then it demands a through exploration of meanings behind such thoughts.

These studies recognising social and cultural construction of organ donation frame the tone of argument of the current study on youth refusal to organ donation in Delhi. Considering young adults as key representatives of future donation system, it becomes more pertinent to understand their reluctance or apathy towards organ donation. While substantial discussion exists on this topic among health practitioners and policy planners in India, there has been a lack of academic focus on this issue from social scientists, particularly sociologists. Drawing from the empirical study, this paper seeks to elucidate the underlying reasons for the refusal of organ donation among undergraduate students in Delhi within a broader critical theory framework.

A Socio-medical History of Organ Transplantation in India

Organ transplantation in India has a relatively short history compared to the developed world. The first case of Kidney transplantation in India dates back to 1970s. During the 1980s and early 1990s, although this activity became more widespread, it was largely restricted to live donors in selected urban centres. In the 1990s, kidney transplants became much more visible with the establishment of additional transplantation centres. According to NOTTO[13] sources, there has been an increase in number of transplants cases from 4,990 in 2013 to 16,041 in 2022.

Extensive studies in India exists exploring organ transplantation issues from legal perspectives or from a rational choice perspective. For instance, reports from the National Organ Transplant Programme indicate, an increasing demand for human organs in India. The figures stated by the organization are as follows:

As per Director General of Health Services, Govt. of India, an estimated 180,000 people suffer from renal failure every year; however, the number of renal transplants performed is only around 6,000. Approximately 200,000 patients die of liver failure or liver cancer annually in India, and about 10-15% of these could be saved with a timely liver transplant. Therefore, about 25,000-30,000 liver transplants are needed annually in India, but only about 1,500 are performed. Similarly, about 50,000 people suffer from heart failure annually, but only 10 to 15 heart transplants are performed each year in India. In the case of corneal transplants, about 25,000 are done every year, against a requirement of 100,000.[14]

Viewed from this perspective existing studies mainly focus on the motivations or barriers components of organ donation process noting the low level of awareness.[15,16] Studies conducted in India also underscore the inadequacy of regulatory mechanisms to prevent illegal trafficking of

human organs.[17-19] Several studies also document mistrust and misinformation surrounding organ donation as significant barrier to organ donation in India.[20,21] The structural factors such as economic disparities are highlighted is some studies.[17,22] Few studies also propose stringent mechanism to regulate illegal trade of organs, implementing educational programmes while examining correlation between awareness levels and willingness to donate.[16-23] Many do also emphasise on government and private stakeholder intervention in these critical matters.[24] These studies while elucidating the complexities surrounding organ transplantation from a positivist or biomedical perspective, fail to consider the perspectives of the donors themselves especially when they express their reluctance towards the acts of donation. In other terms, this discourse tends to depict the process of donating body parts as primarily an informed decision based on empirical knowledge of the donors and interpret donors who show their reluctance as ignorant and lack information . This surely undermines to capture individuals' profound socio-cultural and symbolic dimensions associated with life, mortality, and human corporeal form. Moreover, providing a critical understanding in this context that goes beyond biomedical comprehension of the issue is more important for creating an inclusive and culturally aware public health policies.

MATERIALS AND METHODS

This qualitative study aimed to explore the reasons for refusal or reluctance toward organ donation among youth in Delhi. The research specifically sought to examine how this reluctance is expressed within the broader public discourse that frames organ donation as a life-saving act and promotes it as a "gift of life." Participants for the study were recruited through snowball sampling, initiated via the researcher's social media networks, including WhatsApp, Facebook, and Instagram profiles. Individuals who consented to participate were selected for the study. From these virtual platforms, a purposive sample was drawn to complete a questionnaire consisting of both closed- and open-ended questions, followed by one-on-one telephonic interviews. All participants were undergraduate students who drawn from across different states in India. In total, twelve in-depth interviews were conducted. These individuals were drawn from a broader pool of seventy-nine respondents who had completed the online survey via Google Forms intended to know their general knowledge and attitude towards organ donation.

A hermeneutic approach was utilized to analyse the interview data, allowing for an interpretative understanding of the participants' perspectives. To guide the analysis, typologies of reluctance toward organ donation developed in previous studies were employed as ideal types. Pfaller et al.,[25] proposed a fourfold typology based on their research in Germany, identifying key factors such as (1) information deficits, (2) mistrust, (3) objections to killing, and (4) concerns regarding bodily integrity, noting the potential for these categories to overlap. Similarly, Saxena et al.,26 developed a typology relevant to the Indian context, identifying mistrust of the donation process, fear of responsibility, emotional reactions such as shock and grief, challenges in obtaining familial consent, concerns about the post-mortem appearance of the body, and religious beliefs as critical influences on reluctance. This study framed four types of frameworks to interpret the forms and expressions of refusal and reluctance among the sample respondents. This framework is being designed on the basis of existing literature and recurring theme that emerged during the course of data collection. A tabular representation is provided below.

Table 1: Workflow of the study

Component	Details
Objective	To explore reason for refusal or reluctance towards organ donation among youth in Delhi
Population	Undergraduate students studying in Delhi
Recruitment Method	Snowball sampling through social media network (WhatsApp, Facebook, Instagram).
Data Collection Methods	Online questionnaire (Google Forms, including closed- and open-ended questions) One-on-one telephonic interviews.
Sample Size	79 questionnaire responses; 12 in-depth interviews with participants expressing uncertainty, scepticism, or negativity toward organ donation.
Analytical Approach	Hermeneutic analysis (interpretive understanding of participant narratives) and critical analysis of power and organ donation.
Typologies Developed from Interviews	Mistrust Social conformity Familial authority and bonding Spiritual world views

Findings and Discussion

Four recurrent themes emerged from the study's extensive telephonic interviews regarding respondents beliefs about organ donation and ideas around it. Though these four thematic frames are not exclusive categories of concepts but rather they are indicative patterns which help in understanding the reasons for youth reluctance to be a donor. These are:

1. Mistrust
2. Social conformity
3. Familial Authority and bonding
4. Spiritual World View

I. Mistrust

During the investigation, the researcher encountered personal opinions of respondents mistrusting the process of organ retrieval and donation. This mistrust was created either due to lack of information or due to mis representation of the processes involved in it. Though many of the respondents were not completely hostile to the process, but they expressed their concerns in various ways often by linking it to the institutional facilities or scary stories heard over the media. As a. result few respondents preferred not to accept to be a donor . For instance, Aparna (a pseudonym), a third-year undergraduate student, said:

"Yes, I have heard about it advertisements and large hoardings near hospitals. But I don't have complete knowledge about it as to how it happens; the idea of retrieving human organs sounds so scary! Death itself scares people, and separating body parts from a dead person sounds scarier. It's a topic I would rather not deal with. May be I would be more open to it if I understood it better."

Nirmal is a second year graduation student, expressed similar concerns by asking, 'I want to be an organ donor, but I am just worried that if something happens to me in the process, who will be held responsible for it? I am the only child of my parents. Social work can wait, but not my parents. Will the medial team do everything possible to save my life? I have heard stories of medical negligence, thus my fears are real, I am not just apprehensive only'.

Adding to this, another respondent, Shruti, age 19, said reluctantly, *"I am so young and have never thought about death and donating body parts after death would surely not come to my thoughts. Anyway, if I had to decide right now, I would surely say 'no'. Who would want to be cut into pieces?" (frowning her eyebrows). "I want my body to remain in one piece not in pieces after my death."* Shruti's beliefs have something deeper in its meaning her beliefs and reluctance are not just casual reflections of an younger person but rather it reveals how the younger adults are socialised into thinking about the ritual impurities, integrity of the body and more over how the fear of death is internalised in the subconscious minds of younger adults who are thought generally to be so open. Shruti's view also construct death as an age affair. Death being a natural process comes only through aging. Similarly, Smriti (a pseudonym), a second-year political science student, said:

"We were working on a classroom project about human trafficking. While searching for relevant articles, I came across with how kidney rackets and organ theft happens in India involving health professionals like doctors and nurses. This is so frightening! whom to believe then? One really cannot say 'yes' strongly if such things are happening and getting flashed in newspaper stories so often. Even if you want to participate in a noble cause like saving others' lives, who knows who are the beneficiaries of your organs!"

Pragati aged 20, was very authoritatively asserted, *"It does not matter whether one is saying yes or no to participate in it . Reliable and motivating stories need to reach out to them in order to think about it. One need to be also sure that lives of all individuals are given priority not just the ones having more money. There are instances of how human organs are sold for money even if these are donated for all the needy"* Pragati had never heard of possibility of donating body parts while being alive. She said she would consider to be a donor in only to her family or to a known one and not to strangers. Her refusal to organ donation is conditional and is due to her mistrust in the institutional structure aiding organ retrieval and transplantation.

II. Social conformity

Social conformity is the process in which individual members of the society adjust their behaviours and actions in accordance with the prevailing norms and values of the society. Those who don't confirm to certain societal moral or value standards, society often treat them as deviants. This analysis is rooted in the concept of collective conscience coined by Durkheim. Therefore, conformity towards prevailing norms has always been emphasised in societies to maintain solidarity and to avoid chaos argues Durkheim in his scholarly work. In the present study while assessing younger generations beliefs towards organ donation, few of the respondents showcased their stronger conformity towards their family or community values which was negatively associated with motivations to be a donor. Particularly they confirmed that's the judgments from peers and distant family members do affect them. These judgements are mostly based on the idea that donating body parts for saving life is a noble idea but these are not part of a normalised behaviour as their meanings are fused with beliefs about life and death. One respondent shared that relatives' opinions matter, especially if one is closely associated with them. Decisions about

death rituals are collective affairs and involve consultation with both close and distant family members said Shalini a 20 years old girl. She added: "*This is a big decision! The decision to register or not register for organ donation cannot be made by me alone. Does not matter that it sounds good to me to save someone's life but it's about life and death not about donating money as charity."* She became emotional remembering how her younger uncle's face got distorted after his cornea retrieval. His death was already a shock for all of us but his face was even more shocking for those who came for paying last homage. She added, *"The decision was made when everyone was in shock due to his death, and not everyone was consulted about his cornea donation. We don't know what happens after death, but if there is a belief that spirits never die, then extracting body parts is not a great idea. That belief needs to be changed first to make it happen without guilt. His body has already undergone through pain and later by removing his body parts we surely did not do good to him"* Shalini's narrative highlights how decisions about organ donation after death are influenced by collective beliefs about the body and about life and death. '*Separating body parts is linked to disrespect'*, she asserted. Conformity to family values, religious or traditional belief about bodily integrity therefore are significant factors influencing donors reluctance.

III. Familial Authority or bonding

Familial authority refers to the structured power dynamics within the familial domain that influences individual's decision making process. In the context of India, family remain still a pivotal institution of power shaping individual's decisions, actions and values bypassing the personal autonomy. The decision to donate organs is therefore not a rational one for the member of a family. It is a collective one. To some respondent's family support is needed for all kinds of organ donations living or non-living. Akriti (a pseudonym) said, "*What if I decide to go for it, but my family does not approve? I am educated and well-informed, studying in a big city like Delhi, but my parents are not exposed to these new aspects of medicine. For them, it's a weird 'city thing'. They would put all the blame on my education, if even I try to convince on this.*" Akriti's hesitation to be a donor is rooted in her deeper submission to familial authority and moral obligation. Her apprehension is real as she does not want to disturb the social cohesion and stability within family by making such a decision about something which is completely unknown in her family history.

Another respondent Deepika, added to the above position in a similar line, "*I cannot decide on this sensitive issue. Death cannot be discussed so casually after all. My parents have greater control over my life; I cannot make this decision on my own. Donation, saving life of others sounds good but when it comes down to a persona and a family … there are a lot of things to consider, my family won't approve of it and I can't go against them.*" Fear of death came out as a real fact in her narration along with the importance of familial authority for younger adults in India. Deepika's anticipation of disapproval or rejection from her parents was also echoed in Sreemant's narration. Sreemant, a native of Bihar (a pseudonym) while remembering his brother who died in a road accident said, "*These kinds of campaigns are only prevalent in big cities. In rural areas, death does not bring an end to our memory , we still feel as if our beloved departed person is still around us whenever we think of them, so it is not be acceptable to impose an additional burden on grieving family members by forcibly convincing them and blackmailing them to go for organ donation.*" Sreemant's narrative signify how the reluctance to be donor is rooted in one's emotional experiences with the departed person in the consideration for organ donation.

The role of family in these revelations suggests that acts of organ retrieval and transplantation go beyond medical rationalization theories that view the body as a machine and organ donation need is a universal rational act.

IV. Spiritual World View

Death is not a clinically determined condition but rather is socially and culturally constructed. For instance Mampe[27] argues a good death is a normative idea of living and dying well and is constructed socially and culturally by studying marginalised communities of transgenders. Haddow[28] argues that new inventions and discoveries in modern medicine during the 18th and 20th centuries have further complicated these beliefs by demonstrating that individuals previously thought dead could now be revived. Organ transplantation system is therefore gripped around certain ambiguates which need to be elaborated only though people's lived experiences and though their beliefs and practices not through 'methodological nationalism' -an apt terms used by Jamieson.[29] Organs as 'gift of life' therefore goes contested when one looks at the everyday experiences of individuals , their beliefs on it.

Understanding life and death is connected to the concept of organ donation, though they may appear different themes altogether. Scholars argue that ideas about life and death are significant in understanding people's perceptions of organ donation in cases of brain death or accidental death. Fear of bodily mutilation often arises in these discussions as contradictory ideas not supporting the idea to be an organ donor. As Sanner[30] argues, families of such individuals "generally are not able to imagine a difference between the living and the dead. The dead body was ascribed qualities that only a living individual possesses".[28]

In this context then, a spiritual world view can significantly shape one's reluctance to be a donor. For few respondents, the dead should be respected and that any act of mutilation, such as organ retrieval, can mean a form of disrespect. The body is not a biological entity rather is a spiritual entity. Therefore, body and self are inseparable in their view. Ruby (a pseudonym) stated, "*We see others through our eyes; the same logic applies to the dead. If there is an afterlife thing then it's a crime! Seeing their face before cremation is the last memory that we create before cremation. If their eyes are gone, that last image will never leave one's mind. It's not something you would do to your loved ones after all.*"

Shikha age 20, an undergraduate student at the University of Delhi questions the contradictions involved in the idea of organ donation and one's spiritual world view. She said, "*Deciding to donate organs is not just any casual matter; parents would surely be hesitant to allow us. I am not a very religious person but am sure all do follow rituals of death and birth in their families. It's so strange that we want to ensure that the soul is resting in peace but how is this possible if organs are gifted to other persons and that person is still alive. Is it not a contradiction?*". Her refusal was clearly indicative her dilemma that is rooted in a rational and logical thinking and a spiritual world view that she adhere to as a member of society.

CONCLUSION

The current article aimed to elucidate the 'rational' reasoning of young adults in their 'irrational' decisions to decline their participation in organ donation within a specifically selected demographic of young adults in Delhi. While existing literature pertaining to this topic has specified numerous factors contributing to the reluctance for procuring organs from the deceased

donors, this research paper particularly aimed at analysing the data using a fourfold framework based on the responses of respondents drawn from a qualitative study in Delhi. These categories are not entirely distinct; conversely, they are all interrelated to each other. Despite the limitation of a small sample size, the study revealed deep-seated doubts and apprehensions among respondents regarding organ removal and transplantation. Within the scholarly critical discourses on Organ donation, the biomedical process of organ donation and retrieval is often understood through the lens of exercise of power. For instance Foucauldian disciplinary power[31] conceptualisation may help in understanding how romanticising organs as gifts campaign are rooted in the creation of a disciplined body, normalised citizens to control and exercise power over bodies for purported betterment. Agamben[32] would argue in the similar line to say that through this process exercise of power over bodies are performed for creating a normalised body which is the aim of the sovereign power of the state. Feminist scholars like Butler[33] from a critical perspective therefore are interested in showing that how this biomedical technology that generally aims to safeguard the life of some, puts few selective others , mostly the vulnerable population at the brink of death or exposes them to the corporeal harm involved in organ theft or illegal organ removal process that is based on manipulation, persuasion, deception etc.[34] From a critical theory lens reluctance to donate organs can be interpreted not as an irrational act of the youth but rather this mode of reasoning is a rational one that may have been rooted in the often assumed irrationality of family authority, customs, spiritual world views etc. It is a rational response because is a mode of resistance to the disciplinary powers of biomedical and institutional apparatus. The discourse on organ donation therefore moves beyond the organic life of biological bodies rather they are rooted in individual subjectivities, a symbolic world that sees and imbues diverse meaning to the very act of organ donation. The cited narratives of the young individuals depicts these diversities by disallowing their subjective selves to submit to the politics of biopower argued from a Foucauldian perspective. Refusal attitude therefore means the rational act of resistance that construct the life worlds of these young adults in a meaningful way away from bio ethical rational models. Rather than understanding refusal as an irrational logic, attention need to be paid on understanding the reasons of their reluctance as valid expressions of their rational decision. This also reveals how the narratives of organ transfer caught in between the complex and contradictory structures of life and death.

The study has certain limitations and is acknowledged by the researcher due to smaller sample size. Although the study is based on a limited number of respondents, however it did not prevent it to explore and theoretically explain the cultural embeddedness of organ donation among a sample of youth population in Delhi. The study recommends macro-level empirical research to explore the link between individual factors and social determinants such as caste, class, education, and ethnic identities in shaping attitudes toward organ donation to the future researchers.

Conflict of Interest

There is No Conflict of interest in the paper

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