

**A STUDY ON DEVELOPING MEASURES FOR PROMOTING DECEASED
ORGAN DONATION IN RAJASTHAN**

Dissertation Submitted to



The IIHMR University, Jaipur

*for the partial fulfilment for the award of the degree of
Master of Business Administration (MBA)*

in

Hospital and Health Management

By

Dr. Hansika Parwani

Under the Supervision and Guidance of

Dr. Neetu Purohit

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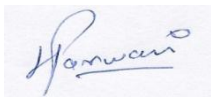
Dr. Hansika Parwani

Under the Supervision and Guidance of

Dr. Neetu Purohit

DECLARATION BY STUDENT

I hereby declare that this dissertation titled **A Study on Developing Measures For Promoting Deceased Organ Donation In Rajasthan** is the bonafide record of my original research work. I declare that it has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.



(Signature)

Name of Student: Dr Hansika Parwani

Date: 28-06-2021

CERTIFICATE

This is to certify that dissertation titled **Assessment of A Study on Developing Measures For Promoting Deceased Organ Donation In Rajasthan** is a record of the research work undertaken by Dr Hansika Parwani in partial fulfilment of the requirements for the award of the degree of MBA Hospital and Health Management from the IIHMR University, Jaipur Under my guidance and supervision and her approach to the research study has been sincere, scientific, and analytical.

Faculty Guide

IIHMR University, Jaipur
Jaipur

Date

School Dean

IIHMR University,

Date

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List of Acronymns

THOA	Transplantation of Human Organs
NTORC	Non Transplant Organ Retrival Centre
RNOS	Rajasthan Network for Organ Sharing
NOTTO	National Organ and Tissue Transplant Organization

**A Study On Developing Measures For Promoting Organ Donation In
Rajasthan**

1.Introduction

Organ donation is the procedure of giving healthy organs or tissues from a living or recently deceased person to a person suffering from end-stage organ failure. The former is called the donor and the latter is the recipient. Organs that can be transplanted include eyes, kidneys, lungs, liver, bone, heart, skin, limbs, pancreas, intestine etc. Organ donation from a living individual is possible for organs such as kidneys, liver, intestine, and bone marrow. Multi-organ donation can happen when a patient is declared 'brain dead'. A deceased donor can save up to 9 lives, giving them a second chance at life.

Brain death and organ donation:

Brain death is when all of the functions of the brain stem have permanently and irrevocably ceased to exist, and there is no electrical activity in the brain. Simply put, it indicates that the person's ability to be cognizant and to breathe has been permanently lost. (2). The ventilators does the work for circulating the oxygen through the body and keep the heart beating. Brain death can occur due to many reasons such as haemorrhage, ischaemia, trauma, tumour etc. The person will not wake up after being declared brain dead. Harvesting organs from brain dead person for transplantation is known as *cadaver transplantation* and THOA Act 1994 declared brain death legal, thus making organ donation possible after declaration of brain death.

Since the heart of the person is still beating after declaration of brain death, it is difficult for families to understand that their loved one is dead. Here is why the need of transplant coordinators come into play. They counsel the families of brain death victims , provide them emotional, and mental support. They guide them for organ transplantation. If the family agrees for organ donation, they stay with them until the body is handed back to them after organ retrieval. Even if the family disagrees with the organ donation, they stay with them to provide emotional support.

Organ Donation Status In India:

With a population of about 1.2 billion people, India's rate of deceased organ donation is only 0.05 per million., i.e., 50 cadaver donors per year (3) . “Every year 500,000 people die because of non-availability of organs, 200,000 people die due to liver disease, and 50,000 people die because of heart disease. Furthermore, 150,000 people are waiting for a kidney transplant every year , but only 5,000 are able to get one.”(4). Organ donation can play a huge role in saving these lives.

The Transplantation of Human Organs and Tissues Act (THOA 1994) governs the rules concerning organ donation and transplantation in India. This law allows the living as well as dead people to donate their organs. The act's principal goal is to control the removal, storage, and transplantation of human organs for therapeutic purposes, as well as to prohibit commercial organ deals. It legalized the concept of BRAIN DEATH.

Since then, many amendments have been rolled out for the same the current one being the THOA 2014. Some of those include:

- Physician, anaesthetist and intensivist were included in Brain death declaration team (earlier only neurosurgeon were included)
- Addition of nontransplant organ retrieval centres (NTORC)
- expanding the definition of near relatives to whom organs can be donated in case of a live donation, near relative now means spouse, son, daughter, father, mother, brother, sister, grandparents, and grand children
- making counselling for donation mandatory
- increasing the penalties in case of misuse of organ donation

NOTTO: National Organ and Tissue Transplant Organization: This is a National agency under MOHFW’s Directorate General of Health Services. The National Human Organ and Tissue Removal and Storage Network is a section of this institution, which was established in 2011 because of the amendment to the Transplantation of Human Organs Act (THOA). The mission of NOTTO is to coordinate and administer the purchase and distribution of organs and tissues, as well as to maintain a national registry of organ and tissue donation and transplantation.

Organ Donation And Status Of Other States In India

Tamil Nadu, Andra Pradesh, Telangana, Kerala, Delhi Gujarat, Maharashtra, Rajasthan, Punjab, and Haryana, have active deceased organ donation programs. In which Tamil Nadu has shown tremendous progress in the last few years. Currently, the state of Tamil Nadu produces approximately seven deceased donors per month, equating to 1.2 per million people in the state per year. Although this is low by worldwide standards, it is about ten times higher than India's overall rate. (5)

Organ Donation And Rajasthan

The deceased organ donation program is new to the state of Rajasthan. It started in the year 2015, the government of Rajasthan started the deceased organ donation program similar to Tamil Nadu, MFJCF work close with the government of Rajasthan to spread awareness about organ donation. The program started with the setting up of RNOS-a web-based organ transplantation registry. Since then 42 deceased organ donations have taken place, saving lives of 150 people(1).

Various awareness campaigns and programs have also been conducted to increase this number. As organ donation has various aspects such as legal, medical, political, the organ donation rate cannot be increased without the proper involvement of all the stakeholders.

The current study aims to plan a roadmap for Rajasthan to increase the current organ donation rate by studying various aspects of organ donation and identifying the barriers for the same.

2.Literature Review

For literature review, PubMed and Google Scholar were searched. Articles were restricted to last 15 years pertaining to Indian context. Key words used for search are organ donation in India, organ donation and transplantation, barriers of organ donation, dimensions of organ donation etc.

Title	Study area	Study objectives	Methodology	Results
“Enlightening Young Minds: A Small Step in the Curriculum, a Giant Leap in Organ Donation Abdul et al, 2021” (6)	Balaji medical college south India	“To assess knowledge, attitudes, and perceptions of organ donation and transplantation”	Cross-sectional Survey of 996 Respondents	Although they had limited knowledge, yet attitudes and perceptions about organ donation and transplantation was positive. Some important points were to include organ donation in the course curriculum
“Barriers and suggestions towards deceased organ donation in a government tertiary care teaching hospital Britzer et al, 2019” (7)	Puducherry South India	“To gain a better understanding of stakeholders' subjective perceptions on barriers to deceased organ donation and their suggestions for improvement, in a government	Qualitative study using socio-ecological model framework Sample size 6	Mistrust in health care, the deceased's unknown will, poor communication, untrained professionals interfering with grief counselling, family background, and a lack of

From the literature review we can see that, there is low knowledge about organ donation but the attitudes of people regarding the same is positive in various areas of the country. If there is high awareness regarding organ donation in some region, it is attributed to high educational status of the population. People need more knowledge before signing up as a organ donor. Practice of pledging organs after death is low, this is due to the fact that awareness regarding the concept of brain death is low. Whereas in medical setting there is high awareness towards. Low awareness in general population is the reason for lower organ donation rates. In India, the potential for success of deceased organ donation program is very high, provided if all the important stakeholders, government, organizations, and public work together.

3.Research methodology

3.1 Research question:

What are the barriers to organ donation and transplantation in Rajasthan?

3.2 Research Objectives

- To identify the barriers to organ donation in Rajasthan
- To examine the policy measures taken by southern India to improve their organ donation rate
- To prepare a road map to promote the organ donation awareness in Rajasthan

3.3 Methodology

A descriptive cross-sectional study was conducted in Jaipur, Rajasthan for 3 months. For sampling, non-probability convenience sampling was used. A structured online

Questionnaire was circulated among the participants. . The eligibility criteria was that they should be of 18 years of age and a permanent resident of Jaipur, Rajasthan.

A total of 108 responses were received. The data was sorted and analyzed using Microsoft excel.

4.Results

There were a total of 108 responses, out of which 102 consented to take part in the study. Table 1 shows the demographic characteristics of the participants. A total of 21 questions were included in the questionnaire. After demographic questions, the first question asked was whether the respondent had heard about organ donation and transplantation. If the respondent answered no, the survey form was submitted.

Table 1: Background characteristics of Participants based on ever heard about organ donation (n=102)

Characteristics	Frequency (n) (n=102)	Percentage
Gender		
Male	40	39.22
Female	62	60.78
Age (in completed years)		
18-30	59	57.84
31-60	43	42.16
60 and above	0	0
Highest level of education		
Attended school, did not finish	2	1.96
Finished school	10	9.80
Finished college, graduate	63	61.76
Post-graduate or higher	27	26.47
Marital status		
Single	72	70.5
Married	29	28.43
Prefer not to say	1	0.98
Religion		
Hindu	88	86.27
Others	9	8.82
Prefer not to say	5	4.90
Occupation		
Employed	49	48
Homemaker	21	20.59
Student	25	24.51
Un-employed	7	6.68
Retired	0	0

Barriers to wards organ donation : 1. Lack

of knowledge and awareness about brain death and organ donation as a barrier

Out of 102 respondents, 11(10.78%) have never heard about the term organ donation and transplantation. Only 31.87% people knew the exact meaning of the term organ donation and transplantation and 68.13% have partial knowledge about the term. As shown in table 2 shows the awareness of participants regarding brain death and organ donation

Table 2: Awareness about Brain death and Organ Donation

Characteristic	(n=91)	(%)
Have you ever heard of the term organ donation and transplantation?		
Yes	91	89.22
No	11	10.78
Knowledge about when can organ be donated		
During life	6	6.59
After death	21	23.08
Both	57	62.64
Don't know	7	7.69

2. Awareness about brain death and its legality

When the participants were asked about when organs can be donated, 62% of them were aware that organs can be donated both during life and after death, while 7% were unaware. Only 63% of the participants knew about brain death out of which 37% participants were aware that brain death person is truly dead. Only 26%(n=58) of the participants were aware that there is a law in India that considers brain death legal. (as shown in table 3)

Table 3: Awareness about brain death and its legality

Ever heard about brain		
-------------------------------	--	--

stem death		
Yes	58	63.74
No	33	36.26
Are you aware that people who are brain dead are truly dead? (n=58)		
Yes	22	37.93
No	23	39.66
Maybe	13	22.41
Awareness about law that recognizes brain death legal (n=58)		
Yes	26	44.0
No	11	18.0
Maybe	21	36.0

3. Source of awareness of organ donation:

The respondents selected more than one answer, media- newspaper, television and social media, were main source of awareness regarding organ donation followed by friends and family. The results are shown in figure 1.

Figure 1: Source of awareness about organ donation

Attitude towards organ donation as a barrier:

Participants of the survey were also asked about their willingness to donate. 58% of the participants were willing to donate the organs of their loved one as a next of kin, in case of untimely death. When asked are they willing to be an organ donor, only 21% stated they would absolutely donate regardless of the circumstances., and 13% said they would never

consider organ donation. The main reason that emerged for not considering organ donation was lack of knowledge (41%). The details of responses are shown in table 4. Participants were also asked if organ donation should be promoted, 43% said it should be promoted, while 38% were not sure.

Table 4:Willingness to donate

	(n)	(percentage)
Willing to donate organs of family member as a next of kin		
Yes	53	58.24
No	16	17.58
Cannot say	22	24.18
Willing to be an organ donor		
Want to donate irrespective of circumstances	20	21.98
Need more information before becoming a donor	44	48.35
Will think about it	15	16.48
Would never consider it	12	13.19
Reasons for not wanting to be a donor (n=12)		
Don't have enough knowledge about it	5	41.67
Don't want to think about death	1	8.33
Organ donation is against my religion	1	8.33
Worried about upsetting family	2	16.67
Worried about organ misuse	3	25.0

Effect of age on attitude towards organ donation

Table 4 shows the age wise response towards should organ donation be promoted. 51.79% belonging to age group 18-30 said that it should be promoted, whereas only 31.43% belonging to age group 31-60 said that it should be promoted.

Table 5: Age wise attitudes towards organ donation

Should organ donation be promoted	Yes	Maybe	No
Age group			
18-30	51.79%	35.71%	12.50%
31-60	31.43%	42.86%	25.71%

4. Knowledge about organ donor card

27% of the participants knew about an organ donor card and of them all were willing to carry an organ donor card to express their desire about organ donation after their death. As shown in table 6

Table 6: Knowledge about donor card

	(n)	(%)
Know about donor card		
Yes	25	27.47
No	66	75.53
Willingness to carry donor card(n=25)	Willing	
Willing	25	100

Key policy measures taken by southern states of India:

Policy actions taken by southern states of India was reviewed. After reviewing following were the key actions taken by them to improve organ donation rates of the state:

- Setting up of regional and state transplant organizations (ROTHO/SOTTO)
- Dividing the state into regions for better coordination of transplant related activities.
- The partnership of the government with the NGOs to increase awareness regarding organ donation
- Participation from hospitals in setting up committees for identifying brain death.
- More and more transplant and non-transplant organ retrieval centres are added in the state.
- Education and training of medical professions regarding declaration of brain death and transplantation coordination
- Passing of separate government orders(G.O) apart from those mentioned in the THOA, to promote organ donation. These include guidelines/protocols to be followed by medical officers and police personnel after declaration of brain death
- Setting up of national toll free organ donation and transplantation helpline
- Training of transplant coordinators and grief counsellors to assist the families of victims of brain dead people.
- Adoption of “Sri Ramachandra protocol for organ donation,” according to which the grief stricken families are first approached for eye donation, if they accept, they are further counselled for donation of other organs. If they deny the request for eye donation, no further probing is done for organ donation.(16)

Gaps identified from the study:

Some of the key gaps that can be identified from our study include:

- Despite the fact that 88 percent of the participants having heard about organ donation, they lack comprehensive knowledge on the subject.
- Only 62% of those polled were aware that organs can be donated both during and after death.
- People are not aware regarding the concept of brain death.
- Only 44% of the participants know that there is law in India, that makes brain death legal

- Awareness regarding donor card is low, only 25% knew about it.
- Rajasthan does not have specific laws regarding organ donation
- Collaboration between NGO's and governmental agencies is missing

Roadmap for Rajasthan

As we can see from our study that there is some partial awareness regarding organ donation in Jaipur Rajasthan. After reviewing policy of southern states and identifying gaps, following things can be done ,to increase the organ donation rates in Rajasthan:

- Increased Participation from government in promoting organ donation: this can be achieved by collaborating with Local NGOs that work for the similar cause
- Training of medical personnel in transplant coordination
- Sensitization of staff of hospitals towards organ donation awareness
- Standard SOPs from government, for hospitals and police personnel, after identification of brain death
- Community outreach programs for raising awareness towards organ donation, as the awareness increases, the donation rates will definitely increase
- Awareness drives regarding key technicalities of organ donation, like brain death, donor card, etc is necessary.

5.Discussion

The current study was conducted in Jaipur, Rajasthan. It was conducted to develop measures to increase the current organ donation rates of Rajasthan. First step was to identify barriers for organ donation and transplantation.

From our study it is seen that 89.22% of the respondents were aware about the term organ donation and transplantation, this number is higher than a study conducted in North-East India in which 79.15% of the participants were aware about organ donation and transplantation(11). Whereas similar to studies conducted in Puducherry(89%), Kanchipuram (86%), and Ahmedabad (86%),(8), (14),(15). People are aware about the term but yet they don't fully understand what it means, as only 62.64% of the participants knew that organs can be donated during one's lifetime as well as after death. This is lower than one study which was conducted in Mangalore, which shows that 94.7% people knew that organs can be donated both during life and after death(10). This may be attributed to the fact that the Zonal Coordination Committee of Karnataka for Transplantation was constituted by the Government of Karnataka in the year 2007 and since then it has been coordinating organ donation related activities and also educating the public regarding the same. Whereas this concept is fairly new for the residents of Rajasthan. We should learn from the states that already have well established deceased organ donation programs, to make progress.

As per our study, 63.74% of the participants heard about the term brain death, out of which only 37.93% of which agreed that brain dead person is truly dead. This result is similar to a study conducted among private medical college students of South India where 32.8% participants accepted brain stem death as true death.

Only 44% of people out of those who knew about brain death were aware that brain death is legal in India, which is still higher than the study conducted in rural India, where only 15.6% of the respondents felt that brain death is a legal form of death.(17).

The main source of awareness for organ donation in our study was found to be Media: newspaper, television and social media, followed by word of mouth from friends and family. This shows us that we can use these sources to increase the awareness regarding organ donation and transplantation.

For the questions which organs can be donated highest awareness was seen for kidney (87%), followed by liver, heart and lungs.

Participants' willingness to donate organs as a next of kin was found to be 58.24%. while 21.98% respondents were completely willing to be an organ donor. The rest 48.35% respondents were willing to be an organ donor if they have sufficient knowledge about it. Among people who would never consider organ donation, the main reason was lack of knowledge (41.67%), followed by worry about organ misuse(25%). This shows that lack of knowledge is one of the barrier for organ donation and without proper knowledge and awareness about organ donation, the rates cannot be increased. We need to provide proper knowledge through the right medium to improve the current organ donation rates.

Unexpectedly in our study, out of people who were unwilling to be an organ donor(n=25), religion played a minor role in their decision. Only one respondent thought that organ donation is against their religion.

When asked about donor card, only 27.47% individuals were aware about what is an organ donor card, and all of them were willing to carry the organ donor card.

This shows, that awareness plays a key role in increasing the organ donation rates. If people are aware they will definitely follow suit.

Limitations of the study: The small sample size of the study is one of the limitation of our study, the results cannot be generalized to larger population but some key points can be taken to move ahead.

6.Recommendations

To increase the current organ donation rates in Rajasthan following things can be done:

1. Media collaboration to raise awareness about the importance of organ donation. Today is the era of social media, using this tool we can increase our reach to so many people which will in turn help saving lives of many.
2. Identify all the hospitals in the state that can start deceased organ donation program. Sensitization of hospital staff regarding organ donation will help, as from our study we can see that doctors were also a source of awareness regarding organ donation.
3. Collaboration between governmental and non-governmental agencies is suggested to improve the organ donation rates of the state

7. Conclusion

In conclusion, the organ donation rates in the state can be increased with the support from all the stakeholders. People are aware about organ donation, but they do not have the complete knowledge. If we focus on increasing the awareness regarding the topic, the organ donation rates will definitely increase. More detailed studies are required to study various other factors, but the key points of this study can be used.

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9. Annexure

QUESTIONNAIRE

- 1) All the personal information collected will be kept confidential and will be disclosed only with your permission. Do you grant your permission?
 - i) Yes
 - ii) No

- 2) Email id

- 3) Gender:
 - i) Male
 - ii) Female
 - iii) Prefer not to say

- 4) How old are you, in completed years of age?
 - i) 18-30
 - ii) 31-60
 - iii) 60 and above

5) What is your highest education level?

- i) Attended school, did not finish
- ii) Finished school
- iii) Finished college, graduate
- iv) Post-graduate or higher
- v) Prefer not to say

6) What religion do you follow

- i) Hindu
- ii) Muslim
- iii) Christian
- iv) Jain
- v) Prefer not to say

7) Marital status

- i) Single
- ii) Married
- iii) Prefer not to say

1) What is your education?

- i) Employed
- ii) Home-maker
- iii) Student
- iv) Retired
- v) Un-employed
- vi) Prefer not to say

2) Have you heard about Organ Donation and Transplantation?

- i) Yes
- ii) No
- iii) (if no ther form terminates here)

3) The term "Organ Donation" means?

- i) The removal of the tissues of the human body from a cadaver
 - ii) the removal of the tissues of the human body from a living donor.
 - iii) the removal of the tissues of the human body for the purpose of transplantation to another person
 - iv) All of the above
- 4) You heard about organ donation through which of the following sources? (can select more than one)
- i) Television
 - ii) Radio
 - iii) Online sources
 - iv) Newspaper
 - v) Family/friends
 - vi) Doctor
 - vii) Others pls specify_____
- 5) Do you know when organs can be donated?
- i) During life
 - ii) After death
 - iii) Both
 - iv) Don't know
- 6) According to you, what organs can be donated? (can select more than one)
- i) Liver
 - ii) Kidney
 - iii) Heart
 - iv) Eyes
 - v) Lungs
 - vi) Skin
 - vii) Bone marrow
 - viii) Others pls specify_____

- 7) Have you heard about brain stem death?
- i) Yes
 - ii) No
- 8) Are you aware that people who are brain dead are truly dead?
- i) Yes
 - ii) No
 - iii) Maybe
- 9) Are you aware that a parliamentary law in India recognizes brain death as a form of death so that organs like kidneys, heart, liver and lungs can be donated to needy patients?
- i) Yes
 - ii) No
 - iii) Maybe
- 10) As the next of kin, would you be willing to donate the organs of your loved one?
- i) Yes
 - ii) No
 - iii) Cant say
- 11) Should organ donation be promoted?
- i) Yes
 - ii) No
 - iii) Maybe
- 12) Are you willing to be an organ donor?
- i) Will think about it
 - ii) Need more information before becoming a donor
 - iii) Would never consider it
 - iv) Definitely want to donate irrespective of circumstances
- 13) If no, why?

- i) I would worry my organs would be misused
- ii) I worry hospital staff might not do their best to save my life if they knew my organs were available for donation
- iii) I think organ donation is against my religion
- iv) I don't want to think about my death
- v) I worry my family might be upset if I donated my organs
- vi) I don't have enough knowledge about it

14) Do you know what an organ donor card is?

- i) Yes
- ii) No

15) If yes, Are you willing to carry an organ donor card and express your desire about organ donation after your death?

- i) Yes
- ii) No