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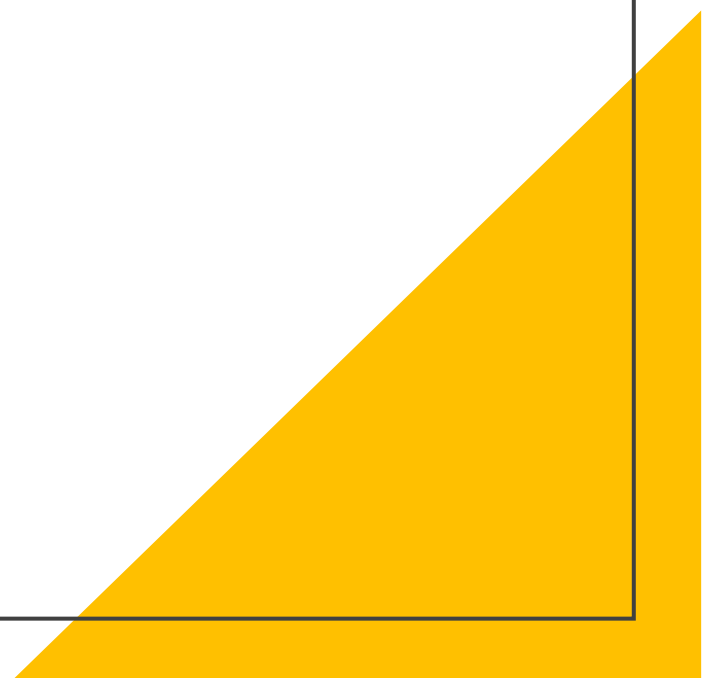
Exploring Complexities of Consent in Deceased Organ Donation: Insights from an Institutional experience in India

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INTRODUCTION



Rate of organ donation in Indian settings is **0.8 per 10,00,000** and ranks among the lowest globally



Despite introduction of **Transplantation of Human Organs Act (THOA)**, the donation rates are still less.



With the Opt-in system of consent, families usually need to decide while they are in difficult, complex, and traumatic conditions




The lack of knowledge, awareness and positive attitudes towards organ donation result in few families agreeing to donate organs. Therefore, delving into family's journey during decision making is essential to gain insight for affirmative consent.



Undertaking: The authors declare that there are no conflict of interests while undertaking this study.

Objective:

Understanding the complexities of consent for deceased organ donation



To gain insight into the experience of the family during the decision-making process.

Methods

Study Designs:
Retrospective exploratory
mixed method study

Study Settings: PGIMER,
Chandigarh, India

Study Population: Families
who gave consent leading
to successful organ retrieval

Study Sample: A purposive
sample of 81 decision-
makers participated in the
study (response rate =
75%).

Time Period: July 2019 –
June 2023 (4 years)

Study Tool : Telephonic
Interviews with semi
structured Questionnaire

Inclusion criteria's:

- Family members of patients who decided to donate organs and successful organ retrieval took place
- Family members > 18 years of age

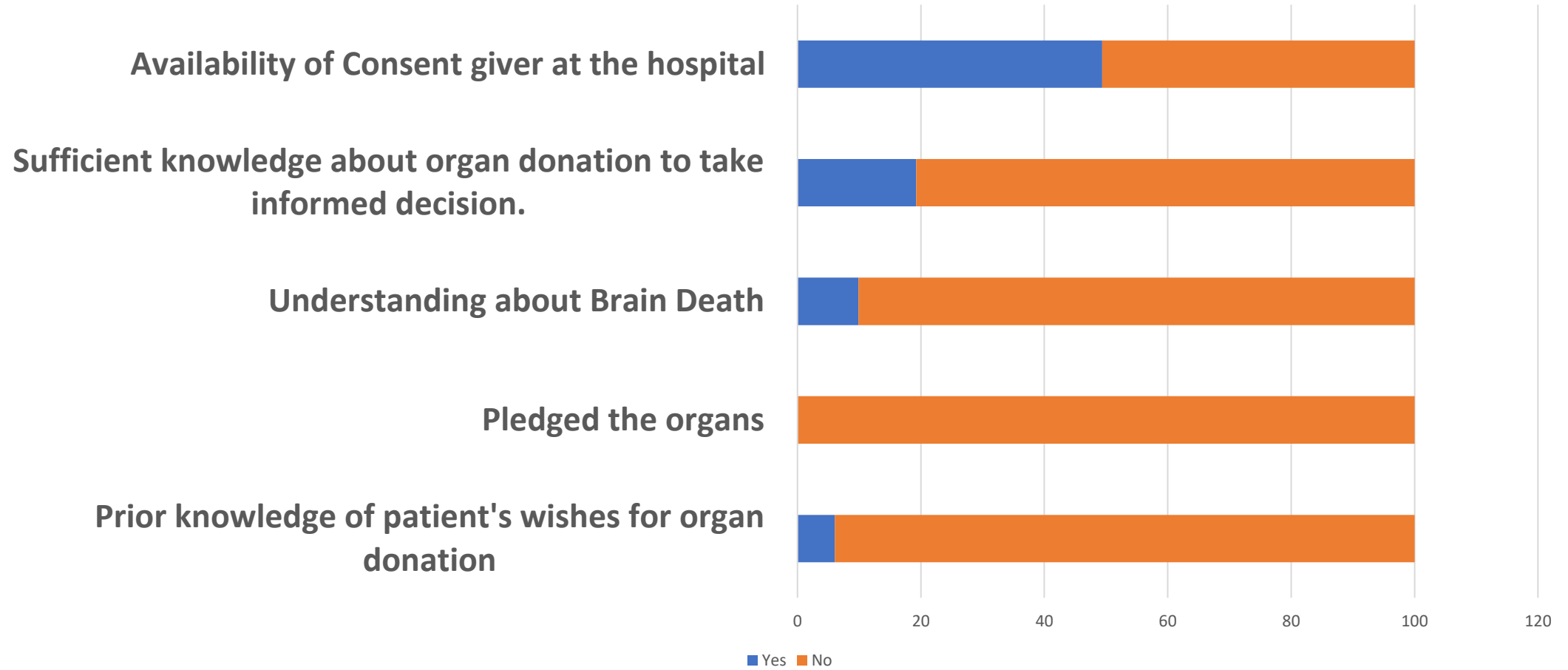
Exclusion Criteria

- Controlled DCD

Demographics of donor and decision maker

Donor				Decision Maker			
Age				Age			
Mean Age	33	17	33±17	Mean Age	38	11	38±11
	N	Percentage	N(%)		Gender		
Above 18	66	81	66(81)	Male	69	85	69(85)
Below 18	15	19	15(19)	Female	12	15	12(15)
	Gender			Education level			
Male	60	74	60(74)	Illiterate	5	6	5(6)
Female	21	26	21(26)	Primary	5	6	5(6)
	Marital Status			Middle	10	12	10(12)
Married	40	61	40(61)	High School	13	16	13(16)
Unmarried	26	39	26(39)	Higher Secondary	22	27	22(27)
	Reason for hospitalization			Graduate	14	17	14(17)
*RSA/RTA	57	70	57(70)	Post graduate/ Professional degree	12	15	12(15)
Fall from Hieght	12	15	12(15)		Relationship with deceased		
Others	12	15	12(15)	Father	16	20	16(20)
	MLC			Mother	2	2	2(2)
**MLC	71	88	71(88)	Husband	6	7	6(7)
**NMLC	10	12	10(12)	Wife	3	4	3(4)
Was deceased the bread earner of the family(Among the adult population)				Bother	10	12	10(12)
Yes	42	64	42(64)	Sister	4	5	4(5)
No	24	36	24(36)	Son	16	20	16(20)
	Dependents on the deceased if Any?			Daughter	2	2	2(2)
Mean	2(1-10)	2	2±2	Brother-in-law	6	7	6(7)
				Others	16	20	16(20)
*RSA/RTA	Road Side Accident/Road Traffic Accident			**MLC/NMLC	Medico-legal Case/Non Medico-Legal Case		

Snapshot



Decision Making

■ Motivators ■ Apprehensions

Motivators	Positive out of death(Burnt and turned to soil why waste		Apprehensions	
Would enable someone to lead a better life by saving their life			None	Disfigurement of body
Our loved one would live on in someone else	Felt the right choice(did something good	Our loved one would have wanted to help others	Social criticism	Fear of doing it the first time
			Organ Trafficking	Death status

Social response:

Positive reactions after sharing the decision (n=67)

- Appreciation and inspiration 97% (n=65)

Negative reactions after sharing the decision 52%(n=35)

- Spiritual concerns and cultural beliefs 17%(n=14)
- Accusations and blame 21%(n=17)
- Selling organs 21% (n=17)
- Rural area, illiteracy and lack of awareness 11%(n=9)
- Emotional and psychological impact 16% (n=13)
- Harassment and bureaucratic hurdles 49% (n=40)

Conclusion:

- Limited knowledge and various social and emotional factors complicate the decision-making process of deceased organ donation.
- Decision related to organ donation is profoundly influenced by family dynamics and community perceptions.
- Addressing these multifaceted factors is essential for improving deceased organ donation rates in the country.

