



Original Research Article

Knowledge and Attitude on Organ Donation among Relatives of Patients on Hemodialysis in a Tertiary Care Teaching Hospital, Puducherry, South India

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ABSTRACT

Background: Hemodialysis patients are waiting to receive the transplant kidneys. As a care giver, the relatives of patients undergoing hemodialysis should know about organ donation and transplantation. So this study will assess the existing knowledge and attitude of relatives of patients undergoing hemodialysis.

Objectives: To assess the knowledge and attitude on organ donation among relatives of patients on hemodialysis

Settings and design: This study was conducted among the relatives of patients undergoing hemodialysis from August to September, 2014, in one of the tertiary care teaching hospital located at Puducherry.

Materials and Methods: a cross sectional study was conducted among 120 relatives of patients undergoing hemodialysis. Using a structured knowledge questionnaire and 4 point likert scale, the knowledge and attitude on organ donation were assessed respectively.

Statistical analysis: Descriptive statistics and Chi-square or Fisher's exact test were used to find out the association between the variables.

Results: 86.7% of the participants had inadequate knowledge and remaining had moderately adequate knowledge and no one had adequate knowledge on organ donation. 4 (3%) had unfavorable attitude, 80 (67%) had moderately favorable attitude and 36 (30%) had favorable attitude towards organ donation.

Conclusion: This study shows that the relatives of patients undergoing hemodialysis are mostly having inadequate knowledge and moderately favorable attitude towards organ donation and they need to be educated about organ donation.

Keywords: Hemodialysis, Knowledge, attitude, organ donation, relatives.

INTRODUCTION

Organ donation is the harvesting of an individual's organs, after he or she dies, for the purpose of transplanting them into another person. In India every year nearly 500,000 people die because of non-

availability of organs, ^[1] it is estimated that every three minutes, a patient requires an organ transplant. More than two lakh Indians require transplantation annually. However, not even 10% get it. ^[2] 150,000 people await a kidney transplant but only

3,000 to 5,000 get one. ^[1,2,5,6] 90% of people in the waiting list die without getting an organ. There is a shortage of organs, and the gap between the number of organs donated and the number of people waiting for a transplant is getting larger. Transplants, as an option, have successful outcomes, and the number of people needing a transplant is expected to rise steeply due to an ageing population and an increase in organ failure. ^[2] The rate of living renal transplant in India is 3.25 per million population and deceased donor transplantation 0.08 per million populations. ^[1,3,4] This is an incredibly small and insignificant number compared to the statistics around the world. Countries like the USA, UK, Germany, Nether lands have a 'family consent' system for donations where people sign up as donors, and their family's consent is required. These countries have seen the donations double per million population averaging between 10-30 per million populations. Other countries like Singapore, Belgium, and Spain have a more aggressive approach of 'presumed consent', which permits organ donation by default unless the donor has explicitly opposed it during his lifetime. These countries have seen the rate of donations double, averaging between 20-40 per million populations. ^[1]

According to a report from the Kidney International Journal about 27,000 related and unrelated living kidney donor (LKD) transplants occur worldwide every year, of which 6,435 take place in the US and 1,768 in Brazil with India figuring in between with about 3,200 transplants. ^[5]

There is a major lack of awareness about organ donation in India, and recent polls and surveys reveal that people would come forth with their wish to donate if they had received more information. A major reason for the shortage of organs is that many people have not recorded their wish about organ donation or discussed it with their families. Myths and misconceptions

about organ donation discourage potential donors from making the decision to donate organs or tissue after death. ^[6]

In Postgraduate Institute of Medical Education and Research, Chandigarh spouses constituted 17.2% of all donors between 2002 and 2006; the percentage is doubled to 34% with spousal and parental donors being equally common in 2012 and 2013. The percentage of related donors (parents, siblings, and offspring) decreased from 73.6% in 2002-06 to 48.4% in 2012-13 mainly due to a decrease in sibling donors. At the Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, spouse donors accounted for only 5% of living donor transplants till 1998 but in 2012 and 2013 has increased to 34.3%. At the All India Institute of Medical Sciences, New Delhi, spouse donors accounted for 27.7% of living donor transplants over the last decade. Given the increasing number of spouse donor transplants, it is reassuring to see that outcomes of such transplants are not inferior to those of related donor transplants. However, efforts should continue to be made to motivate all potential-related donors before a spouse donor is accepted. ^[7]

According to the Indian Law, for non related donor, an approval has to be taken from the government authorization committee ^[8] but the first relative (father, mother, brother, sister, son, daughter and wife) can donate organs without permission from the government. ^[9] Recently, in the new Gazette grandparents have been included in the list of first relatives. ^[4]

The first live related donor kidney transplant is done on March 2012 at Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Puducherry. ^[10] The cadaveric organ transplantation activity is started at Puducherry in 2013 and the first cadaver transplant is done at JIPMER on December 2013. ^[11] Indira Gandhi Government

General Hospital, Puducherry offers full fledged renal transplant at free of cost provided the patient and donor has first degree relationship. [12]

So the relatives of hemodialysis patients who can donate their kidneys without much legal procedures and less cost can be motivated to donate their organs to the patient.

By keeping it in mind this study was done with the following objective:

- To assess the knowledge and attitude on organ donation among relatives of patients on hemodialysis.

MATERIALS AND METHODS

Study Design: A cross sectional study conducted during August to September, 2014 among the relatives of patients receiving hemodialysis in one of the tertiary care teaching hospital located at Puducherry.

Study Instrument & Scoring: The study instrument consists of 3 sections. Section A contains the demographic variables of the study participants. Section B consists of knowledge questionnaire. Section C contains 4 point Likert scale. The tool was evaluated by 4 nursing experts. The knowledge questionnaire consists of 9 questions regarding knowledge on organ donation and one question regarding the willingness to register as an organ donor. Each correct answer was given with one score and the maximum score was 9. Scores below 5 were considered as inadequate, 5 to 6 as moderately adequate and above 6 as adequate knowledge. Section C contains 4 point Likert scale (Strongly agree, Agree, Disagree, Strongly Disagree) to assess the attitude on organ donation. For the ease of analysis attitude statements were collapsed in to dichotomous (Agree, Disagree). There were 10 statements including positive and negative statements in the Likert scale.

Data Collection Method: This study was approved by the Institutional Review Board consisting of Ethical Committee. The hemodialysis patient's relatives (120) such as parents, grandparents, siblings, children, grandchildren and spouse were included in this study. Convenience sampling method was used to select the study participants. The study participants were informed about the purpose of study and participant information sheet was provided to them. Oral consent was taken from each participant and also assured that confidentiality of the information will be maintained. Interview method was used to collect the data. Descriptive statistics and Chi-square or Fisher's exact test were used to find association between variables. All tests were two sided and p value less than 0.05 considered statistically significant. SPSS Package and MS Excel were used in data analysis.

RESULTS

A total of 120 individuals participated in the study, comprising of 58 (48.3%) males and 62 (51.7%) females. More than one fourth (28.3%) of the respondents were aged 18 - 27 years and majority, (64.2%) were Hindus. Most of them (74.2%) were married and 73.3 % came to know about organ donation through mass media. (Table 1)

Knowledge on Organ Donation: 86.7% of the participants had inadequate knowledge and remaining had moderately adequate knowledge and no one had adequate knowledge on organ donation.

Attitude Regarding Organ Donation: Table 3 shows that about 60% of the participants agree selling and buying of organs, nearly half of them (47.5%) believe that organ donation will disfigure the donor's body. Most of them (83.3 %) accept that the donor can live a healthy life with one kidney and 92.5 % stated that their

religion accepts organ donation. 90% of the participants believe that the organs of a

deceased person can be donated instead of being wasted.

Table 1: Socio demographic characteristic of study participants (n = 120)

Characteristics	Frequency	Percentage
Age group (years)		
18 – 27	34	28.3
28 - 37	18	15.0
38 – 47	32	26.7
48 – 57	21	17.5
> 57	15	12.5
Sex		
Male	58	48.3
Female	62	51.7
Religion		
Hindu	77	64.2
Christian	38	31.7
Muslim	5	4.2
Education		
Illiterate	20	16.6
Primary	28	23.3
High school	29	24.3
Higher Secondary	13	10.8
Diploma / Degree	30	25
Marital status		
Married	89	74.2
Unmarried	31	25.8
Area of residence		
Urban	72	60.0
Rural	48	40.0
Participants relationship to the Patient		
Parent	26	21.7
Grand parent	1	0.8
Children	29	24.2
Sibling	20	16.6
Grand children	17	14.2
Spouse	27	22.5
Source of knowledge about organ donation*		
Mass Media	88	73.3
Health personnel	15	12.5
Family members / friends	19	15.8

* multiple options were given

Table 2: Knowledge level of study participants on organ donation (n = 120)

Knowledge level (score)	Frequency (N)	Percentage (%)
Inadequate (0 -4)	104	86.7
Moderately Adequate (5 – 6)	16	13.3
Total	120	100

Table 3: Attitude of study participants regarding organ donation (n = 120)

Statements	Agree N (%)	Disagree N (%)
Organs can be sold or bought	72 (60.0)	48 (40.0)
Organ failure patient can receive an organ from an unrelated donor such as spouse, adopted parent/child or a friend.	105 (87.5)	15 (12.5)
There are age limits in organ donation	71 (59.2)	49 (40.8)
If the donor is under 18years, parent or guardian must give permission for organ donation	91 (75.8)	29 (24.2)
People with diabetes and hypertension should not donate organs	101 (84.2)	19 (15.8)
Organ Donation will disfigure the donor's body.	57 (47.5)	63 (52.5)
Donor can live a healthy life with one kidney	100 (83.3)	20 (16.7)
My religious norms accept organ donation	111 (92.5)	9 (7.5)
The organs of a deceased person can be donated instead of being wasted	108 (90.0)	12 (10.0)
Organs can be donated only after death	79 (65.8)	41 (34.2)

Table 4: Association between Knowledge level and Socio-demographic variables (n = 120)

Variables	Knowledge Level		χ^2	p value
	Inadequate N (%)	Moderately Adequate N (%)		
Gender				
Male	49 (47.1)	9 (56.3)	0.46	0.50
Female	55 (52.9)	7 (43.8)		
Religion				
Hindu	67 (64.4)	10 (62.5)	-	0.89*
Christian	32 (30.8)	6 (37.5)		
Muslim	5 (4.8)	0 (-)		
Educational level				
No education	19 (18.3)	0 (0.0)	-	0.14*
Primary	25 (24.0)	3 (18.8)		
High school	25 (24.0)	3 (18.8)		
Higher secondary	9 (8.7)	3 (18.8)		
Diploma/Degree	26 (25.0)	7 (43.8)		
Marital status				
Married	80 (76.9)	9 (56.3)	-	0.12*
Unmarried	24 (23.1)	7 (43.8)		
Place of residence				
Urban	63 (60.6)	9 (56.3)	0.11	0.74
Rural	41 (39.4)	7 (43.8)		

*: using Fisher's exact test

Table 5: Association between Knowledge and Attitude regarding organ donation (n = 120)

Statements	Knowledge Level		χ^2	p value
	Inadequate N (%)	Moderately Adequate N (%)		
Organs can be sold or bought				
Agree	68 (94.4)	4 (5.6)	9.42	0.003
Disagree	36 (75.0)	12 (25.0)		
Organ failure patient can receive an organ from an unrelated donor such as spouse, adopted parent/child or a friend.				
Agree	95 (90.5)	10 (9.5)	-	0.005*
Disagree	9 (60.0)	6 (40.0)		
Organ Donation will disfigure the donor's body.				
Agree	57 (100.0)	0 (0.0)	16.07	< 0.001
Disagree	47 (74.6)	16 (25.4)		
Organs can be donated only after death				
Agree	76 (96.2)	3 (3.8)	18.19	< 0.001
Disagree	28 (68.3)	13 (31.7)		

*: using Fisher's exact test

Association between Knowledge Level and Socio-Demographic Variables:

Gender, religion, educational level, marital status and place of residence have no significant difference on knowledge level (Table 4).

Association between Knowledge and Attitude:

Table 5 shows the association between Knowledge and Attitude on organ donation. The attitude statements such as "Organ donation will disfigure the donor's body" and "Organs can be donated only after death" were significant with knowledge level at the P value of < 0.001.

DISCUSSION

The hemodialysis patients are mostly accompanied with their relatives for hemodialysis. In this study these relatives were interviewed to know about their knowledge and attitude level on organ donation. Commonly the hemodialysis patients were accompanied with their children (24.2 %), spouses (22.5%), parents (21.2%), siblings (16.6%), and grand children (14.2%) and only one had accompanied with grandparent.

Though the study participants often visit the hospital along with their relative

who is receiving hemodialysis most of the participants (73.3%) in this study came to know about organ donation through mass media and only 12.5 % of participants through health personnel and 15.8 % through their friends and family members. It is more or less same with the study done by Mithra P et.al. In that study majority of the study participants (68.8%) responded that major source of their information regarding organ donation was through the media including television, radio and print media. Family and friends were the source of information in 10% of the study population. [13] In a study done at Chennai by Annadurai K. et.al among college students, only 34.1% heard about organ donation from health care workers and 53 % from print and electronic media. [14] In a study done among health care workers in a public hospital in India, about 15% of participants had no or incomplete knowledge about the organ donation programme in the hospital. Almost 90% of participants had no personal experience of the organ transplant scenario. [15] So the health care workers first need to be educated about organ donation so that they can talk to the patients and their relatives about organ donation.

In the present study all the participants knew what organ donation is and 14% of the participants only knew what brain death is. In a study done by Mithra P et. al. also all the participants had heard about organ donations, and a total of 14.9% respondents had heard about brain death. [13]

Among 120 participants 79 (65.8 %) participants were aware of tissue donation such as cornea and skin. It is the same with the study done in the Tertiary Care Centers of Coastal South India. In that study also 66% of the participants knew what all the tissues can be donated for transplantation. [13]

About 104 (86.7 %) participants knew that kidney and portion of liver can be

donated by a living donor. It is less comparing with the study done by Mithra P et. al. where 95.4% participants were aware about living organ donation. [13]

In this study 32 (27%) participants were aware about how to donate the organs after death and 29 (24%) participants aware when the eyes are removed for donation after death. Only 18 (15%) participants knew how the organs are distributed nationally.

Among 120 participants 63.3 % expressed their willingness to register as an organ or tissue donor, among them 45.8 % participants said they will inform their family members about their decision to donate organs. It is high comparing to a study done at western India among general population, where only about 47% of people said they would consider donating organs. [16] This may be because of the relatives seeing their family member suffering with renal failure and knowing the need of organs for transplantation during organ failures. But the willingness to carry a donor card and also inform their family members about their wish to donate their organs were high (89%) among nursing students at Pondicherry according to a study done by Santhi A et.al. [17]

Only 59% participants of this study expressed that they will spread the importance of organ donation. It is less when comparing with the study done by Annadurai K.et.al. In that study 75% of the college students who participated in the study were in favor of organ donation promotion in the future. [14] The reason for this difference may be the college student's enthusiasm in creating the awareness to the public.

Most (86.7%) of the study participants had inadequate knowledge and remaining had moderately adequate knowledge and no one had adequate knowledge on organ donation. It was

contrary to the study done at rural settings of Kerala. In that study 53% of the participants had good knowledge regarding organ donation and only 4% had poor knowledge. [18]

In the present study 30% had favorable attitude, 67% of the participants had moderately favorable attitude, and only 3% had unfavorable attitude towards organ donation. It is little different from the study done by Santhi A.et.al among the nursing students at Pondicherry, where 3.3 % had favorable attitude, 87.3 % had moderately favorable attitude and 9.3 % had unfavorable attitude towards organ donation. [17]

In both the studies most of the participants were having moderately favorable attitude towards organ donation.

Among 120 participants 83.3 % of the participants believed that the donor can live a healthy life with one kidney. It is different from a study done in the Rural Kerala where 50% of the participants thought that live organ donation can cause severe health problems. [18]

In the present study gender, religion, education, marital status and place of residence have no significant difference on knowledge level. It is different from a study done by Saleem T et al at Pakistan, where education and socioeconomic status were found to have a significant association with knowledge scores of organ donation. [19]

In this study significant difference was observed in gender especially males with respect to the attitude statement “Organ Donation will disfigure the donor’s body”. About 58.6% of the males believed that organ donation will disfigure the donor’s body.

CONCLUSION

The relatives of hemodialysis patients are having mostly inadequate knowledge. But most of them have moderately favorable attitude towards organ

donation. Though the donation is for their near relatives the donor has the right to say ‘NO’ for the donation. It is the right of each individual to take decision on donation of their organs. To improve the cadaver donation and also live donation by the near relatives of hemodialysis patients they need to have adequate knowledge on organ donation. So they need to be educated about organ donation. Also 59 % of the participants expressed that they want spread the importance of organ donation to others around them. Without adequate knowledge they cannot clarify the doubts of others. So Measures should be taken to educate the relatives of hemodialysis patients with the needed information on organ donation. So that they can make decisions easily in the near future when there is an urgent need of kidney for their relative.

As mass media has wider coverage it can be used for creating awareness on organ donation. Even the health personnel working in dialysis unit should be trained to talk about organ donation to the relatives of patients on hemodialysis.

In this study 63.3 % expressed their willingness to register as an organ or tissue donor, among them only 45.8 % participants said they will inform their family members about their decision to donate organs. The implications of this study are to stress the importance of educating the relatives of hemodialysis patients about organ donation and motivate them to register as an organ donor. This can be achieved through the utilization of mass media, and conducting open discussion with the relatives of patients on hemodialysis regarding organ donation, its risks and benefits and the importance of organ donation.

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