KAP STUDY

Knowledge, attitudes and practices towards deceased organ donation among parents of children with End Stage Kidney Disease

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Abstract

Objective: To assess the knowledge, attitudes, and practices (KAP) towards deceased organ donation (DOD) of the parents/guardians of children with end stage kidney disease (ESKD).

Methods: This cross sectional survey was conducted between April and December 2020. A structured questionnaire was filled to assess the sociodemographic information, knowledge, attitude, and practice about DOD.

Results: A total of 130 participants with a mean age of 37±7 years were included in the study. Among all, 66 (50.8%) claimed that they had prior knowledge about DOD. However, on further questioning, no one knew who can be the deceased organ donor. Their responses about registration place and permission from religion were positive in 24(36.4%) and 31(47.0%) cases respectively. Regarding attitude, positive responses to willingness to get registered and discussing DOD in social circle were given by 37(56.1%) and 21 (31.8%) participants respectively. Only one participant was registered as donor. The remaining 64(49.2%) participants who had no prior knowledge were given relevant information and were interviewed after one week. Only 24(37.5%) showed willingness to get registered as donors and 06 (9.4%) participants discussed the topic of DOD in their social circle.

Conclusion: The results showed that the knowledge, attitudes, and practices of people who are most desperate for transplantation of their children were poor and did not change significantly even after providing them relevant information.

Keywords: Dialysis, transplantation, Deceased Organ Donation, Knowledge. (JPMA 72: 504; 2022)

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Introduction

In 2008, the global prevalence of end stage renal disease (ESKD) for children (0–19 years) was estimated at 18–100/million age matched population.[1] Pakistan has a population of 207 million people, out of which, around 35% are below 14 years of age.[2] This translates into a minimum of 1300 and up to 7200 new children who require renal replacement therapy (RRT) every year. Treatment facilities with dialysis and transplantation are limited, expensive, and mostly available in large cities.[3] The source of organs is mainly from live-related donors and deceased organ donation (DOD) has not picked up even after all the efforts to raise awareness among the public since 2010. So far, there have been only four local deceased organ donors in our country, (Personal Communication) despite the untiring efforts to educate and convince our nation on multiple fronts.

The major issues identified in other countries, which are also struggling to promote DOD, are public attributes such as myths, religious misconceptions, lack of knowledge, and misunderstood decrees.[4-6] Age, gender, socioeconomic status, education level, culture, ethics, and religion have been identified as influencing factors in other surveys done in our country.[7-9]

The concept and practice of deceased organ donation is one of the most difficult conundrums for the public. It is carried out through a social agreement based on knowledge and awareness, which forms the basis for turning one's death into another's life.[10] The complexity of human nature, cultural influences, the interplay between personal and social conscience, religious opinion, doubts, fears prevailing in the society from years, and transplant tourism represent important determinants which lead to shaping beliefs and general opinions on donation.[11-13] A study from Ethiopia reported that about 16.9% health care professionals believe that donated organs are misused.[14] The public must understand the intricacy of organ transplantation and participate to solve the problem of organ shortage, as this shortage indicates that the society is not aware that transplantation is a daily and urgent medical practice.[15] Due to a shortage of organs at the global level, every year at least 20% of patients die while on waiting lists.[8] Those having the knowledge have mistrust because of illegal transplantations. Pakistan, over the years, has become hub for illegal renal transplants as, according to World Health Organization (WHO) report, Pakistan is included in the top five countries where organ trafficking takes place.[9,13]

This study was designed to evaluate the knowledge, attitude, and practices towards DOD among people who

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are in dire need of it. The latter are the parents/guardians of children who are on maintenance haemodialysis two to three times per week. These parents are intimately associated with the pre-transplant workup of children and are in regular contact with healthcare personnel in haemodialysis units, and our hypothesis was that they will have better knowledge and will be willing to donate their organs post-death. To our knowledge, there is no study available in literature investigating the knowledge, perceptions, and actions of parents of dialysis-dependent children. This study will help to identify specific areas that should be targeted in our efforts to promote DOD in Pakistan.

Subjects and Methods

This cross-sectional survey about knowledge, attitudes, and practices (KAP) was carried out on 130 parents/guardians of children with ESKD between April and December 2020. The sample size was calculated using Raosoft Sample Size Calculator(http://www.raosoft.com/samplesize.html).[16] We used margin of error 5%, confidence interval of 95%, population size of 200 (the number of parents visiting the pre-transplant clinic in a year) and the response distribution of 60%.[7] Those parents/ guardians were included in the survey, whose children were less than 18 years age at the time of initiation of dialysis, who were regularly receiving haemodialysis, and had undergone the pre-transplant workup of LRRT. The Institutional scientific committee and ethical review committee (ERC) approved the study. After taking written informed consent, a pre–designed questionnaire was filled by the researcher for each of the study participant.

Initially, the sociodemographic details were collected and then parents were divided into two groups by asking if they knew beforehand about DOD. Those who claimed to know about DOD were asked more questions regarding their actual level of knowledge, attitudes, and practices toward DOD. Those parents/guardians who did not know this concept of organ donation were provided with the knowledge both verbally and through pamphlets. They were then re-evaluated, after one week, when they came to the dialysis unit to determine any change in their attitudes towards DOD.

Knowledge regarding DOD was assessed based on three domains which included; knowledge about who can be the deceased organ donor; the registration place of DOD; and whether religion allows it or not. Attitudes were assessed based on two domains; willingness to get registered as DOD and whether they had discussed about deceased organ donation with their family, friends, and other people, or not. Practice regarding DOD was assessed on their current registration status as donor.

Those who answered all the three questions about knowledge were assumed to have good knowledge; likewise, those who were willing to get registered as deceased organ donor and had discussed about it in their social circle were assumed to have positive attitudes towards DOD. Those who were registered and had the donation card were labelled to have positive practice regarding DOD.

Regarding those parents/guardians, who were given knowledge about DOD, upon re-evaluation after one week; were labelled to have positive attitudes if they were willing to be registered as deceased organ donor, and had discussed about it in their social circle.

Results

A total of 130 parents/ guardians were included in the study. The mean age of all participants was 37±7 (Range:23-54) years. Table 1 depicts the main demographic, educational and socioeconomic characteristics of the study participants. Almost half of the respondents were less than 40 years and were mothers. All, except one (0.8%), of the participants were Muslims. Majority 107(82%) of the responders belonged to Urdu speaking ethnicity, were urban dwellers and basic amenities were available to 99 (76%) of them. More than half 73 (56%) were educated with 93(72%) being employed. The monthly earning of 103 (79%) was less than 10,000 PKR (less than two USD/day). The results about prior knowledge of the participants about DOD are shown in Figure.

The results of questions, asked from those having prior knowledge about DOD are given in Table 2. Although 66(51%) participants claimed to have prior knowledge of DOD but no one knew who can be a deceased organ donor, either they answered incorrectly 35 (53%), or they said they do not know about it, 31 (47%).Altogether 24 (36.4%) participants knew about the registration centre of DOD and only 31(47%) participants knew that DOD is permitted in their religion. In this cohort, majority were younger than 40 years of age, females, having some level of education, belonging to Urdu speaking ethnicity and were urban dwellers with basic amenities available to them (*p*-value <0.05). Regarding attitudes, 37 (56%) participants were willing to get registered for DOD and 21(32%) had discussed the topic in their social circles. These participants were also mostly younger than 40 years, females, belonging to Urdu speaking ethnicity, educated, employed and urban dwellers. As regards to practice, there was only one (01) participant who was registered as a potential deceased organ donor.

Table-1: The main demographic, educational and socioeconomic characteristics of all study participants and a comparison between those who claimed to have prior knowledge about deceased organ donation and who did not (n=130).

	Total	Knew about deceased organ donation (n=66)	Did not know about deceased organ donation (n=64)	p- value
	n (%)	n (%)	n (%)	
Age				0.386
<40 years	70 (53.8)	38 (54)	32 (45.7)	
>40 years	60 (46)	28 (46.6)	32 (53.3)	
Relationship with patient				0.236
Father	45 (34.6)	23 (51)	22 (48.8)	
Mother	64 (49.2)	29 (45)	35 (54.6)	
Guardian	21 (16)	14 (66.6)	07 (33.3)	
Gender				0.578
Male	56 (43)	30 (53.5)	26 (46.4)	
Female	74 (56.9)	36 (48.6)	38 (51)	
Ethnicity				0.533
Urdu	40 (30.7)	25 (62.5)	15 (37.5)	
Others	90 (69.2)	41 (45.5)	49 (54.5)	
Education				<0.05
Uneducated	57 (43.8)	18 (31.5)	39 (68.4)	
Primary	28 (21.5)	10 (35.7)	18 (64.2)	
Secondary and above	45 (34.6)	38 (84.4)	07 (15.5)	
Employment				0.141
Employed	93 (71.5)	51 (54.8)	42 (45.16)	
Unemployed	37 (28.4)	15 (40.5)	22 (59.4)	
Earning				<0.05
Less than 10000 PKR	102 (78.4)	44 (43.1)	58 (56.8)	
10000 to <20000 PKR	20 (15.3)	15 (75)	05 (25)	
>20000 PKR	08 (06)	07 (87.5)	01 (12.5)	
Area of living				<0.05
Urban	107 (82)	60 (56)	47 (43.9)	
Rural	23 (17.6)	06 (26)	17 (73.9)	
Basic amenities at home				<0.05
Yes	99 (76)	60 (60.6)	39 (39.3)	
No	31 (23.8)	06 (19.3)	25 (80.6)	

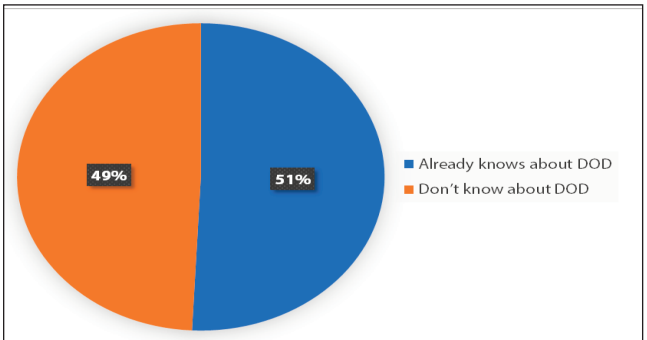

Figure: Frequency of participants having prior knowledge about deceased organ donation versus those who did not. (n = 130).
DOD: Deceased Organ Donation

As no participant could answer all the three questions about knowledge correctly, so no participant had adequate knowledge, 16 participants answered positively for questions regarding attitude so they were assumed to have positive attitude and only one participant had positive practice as she was the only registered participant of our cohort.

The remaining 67 (51.5%) participants who lacked prior knowledge were given relevant information by the researcher and were reassessed in one week regarding any change in their attitude. The results of questions are given in Table 3. Only 24(37.5%) showed willingness to be registered as DOD and 06(9.4%) participants discussed the topic of DOD in their social circle. In fact, 21 (33%) participants did not plan to discuss the topic of DOD in their social circle. Even after imparting education to them, none of the participants got themselves registered as deceased organ donor.

Discussion

This study included only a highly selected group of people whose children had ESKD, and were receiving maintainance haemodialysis. The reason of selecting this group was that as they have undergone pre-transplant evaluation and now are in the dialysis unit they interact with the doctors, nurses, technical staff and other patients regularly. They would have explored all possible options of transplantation and would have sufficient knowledge, positive attitudes, and practices toward DOD. As it has been reported previously, individuals who regularly receive information about organ donation or remain in frequent contact with healthcare workers are more likely to donate an organ.[17]

We found that half of this cohort knew beforehand about the option of DOD. One survey, done on organ donation in a population-based cohort from Pakistan, reported that 60% of respondents had adequate knowledge about organ donation and 50% participants knew that organs can come from a cadaver.[7] Another study from Pakistan surveyed undergraduate medical students and found that 12% had up-to-date knowledge about the progress of DOD in Pakistan.[18] The reason for this difference in the level of knowledge is not exactly clear, but it could be due to different study cohorts and the different tools used to assess the knowledge. Another reason the authors could think of is reporting bias among the participants. It is possible that participants in our cohort were not willing to become a deceased organ donor. When a physician or researcher from the same institute approached them, they might have assumed that their refusal may have a negative impact on the treatment of their child, so they would have found it a better choice to deny any knowledge about DOD.

Table-2: Results of questions about knowledge, attitudes and practices asked from those who claimed to have prior knowledge about deceased organ donation. (n=66).

Questions	Options	n (%)
Knowledge		
Do you know who can be a deceased organ donor?	Any one after death	35 (53.0)
	Only brain dead declared person who died in intensive care unit	0
	Don't know	31 (47.0)
Do you know about the registration place where a person can get registered and get a donor card?	Yes	24 (36.4)
	No	11 (16.7)
	Don't know	31 (47.0)
Does your religion permit deceased organ donation?	Yes	31 (47.0)
	No	05 (7.6)
	Don't know	30 (45.5)
Attitudes		
Are you willing to get registered for deceased organ donation and get a donor card?	Yes	37 (56.1)
	No	08 (12.1)
	Want to discuss with family	18 (27.3)
	Don't know	03 (4.5)
Have you discussed about deceased organ donation with your family, friends or other people?	Yes	21 (31.8)
	No	41 (62.1)
	Don't plan to	04 (6.1)
Practices		
Have you registered yourself to become a deceased organ donor and have the donor card?	Yes	01 (1.5)
	No	65 (98.5)

Table-3: Results of questions about attitudes after giving information about deceased organ donation (n=64).

Questions	Options	n (%)
Are you willing to get registered for deceased organ donation and get a donor card?	Yes	24 (37.5)
	No	03 (4.7)
	Want to discuss with family	23 (35.9)
	Don't know	14 (21.9)
Have you discussed about deceased organ donation with your family, friends or other people?	Yes	06 (9.4)
	No	37 (57.8)
	Don't plan to	21 (32.8)

Another important factor identified in our cohort was lack of formal education among parents. Those parents who had received more than secondary education were more likely to have knowledge about DOD. They would be able to read the information banners and pamphlets displayed around the waiting area of dialysis unit. Lack of knowledge about DOD had been a reason for refusal to become a donor and people with more education were more willing to donate organs as shown in studies from other countries across the globe.[19-22]

People from the same religion can have different interpretation of how their religion encourages or discourages organ donation and transplantation. In this study, we found that 47% participants claimed to know about the religious aspect of deceased organ donation. A study from Pakistan has reported that one third of the participants knew that organ donation is permitted in the religion.7In the religion of Islam, there are no clear recommendations about deceased organ donation from Quran or Hadith; however, scholars from all different sects have analyzed the issue and have allowed deceased organ donation. All these fatwas have been compiled and printed in a book, which is available on request, free of cost at this institute. It is very unlikely that a person who is seeking the religious perspective of DOD would not get any guidance. As mentioned above, it is possible that parents who are not willing for DOD may have opted to deny any knowledge on any aspect.

Zhang et al, in a survey, revealed that the majority of Chinese were favourably inclined toward organ donation, yet their actual donation rates were quite poor. The authors ascribed this disparity to policy weaknesses.[23] In the present study, 56.1% of those having prior knowledge about DOD were willing to donate and almost negligible number of people had actually got themselves registered. One study mentions positive attitudes of 60% and another study mentions 30% participants were willing to donate organs after death.[21,22] The reason for low willingness in our study, among parents who are in dire need of organ for their children is still very poorly understood. Even when education was provided to them on one-to-one basis, they were not willing to participate in DOD in most cases. There could be many confounding factors in these results, but it has been clearly demonstrated that there is an intrinsic inhibition against DOD in our society. Further qualitative studies with in-depth interviews are required to identify the main source of reluctance of our population about DOD.

This pilot study has many limitations too. The researcher was part of the health care providing team, and, therefore, there can be a significant reporting bias despite of all the reassurances about confidentiality. The sample size was small, and participants were from one centre, so the results cannot be generalized. However, this study has given an insight that in order to get a successful DOD programme in this country, we need to identify the reservations of general population first and then come up with targeted educational programmes to address those specific issues. If we can address the concerns of people about DOD we can overcome the shortage of organs for transplantation.

Conclusion

The results of the present study show that the knowledge, attitudes, and practices of parents of children with ESKD who are themselves in a dire need of DOD are poor, even

after giving them relevant information. There seems to be an intrinsic inhibition against DOD and further in-depth interviews are required to identify these factors first, so that they can be targeted in the educational drives to promote DOD in our country.

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Conflict of Interest: None.

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