

Kidney Donation, Preference and Determinants in Pakistan

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ABSTRACT

Objective: Pakistan has a dual burden of communicable and non-communicable diseases. The major indication of renal transplantation is end stage renal disease due Diabetes and hypertension, which is also a cost effective treatment significantly decreasing mortality and morbidity in these patients. **Material & Methods:** This cross-sectional study was carried out in Pakistan to determine the level of awareness among the general population regarding kidney donation and their willingness to donate. The total number of participants who completed a questionnaire was three thousand five-hundred and twenty. 56% were male while 44% female. The sample included people of all ages from all educational and ethnic backgrounds. **Results:** Among participants 63.5% were found to be aware regarding kidney

donation and 46.6% showed a willingness to donate to a first degree relative (FDR). Only 11.5% were willing to donate to someone other than a FDR. Females were found to be more willing to donate to both a FDR and a non-FDR with a male to female ratio of 0.7 (95% C.I). A small percentage (16.7%) albeit important believed organ donation should be declared illegal. **Conclusion:** Awareness regarding kidney donation and educational status were found to be linked, with people educated at a higher level having greater knowledge about the topic. All stakeholders need to develop a comprehensive strategy to decrease the overall health burden of end stage renal disease and promote legal renal transplantation. **Key words:** Kidney, Donation, Determinants, Burden

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INTRODUCTION

Pakistan is a South East Asian country with a population of over 180 millions.¹ The annual incidence of end stage renal disease or ESRD is estimated to be more than a 100 new cases per million annually.² Since there are limited regional or federal registries, the exact number of cases is not certain. It is thought the actual figures are higher owing to the poor socio-economic conditions of the vast majority of the population

and the high prevalence of untreated diabetes mellitus and hypertension as both the conditions are leading causes of chronic renal failure worldwide.^{3,4}

According to a research carried out in India and Pakistan in 2003, Chronic Glomerulonephritis accounts for almost 37% of cases of ESRD in Pakistan.⁵ Chronic interstitial nephritis, Diabetic Glomerulopathy and Hypertensive nephrosclerosis were found to be other leading causes of ESRD all of which eventually lead to renal insufficiency and failure in a matter of years. Patients with ESRD require renal replacement therapy like hemodialysis for the rest of their lives to prevent the development of overt azotemia and consequently uremia which if not treated can be

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fatal.⁶ The only cure for these patients remains Renal transplantation. There have been numerous studies which suggest renal transplantation not only offers a cure but is also the best cost-effective procedure with the greatest long term survival as compared to other methods of renal replacement which have become a burden on many economies of developed nations around the world.⁷ In Pakistan due to the inadequate providence of health care facilities, renal replacement therapy is not only extremely expensive but also out of reach for the greater part of the population. There are only a handful of public and charitable hospitals which provide free services to patients with ESRD and are largely over-burdened.⁸

Kidney transplantation is usually classified as either living-donor or deceased-donor transplantation, previously known as cadaveric transplantation. Living donors are further classified as related and non-related donors. This classification is based on whether there is a biological relationship between a donor and the recipient.⁹ Pakistan's first deceased-donor transplantation took place at Sindh Institute of Urology and Transplantation in the year 1995.¹⁰ Since then, thousands of kidneys have been transplanted from both live and deceased donors to patients with end stage of renal failure all over the country and has undoubtedly saved a lot of lives.

Regrettably though Pakistan has also become one of the countries with a thriving black-market for organ transplantation especially for kidneys. This so called 'transplant tourism' is seen in many other developing countries like India, Philippines, Egypt and China where people from various countries like the United States and Australia come looking for poverty-stricken donors who are willing to donate even a kidney in exchange for a minimal monetary benefit.^{11,12} This is not only a violation of human rights but it is also considered an illegal practice. More often than one can imagine, these poor donors are left in a very grave condition once the procedure is done, with no long term medical follow up or medications.

To curb this problem, the government passed a legislation in 2007 known as 'Transplantation of Human Organs and Human Tissue Ordinance'

(THOTO) which became a part of law in 2010.¹³ The law if implemented strictly may be able to limit organ trade to a certain extent but the prospect still looks grim due to the government's continuing ignorance regarding the need for a central registry of transplantation and regulation of all transplants being done both publicly and commercially.

Promoting people to become organ donors and raising awareness among the general population about organ transplantation and how they can save lives even after they have passed away can see a rise in the trend of legal organ donation by people willing to do so.

All over the world especially in developed countries people volunteer to donate their organs after they are dead and every year deceased organ donation saves many lives and likewise, live-organ donation as in the case of kidney donation to a relative is accepted and even encouraged after proper counseling. These study objectives were to estimate the awareness of organ donation among people of Pakistan and to raise awareness among the general population regarding organ donation.

MATERIALS & METHODS

This cross sectional study was conducted during January 2014 - July 2014 in three of the four provinces of Pakistan. The respondents were randomly selected and were above eighteen years of age. Inclusion criteria included Pakistanis residing in Punjab, Sindh or KPK provinces. The knowledge and attitude were evaluated through a self-administered questionnaire which was translated to Urdu and three local provincial languages besides English. Oral and written consent was obtained from all participants before the start of the study and their identity was remained confidential by assigning them a random number. The respondents were briefed regarding kidney donation and associated problems after the filling of the questionnaires by an urologist and were given the opportunity to ask any query regarding the issue. The sampling was done through multistage stratified random selection and Chi square test was applied to yield frequencies. Social Package for Statistical Software (SPSS) version 17 was used to analyze the data.

RESULTS

The total number of initially recruited sample were 4100, however the final number of respondents who participated and completed the questionnaire was 3520, with the response rate of 85.8%. Males were 56% while females were 44%.

Table 1a: Demographics (Gender) of the participants N=3520

Educational Status	Male n=1980 (% of male)	Female n=1540(% of female)	Total N=3520(% of total)
Non educated*	376(19.0)	280(18.2)	656 (18.6)
Primary or Secondary**	1054(53.2)	844(54.8)	1898 (53.9)
Graduate or above	550(27.7)	416(27.0)	966 (27.4)

*Non educated/Uneducated: Never attended school

**Secondary education is equivalent to high school in the United States

Table 1b: Demographics (Ethnicity) of the participants N=3520

Ethnicity	Male n=1980 (% of male)	Female n=1540(% of female)	Total N=3520(% of total)
Punjabi	830 (42.0)	595 (38.6)	1425 (40.5)
Sindhi	604 (30.5)	577 (37.4)	1181 (33.5)
KPK*	546 (27.5)	368 (23.8)	914 (26.0)

In total 68% of the males and 57.6% of the female had heard regarding kidney donation with a male/female OR 1.2 (0.13-3.14). 46.6% of the respondents asserted that they were willing to donate kidney to their first degree relative in a life threatening condition, however this willingness declined to 11.5% if that was the case other than their first degree relative. Only 16.7 % of the sample size believed that the kidney donation should be declared illegal in the constitution.

Table 2: Perception regarding kidney donation (Gender breakdown)

Questions	Male n=1980 (% of male)	Female n=1540 (% of female)	Total (%) N=3520	Male/Female OR (95% C.I)
Heard regarding Kidney donation	1348 (68.0)	887 (57.6)	2235 (63.5)	1.2 (0.13-3.14)
Kidney can be donated by living human	834 (42.1)	689 (44.7)	1523 (43.2)	0.94 (1.73-5.78)
Kidney can donated after death	764 (38.5)	581 (37.7)	1345 (38.2)	1.0 (0.21-4.68)
Willing to donate kidney to first degree relative in a life threatening condition	802 (40.5)	838 (54.4)	1640 (46.6)	0.7 (4.9-16.4)
Willing to donate kidney to other than FDR	201 (10.1)	203 (13.1)	404 (11.5)	0.7 (0.3-2.6)
Kidney Donation should be declared illegal	306 (15.4)	284 (18.4)	590 (16.7)	0.8 (3.5-6.9)

Table 3: Perception regarding kidney donation (Educational status breakdown)

Questions	*Non-educated (% of uneducated) n=656	**Primary and secondary educated (% of P&S educated)n=1898	Graduate and above (% of graduate and above)n=966	Total (%) N=3520
Heard regarding Kidney donation	162 (24.7)	1117 (58.8)	956 (99.0)	2235 (63.5)
Kidney can be donated by living human	73 (11.1)	807 (42.5)	643 (66.5)	1523 (43.2)
Kidney can donated after death	44 (6.7)	757 (39.8)	544 (56.3)	1345 (38.2)
Willing to donate kidney	87 (13.2)	950 (50.0)	603 (62.4)	1640 (46.6)

to first degree relative				
Willing to donate kidney to other than FDR	69 (10.5)	147 (7.7)	188 (19.4)	404 (11.5)
Kidney Donation should be declared illegal	89 (13.5)	249 (13.1)	252 (26.0)	590 (16.7)

The highest level of knowledge regarding live kidney donation was found in the respondents who held higher education, graduate/ above: 66.5%, primary/secondary education: 42.5, un educated: 11.1%.

Table 2: Perception regarding kidney donation (Ethnicity breakdown)

Questions	Punjabi(% of the Punjabis) n=1425	Sindhi (% of Sindhi) n=1181	KPK residents (% of KPK residents) n=914	TOTAL (%) N=3520
Heard regarding Kidney donation	986 (69.1)	850 (72.0)	399 (43.6)	2235 (63.5)
Kidney can be donated by living human	681 (47.8)	662 (56.0)	180 (19.7)	1523 (43.2)
Kidney can donated after death	538 (37.7)	621 (52.6)	186 (20.3)	1345 (38.2)
Willing to donate kidney to first degree relative	739 (51.8)	604 (51.1)	297 (32.5)	1640 (46.6)
Willing to donate kidney to other than FDR	158 (11.0)	107 (9.0)	139 (15.2)	404 (11.5)
Kidney Donation should be declared illegal	147 (10.3)	207 (17.5)	236 (25.8)	590 (16.7)

DISCUSSION

The results indicated that knowledge among the general population regarding kidney donation is inadequate. Only 63.5% of the respondents, 68% males and 57.6% females knew about the procedure. The results are comparable to a similar research carried out in Pakistan in 2009 in which 60% of the people were found to be aware about kidney donation.¹⁴ This slight increase may be attributed to the growth of telecom and media industry in the past five years and wide availability of internet all over the country which has made information easily available to the masses.

When further questioned, only 43.2% were aware about live-donor transplantation; transplantation is a procedure in which a kidney is donated by a live person. Females were found to be slightly more knowledgeable about transplantation with a percentage of 47% as compared to males where 42.1% of the respondents were found to be aware. Similar was the case seen when the respondents were asked whether a kidney can be donated after death (deceased-donor). Over 61.8% had no idea that organs can be donated even after death. It

became quite evident that a lot of people not only do not know about organ donation but they also do not know about the fact that donation of organs can also be done after death.

All over the world, each year, deceased-donor transplantation saves thousands of lives. In Pakistan however due to this general lack of unawareness, there are hardly any registered donors and patients therefore largely depend on live-donors.¹⁴

In a developing country like Pakistan there are a number of factors which have led to a lack of understanding regarding organ donation in the community. Low literacy rate is a leading factor. The educational status breakdown in table 3 shows that only 24.7% of un-educated respondents had previously heard about kidney donation as compared to 58.8% and 99% of people educated at primary/secondary level and at graduate level or above respectively. Interesting to note was the fact that even though 99% of university graduates knew about kidney donation, only 66.5% and 56.3% of them knew about live-donors and deceased-donors respectively. So, even though the likelihood of people having

knowledge about the process increased with the increase in educational status, people still are not adequately aware about the possible choices they have with regard to being a donor. This shows that there is a dire need to educate more people about it to reduce the increasing burden on the transplant waiting list.¹⁵

The topic of kidney donation can be included in the primary or secondary curriculum to improve people's understanding regarding it. Moreover organizations like UNOS (United Network of Organ Sharing) can be established by the government; whose main aim would not only be to coordinate organ donation and procurement but it could also work to raise awareness among the population to encourage more people to become donors.¹⁶

Even though legislation was passed to curb the illegal organ trade prevalent in the country, the government still has to address to the root cause of such activities. When the patients especially the rich and elite cannot find a legal live-donor, they resort to the so called kidney vendors. An organization like UNOS if established by the government would increase both the number of live-donors and registered donors; people who are willing to donate after they are deceased. It would lead to a greater and timely availability of organs for people on the waiting lists. It could also possibly in the long term curtail the illegal organ trade. As for the transplant tourism is concerned, stricter check must be ensured on all medical institutions and criminal cases should be filed against those physicians found guilty of the practice.^{17,18}

When asked about the willingness to donate a kidney to a loved one or a first degree relative, 46.6% said they would do so if it meant it could save their lives. The willingness dropped to 11.5% if it was being done purely due to altruistic reasons; donation to someone other than a first degree relative. In Pakistan with a closely-knit family system some people might feel obligated to do so if a close family member was in need despite having reservations. On the other hand some might even volunteer to donate if it could save a life of someone they had a close emotional relation to, like a sibling or a parent. Similar were the findings in the research carried out in

Pakistan.¹⁴ Another research published in 2002 showed that 81% of the respondents were willing to donate a kidney to their child and 67% and 66% to their parent or sibling/spouse respectively.¹⁹

The general concern regarding kidney donation which is a disincentive for most people stems from the fear of future complications to donor's own health in the long term and failure of the remaining kidney. A person would generally not like to risk his own life for another especially for a stranger who he hasn't even met and has no connection to whatsoever and this is also reflected by the results discussed above. A lot of researches now suggest that the peri-operative and long-term complications are actually very minimal.¹⁹ So it is important to educate the general public about how safe the procedure now is especially when donors are well-screened because majority of people who are otherwise willing to donate do not do so over such concerns.

As opposed to the research carried out in Pakistan, our research showed a strong gender association with the willingness to donate.¹⁴ 54.4% of females as compared to only 40.5% males showed a willingness to donate to a first degree relation (male to female ratio of 0.7). Such a gender imbalance was also found in a research carried out in Switzerland where 65% of kidney donors were females.²⁰ The research suggested that one of the main reasons why more women volunteer to do so than men is the fact that men are the main earners or bread-winners and risking their health would mean risking the finances of the whole family. Same is true for Pakistan and so this might be a reason why 60% of the males declined to donate a kidney even to a first degree relative with a fatal condition. Another reason that may be a cause is the higher rate of men developing end stage of renal disease.^{21,22}

Gender imbalance was also seen in another research in 2003 where women were not only more willing but were also more open to family discussions about it.²³ Another important reason for this disparity, that may be argued over is that women empathize more so than men. Women are usually more compassionate and relate themselves to situations which may motivate them to volunteer in situations where a dear one is in need. Various researches have shown that targeting

whole families and counseling them over organ donation not only may lead to more people signing the donor card but also promote and enhance people's understanding in this regard and remove a lot of prevailing stigmas in the society. Religious and ethical reasons also hold people back from volunteering to become donors. 16.4% of the respondents believed kidney donation should be declared as illegal. A major deterrent for such people is their belief that is forbidden in Islam. A ruling by Islamic Fiqh council held in Jeddah, Saudi Arabia declared organ donation as permissible in Islam as long as the donor is not harmed in any way and is not selling his organs for a monetary gain; the matter is still however widely debated over in Pakistan where the scholars remain largely divided.²⁴ To encourage more people to become both live and deceased-donors, an Islamic Council should be formed and meetings between leading physicians and surgeons and Islamic scholars be organized by the government to come to a ruling in the favors of organ donation as done in Saudi Arabia. This would address to various misconceptions people have regarding permissibility of organ donation in Islam and increase acceptance in the society.

CONCLUSION

A lot needs to be done in Pakistan to raise the number of both live and deceased-donors. The government needs to play a central role in the formation of a central registry and an organization like UNOS to coordinate and regulate kidney donation and transplantation and also to raise awareness among the general population regarding the topic to motivate more people to become registered donors. The topic of organ donation can also be included in the curriculum at primary or secondary level to increase understanding about the matter. Non-governmental organizations can also play a vital role in increasing awareness among the public. To curb the ongoing organ trade within the country the government and law enforcement agencies need to closely monitor all transplant centers. To set a paradigm, those found guilty of such practice according to the THOTO legislation, should be heavily fined and sentenced to prison. A religious consensus also needs to be made regarding the

topic to encourage those to become donors who have reservations due to a belief that organ donation is not permissible in some faiths.

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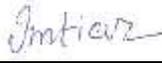
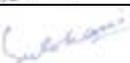
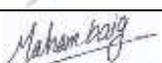
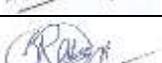
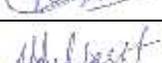
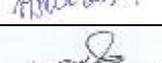
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