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Kidney donation: bridging the gap in the shortage of kidney transplants in Malaysia

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Abstract

Purpose – The purpose of this study was to identify factors that affect willingness to donate kidneys posthumously among Malaysians.

Design/methodology/approach – A questionnaire-based cross-sectional study assessing demographics, attitude, spirituality, knowledge and willingness to donate a kidney was conducted among adult Malaysians with oral informed consent. The total number of samples was 1,001 respondents. Univariate and multivariate logistic regression was performed.

Findings – A total of 29.17% (n=292) were willing to donate kidneys, while the remaining 70.83% (n=709) were not. The mean spirituality score was 80.95 ± 13.79 (maximum score 100), mean attitude score was 52.88 ± 8.074 (maximum score 70) and mean knowledge score was 1.84 ± 0.99 (maximum score 5). A higher score demonstrated a stronger spiritual level, positive attitude and better knowledge. Factors affecting willingness to donate a kidney were ethnicity (odds ratio [OR] = 15.625, 95% confidence interval [CI] = 0.043–0.094) and attitude toward kidney donation score (OR = 0.924, 95% CI = 0.902–0.945).

Originality/value — Culture-specific steps to improve programs that may contribute toward improving kidney donation posthumously among Malaysians should be developed. Results drawn from this work demonstrate that policymakers, health-care workers and stakeholders should work together to promote effective policies and program implementation to reduce the ever-increasing gap between the need and shortage crisis of kidney donation.

Keywords Kidney donation, Kidney transplants, Malaysia

Paper type Research paper

Introduction

Kidney transplantation is the gold standard of treatment for end-stage kidney disease (ESKD) [1]. Kidney transplant patients have reported better survival compared to dialysis patients, with a five-year unadjusted allograft survival rate of around 80% [2]. In Malaysia, kidney transplantation has brought dramatic clinical improvements in patients with a



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one-year allograft survival rate reported to be 85% in deceased donor kidney transplants and 96% in living donor kidney transplants [3]. The estimated cost a patient spends on dialysis is estimated to be RM38,138 (US\$11,137) for each patient per year undergoing dialysis, whilst the cost of a transplant is an average of RM29,482 (US\$8,609) for each patient per year [4, 5]. By taking the average cost per patient, the estimated cost incurred to treat ESKD patients per year in Malaysia by 2040 is approximately RM4,381,708,760 (US\$1,062,490,000) for dialysis, compared to RM3,286,281,570 (US\$796,867,500) for transplant patients [4, 5]. Thus, kidney transplant has clear clinical benefits and may reduce the expensive cost of dialysis dependency in the long run.

Despite the success of kidney transplants, kidney shortage is a universal problem [1]. The lack of availability of kidney donors observed in most countries around the world [6] highlights the need to overcome the current shortage. Most kidney patients are put on waiting lists for long periods, hoping for cadaveric donors [6]. Although Asia is the most populated region in the world, it has the lowest rate of kidney transplantation and the greatest growth rate for numbers of people entering chronic kidney disease and ESKD [1]. The discouraging environment of kidney donation is even more concerning in Malaysia, which reports among the lowest kidney donation rates globally [7], reporting approximately 30 to 40 actual kidney transplants each year [8]. With over 21,000 currently on the waiting list [8], the current kidney donation rate is unable to meet the increasing demand among Malaysians.

There are immense challenges faced in obtaining kidney donors posthumously. These challenges are multifactorial and include but are not limited to religion, spirituality, culture, beliefs, attitude and knowledge [9, 10]. With most countries becoming increasingly multicultural, different nuances toward religious, spiritual and cultural approaches to kidney donation may occur. Evidence has shown that religion does play a vital role in decision-making [10], with many opting not to donate for fear of religious prohibition [9]. In addition to this, sociocultural beliefs and tradition are also known to affect kidney donation [10], with many inclined to feel that donation of organs, in general, is a mutilation of the body. Lack of awareness, poor knowledge of kidney transplantation and consent and insufficient investment in transplantation infrastructure and workforce development are also among the reasons for the shortage of kidney supply [9, 10].

In Malaysia, due to the low availability of donors, identifying reasons for willingness to donate kidneys posthumously is essential. Current educational packages are often exclusively based on knowledge of kidney donation and rarely consider the need for balance public information with the varying degree of spirituality or attitude, especially in a multicultural community. Thus, a deeper understanding of willingness to donate kidneys in relation to knowledge, attitude and spirituality may aid in developing educational programs and highlight areas that require improvement and implementation of policymakers and health-care workers. This is especially a concern as statistics show that there is a stark difference in kidney donation rates between ethnicities [3], a pertinent challenge in a multicultural society. This study aimed to identify the level of spirituality, attitude and knowledge of organ donation and its association with willingness to donate kidneys.

Methodology

Study design

A cross-sectional study was performed in Kuala Lumpur and Pahang, Malaysia.

Self-administered questionnaires were distributed in both English and Malay in public places such as shopping malls, bus stops, train stations and online forms distributed via email and social media such as Facebook. Respondents were recruited through convenient sampling with oral or written informed consent. Malaysians aged 18 years and above without kidney disease were included.

The sample size required for the study questionnaire was 384 respondents (5% margin error and 95% of confidence error), based on a population of 3.5 m adults in Kuala Lumpur and Pahang [11]. Kuala Lumpur and Pahang were chosen to represent the highest and lowest levels of population density in Malaysia, <100 persons per square kilometer in Pahang and >1,501 persons per square kilometer in Kuala Lumpur [11], as a representation of the Malaysian public.

For factor analysis, a minimum total of ten observations per variable were required; however, the scale of sample size adequacy of 1,000 or more samples was categorized as excellent sample size adequacy for a dichotomous outcome [11]. Therefore, a minimum total of 1,000 participants were targeted to also allow for possible exclusions due to incomplete questionnaires as well as subanalysis of questionnaire scores [11].

Questionnaire

The questionnaire consisted of data on demographics and willingness to donate a kidney, spirituality, attitude and knowledge of kidney donation. Demographic characteristics collected were age, gender, ethnicity and educational background. Education background was based on the Malaysian education system that divides the final two years of education into either science (subjects that include biology, chemistry and physics) or art (does not include biology, chemistry and physics) studies. Other information gathered was a willingness to donate kidneys posthumously and the presence or absence of long-term illness (e.g. asthma, hypertension, etc.).

Assessment of spirituality and attitude toward kidney donation was based on previous work [12]. Spirituality was assessed based on 20 items. The spirituality questionnaire was used as it was able to measure spirituality regardless of differences in religion by measuring four core dimensions of spirituality. The first few items represent those that believe in religion related to the presence of God. Items 11 to 15 assessed the conscious perception of others and the environment, termed mindfulness, reflected mainly in Buddhism. Other items measured were the search for meaning and feeling of security, which was able to assess spirituality from meaningful existence as well as a feeling of trust within the world which covers other beliefs. The response was based on a five-point Likert scale, ranging from 1: not true at all to 5: absolutely true [12]. A total score was calculated (maximum 100), with a higher score demonstrating a stronger spiritual level.

Attitude was assessed based on 14 items [12]. Respondents answered based on a five-point Likert scale ranging from 1: strongly agree to 5: strongly disagree [12]. A total score was calculated (maximum 70), with a higher score demonstrating a more positive attitude toward kidney donation.

Knowledge toward kidney donation was determined based on five items from previous work [13]. A correct answer was given a mark of 1 and 0 for an incorrect answer [13]. The total score was then calculated (maximum 5), with a higher score demonstrating better knowledge.

A pilot test was conducted on 20 respondents to evaluate the content validity and reliability of the survey. Cronbach alpha's reliability coefficient obtained was 0.84. The average completion time was 15 min, and the respondents agreed that the questions were comprehensive.

Data analysis

The data obtained were analyzed both descriptively and analytically using SPSS software, version 23.0. Descriptive analysis was performed. Categorical data (gender, education, ethnicity, presence of long-term illness, willingness to donate a kidney) were summarized using frequency and percentage. Continuous data (age, spirituality score, attitude toward kidney donation score and knowledge score) were summarized using mean and standard

deviation. Univariate logistic regression was performed to determine predictors of willingness to donate a kidney among the study population. All factors in the univariate logistic regression with an arbitrary p-value of 0.25 and below were then entered into the multivariate logistic regression to adjust for confounding variables [14]. The performance and accuracy of the model in predicting kidney donation were measured. A p-value of less than 0.05 was considered statistically significant.

Ethics approval

Ethical approval was obtained from the Universiti Kebangsaan Malaysia Research Ethics Committee (JEP-2019-425).

Results

Demographics

A total of 1,001 respondents were included in the study (Table 1). The mean age of the respondents was 21.9 ± 4.7) years, ranging from 18 to 62 years old. Most respondents in this study population were female (n=747,74.6%). A total of 63.0% were Malays (n=631), 32.7% Chinese (n=327), 2.2% Indians (n=22) and 2.1% other minority ethnic groups (n=21). The majority of the respondents (n=921,92.0%) did not have a long-term illness compared to the remaining 7.9% (n=80). Overall, a total of 29.2% (n=292) were willing to donate kidneys posthumously, while the remaining 70.8% (n=709) were not willing to donate kidneys.

Spirituality score

The average spirituality score of the respondents was 80.9 ± 13.8 . The scores ranged between 27 and 100 (maximum possible score = 100) (Table 2). A higher score demonstrated a stronger spirituality level. No significant findings were demonstrated between willingness to donate kidneys and spirituality score.

Demographic characteristics	Value
Age, mean \pm SD	21.96 ± 4.74
Gender, n (%) Male Female	254 (25.37) 747 (74.63)
Education background, n (%) Science Non-science	736 (73.53) 265 (26.47)
Ethnicity, n (%) Malay Chinese Indian Others	631 (63.04) 327 (32.66) 22 (2.20) 21 (2.10)
I have a long-term illness, n (%) Yes No	80 (7.99) 921 (92.01)
Willingness to donate kidneys, n (%) Yes No	Demog characteristics 292 (29.17) 709 (70.83) population (n =

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Table 2.

study

Spirituality among the

population (n = 1,001)

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No	Spirituality items	1 = Not true at all	2 = Hardly true	$ n (\%) \\ 3 = \text{Not} \\ \text{sure} $	4 = Rather true	5 = Absolutely true
1	I trust in God	24 (2.4)	61 (6.1)	70 (7.0)	135 (13.5)	711 (71.0)
2	My faith helps to cope with problems	30 (3.0)	63 (6.3)	89 (8.9)	246 (24.6)	573 (57.2)
3	I trust my faith for decisions	29 (2.9)	59 (5.9)	89 (8.9)	295 (29.5)	529 (52.8)
4	I feel the love of God	32 (3.2)	62 (6.2)	118 (11.8)	180 (18.0)	628 (62.7)
5	I feel that God is my friend	105 (10.5)	82 (8.2)	199 (19.9)	235 (23.5)	380 (38.0)
6	My life means searching and asking	12 (1.2)	58 (5.8)	165 (16.5)	411 (41.1)	355 (35.5)
7	I look for insight and coherence	6 (0.6)	53 (5.3)	176 (17.6)	432 (43.2)	334 (33.4)
8	I try to have an open mind	8 (0.8)	40 (4.0)	76 (7.6)	414 (41.4)	463 (46.3)
9	I try to expand my soul	17 (1.7)	50 (5.0)	147 (14.7)	406 (40.6)	381 (38.1)
10	I search for the spirit	31 (3.1)	69 (6.9)	214 (21.4)	370 (37.0)	317 (31.7)
11	I try to deal consciously with others	6 (0.6)	47 (4.7)	108 (10.8)	481 (48.1)	359 (35.9)
12	I deal consciously with the environment	9 (0.9)	50 (5.0)	147 (14.7)	464 (46.4)	331 (33.1)
13	I try to help others	5 (0.5)	46 (4.6)	50 (5.0)	432 (43.2)	468 (46.8)
14	I try to be patient and tolerant	6 (0.6)	46 (4.6)	64 (6.4)	405 (40.5)	480 (48.0)
15	I try to be empathetic with others	7 (0.7)	49 (4.9)	65 (6.5)	416 (41.6)	464 (46.4)
16	I feel peace deep inside me	17 (1.7)	76 (7.6)	225 (22.5)	418 (41.8)	265 (26.5)
17	My life is peace and joy	19 (1.9)	71 (7.1)	207 (20.7)	431 (43.1)	273 (27.3)
18	I feel at one with the world	46 (4.6)	99 (9.9)	396 (39.6)	280 (28.0)	180 (18.0)
19	I see a friendly world around me	33 (3.3)	104 (10.4)	284 (28.4)	372 (37.2)	208 (20.8)
20	I feel there is a lot of love in the world	21 (2.1)	95 (9.5)	202 (20.2)	387 (38.7)	296 (29.6)

Attitude toward kidney donation

The mean attitude score on kidney donation was 52.9 ± 8.1 , with scores ranging between 14 and 70 (maximum possible score = 70), Table 3. A higher score demonstrated a more positive attitude to donate. Those who were willing to donate a kidney had higher attitude scores (59.6 \pm 8.2) compared to those who were not willing to donate a kidney (51.4 \pm 7.5), (U = 64,338.5, p < 0.001).

Knowledge on kidney donation

The mean level of knowledge score on kidney donation was 1.8 ± 0.9 , ranging from 0 to 5 (maximum possible score = 5), Table 4. There were no significant findings observed between knowledge and willingness to donate kidneys.

Factors that affect willingness to donate a kidney

Univariate logistic regression was performed to determine the relationship between various potential predictors and the willingness to donate kidneys among the study population (Table 5). All factors in the univariate logistic regression with an arbitrary *p*-value of 0.25 and below (age, gender, ethnicity and attitude toward kidney donation score) were then entered

		1 = Strongly		n (%)		5 = Strongly	Kidney donation in
No	Attitude	agree	2 = Agree	3 = Neutral	4 = Disagree	disagree	Malaysia
1	Donating kidneys to another person after	390 (39.0)	354 (35.4)	206 (20.6)	22 (2.2)	29 (2.9)	
2	your death is humane A dead person is ruined by kidney transplantation	209 (20.9)	373 (37.3)	323 (32.3)	69 (6.9)	27 (2.7)	359
3	I do not think that it is part of my religion to donate kidneys after death	179 (17.9)	275 (27.5)	370 (37.0)	122 (12.2)	55 (5.5)	
4	Kidney transplantation saves lives	556 (55.6)	328 (32.8)	72 (7.2)	18 (1.8)	27 (2.7)	
5	Kidney transplantation insults human rights	308 (30.8)	339 (33.9)	227 (22.7)	83 (8.3)	44 (4.4)	
6	Kidney transplantation improves life in the community	388 (38.8)	404 (40.4)	162 (16.2)	20 (2.0)	27 (2.7)	
7	If we donate kidneys after our death, we will prolong the life of another person	394 (39.4)	350 (35.0)	175 (17.5)	44 (4.4)	38 (3.8)	
8	Kidney donation disturbs the peace of a dead person	323 (32.3)	332 (33.2)	269 (26.9)	60 (6.0)	27 (2.7)	
9	It is not important for a person to be buried with their kidneys	113 (11.3)	151 (15.1)	502 (50.2)	153 (15.3)	82 (8.2)	
10	The spirit of a dead person is not peaceful if their kidneys live in the body of another person	352 (35.2)	319 (31.9)	253 (25.3)	47 (4.7)	30 (3.0)	
11	It is possible to cure some illnesses through kidney donation	312 (31.2)	420 (42.0)	167 (16.7)	66 (6.6)	36 (3.6)	
12	If we decide to donate kidneys, it is like we	294 (29.4)	369 (36.9)	208 (20.8)	86 (8.6)	44 (4.4)	
13	A dead person does	143 (14.3)	162 (16.2)	429 (42.9)	189 (18.9)	78 (7.8)	Table 3. Attitude toward
14	not need any kidneys Kidney donation insults human dignity	306 (30.6)	371 (37.1)	245 (24.5)	44 (4.4)	35 (3.5)	kidney donation among the study population ($n = 1,001$)

into the multivariate logistic regression to adjust for confounding variables [14]. The multivariate logistic regression model was statistically significant ($\chi^2 = 358.038$, df (7), p < 0.001). It was demonstrated that ethnicity and attitude on kidney donation scores were predictors of willingness to donate kidneys. It was demonstrated that Chinese were 15.6 times more willing to donate their kidney compared to Malays (95% confidence interval

JHR 36,2	No	Knowledge items	n (%)
50,2	1	On average, patients who receive a kidney transplant	
		Live longer than patients who remain on dialysis ^a	801 (80.0)
		Live as long as a patient on dialysis	172 (17.2)
		Live less than patients on dialysis	28 (2.8)
	2	On average, a transplanted kidney from a living donor will	
360		Last longer than a kidney from a donor who has dieda	363 (36.3)
		Last the same amount of time as a kidney from a donor who has died	557 (55.6)
		Last less than a kidney from a donor who has died	81 (8.1)
	3	After the surgery for kidney donation, a living kidney donor	
		Will be likely to return home about 2–3 days after surgery ^a	121 (12.1)
		Will be likely to return home 5–7 days after surgery	49 (4.9)
		Will be likely to return home two weeks after surgery	324 (32.4)
		Will be likely to return home three weeks after surgery	147 (14.7)
	4	An acceptable living kidney donor must have the same blood type as the recipient	
		True	837 (83.6)
		False ^a	164 (16.4)
Table 4.	5	A person over 60 years cannot be a living kidney donor	
Knowledge on kidney		True	609 (60.8)
donation among study		False ^a	392 (39.2)
	Note(s): a	= correct answer	

	Variables	B	Univariate OR	Univariate logistic regression OR 95% CI	
	Age Gender (male-ref.) Education background (science-ref.)	0.030 -0.342 0.158	1.030 0.710 1.171	0.990-1.072 0.476-1.060 0.787-1.741	0.142 0.094 0.437
	Ethnicity (Malay-ref.) Chinese Indian Others Presence of long-term illness (yes-ref.) Spirituality score Attitude on kidney donation score Knowledge on kidney donation score	-2.886 -2.999 -1.781 0.357 -0.006 -0.077 -0.073	0.056 0.050 0.169 1.429 0.994 0.925 0.930	0.036-0.087 0.018-0.139 0.061-0.465 0.745-2.740 0.981-1.007 0.904-0.948 0.781-1.107	<0.001 <0.001 0.001 0.283 0.362 <0.001 0.413
	Variables (reference)	В	Multivariate OR	logistic regression 95% CI	<i>p</i> -value
	Age Gender (male-ref.)	0.025 -0.385	1.025 0.681	0.986-1.065 0.459-1.009	0.205 0.055
Table 5. Univariate and multivariate logistic regression on willingness to donate a kidney	Ethnicity (Malay-ref.) Chinese Indian Others Attitude on kidney donation score Note(s): ref.: reference. Continuous vari knowledge of kidney donation score): a represented				

[CI] = 0.043–0.094, p < 0.001); Indians were 19.23 times more willing to donate kidneys compared to Malays (95% CI = 0.019–0.145, p < 0.001), while other ethnic groups were 5.85 times more willing to donate their kidneys compared to Malays (95% CI = 0.062–0.472, p < 0.001). An increment in 1 unit of the attitude toward kidney donation score increased the likelihood of kidney donation by 1.1 times (95% CI = 0.902–0.945, p < 0.001). The model was able to explain 65.1% of the variance in willingness to donate a kidney and correctly identified 87.7% of the cases.

For findings on ethnicity, further analysis was performed between ethnicity with a willingness to donate kidneys, spirituality, attitude and knowledge score. Among the different ethnicities 67/631 (10.6%) of the total Malays, 202/327 (61.8%) Chinese, 16/22 (72.7%) Indian and 7/21 (33.3%), other ethnicities reported that they would donate kidneys posthumously. There were statistically significant differences between ethnicities and spirituality levels ($\chi^2 = 230.2$, df (3) p < 0.001). Malays had the highest spirituality score (86.0 ± 9.1), followed by other ethnicities (85.4 ± 8.8), Indians (79.9 ± 11.5) and Chinese (70.9 ± 16.0). There were also statistically significant differences between ethnicity and attitude score ($\chi^2 = 35.136$, df (3) p < 0.001). Indians had the highest attitude score (57.0 ± 8.6), followed by Chinese (54.9 ± 8.6), Malays (57.2 ± 7.5) and other ethnicities (50.9 ± 10.3). No significant findings were observed between ethnicity and knowledge scores.

Discussion

ESKD is a complex disease that is a major public health concern in developing countries [7], including Malaysia. Although kidney transplantation is proven to be the best current treatment in improving ESKD patients [2], the supply of posthumous donors is still lacking [3]. Often in kidney donation, altruistic motives of family members or close friends are barely sufficient in balancing the urgent need for the organs, and the steep spiritual and cultural traditions present in a multiethnic country provide further obstacles. Asian communities have long been reported to be much more wary and reluctant when it comes to organ donation [15], evident in the current work, with a willingness to donate kidney posthumously observed in only a third of the study population. This poor outcome is not entirely surprising given the low number of kidney transplantations performed each year in Malaysia [3]. Addressing the social contours of low kidney donors in a multiethnic population is crucial and aids in improving the current approach in kidney donation.

It was interesting to note that ethnicity was determined to be a predictor of posthumous kidney donation in a multiethnic country such as Malaysia. The main ethnic groups are Malays, Chinese and Indians, with the remaining population from other origins [16]. Non-Malays were significantly more willing to donate kidneys compared to Malays. Malays are not fully against kidney donation [16]; various reasons can be accounted for the outcome.

Firstly, all Malays in Malaysia are Muslims, and among culture-specific issues among Malays is that although organ donation is permitted in Islam, quite a number feel that organ donation was tantamount to the abuse of the human body which belongs to God [16]. This was further supported by the current work which shows that the majority of Malaysians agreed with the statement relating to bodies being ruined via transplantation.

Furthermore, most Malays refused to donate a kidney due to the lack of transparent disclosure or discussion on this issue [17]. This finding concurs with national reports that show Malays donated organs the least among the three main ethnicities [3]. Hence, in order to change the perception of the Malay community, there is a need for a much more comprehensive cultural-specific discussion and public dissemination of kidney donation information that allows us to address concerns among the various ethnicities. Despite the possible link of ethnicities and religion in the Malaysian setting, there was no association

between the spirituality score and willingness to donate as the score identified spiritual levels irrespective of religious beliefs, focusing more on varying core dimensions of spirituality [12].

A more positive attitude toward kidney donation has also led to increased willingness to donate kidneys [18], similarly observed in the current work. Those with a more positive attitude toward donating kidneys are among those exposed to various comorbid diseases [19] and are more aware of the urgent need for donation. Interestingly, attitude is very often linked to knowledge, which many try to improve through appropriate dissemination of knowledge [20]. However, among Malaysians, most were still not willing to donate kidneys, despite appropriate knowledge dissemination [21], which is possibly why there was no significant association between knowledge and willingness to donate a kidney in the current work. Most alarming was the low knowledge regarding kidney donation, consistent with previous work [21], with the majority only scoring a fifth of the answers correct, which demonstrates the lack of exposure to kidney donation among the public.

Further studies need to be performed to identify ways to improve attitude toward Malaysians to promote kidney donation that does not only involve improving knowledge on kidney donation but also alternate ways that also address inhibitions associated with Malaysian culture. The findings may suggest that culture-specific challenges on posthumous kidney donation have led to a low kidney donation rate and shortage in Malaysia. Factors influencing decisions regarding kidney donation have been multifactorial, although with different findings from one population to another [18, 19].

Limitation

However, as with all questionnaire-based studies, this study does have a few limitations. The results of the work are dependent on the honesty of the respondents when answering the questionnaire. It was also noted that during data collection, a number of respondents declined to answer the questionnaire as the level of spirituality was assessed. This work was limited to two states in Malaysia, thus requiring expansion of the study to other states to grasp a better picture of the current restrictions on kidney donation. Thus, a generalization of the results should be done with caution. Despite this, one of the strengths of the study is that it provides insight into the differences in the willingness to donate kidneys among ethnicities. It is concluded that a local guide on culture-specific information that addresses ways to improve attitude toward donation should be developed to ensure that appropriate steps are taken to overcome challenges in donating kidneys among Malaysians.

Conclusion

Organ donation is an emerging topic of public health importance as a result of the everincreasing gap between the need and shortage crisis of kidney donation. There was no association between spirituality and knowledge with willingness to donate kidneys in the present work. Nevertheless, the poor knowledge of Malaysians regarding kidney donation suggests the need for a more comprehensive educational program to be disseminated to the public. The attitude was found to significantly affect willingness to donate kidneys, and the association between attitude and ethnicity toward posthumous kidney donation is crucial and should form the basis of developing a more personalized educational approach to aid in improving the numbers of kidney donors in a multiethnic Malaysian community. To that end, future efforts should be focused on identifying ways to develop a more focused national campaign, specific to local needs.

Conflict of Interest: None

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