

Family Perceptions, Knowledge, and Willingness Toward Kidney Organ Donation Among Family Members of Dialysis Patients at a Teaching Hospital in Kuala Lumpur

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Abstract- Kidney transplantation remains the most effective treatment for end-stage kidney disease (ESKD), yet Malaysia continues to experience a critical shortage of donor organs. Family members play a central role in both living and deceased organ donation decisions, particularly in collectivist societies where shared decision-making is normative. This quantitative cross-sectional study examined the perceptions, knowledge, attitudes, and willingness toward kidney donation among 100 family members accompanying dialysis patients at the Nephrology Unit of a Teaching Hospital in Kuala Lumpur. A validated questionnaire was used to assess demographics, knowledge of transplantation and brain death, attitudes toward donation, cultural and religious beliefs, and willingness to donate either while living or in the event of brain death. Findings revealed moderate knowledge levels, with 78% understanding that a single kidney can sustain normal life and 70% recognizing the safety of living donation. Positive attitudes were prevalent, and 72% expressed willingness to donate a kidney to a relative. Notably, 90% believed their religion permits organ donation. However, acceptance of deceased (cadaveric) donation remained low, with only 28% willing to consent to organ retrieval after brain death. Major barriers included confusion about brain death, emotional difficulty, mistrust of the healthcare system, and family disagreement. Knowledge and positive attitudes were significantly associated with willingness to donate. The study underscores the importance of targeted education, improved communication about brain death, and culturally sensitive counselling to enhance donor acceptance. These findings contribute valuable insight for healthcare providers, transplant coordinators, and policymakers seeking to strengthen Malaysia's organ donation landscape.

Index Terms- Quality of Life, Hemodialysis, End-Stage Renal Disease, ESRD, Emotional Well-being, Depression, Chronic Kidney Disease, Malaysia.

I. INTRODUCTION

Kidney failure remains a major public health challenge in Malaysia, driven by increasing rates of diabetes, hypertension, and ageing populations. With more than 40,000 dialysis patients nationwide, the demand for kidney transplantation continues to escalate. Kidney transplantation offers superior long-term outcomes compared to dialysis, including improved survival, reduced complications, and better quality of life. However, despite these advantages, Malaysia's organ donation and transplantation rates remain among the lowest in the region [1]. The persistent shortage of donor kidneys results in long waiting times, increased mortality risk, and financial strain on the healthcare system.

Family members are essential stakeholders in organ donation decisions, especially in cultures such as Malaysia's, where collective values influence choices regarding health, illness, and death. In many situations, family members must provide consent for deceased organ donation or may serve as potential living donors. Their knowledge, perceptions, cultural influences, and emotional readiness significantly shape the likelihood of organ donation [2]. Understanding these factors is therefore crucial for improving Malaysia's donor pool and strengthening transplant programmes. This study explores the perceptions, attitudes, and willingness of family members of dialysis patients at the Nephrology Unit, Teaching Hospital Kuala Lumpur. By assessing their knowledge, religious beliefs, concerns,

and acceptance of both living and deceased organ donation, this research provides important insight into the barriers and opportunities for improving organ donation rates in Malaysia.

II. LITERATURE REVIEW

Kidney transplantation is widely recognised as the most effective treatment for end-stage kidney disease (ESKD), offering superior survival, improved quality of life, and reduced long-term healthcare costs compared to dialysis. The global burden of kidney failure continues to rise, increasing the urgency for effective organ donation systems. Despite medical advancements, the persistent shortage of donor kidneys remains a central barrier to improving transplant outcomes worldwide. International data indicate significant disparities in donation rates, with countries such as Spain, the United States, and the United Kingdom achieving higher procurement levels due to robust legislative frameworks, structured opt-out systems, and long-standing public education campaigns [6]. Conversely, many Asian countries including Malaysia report lower donation rates largely due to cultural sensitivities, family hesitancy, and limited understanding of brain death [10].

In Malaysia, the organ donation landscape has been shaped by complex intersections of culture, religion, and public awareness. Although the Ministry of Health has implemented campaigns to increase donor registration, progress remains slow. Research consistently shows that misconceptions about brain death, concerns regarding surgical risks, and uncertainty about religious permissibility remain major obstacles [12]. However, more recent studies challenge the long-standing narrative that religion is a dominant barrier. Evidence indicates increasing acceptance among Malaysians, with major religious bodies including Islamic, Christian, Buddhist, and Hindu councils openly supporting organ donation as an act that aligns with values of saving human life [8]. Despite this, many families remain unaware of official religious stances, indicating a gap between authoritative declarations and public understanding.

Family involvement plays a central role in organ donation decision-making, especially within collectivist societies. Malaysian families tend to make health decisions collectively, and emotional, cultural, and generational influences significantly shape outcomes. Family members often serve as primary caregivers for dialysis patients and therefore hold substantial influence over decisions related to both living and deceased donation. Studies show that willingness to donate is strongly associated with emotional connection, perceived responsibility, and trust in the healthcare system [11]. When families understand the process and benefits of transplantation, they are more likely to support donation. However, emotional distress, fear of surgical complications, cultural pressure to preserve the body, and mistrust toward medical institutions frequently lead to refusal [16].

Knowledge and awareness remain strong predictors of positive perceptions toward organ donation. Individuals with a clear understanding of transplantation safety, donor eligibility, the irreversible nature of brain death, and long-term outcomes for recipients tend to hold more favourable attitudes and are more likely to consent to donation [3]. Yet misconceptions persist. One of the most common misconceptions is the belief that brain-dead patients might recover if given more time, despite clinical evidence indicating otherwise. This misunderstanding reduces willingness for deceased donation, contributes to emotional conflict within families, and undermines trust in medical decisions [14]. The challenge is compounded by the fact that brain death is not widely discussed in community settings and often only introduced during emotionally intense clinical scenarios.

Cultural and religious beliefs also contribute significantly to organ donation perceptions. Certain cultural norms prioritise preservation of bodily integrity after death, leading some families to refuse donation regardless of religious permissibility. Additionally, the influence of elders and the emphasis on consensus decision-making can complicate the process, as a single dissenting family member may prevent donation even when others agree. Recent research, however, indicates that cultural and religious influences are evolving, with more individuals acknowledging that organ donation is compatible with values of compassion, charity, and communal support [5,8]. These shifts highlight the importance of culturally sensitive educational approaches that address both emotional and informational needs.

The Health Belief Model (HBM) remains one of the most widely adopted frameworks in organ donation research as it offers a comprehensive structure for understanding decision-making. The model emphasises perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy as influential components. Applying the HBM to organ donation allows researchers to examine how individuals weigh the risks and benefits of kidney donation and how emotional, cognitive, and cultural factors shape decisions. Studies using the HBM have shown that perceived benefits, such as saving a life or improving the wellbeing of a loved one, strongly motivate willingness to donate, while perceived barriers including fear, misinformation, and cultural expectations to reduce acceptance [11].

Overall, the literature demonstrates that organ donation decisions are shaped by an interplay of knowledge, cultural and religious values, emotional readiness, and trust in healthcare providers. While attitudes toward kidney donation, particularly living donation, are becoming more positive, acceptance of deceased donation remains limited. Strengthening public understanding of brain death, enhancing

trust through transparent communication, and involving families early in the counselling process are key strategies to improve donation rates in Malaysia. These findings affirm the need for targeted, culturally sensitive interventions to address persistent misconceptions, support family dialogue, and align public understanding with current medical and religious knowledge.

III. METHODOLOGY

This study employed a descriptive cross-sectional quantitative design to assess perceptions, knowledge, attitudes, and willingness toward kidney donation among family members of dialysis patients at the Nephrology Unit, Teaching Hospital Kuala Lumpur. A cross-sectional design was selected because it enables the evaluation of participant characteristics at a specific point in time and is widely used in behavioural, clinical, and public health research. The study was conducted in a tertiary teaching hospital that provides comprehensive nephrology and dialysis services. Family members accompanying patients for dialysis sessions were chosen as the study population because they are readily available in the clinical setting and often play an essential role in caregiving and decision-making. A total of 100 family members participated in the study. Convenience sampling was employed due to the natural accessibility of potential respondents within the unit. Participants were eligible if they were aged 18 years and above, were family members or close relatives of a dialysis patient, were able to understand English or Malay, and provided informed consent. Individuals with cognitive or hearing impairments, non-family caregivers, or those who declined participation were excluded to ensure data quality and accuracy. Data were collected using a structured questionnaire that comprised four sections: demographic information, knowledge of kidney donation, attitudes toward organ donation, and willingness to donate.

The questionnaire items were adapted from relevant literature and refined to suit the Malaysian cultural and clinical context. Content validity was established through expert review, and pilot testing was conducted to improve clarity and suitability of items. Reliability analysis demonstrated acceptable Cronbach's alpha values for all constructs: knowledge ($\alpha = 0.78$), attitudes ($\alpha = 0.82$), and willingness to donate ($\alpha = 0.80$), indicating good internal consistency. Ethical approval was obtained from the hospital ethics committee prior to data collection. All participants were informed that participation was voluntary and that confidentiality would be strictly maintained. Data were collected in a private, quiet area of the nephrology unit during dialysis visiting hours to ensure privacy and minimise interruptions. Descriptive statistics were used to summarise demographic characteristics and questionnaire responses. Inferential statistical analyses, including chi-square tests and Pearson correlation analyses, were performed to explore associations between knowledge, attitudes, and willingness to donate. A significance level of $p < .05$ was used to determine statistical significance.

IV. FINDINGS AND DISCUSSION

A total of 100 family members participated in the study, with most respondents aged between 25 and 55 years (Table 1). This age distribution reflects a population in active caregiving roles, consistent with typical Malaysian family structures where adult children or spouses often accompany patients to dialysis appointments. Most respondents were Malays, reflecting the demographic composition of patients at the teaching hospital. The majority were close relatives, particularly spouses, adult children, and siblings, who play significant emotional and decision-making roles in chronic illness management. This demographic profile is important because younger, educated, and caregiving focused populations tend to demonstrate greater awareness and openness toward organ donation compared to older groups.

Table 1: Demographic Characteristics of Participants (N = 100)

Variable	Category	n	%
Age Group (years)	18–24	6	6.0
	25–34	22	22.0
	35–44	28	28.0
	45–55	32	32.0
	> 55	12	12.0
Gender	Male	38	38.0
	Female	62	62.0
Ethnicity	Malay	70	70.0
	Chinese	12	12.0
	Indian	10	10.0
	Others	8	8.0
Relationship to Patient	Spouse	30	30.0
	Adult Child	40	40.0
	Sibling	20	20.0
	Parent	8	8.0
	Other relative	2	2.0
Education Level	Secondary School	36	36.0
	Diploma	28	28.0
	Degree	26	26.0

	Postgraduate	10	10.0
Monthly Household Income	< RM 2,000	22	22.0
	RM 2,000–4,999	40	40.0
	RM 5,000–7,999	26	26.0
	≥ RM 8,000	12	12.0

Knowledge of kidney donation among participants was moderate, highlighting both strengths and important gaps. While 78 percent recognised that an individual can live healthily with one kidney and 70 percent understood that living kidney donation is medically safe, only 48 percent correctly understood the concept of brain death. This gap in understanding brain death mirrors findings from previous Malaysian studies that reported confusion regarding end of life definitions and mistrust toward clinical declarations of death. The implication is critical because deceased donation depends on accurate family understanding of brain death. Limited knowledge directly contributes to low consent rates. Families may interpret ventilatory support as signs of life and thus resist organ donation out of emotional fear or hope for recovery. This suggests an urgent need for structured, clear, and empathetic explanations from healthcare providers when discussing brain death with families.

Attitudes toward organ donation were generally positive. A high proportion of respondents agreed that organ donation saves lives and viewed it as an act of charity. Furthermore, 76 percent were comfortable discussing organ donation within the family. These findings suggest that cultural values of empathy, altruism, and family responsibility remain strong facilitators of positive attitudes toward organ donation. They also reflect an increasing shift in public mindset as Malaysian families become more informed through exposure to health campaigns, social media, and personal experiences with chronic illness. The comfort level in discussing organ donation within the family is particularly encouraging because previous research shows that families who openly communicate about donation are significantly more likely to consent when faced with real life decisions.

Religious and cultural perspectives revealed encouraging insights. A large majority of participants believed that their religion allows organ donation, while only a small number were unsure, and none believed that donation is prohibited. This contradicts older studies that often identified religion as a major barrier. Increasing awareness of religious rulings, especially official statements that permit organ donation, indicates improvement in religious education and public messaging. This shift demonstrates the effectiveness of campaigns involving religious leaders to disseminate accurate information. However, religion alone cannot fully explain willingness because religious beliefs were not significantly associated with willingness to donate. This suggests that while religious acceptance is high, other factors have stronger influence, particularly emotional and cognitive barriers.

Willingness to donate a kidney while alive was high. A total of 72 percent expressed readiness to donate to a relative, reflecting the strong value placed on family support in Malaysia. This aligns with Asian cultural norms that emphasise familial duty and emotional obligation. The strong willingness for living donation also indicates that families recognise the potential benefits of transplantation for improving the patient's condition.

However, acceptance of deceased donation remained markedly low. Only 28 percent reported willingness to consent to organ retrieval after death, while 72 percent declined. Participants attributed their reluctance to emotional difficulty accepting the declaration of death, fear that the patient might recover, mistrust of hospital motives, cultural expectations regarding preservation of the body, and family disagreement. These findings highlight the complex emotional and cultural dimensions of donation decisions after death. This emotional resistance is consistent with other studies showing that families struggle to reconcile the appearance of a warm and ventilated body with the concept of irreversible death.

Statistical analysis showed that greater knowledge was significantly associated with higher willingness to donate. Participants with better understanding of transplantation benefits and donor safety were more open to donation. Better understanding of brain death also predicted acceptance of deceased donation. Meanwhile, religious beliefs were not significantly associated with willingness to donate. This indicates that knowledge and cognitive understanding have a stronger influence on decision making compared to religious factors.

Family dynamics played a significant role in donation decisions. Many respondents noted that even if they personally agreed to organ donation, the final decision often depended on achieving consensus among multiple family members, especially elders. In collectivist cultures such as Malaysia, health decisions are rarely made individually. Instead, family hierarchy, emotional obligations, and cultural expectations influence outcomes. A single dissenting family member may lead to refusal, even when others support donation. These patterns highlight the need for family-based counselling approaches in transplantation and organ procurement programs.

Overall, the findings indicate that the Malaysian public is increasingly open to living organ donation, guided by altruism and familial responsibility. Religious barriers have decreased significantly, reflecting successful educational efforts. However, deceased donation remains a major challenge due to emotional distress, misconceptions, mistrust, and complex family dynamics. Addressing these issues

requires comprehensive and culturally sensitive strategies that focus on improving knowledge, strengthening trust, and increasing public exposure to compassionate and accurate information about brain death.

V. CONCLUSION

Family members of dialysis patients in this study had positive attitudes and strong willingness toward living kidney donation. Religion did not act as a barrier, and most participants viewed organ donation as an altruistic, life-saving act. However, deceased donation remained poorly accepted due to emotional, cultural, and cognitive barriers especially misunderstanding of brain death and family decision-making dynamics. Addressing these barriers through targeted education, improved communication, and culturally sensitive counselling is crucial for increasing organ donation rates in Malaysia. With enhanced public understanding and stronger trust in the healthcare system, Malaysia's transplantation outcomes may be significantly improved.

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