Review article:

Ethical issues in Kidney Transplantation and "An" Islamic perspective

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Abstract

Kidney transplantation (KT) is currently the most realistic treatment option for patients with end-stage renal disease (ESRD) as it enables them to live longer and provides better quality of life post-transplantation. Before the 1960s, all these patients would die as there was no treatment available. It is the commonest solid organ transplantation carried out in the world at the moment. Organs are harvested from living or cadaveric donors, with living kidney donor organs generally functioning better and for longer periods of time compared to the latter. Issues surrounding organ transplantation in general and kidney transplantation in particular, are fraught with ethical dilemmas due to the shortage of organs, the logistics behind the acquisition of organs, use of living donors including minors and the black market that has sprouted thereof. Entwined in this quagmire are the legal, social and psychological consequences for the individuals involved and the society at large. It is further compounded by religious concerns, which have a significant influence on the society's acceptance of the practice of organ donation. The practice of organ transplantation is generally accepted by most Islamic scholars as it is concordant to the objectives of Islamic Law (*maqasid al Sharī'ah*) which prioritize the preservation of human life. However, resistances do arise from some jurists and even physicians of the same Islamic faith despite a fatwas decreeing that organ and tissue transplantations are permissible in Islam under certain conditions. The take-up of organ-donation is still largely poor especially among Muslims. This article therefore hopes to explore the various moral and ethical issues surrounding KT as well as the Islamic viewpoints emanating from it. We hope that this knowledge and understanding will benefit both health-care personnel and the public in general.

Keywords: kidney transplantation; ethical issues; public opinion; Islamic perspective; Organ donation euthanasia

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Introduction

Kidney transplantation (KT) has proven indisputably the treatment of choice for most patients with end stage renal disease (ESRD). Many studies conducted in Malaysia and abroad have established that it can provide a better quality of life, long-term health benefits and is more cost-effective in the long run than other treatment options including dialysis.[1, 2] During the past several decades, KT has been increasingly used for the treatment of ESRD patients worldwide. But there is a major shortage in the availability of organs. This leads to potentially preventable death and ill health among large number of people. Yet the resources needed to meet the demand for organs are potentially available. Every day a large number of patients die in hospitals following withdrawal of life-sustaining treatment (LST), whose organs could potentially save the lives of others. Currently, there

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are over two million ESRD patients globally who requires renal replacement therapy (RRT) to sustain life[3]. In 2007 there were more than 100,000 patients on the waiting list for a deceased donor organ in the US, 18 patients die per day while waiting for transplants.[3] According to the National Renal Registry of Malaysia, there were 39,711 ESRD patients on dialysis in 2016, out of which 20,000 were eligible for renal transplantation[4]. The Muslim Council of Malaysia ('Fatwa Kebangsaan') has supported organ transplantation as early as 1970; as it was considered an act of charity[5]. There has always been a very small take up rate for organ donation in Malaysia, while the need for organs has risen steeply over the same time. Organ transplant surgeries were performed actively only since 1997.The ethical issues surrounding KT are numerous including the shortage of organs and the procedures used in acquiring and distributing them. The issues are further compounded by religious concerns in which previous research has shown that religiosity is a significant predictor of organ donation acceptability. [6] The purpose of this article is to explore ethical issues raised by some of the proposed strategies to address the severe shortage of organs as well as the Islamic viewpoint emanating thereof which may benefit both health-care personnel as well as patients.

Ethical Issues in KT: The KT has revolutionised the treatment of ESRD, however there is a severe shortage of available organs. Thousands of ESRD patients die every year on the waiting lists. The main ethical issues surrounding organ transplantation in general and KT in particular, are the logistics behind the acquisition of organs, public outlook and motivation, organ trade and trafficking and the incentives for donors. This has led in the past changes in legal status and clinical care of dying and dead patients and acceptance of brain death criteria. The organ allocation and fairness in their distribution seeks to balance the needs of individuals and a widely approved criteria is to give priority to those who need it urgently and who expect greater benefit.[7] The lack of clear consensus regarding these issues results in differences in practice, not only among countries but also among transplant canters. Entwined in this quagmire are the legal, social and psychological consequences for the individuals involved and the society at large. Many studies have been conducted worldwide to clarify the public perceptions to human organ donation and transplant. On the whole, Asians are more reluctant to donate organs because of certain socio-cultural beliefs and customs.

Cadaveric organ donation is ideal because multiple organs can be harvested at one session for maximal benefit to others without any harm to the donor. Regrettably it has remained low in most Islamic countries as it is hindered by cultural traditions, social norms, lack of public education and awareness, superstition, lack of approval and support by some Islamic scholars, or lack of government infrastructure.[8-10] Malaysia has one of the lowest cadaver organ donation rates in the world with the current rate standing at 0.6 donors per million people in the population (pmp), as compared to the 46.7, 7, 9.95 and 4.3 cadaver donors pmp in Spain, Turkey, Korea and Thailand respectively. [11] This can only be attributable to a cultural aversion to organ-donation which is prevalent across all races in Malaysia. A similar scenario can be seen in countries like Myanmar (0.02), Guatemala (0.52) and Bulgaria (1.14).[11] Some countries have high rates of cadaveric organ donors such as Spain, Austria, Croatia, USA, Norway, Portugal, Belgium, and France; other countries such as Egypt and Bangladesh, Pakistan, Jordan, and Georgia, it is virtually zero. [12] Every day a large number of patients die in hospitals, whose organs could potentially save the lives of others, but most of these organs are either buried or burned. Therefore it is important to identify ways to increase this donor pool.

Previous studies have found negative correlations between religiosity and willingness to donate organs across a wide range of cultures. [13- 15] However religion is also cited a primary reason to donate organs to save the life of another person. [16] While majority of religions believe that a dead body should not be desecrated rather treated with great respect; all feel that saving a life is of prime importance to preserve life, even if means trespassing certain restrictions. Therefore, organs donation is not only permitted, rather highly praised. [17] In Malaysia, kidneys can be harvested from the deceased if he has pledged for donation prior to death.[18]Currently the shortage of organ donations pose a great challenge to the Malaysian health care system.

Recognition of the severe shortage of organs has prompted the transplant community to pursue different strategies to procure cadaveric organs: an opt-in (explicit consent), opt-out (presumed consent), donation after brain death, donation after controlled cardiac death, and extended criteria for deceased donors. [19] In "opt-in" organ donation system, which is currently also practiced in Malaysia, the individual signs up a donor card, or contacts the National Donor

Registry to become a donor when he is alive and this is recorded in a document. In the absence of clearly expressed voluntary consent, the family or person lawfully responsible for the body of the deceased may be approached regarding donation. However due consideration is given to the wishes of the deceased and their loved ones, even if the deceased had registered as an organ donor. Islam encourages Muslims to save life based on interpretation of the Qur'anic verse "*Anyone who saves one life it would be as if he saved the life of the whole people"*.[20]Despite such clear instructions, Muslims in general are somehow reluctant to sign up donor card. In "opt-out" system all individuals would presumably consent to donate their organs for transplant unless the person specifically registers an objection to being a donor while alive. There is evidence that presumed consent would increase the donation rate by 25–30% in the US or UK than explicit consent.[21]Such a system is practiced in neighbouring Singapore as well. A number of countries have moved to, or are considering proposals for, opt-out consent system as it provides the transplant team the authority to remove any organ with no need for further explicit consent.[21] However, the ethical dilemma with "opt-out" system is whether we respect public rights as individuals to self-determine? Some clinicians caring for patients at the EOL believe that it might damage the relationship of trust between them and the families with the concern that death may be declared prematurely. The "opt-out" system has not been adopted in developing countries, probably due to socioeconomic and cultural reasons or potential donor's family response. [22] Recently, some religious authorities have ignored family permission and allow cadaver-organ removal even if the deceased person had not made a declaration for organ donation. [23] It is also allowed if the deceased person had made a statement to donate his organs and money obtained from the recipient, be spent to pay his debts or for public welfare. [23] Thus, there has been a progressive relaxation in the organ - specific selection criteria. [24]

Traditionally transplant programs have followed the dead donor rule (DDR) which stipulates that organs should be procured only after a person is determined as "dead". [25] Many mainstream religions believe that death is associated with the cessation of breathing (cardio-pulmonary death).[26, 27]Brain death is human death determined by neurological criteria which was first proposed by the Harvard Medical School Ad Hoc Committee in 1968; a new set of criteria for death based on "*irreversible coma*" with "*no discernible central nervous system activity*" to allow procurement of organs from patients whose hearts had not stopped. [28] In most instances they are young people who have died due to automobile accidents, suicide, murder, spontaneous bleeding in the brain, cardiac arrest and so forth. Many physicians and ethicists, bereaved families and the general public believe that the concept of brain death violates the traditional religious concepts of determining death and that these death criteria have been put in place to facilitate availability of organs for transplant.[29, 30]Currently majority of Muslim scholars and organisations have acknowledged brain death as true death.[31]

Further some countries have developed all or part of their transplantation policy on donation after controlled cardiac death (DCD).[32]The terminally ill patients who are dying or have no hope of recovery, are considered as organ donors under certain conditions as they have a potential to ease the shortage in organ supply. The actions leading to their deaths are widely thought to be acceptable.[33] Organ procurement teams retrieve organs from them as a routine part of EOL care, once they know that the patient had wished to be a donor. [34, 35]Many people postulate that these death criteria are linked to organ transplantation, and supply of organs.[36]This has led to several highly publicized cases in which the press alleged that physicians prematurely determine death merely to procure organs for transplantation. [37, 38] In an attempt to clarity to these issues, in 1981 a presidential commission articulated the Uniform Determination of Death Act, which states that "An individual who has sustained either 1) irreversible cessation of circulatory and respiratory functions, or 2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead". [39] Thereafter treating brain dead individuals as dead became the standard clinical model and majority of transplants performed today use organs retrieved from brain dead patients whose hearts continue to beat owing to mechanical ventilation.[24] Islamic scholars representing all Islamic countries have given approval to equate brainstem death with cardiovascular death. [40] In 1996, The Malaysian Medical Council recognized and accepted brain death. [41]

Similarly in recent years there has been a growing interest in donors who have severe and irreversible brain injuries but do not meet the criteria for brain death such as permanent vegetative state patients. It is argued that their organs can be removed because

they have no prospect of regaining consciousness and continuing life cannot benefit them. [42] The DDR, a categorical requirement of transplantation is, being challenged and several scholars have called for its abandonment, claiming that it is a great hindrance to procure organs for transplantation. [43] In many prosperous societies of the west, the majority of kidneys are obtained from heart-beating, brain-dead individuals; and this practice takes place under the umbrella of proper laws.

The period between withdrawal of LST and death is a major determinant of the quality of the organs retrieved for transplantation.[44, 45] Some medical ethicists suggest for organ donation euthanasia' (ODE) to maximize the number and quality of organs for transplantation.[46] They claim it is superior to the current practice of removing LST from such patients, waiting until they die, and then retrieve their organs, since organs rapidly develop ischemic injury if their blood and oxygen supply is compromised. They suggest that the surgeon should put such patients under general anaesthesia and remove their organs rather wait for their death following withdrawal of LST. The surgical procedure would be a form of ODE. According to them; this option would give more viable organs. ODE is currently practised in countries like Belgium and the Netherlands.

Ethical Issues regarding the living donors: Living donor organ transplantation (LDOT) has been controversial because of the basic "do no harm" principle in medicine.[7] LDOT both related and nonrelated has become more common in recent years, with significant increases in the number of living unrelated donors (LURD). Donors are most often close family members, spouses, friends or co-workers of the recipient. LDOT is far superior in terms of patient survival and quality of life when compared with cadaveric organ KT.[47- 49]It eliminates the recipient's waiting time. However two major ethical issues governing LDOT are: the autonomy of the person to donate, and the safety of the operation. According to "Principles of Biomedical Ethics" patients can choose whatever they find appropriate. Potential donor must be fully informed, free from coercion to donate, prove decisional capacity and donation must be altruistic.[50] Donation should not be offered under pressure from other family members, for example when a loved one is suffering. [51] LDOT poses certain (short-term and long-term) risks to the donor, which must be discussed with the donor or their families to reach a choice that is best for them. Nowadays, open nephrectomy donor mortality rate is less than 0.03%, and the outcome and expected quality of life are similar to those of the general public. [52] Further, the laparoscopic kidney removal has reduced preoperative morbidity, aesthetic results and shortened the time for the donor to resume his routine activities.[53] According to a large, single-centre study including 3,698 kidney donors, the risk of long-term complications, including development of ESRD and hypertension is similar to that of the general population.[54]LDOT is morally admirable if motivated by compassionate concern and love for the potential recipient as it provides a way of giving the gift of life to these patients. The donor may experience a psychological benefit by contributing to the improved health of the recipient or loved one. Thus the benefits to both donor and recipient outweigh the risks associated with donation and transplantation.

Procurement of Organs through financial incentives: During the past, several approaches have been adopted to increase altruistic organ donations, but the gap between supply and demand has worsened over time. Although there is a worldwide consensus that the purchase or sale of human organs is not allowed, it has emerged as the major problem in the practice of organ transplantation.[55] Some transplant experts believe that supply of organs can be increased by providing some sort of financial incentive or social benefits to the donor. Opponents argue that it may promote coercion, corruption as well as an illegal and unregulated organ trade.[56, 57] It violates the principles of justice and human dignity, runs counter to religious teaching and is therefore ethically unacceptable.[55]Those in favour of financial incentives cite the example of Iran where a rewarded LDOT program has eliminated the waiting list.[58, 59] Lately, a new category of incentives is employed in Saudi Arabia to living related donors, who receive the King Abdul-Aziz Medal, grade 3 for their sacrifice.[60]Recently, it is legally permissible to reimburse donors' expenses associated with "travel, housing, and lost wages."[61] Human trafficking for organ removal (HTOR) is an organised crime that has affected almost every country in the world. The increasing ease of communication in the 21st century has made it a global issue, accounting for about 10% of organ transplants performed yearly in the world. [62] It involves a host of players: a recruiter who identifies the vulnerable people, the desperate seller, buyers, middlemen, hospital or clinic staff and medical professionals, and organ banks where the organs are stored.[63] Majority of trafficking victims

are desperately poor, illiterate manual labourers, refugees, and prisoners and ignorance makes them vulnerable to fraud and deception by brokers.[64,65] In Bombay, there have also been some cases of kidnapping where victims regain consciousness to find that one of their kidneys was removed while they were drugged.[66]Many affluent patients in urgent need of organs now travel national or international routes to secure a commercial transplant. [67, 68] Due to the increasing problems associated with organ trade and transplant tourism the Transplantation Society (TTS) and the International Society of Nephrology (ISN) recently issued the Istanbul Declaration stating: 'Organ trafficking and transplant tourism violate the principles of equity, justice and respect for human dignity and should be prohibited'.[69] Although Declaration of Istanbul has a lot of support across the globe, HTOR still thrives in many countries due to demand for organs.

Islamic Perspective: The issue of organ transplantation and the permissibility of organ donation have been debated among contemporary scholars from multiple schools of jurisprudence around the globe, bringing with them multiple religious and cultural nuances especially since it has not been specifically mentioned in the main sources of reference, namely the Qur'an and Hadith. These views are therefore based upon the general and broad guidelines of the *Shari'ah* and its interpretation thereof. Thus, the resultant differences of opinion do not carry any connotations of being right or wrong and are all generally in accordance with the *Shari'ah*. Islam allows for such differences in opinion as long as they are substantiated by Islamic principles.[70-74]

Saving lives is paramount in Islam as the following verse from the Qur'an illustrates, *"Whosoever saves a life, it is as if he has saved all mankind."* [20] Moreover, it is the religious duty for the sick to seek treatment as stated by Prophet Muhammad (SAW) *"O worshipers of God, seek treatment for Allah has not made a disease without appointing a remedy for it, with the exception of one disease, old age."* In this respect, since KT has proven successful in saving lives of ESRD patients, it is therefore permissible by the *Shari'ah* (Islamic Law) and most modern researchers in Islamic Jurisprudence have also upheld this legality. [75]

Islamic scholars have discussed the issue of organ donation since the 1950s in various conferences throughout the world, including Malaysia, and concluded that it is allowed. The Council of the Islamic Fiqh Academy of the Muslim World League, Makah, Saudi Arabia, at its eight working session (1985), resolved that it would be permissible in *Shari'ah* to remove an organ from a dead person and to transplant it into a living recipient, on the condition that the donor was a sane person and had wished it.

On the other hand, the human body, whether living or dead, is sacrosanct and its violation is forbidden (which happens when organs are removed from a cadaveric donor). Allah (SWT) says: *"And verily we have honoured the children of Adam"* [76] However, a greater emphasis is placed on the rights of the living which supersede those of the dead, hence the *Sharī'ah's* choice of allowing organ donation in the pursuit of saving lives. Cadaveric organ donation should not be considered as violation of the body as long as the surgery is performed in a respectable way, taking care to preserve the cadaver's appearance and dignity. The overarching Islamic principle (*qaidah al fiqh* – principle in jurisprudence) that reconciles the two is that 'necessity overrides prohibition' (*al-darurat tubih al-mahzurat*). [75]

In the case of living donor, the principle of doing no harm - *premium non nocere* - is invoked. Organ donation is an act of charity, benevolence, altruism and love for mankind. Allah (SWT) loves those who love fellow humans and try to mitigate the sorrow of others and relieve their misfortunes. Any action carried out with good intentions and which aims at helping others is respected and indeed encouraged, provided no harm is inflicted.[77] Islamic scholars have agreed on donation of an organ whose loss would usually cause no harm or a minimal to the donor, provided the benefit to the recipient is greater than the harm. It invokes the principle of accepting the lesser harm when faced with two evils, "when comparing between two ill deeds, consider which is the greater in harm and do the other".[75] The donor must donate the organ voluntarily and without financial incentive or compensation. According to Sheikh Yusuf Abdullahal-Qaradawi an Egyptian Islamic scholar, organ donation or a body part is allowed to someone who needs it for cure and this is considered to be a continual donation *(Sadaqah jariyah)* as long as the recipient benefits from it[78]. Legal guardians are allowed to donate organs of their deceased family member who has not instructed otherwise, and it is permissible for Muslims to receive organs from non-Muslims. However the payment for transplantable organs from either living or dead is condemned by most Islamic scholars, and is even considered to be a crime in some Islamic countries.[79, 80] Organ sale especially kidneys, which is prevalent exist in many

developing countries, including the Arab and Muslim world is unanimously forbidden by Islamic scholars. The dilemma of accepting brain death as an adequate criterion for the donor's death has been debated since the 1980s. Islamic scholars representing all Islamic countries have given approval to equate brainstem death with cardiovascular death.[31] From this, it may be implied, although not categorically stated, that it is permissible to retrieve organs from brain dead patients for transplantation purposes on the condition that it is authorized by the family of deceased person. In Malaysia the issue of organ transplantation has been discussed since the 1960s. As a result, a fatwa was issued as early as 1970 by the National Fatwa Council which states that organ and tissue transplantation were permissible under certain conditions. [81] Its latest 'version' was issued by the Penang Fatwa Committee in 2009.

Conclusion: A number of ethical issues concerning KT have been highlighted in this paper. These issues concern the donor, the recipient, means of procuring organs and the issue of distributive justice. Cadaveric organ donation is ideal because multiple organs can be harvested at one session for maximal benefit to others without any harm to the donor who is dead. Therefore it is important to identify ways to increase this donor pool. DDR is a safeguard against abusive misuse by prohibiting the extraction of vital organs from vulnerable patients and thus helps to maintain public trust. Abandoning it can create public distrust in the transplant system and result in an overall decline in organ donation. Islam aspires to the highest level of behaviour at the individual, family and community levels. ODE would be a form of killing – active euthanasia, which all monotheistic religions view as a crime, just like any other murder. It violates the time-honoured principle of medical ethics, "*Do No Harm"*. Patients in need of care should not be regarded as a source of organs to save the lives of other patients. Proponents of euthanasia maintain that allowing a patient to die is to exercise his autonomy by ending suffering beyond endurance. Ethical decision must balance the rights of the individual, views of the society as a whole and the desires and wishes of the family or those close to him. The exercise of autonomy therefore, cannot include the ending of one's life. Islam like other religions upholds the sanctity of life and every act on the part of physician which involves killing of terminally ill patient is prohibited. Legalising ODE will have major clinical implications and its worst victims would be the elderly, mentally-retarded, patients with neurodegenerative conditions like amyotrophic lateral sclerosis (ALS), or multiple sclerosis (MS), the disabled and even children and new-born with disabilities.

The majority of Islamic scholars permit organ donation and indeed encourage it, provided no harm is inflicted. Contemporary *ulama* permit live kidney donation but the wellbeing of the donor must be considered above the health of the recipient.

Awareness regarding organ donation can be improved through social media, education in schools and targeted media channels, organising talk shows or organising sports event to convey the message that organ donation is an act of charity and allowed in Islam. The health professionals across the board, especially the Muslims, should also play a role in educating the public regarding it.

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