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Saudi Journal of Kidney Diseases and Transplantation

Review Article

Kidney Transplantation: Ethical Challenges in the Arab World

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ABSTRACT. There is a wide gap between organ supply and demand, which results in a very long waiting time for kidney transplantation and an increasing number of deaths of the patients while on the waiting list. These events have raised many ethical, moral and societal issues regarding organ donation, allocation and use of living donors through exploitation of the poor for the benefit of the wealthy. Success in the implementation of kidney transplantation programs in a country depends on various factors including the economic situation, religious approval, public views, medical expertise and existing legislation. The public attitude toward donation is pivotal in all transplantation programs; increasing the awareness of the leaders of religion is vital in this regard.

Introduction

Organ transplantation has become one of the most effective ways to save lives and improve the quality of life for patients with end-stage organ failure in developing and developed countries. ¹⁻⁴

Kidney transplantation, one of the most common transplant procedures in the world, has, besides the medical or pharmaceutical aspects, cultural, educational, ethical and psychological elements.

Data available on the exact prevalence of various Correspondence to:

Dr. Hassan Chamsi-Pasha Department of Cardiology, King Fahd Armed Forces Hospital, P. O. Box 9862, Jeddah 21159, Saudi Arabia. E-mail: drhcpasha@hotmail.com kidney diseases in the Arab world are very limited.⁵ A recent review, which included 44 studies from the countries of the Gulf Cooperation Council (GCC), which consist of Saudi Arabia, the United Arab Emirates, Kuwait, Qatar, Bahrain and Oman, showed that the incidence of end-stage renal disease (ESRD) has increased, while the prevalence and mortality rate of ESRD in the GCC countries have not been reported sufficiently.⁶⁻¹¹

The first successful renal transplantation in the Arab world took place in Jordan in 1972. Surprisingly, the kidney transplanted was from a non–heart beating deceased donor. Many Arab countries started their transplantation programs in the 1970s and 1980s, but all have been from living related donors. Very few Arab countries managed to start deceased donor programs, notable among which is the Kingdom of Saudi Arabia. 12,13

Islamic Opinion

A common thread that binds all religions of the world is that the saving of life overrides all objections, and no religion is against organ donation. Islam has given permission for organ and tissue transplantation to save human lives or vital organs (providing that other treatment options were assessed and other conditions were met). In fact, the Quran states that "whoever saves the life of a human being, it is as if he has saved the life of all mankind ...". 15

The donation of organs is an act of charity, benevolence, altruism and love for mankind. God loves those who love fellow humans and try to mitigate the agony and sorrow of others and relieve their misfortunes. Any action carried out with good intentions and that aims at helping others is respected and indeed encouraged, provided no harm is inflicted.

Human organs are not a commodity and, therefore, they should be donated freely in response to an altruistic feeling of brotherhood and love for one's fellow beings.¹⁶

The Saudi Grand Ulama Fatwa no. 99, 1982 addressed the subject of autografts, which was unanimously sanctioned. It also sanctioned (by a majority) the donation of organs both by the living and by the dead, who made a will or testament, or by the consent of the relatives (who constitute the Islamic next of kin). The regulations in Saudi Arabia initially restricted the genetically related donors or spouses, but many of these restrictions were later removed. 16-18

There are still some uncertainties about deceased organ donation even among some international Muslim scholars. ¹⁹ They refused to acknowledge brain death as death, although it allowed turning off the ventilators once the diagnosis of brain death is clinically declared. In addition, they allowed taking organs from non-heart beating cadavers, but adamantly refused taking the organs while the heart is still beating and the circulation is still running even as a result of being on the ventilator. Accordingly, we still observe high refusal rates of the relatives of the brain dead persons to donate the organs of their dear ones, including Saudi Arabia.

Continued meetings with the Islamic scholars may overcome this obstacle.

Finally, the education of religious leaders and the public is of vital importance in changing the cultural beliefs and practices of organ donation, given that Islam does not forbid organ or tissue donation. ^{20,21}

Challenges in Kidney Transplantation

The decision to donate organs is an essential step in the process of transplantation. It is based on personal or familial opinions that are strongly influenced by many factors, including education, socioeconomic status, religion and cultural characteristics.

Arab countries have poor transplant rates because of a combination of factors including low levels of infrastructure, an insufficient trained workforce, lack of a legal framework governing brain death, religious, cultural and social constraints, patient apprehension, physician bias, commercial incentives that favor dialysis and geographical remoteness.²

Transplantation from deceased donors is still scarce in many Arab countries. In Oman, almost all transplantations depend on living related donors despite the permission from religious and legal authorities to the use of deceased donors.²²

Respecting the will of the deceased person is a common point in the different regulation systems for the procurement of post-mortal organs for transplantation. The opt-in (required consent) systems claim a higher respect for the requirement of consent than the opt-out (presumed consent) systems.²³ All Arab countries that have deceased organ programs follow the opt-in system. The only exception is Tunisia, which has had an opt-out system since 1991.²⁴

The beliefs of Islamic leaders of religion may affect the process, either in a negative or a positive way, as they are consulted frequently for advice on donation.²⁰

Close relatives usually keep their hopes high and usually prefer to think that the patient will get well; therefore, it is very hard for them to decide about organ donation. For this reason, it is for the best that the person himself should decide about organ donation while alive.²¹

Public Knowledge and Attitudes toward Organ Donation

It is essential to offer patients all appropriate and available treatment options. However, it seems that nephrologists do not talk enough about renal transplantation to their patients. In a Moroccan study of 120 patients, the main problem was the lack of information of hemodialysis (HD) patients about renal transplantation; 52.5% had no information on this topic.²⁵ The attitude of other countries is almost the same or slightly better. In the state of Oatar, 30% of 762 Qatari citizens did not have any idea about organ donation programs. Nevertheless, 38% of them would be willing to donate an organ for a relative or a friend. ²⁶ The attitude of 521 doctors and nurses working in intensive care units and emergency departments showed 85% with favorable attitude toward postmortem organ donation, although 75% of them did not have a precise concept of brain death.²⁷

In Saudi Arabia, 92% of the Saudi citizens knew that organ donation saves lives, but only 42% expressed their willingness to donate after death. Religious concerns caused 27% of them to refuse post-mortem donation.²⁸

The survey of Mohsin et al showed that 38% and 32% of the Omani subjects had either a relative or a friend with chronic kidney disease (CKD) or a renal transplantation, respectively. The results showed an acceptance of kidney donation during life. Nevertheless, it showed a low willingness for donation after death among the Omani population, including university graduates.²²

In Tunisia, only 59% of 702 health care workers had favorable attitudes toward donation. Reasons for refusal included religious concerns in 26%, with 10% refusing donation for ethical reasons.²⁹

Another factor that limits access to renal transplantation is the cost of transplantation; 41.7% of patients believe that transplantation is more expensive that HD. It is now widely

accepted that transplantation therapy is associated with markedly decreased costs of health care for society. Of course, the cost of renal transplantation is more expensive in the first year, but after about two years, it should be less costly than any form of HD.³⁰

One of the concerns of transplant candidates pursuing living donor kidney transplant is the potential financial impact on the donor. Kidney donors face direct and indirect, expected and unexpected costs and negative financial consequences related to donation.³¹

We believe that education and awareness programs must address both the positive aspects and the fears of donation.

Public Media Campaigns

Public media campaigns should "demand the highest standard of transparency and accuracy of information related to healthcare issues so as to enable the general public to make informed decisions about health and lifestyles." In order to overcome these ethical concerns and rehabilitate the ethical image of these media campaigns, Rady et al propose five practical guidelines: "(1) media campaigns should communicate accurate information to the general public and disclose factual materials with the least amount of bias; (2) conflicting interests in media campaigns should be managed with full public transparency; (3) media campaigns should disclose the practical implications of procurement as well as acknowledge the medical, legal and religious controversies of determining death in organ donation; (4) organ donor registration must satisfy the criteria of informed consent; (5) media campaigns should serve as a means of public education about organ donation and should not be a form of propaganda."³² Finally, the media campaigns should be repeated in different forms and shapes.

Rewards and Compensations for Kidney Donation

Despite the multiple advantages and benefits of transplantation, there is a clear discrepancy 492 Chamsi-Pasha H, Albar MA

between the number of transplants and the number of patients awaiting transplantation.

This disparity has been mainly attributed to the gap between the supply of organs and the increasing prevalence of ESRD.³³ The consistent increase in the gap is expected to continue into the foreseeable future.³⁴ As an increasing number of transplant programs are willing to consider genetically unrelated donor candidates, the number of living unrelated transplants has increased over the past several years.³⁵

The subject of payment, whether in the form of incentives, rewards or compensation for living donation, is a highly controversial topic that has been debated among experts in the field of transplantation. Some have suggested that providing incentives or removing disincentives for organ donation will lead to an increase in organ donation.^{36,37} There has also been significant debate surrounding the option of a regulated system of incentives for donation.^{38,39}

Ghahramani et al³⁵ explored the views of 1280 nephrologists from 74 countries around the world about rewards and compensations for kidney donation. Seventy-five percent agreed to donor health insurance, 26% favored direct financial compensation and 31% agreed to financial rewards for unrelated donors. Sixty-six percent believed that rewards will lead to increased donation. Seventy-three percent indicated that rewards will lead to exploitation of the poor and 78% agreed to legislation prohibiting organ sales. Thirty-seven percent believed that rewards will negatively impact deceased-donor transplantation. Nephrologists from India/Pakistan and the Middle East had more favorable views about rewards, while respondents from Latin America and Europe, older than 50 years, female nephrologists and those practicing in rural areas had less-favorable views.³⁵

Encouraging donation by the government (by any means) is allowed by Islamic Jurists, and is practiced in Saudi Arabia, Gulf Countries and Iran.

Organ Trade

Paying people to donate their kidneys is one of

the most contentious ethical issues being debated at the moment. The most common arguments against this practice include:

- Donor safety
- Unfair appeal of financial incentives to the economically disadvantaged
- Turning the body into a money-making tool "commodity"
- Wealthy people would be able to access more readily.

The idea of non-financial incentives may be rising in popularity as a way to entice people to donate their organs. Financial incentives aimed at encouraging living donation have received much attention from bioethicists lately. Most experts argue that buying and selling human organs is an immoral and disrespectful practice.⁴⁰ The moral objection raised most is that selling organs will appeal to the socioeconomically disadvantaged (poor, uneducated people), and that these groups will be unfairly pressurized to sell their organs by the promise of money. International trade in human organs occurs particularly in the developing countries of the world, where deceased organs are not easily available and marked disparity in wealth exists.⁴¹ It is estimated that since 1980, over 2000 kidneys are sold annually in India, Iraq, Philippines and elsewhere to wealthy recipients from the Middle East, the Far East and Europe. Human organ ("Kidneys") trade has shifted from India to Pakistan.42 The World Health Organization (WHO) argues that transplantation promotes health, but the notion of "transplantation tourism" has the potential to violate human rights or exploit the poor, to have unintended health consequences and to provide unequal access to services, all of which ultimately may cause harm. Thus, the WHO called to ban compensated organ transplantation and asked member states to protect the most vulnerable from transplant tourism and organ trade. 43 However, as disincentives become a must, adding incentives back, such as improving life condition for organ donors after donation, becomes difficult.44

The debate over the legitimacy of the trade in organs continues, although it would appear that

the opponents of trade have already prevailed. One of the manifestations of this victory is the Istanbul declaration of May 2008. Organ trading has been outlawed in most countries, forcing patients to adopt new strategies in their search for organs.⁴⁵

In the past two decades, countries commonly known as exporters of organs, such as India and Pakistan, have enacted legislations aimed at curtailing transplant tourism by prohibiting organ sales. ⁴⁶ Although necessary, these legislations are deemed as insufficient. Issues relating to organ sales and transplant tourism cross national borders, and to reduce exploitation of the poor in these countries, strict enforcement and consistent global monitoring are required. ⁴⁷

The Future

The increasing number of patients who suffer from chronic kidney diseases combined with organ shortage have directed the attention of researchers to new alternatives in the fields of regenerative medicine, including cell-based therapies and tissue bioengineering. Despite the promise of ongoing work for therapy of chronic renal failure, caution is required as a large gap still exists between scientific knowledge and clinical translation for safe, effective stem cell-based therapies. Regenerative medicine, bioengineering and stem cell research are new rapidly expanding fields that will help in the near future to reduce the number requiring solid organ transplantation.

New and exciting developments in fields such as pharmacology, genetics or bioengineering can give a boost, in the next decade, to a new era of diagnosis and treatment of kidney diseases, which should be made available to more patients.⁴⁹

Prevention of ESRD could be effected by reducing the number of patients suffering from diabetes, obesity and hypertension, which cause more than 50% of ESRD in the Arab countries.

The public should also be educated against taking pain-killers and non-steroidal anti-inflammatory drugs for long periods without medical supervision and, in many cases, without any medical prescription. The dangers of quack doctors and herbal medicine should be strongly highlighted. The effect of lead and other pollutants on the community should be reduced to the minimum if not possible to eliminate them completely.

In conclusion, kidney transplantation is a complicated issue from the ethical and practical perspective. The increasing incidence of ESRD and the inadequate donation of kidneys, especially from the deceased, have created a wide gap between organ supply and demand. These events have raised many ethical, moral and societal issues.

Public and patient understanding of brain death and deceased organ donation needs further attention and participation of the media, physicians, nursing staff and leaders of society.

The Arab countries have a high prevalence of CKD risk factors, e.g. diabetes, obesity and hypertension. Unfortunately, the magnitude of CKD in the Arab world has not been studied well. There is an urgent need to conduct proper epidemiologic studies on CKD in the Arab world, and every effort should be made to prevent CKD by controlling the main causes of the same. Finally, new developments in the fields of pharmacology, genetics and bioengineering may give a boost to this field.

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