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Reaching self-sufficiency in deceased organ donation in Asia: harsh realities and ethical concerns

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Although trials to exchange failing human organs with new ones started in the beginning of the past century, the first breakthrough came in December 1954, when the first successful kidney transplant between identical twins was performed in Boston, USA, by Dr Joseph Murray. Since then transplantation has come a long way to be recognised as the treatment of choice for thousands of new patients afflicted yearly with organ failure around the world.

The World Health Organisation (WHO) estimates indicate that over a million transplants are required every year to satisfy the global need, but the actual number of transplants does not exceed one hundred thousands, ie only 10% of the need (1). There are many causes for this disparity including economic, social, and organisational factors but shortage of organs is the restricting factor in many parts of the world. Needless to say that in Asia this disparity is most obvious (1,2).

Sources for organs

Organs come from two sources: living and deceased human beings. Living donors are limited to donating either one of double organs (kidney) or part of a single organ such as the liver, whereas multiple organs and tissues can be recovered from a single deceased donor allowing multiple transplants from one source. In the developed world, both sources are used to the maximum in order to decrease the gap between availability and demand for organs, leading to high rates of transplantation of various organs, especially in Europe and North America.

On the other hand, deceased donation is uncommon in Asia and the majority of transplants are limited to organs that can be obtained from living donors. This limitation has severely affected both number and type of transplants performed.

Consequences of organ shortage

The success of transplantation in saving lives and improving its quality has increased demand for organs and created an illegal and unregulated market in many parts of the world. WHO estimates that 10% of all kidney transplants in the world come from paid donors.

These practices are more common in regions with a shortage of deceased organ donors when living donors cannot satisfy the need. An abundance of poor and vulnerable people in many Asian countries, willing to sell their kidneys (3,4) in return for a few thousand dollars, created a wave of transplant tourism since the 1980s. A large number of patients, from well off countries, travel to countries such as India, Pakistan and the Philippines to buy kidneys from vendors and intermediaries. These organised

organ sales were facilitated by doctors, hospitals and even travel agents, and sometimes by governments. In Iran, kidney sale was regulated by the government, and vendors were paid officially in order to satisfy the need for kidneys.

In China, executed prisoners became the source of multiple organs, such as heart, liver, and kidneys, against international regulations which do not consider prisoners sentenced to death in a position to give consent for organ donation. Many, if not most, of these organs were sold to wealthy patients from the Middle East, South East Asia, and Europe (5).

Declaration of Istanbul and WHO guidelines

In response to the spread of these unethical practices, the need arose for an international move, which was spearheaded by The Transplantation Society with support from the International Society of Nephrology and WHO.

Several meetings were held in different countries which culminated in a large meeting held in Istanbul in 2008. In this meeting, 152 participants from 78 countries agreed on a set of principles opposing organ trafficking, transplant tourism, and commercialism.

The Declaration of Istanbul (DoI) (6) was soon endorsed by the majority of transplant and nephrology organisations around the world. A custodian group (Declaration of Istanbul Custodian Group, DICG) was formed to follow up the implementation of DoI around the world. Since the declaration, new laws and regulations came into effect aiming at putting an end to transplant tourism with success stories in many countries (7).

In addition, WHO introduced a set of guiding principles on organ transplantation outlining an ethical and acceptable framework for transplantation of human organs. These principles were endorsed by the sixty-third World Health Assembly in May 2010, in Resolution WHA 63.22 (8).

Both DoI and WHO recommended maximising donation from the deceased as an alternative to organ trafficking and commercial transplantation (9).

Organ shortage in Asia

Although organ shortage is a global problem, it is worse in Asia. Data published by WHO's Global Observatory (1) indicate that in most Asian countries the number of organs transplanted per million population (pmp) is between 2.5 and 9.9 compared to over 50 in most European countries.

A good number of kidney transplants are performed in Asia (10) indicating that infrastructure for transplant services is available; but a majority of these kidneys come from living donors and only 5.6% from deceased donors, compared to 70% from the same source in Europe. When it comes to organs other than the kidney, the problem is even more obvious. On average, less than 1 liver transplant is performed pmp in Asia (83% from living donors) compared to 9.5 in Europe (1). Heart transplantation, which depends solely on deceased donation, is extremely rare in Asia.

These harsh realities indicate that the crucial issue is the shortage of deceased donation in Asia. Many Asian countries lack deceased donor programmes and when available the number of donors is very small, ie in the range 0–4.9 pmp (1). In Europe, the range in most countries is 15–20 pmp and is over 25 in several countries (1). Bearing in mind that several transplants are performed from each deceased donor, the severe shortage of organs in Asia becomes obvious.

Several factors are responsible for the shortage of deceased donation in Asia, such as availability of resources and proper organisation but even countries with a high Human Development Index (HDI) such as Japan suffer from this shortage, indicating a cultural or religious problem. Of course, there is no shortage of potential deceased donors in hospitals but turning them into actual donors requires a donation culture which is presently lacking in most Asian countries.

Overcoming organ shortage to achieve self-sufficiency

Pressures exerted over the past six years since the DoI have failed to put an end to illegal transplantation in Asia, and many activities continue underground and will not cease unless enough organs are available for patients in need (11). The only way to fulfil the demand for organs is by expanding the use of deceased donors. Despite the obstacles this may be achieved by the following means:

1. Laws and regulations

Many Asian countries still lack adequate legislation to allow or expand deceased donation and to protect specialists involved in the process (12). Compulsory referral of all possible cases of brain death in hospitals and presumed consent law (when every deceased is considered to be a donor unless he objected during his lifetime) have been effective in many European countries and may increase donors in Asia.

2. Transparency and fair allocation of organs

The public in many Asian countries may have problems in trusting authorities especially when it comes to looking after seriously ill patients in hospitals, declaring brain death, and equal distribution of organs. Hence, transparency and a fair organ allocation system are essential for a successful programme in order to gain public support especially in countries where public mistrust is common.

3. Adequate organisation and budget

Organ procurement is an important and demanding specialty, requiring special training of transplant coordinators and intensive care unit (ICU) staff on identification of possible donors, donor maintenance, family approach, and organ recovery. Many governments fail to realise the importance of organ procurement from the deceased, not only in saving and improving quality of life, but also in saving money spent on taking care of patients with end-stage organ failure. A budget

needs to be allocated by the state for this purpose and to provide facilities such as adequate offices, means of transport, and communication.

4. Involving public media and religious authorities

Adverse media is devastating for any transplantation programme especially when they report illegal practices such as organ sale or publish stories on crimes committed to obtain organs. It affects public trust and people will be reluctant to donate organs to a corrupt system.

On the other hand, showing the public the humane aspect of transplantation and how organ donation can save the lives of children and adults will encourage people to support it. Religious leaders have great influence on public opinion in most Asian countries and their understanding and support is essential. Most religions encourage the saving of lives; but there is misunderstanding and divisions on the recognition of brain death (13).

5. Promote donation in schools

The development of a donation culture needs to be implemented at a young age. Many countries have been promoting donation and transplantation in school curricula in order to develop such a culture, which is presently missing in many Asian countries.

6. Provide incentives and remove disincentives

Removing disincentives by reimbursing donors for any financial loss due to donation, such as wages lost due to sick leave after donor operations and covering transport and accommodation costs are accepted by the DoI (4) but providing monetary incentives to donors is prohibited (14).

Some countries such as Kuwait and Saudi Arabia achieved good deceased donation rates by providing financial support to donor families in need. In both countries there is a large expatriate population, most of whom are low-income workers and when they die, their families lose the little money they were receiving monthly and may not even be able to repatriate the body of their deceased to his home country. The governments in both countries cover the costs of repatriation and also provide the family with some financial support to help them manage for a while before finding an alternative source of income. The organs generated are distributed free of charge to patients on the waiting lists.

The proponents of such a system argue that this is different from inducing a living donor as the person is dead and you are providing support to a devastated family at a time of great need (15). Religious authorities also support this solidarity with poor donor families, although they object to inducing living donors.

However, this cash payment is debatable and contradicts the principles of the DoI and WHO. Offering fixed cash payment is considered as an unacceptable pressure on poor families to give consent, when many of them might refuse if the reward were not offered. Such an offer can be considered as coercion similar to coercing a living person to donate an organ for money.

This model can be modified to provide humanitarian support to donor families, if needed, within an ethically acceptable framework, not including fixed cash payments. This could be done in the form of educational grants provided to the deceased's children to continue their education, or providing a long-term interest-free loan to allow the family to start a small business to sustain itself. This support can be provided and managed by charities.

Success stories

Achieving self-sufficiency in transplantation in Asia is certainly not easy but there are countries that are moving fast towards this. A good example is Iran (16), a populated country with the same cultural, religious and socioeconomic background as many other Asian countries. There was hardly any deceased donation before the year 2000. After passing a law recognising brain death, and allowing organ procurement from the deceased, the rate of deceased organ donors jumped from less than 0.2 to over 10 pmp in 13 years and the rate is still rising (2).

The transplant programme in Namazi hospital in Shiraz, Iran, is a reflection of this success. With over 350 liver transplants every year (86% from deceased donors), it has become the largest liver transplant programme in the world. Since 2008, 92% of kidneys transplanted have been from deceased donors, the rest being from living related donors. The programme is based on altruistic donation (17). The programme achieved this by excellent organisation of organ procurement units, especially in Tehran, and support from the government, media, and religious leaders. The incentives provided to donor families are non-financial. The families of the deceased donors are honoured by the media and authorities, and the body of the donor is buried in a martyr's graveyard, considered a great honour in Iran. As a gesture of appreciation, families also receive priority in accessing health services.

This efficient model could work well in Asia and be effective in abolishing the black market for organs by providing life-saving organs for patients in need (18).

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Deceased donor renal transplantation and the disruptive effect of commercial transplants: the experience of Oman

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Abstract

The Oman Renal Transplantation Program was established in 1988 as a joint venture between Sultan Qaboos University and the Ministry of Health. It began with both living related donor (LRD) and deceased donor (DD) transplants. Over the next nine years, while the LRD programme progressed relatively well, there were only thirteen DD transplants. Two of the DD kidneys were obtained from overseas via an active collaboration with the Euro-transplant organisation, and one DD kidney was obtained from Saudi Arabia within the Gulf Cooperative Council exchange programme. The rest of the DD kidneys were obtained in Oman. The Omani DD programme, although it was a pioneering effort in the Gulf region at the time, was not entirely sustainable. In this paper we focus on the challenges we encountered. Among the major challenges was the absence of resources to establish a dedicated DD programme and particularly the failure to develop a cadre of dedicated transplant coordinators.

Background

End-stage renal failure is managed by dialysis or transplantation, and patients have a right to them where these modalities can be provided. Because of the almost universal shortage of donors, most successful programmes depend on both related donors (either living related donors (LRD), or living unrelated donors (LUD) and deceased donors (DD). In most developing countries, it has been difficult to establish DD programmes because that requires a huge amount of government support, not least by providing the legal framework and establishing brain death criteria as constituting death – the latter to be done unequivocally, with the population being aware and participating in the process. In some countries, there has been, for a long time, a lack of clarity on this issue, based often on religious or cultural interpretations. In Oman, we did develop transplant regulations in 1994 that were endorsed by formal ministerial decrees. Though the civil authorities have accepted the brain death criteria, the religious authorities have not yet publicly accepted them. As a result, although organs have been retrieved from deceased persons on rare occasions, the situation has become equivocal. Self-sufficiency in organs for transplantation is not possible at the moment without an active DD programme. The absence of such a programme will ultimately lead to the flourishing of disruptive transplantations which include rampant commercial transplants in neighbouring countries, and on rare occasions, transplants from executed prisoners in countries such as China.

The Omani experience

The Oman Renal Transplantation Program was established in 1988 as a joint venture between the two major academic and service institutions of the country, namely Sultan Qaboos University and the Ministry of Health. Transplantations were performed using both DD and LRD. Relationship was defined by blood or marriage. We did not, and still do not, accept LUD for fear of hidden commercialism, although most developed countries have now accepted this mode of donation with proper ethical and legal measures (1–4). This policy may