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Pakistan’s experience with kidney transplantation and trade: a call for international solidarity

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Abstract

Pakistan has taken a long and tortuous road towards curbing the trade in organs within its borders. Yet, despite the phenomenal gains, several challenges remain in this area. For example, robust and sustainable deceased donor programmes must be established to meet the needs of a country which has a high prevalence of

kidney disease and failure. Further, it is necessary to offer an alternative source of organs for transplantation to desperate patients who resort to buying these from the “market”. Cultural factors and religious beliefs about the sanctity and inviolability of the corpse, as well as the lack of public and professional education regarding the procurement of organs from the deceased, pose considerable barriers that must be surmounted.

We believe it is equally important that transplant professionals and the governments of affluent countries consider measures to discourage, if not prevent, their citizens from travelling to impoverished countries such as Pakistan to buy organs. Without a commitment, ethical and legal, to international solidarity in this matter, the goals that are already difficult for developing countries to achieve, ie, establishing deceased donor programmes and bringing an end to organ trafficking, will be even harder to achieve.

"Why should I give takleef (harm/trouble) to my family if I can buy a kidney?"

(Patient awaiting kidney transplant)

Pakistan, a low-income country with a population of 185 million, has been waging a long battle, against great odds, to counter tourism and trade in organs in the country. For over two decades, patients from different countries, particularly from the Middle Eastern region, have been travelling to Pakistan for kidney transplantation using kidneys bought from its most disadvantaged citizens. The struggle against such practices has united and galvanised concerned members of the medical community, together with the media, leaders of civil society, members of the judiciary, including the former Chief Justice of the Supreme Court of Pakistan, and human rights organisations (1–4). A Transplant Ordinance was passed in 2007. Ratified into law in 2010, it criminalised the purchase and sale of organs. The result was a dramatic drop in the number of transplants carried out with vended kidneys. However, complete control is yet to be achieved. We believe that one of the major hurdles is the absence of deceased donor programmes, due to which many desperate patients take recourse to kidney vendors.

Our experience also highlights the fact that national efforts, in isolation, can go only so far in preventing organ trafficking which, by its very nature, recognises no borders. Poor countries such as Pakistan cannot win this battle single-handedly. There is need for a consensus among the international transplant community that healthcare professionals and the governments of affluent countries, from which transplant tourists originate, also have a moral and legal responsibility to take proactive steps to discourage/deter their citizens from engaging in this practice. We believe that the elimination of transplant tourism requires solidarity among transplant professionals across the globe, a joining of hands, that goes beyond signing international declarations. The recent steps taken in Israel show that affluent countries can also adopt effective regulatory measures to reduce the number of their citizens travelling to other countries for transplants (5,6).

This article provides a brief overview of the steps Pakistan has taken since the 1990s to control the kidney trade and outlines the local hurdles that have been overcome in this process. We argue that overcoming reluctance to deceased donation and establishing deceased donor programmes are essential for developing countries aiming to achieve self-sufficiency in transplantation, and that doing so can also assist in reducing commerce in organs. Achieving self-sufficiency

is a recommendation of the World Health Organization (WHO) and was endorsed by the Declaration of Istanbul at a meeting attended by over 90 international transplant-related organisations and 152 delegates (7,8). We will also elaborate on our belief that it is the ethical responsibility of medical communities and associations concerned with transplantation to undertake pro-active measures, such as educating patients with renal failure on the illegality of transplantation with vended organs and the risks connected with it. Finally, we will discuss the need for national governments to consider laws that discourage their citizens from cross-border organ tourism.

Overview of kidney transplantation and trafficking in Pakistan

The long road to a transplant law: In Pakistan, the first kidney transplants occurred in the late 1970s, when neither relevant national laws nor institutional regulatory mechanisms were in place. However, it was not until the mid-1980s that a systematic, organised kidney transplantation programme, using living related donors, was initiated in the Sindh Institute of Urology and Transplantation (SIUT), a public sector institution in Karachi (9). By the 1990s, due to its lucrative nature, kidney transplantation began to be increasingly offered by private hospitals around the country. Media reports began to emerge about kidneys being bought or "stolen" from impoverished labourers and kiln workers. Following the first Gulf War in Iraq (1990) and the passage of the Indian Transplant Law (1994), the stream of affluent patients with renal failure, hailing from different countries, shifted towards Pakistan in search of kidneys. By the turn of the century, private sector hospitals, mostly in the province of Punjab, were openly advertising "transplant packages" to lure foreign patients and Pakistan had acquired the reputation of being the "kidney bazaar" of the world (10,11).

In the first decade of this century, a national campaign led by SIUT grew into a national movement to pressure the government to enact laws on organ transplantation and the criteria for brain death, as well as to pass legislation prohibiting trafficking in organs. The movement was backed by a cadre of healthcare professionals and organisations, as well as prominent members of civil society. Journalists and the local media played a key role in keeping the issue alive through interviews with kidney vendors. Transplant physicians and faculty members from the Centre of Biomedical Ethics and Culture, SIUT, in Karachi carried out ethnographic and social studies which brought to light the abysmal condition of those who had sold their kidneys. The results of these studies were highlighted in the local press and international journals (12,13). Additional pressure was brought to bear on the government through collaborations between the faculty and WHO, the Asian Task Force on Organ Trafficking, and the Istanbul Group Against Organ Trade.

Subsequent events: In 2006, persistent recalcitrance on the part of government officials, who were supported by an influential pro-organ-trade lobby that was opposed to a transplantation

law, led the then Chief Justice of the Supreme Court to take suo moto notice of cases of the purchase and sale of kidneys in the country. He ordered the government to take immediate steps against these practices. A year later, the Transplantation of Human Organs and Tissues Ordinance was promulgated by a Presidential decree. The Ordinance criminalised commerce in organs and prohibited the transplant of organs in foreigners. It provided for heavy penalties for all parties involved in these practices. The Ordinance also instituted a national body, the Human Organ Transplantation Authority (HOTA), to register and monitor institutions offering transplants in Pakistan. According to a personal communication by HOTA, it had registered 25 institutions since its inception in September 2007 until December 2012. During this period, a total of 3601 transplant activities were registered. These included kidney, liver, cornea and bone marrow transplants.

Several attempts were made by the influential pro-organ-trade lobby to weaken the Ordinance before it could become law. In 2008, a private member bill was introduced in the National Assembly, but this was eventually withdrawn following strong anti-lobbying efforts. Perhaps the most serious challenge was a petition filed in 2009 in the Federal Shariat Court (FSC) against members of the Federal government. The Constitution of Pakistan forbids the enactment of laws contrary to the Qur'an and Sunna, and the petitioners claimed that certain clauses of the Ordinance (including the prohibition of financial compensation and transplantation in foreign patients) were contrary to the teachings of Islam. Over the course of a year, the FSC held several hearings, which were open to the general public, after which the justices gave a unanimous ruling rejecting the petition (14).

The promulgation of the Ordinance initially led to a precipitous drop in the number of transplants (estimated to be around 2000 or more annually) using vended kidneys. However, from 2008 onwards, sporadic reports began to appear in the media about foreigners who had undergone transplantation in private clinics in Punjab. Complaints were also received from colleagues in the field of transplantation in the Middle East (Kuwait, Oman, Saudi Arabia, the United Arab Emirates, Egypt, Palestine, etc.) after they were consulted by patients who had developed severe complications following kidney transplants carried out in Pakistan. Attempts to obtain the details of these cases from the healthcare professionals of these countries in order to pursue investigations in Pakistan were generally unsuccessful due to concerns relating to "patient confidentiality". In 2009, however, following the failure of HOTA to take appropriate action, SIUT again approached the Supreme Court directly, drawing its attention to two private hospitals in Punjab (Lahore and Rawalpindi) that were involved in carrying out transplants for foreigners. The Chief Justice issued a warning to the personnel of both hospitals (vide order 9.7.2009) and the hospital in Lahore subsequently discontinued all transplant services. However, reports suggest that the institution in Rawalpindi, as well as some fly-by-night private clinics in Punjab, are still surreptitiously carrying out transplants in non-Pakistani citizens.

The Ordinance was finally ratified unanimously into national law by the National Assembly and the Senate in 2010 (15). Attempts were initiated to register transplant institutions and obtain annual reports from them, but overall, the attempts of the federal HOTA within the Ministry of Health remained largely unsatisfactory in terms of investigating and taking punitive action against institutions suspected of trade in organs. In September 2011, a joint petition (Constitution Petition No.55 of 2011) was filed in the Supreme Court against the Federation of Pakistan and provincial health secretaries by members of civil society, including leading lawyers, physicians (including faculty members of the SIUT and CBEC), journalists, philanthropists and the chair of the Human Rights Commission, pleading that the trade in organs violates the fundamental rights of the citizens of Pakistan. The results of the petition are pending, although several hearings have taken place. It is obvious that the road to ethical transplantation has been riddled with challenges (16).

Recent developments: In 2010, via Amendment 18 of the Pakistan Constitution, many services and regulatory functions were shifted from federal to provincial jurisdiction. This includes health services, such as those offered by the federal HOTA. Due to continuing concerns about commercial practices related to organs, in August 2012 the Chief Justice ordered that provincial HOTAs be instituted in Sindh, Punjab, Balochistan and Khyber Pakhtunkhwa within six weeks to oversee and regulate human organ transplantation (17,18). At the time of writing this article, all four committees had been constituted via an Act of Parliament. The body in Sindh (SHOTA) has started functioning and held its first meeting recently. It is hoped that the provincial HOTAs will be far more effective than their federal predecessor.

Need for deceased donor programmes

In many countries in the West, deceased donor programmes are the source of a significant number of the organs used for transplantation (19–21). In contrast, most developing countries do not have deceased donor programmes in place due to the absence of appropriate infrastructure and logistics, cost issues, and lack of trained medical and paramedical health professionals. Organs for transplantation procedures are obtained mostly from living donors, related and unrelated. This also holds good for kidney transplants, which are now among the most frequently performed procedures in these countries. Recently, some developing countries have taken initiatives to introduce deceased donor programmes. Reports from Shiraz, Iran and Tamil Nadu, India suggest that the introduction of such programmes has not only increased the number of kidneys available for transplantation, but may also be helping to decrease the number of illegal and unethical transplants using kidneys that have been bought (22–26). There are some early indications that China's move to initiate transparent, voluntary deceased donor programmes may help to eventually rid the country of the practice of using executed prisoners as a source of organs – a practice which has made China a pariah within the international transplant community (27).

Pakistan is yet to take organised, systematic, national or provincial measures for the introduction of deceased donor programmes. In the three decades since kidney transplantation began to be carried out in the country, 26 kidney transplants from deceased donors have taken place, all in SIUT, using kidneys flown in from Europe, courtesy of the Eurotransplant Foundation (28). During this same period, only four Pakistanis, declared brain dead, have donated their kidneys for transplantation. In these cases, the family members had approached SIUT, (in one case, Shifa Hospital in Islamabad), stating that the deceased had expressed a wish during conversations at some stage in their life that their organs be donated in the case of their death. These are isolated cases and the situation will not change unless organised efforts are made to educate the public and established systems are put in place for potential donors and their families to approach. A neurosurgeon in Karachi estimates (personal communication) that over 1000 individuals are pronounced brain dead in the five busiest hospitals of the city every year. Needless to say, many of these individuals could have been potential deceased donors. At present, there is no mechanism in place to tap potential sources of organs for transplantation. The situation is compounded by the dearth of trained critical care healthcare professionals and counselling teams that can engage with the families of such patients.

There is, however, increasing awareness among transplant professionals in Pakistan that establishing deceased donor programmes is an essential and not an optional step. It is being recognised that such programmes are necessary for augmenting the insufficient number of transplantable kidneys available from living donors in a country in which the estimated prevalence of renal disease is 100 per million population, with a large number of patients progressing to end-stage renal failure each year (29). On the basis of the experience of Iran and India, it is also believed that greater availability of organs from deceased donors may help to control kidney trafficking in the country. However, a great deal of spadework is required before this objective can be achieved. This includes training and educating healthcare professionals in the critical and intensive care units of the relevant institutions on the criteria for brain death, as well as the ethical and sociological factors that are central to interacting with grieving families. Further, systems that are transparent and free from conflicts of interest will need to be established. This can be achieved through a clear separation of those providing end-of-life care to potential donors, the transplant team itself, and others responsible for approaching the families to assess their willingness to allow the donation. In the absence of these steps, the transplant community risks losing the trust of the public further. As it is, due to Pakistan's history of commerce in kidneys, some believe that physicians and their institutions engage in dishonest practices to obtain kidneys from the impoverished and transplant them into the rich for monetary gain (13).

A crucial and equally important step will be to gain the confidence of the public, as well as public acceptance of and support for the programmes. For this, healthcare professionals

– in person, through civil society organisations, and using the popular press and media – will have to involve themselves in organised, regular and sustained activities to interact with the public about deceased organ donation. This is necessary not only to provide information on what deceased organ donation involves, but also to convince them that donation following death is not a “medical” issue, but one of shared social responsibility of citizens towards one another. In the absence of such an effort, robust deceased donor programmes will not be possible. The importance of this approach is illustrated by the experience in Spain, which has the highest rate of deceased donation in the world, and more recently, that of Tamil Nadu in India (23,30).

Pakistan has a majority Muslim population and it is reported that there is a reluctance among them to embrace deceased organ donation, often on the basis of religious interpretations (31,32). A major issue, therefore, will be to understand their sentiments and tackle them with sensitivity. This attitude of the public is reflected in a couple of surveys undertaken in Pakistan (33,34). The reluctance based on religious views, combined with a lack of knowledge of what deceased donation entails, also became evident in the recent empirical research we undertook in Karachi. We found that whereas our interviewees were familiar with, and mostly supportive of, living kidney donation, many believed that the human body belongs to God and is given to humans on trust, and that removing organs from a corpse is equivalent to its mutilation – an act strictly prohibited in Sharia (Muslim law) (35).

This finding is ironical in the light of the fact that the Muslim ulema in renowned Islamic centres have approved of the criteria for brain death, and have pronounced (as majority opinion) that both living and deceased organ donations are not only permitted, but are also praiseworthy acts. This is in consonance with the view advocated by Muslim transplant professionals (36,37). On the other hand, as found by our studies, most Muslims' beliefs about right and wrong and about permitted and prohibited acts in Sharia law are more in the nature of a socially constructed understanding of Islam. This understanding has been passed down the generations and influenced by the opinions of local religious leaders rather than by juristic edicts originating from distant Islamic centres. Unless attempts are made to proactively and effectively engage with cultural and religious opposition, it will be difficult to get the Pakistani public to “own” and support deceased donor programmes.

Sharing the burden

Countries like Pakistan must continue to address the problems of inadequate infrastructure, lack of mechanisms for oversight and corruption, which feeds the lucrative transplant business. All these factors combine to make the consistent enforcement of the transplant law difficult and the most disenfranchised citizens thus continue to be exploited. However, the difficulties are compounded by the absence of active measures – legislation and ethical policies, at the government and

professional levels – in other countries to at least discourage, if not prevent, their citizens from travelling abroad to buy organs.

In this context, it is encouraging that the Declaration of Istanbul Custodian Group (DICG) is considering the issue of extraterritorial jurisdictions relating to transplant tourism, and may possibly arrive at some guidelines.

“Rights” of patients versus responsibilities to others: Those who advocate commercial transactions in human organs, whether as “regulated” markets or cross-border transplant tourism, use the arguments of autonomy, the rights of the individual and freedom of choice to justify the practices of buying and selling organs. In this paradigm, the principles of solidarity and social responsibility, indeed even the laws of countries, are marginalised. When the affluent buy organs from the impoverished on the basis of the perceived primacy of freedom and the right of individuals to seek treatment, regardless of all else, the existing global inequities are perpetuated and intensified. It is also ironical that in many instances, such patients are citizens of countries in which buying and selling of human organs are illegal, and they travel for transplantation to another country where such practices are also against the law as this exploits those most vulnerable individuals. The lack of measures to hold such patients responsible when they return home is lamentable, and the tendency to blame the “host” countries for not doing enough smacks of hypocrisy and double standards.

An individual’s right to privacy and the confidentiality of the physician–patient relationship are also cited as reasons for the inability/reluctance to provide information to aid the investigation of those travelling abroad for illegal transplants (as we have faced in Pakistan). However, privacy and confidentiality are not absolute principles. We feel that transplant professionals and their associations must begin to discuss how to balance these principles against the costs to the healthcare systems of their countries and to the “host” countries. This is a necessity because many patients return to their native country with several complications, and also because organ tourism harms countries that are struggling to control trafficking in organs within their borders. In our opinion, claims to privacy should not outweigh fairness and justice.

Transplant professionals’ responsibilities towards patients: It is well established that patients undergoing transplantation with vended organs suffer relatively higher rates of complications, including life-threatening infections, graft failure and death (38,39). It is not clear how well these patients know and understand this. It is also not clear whether, in their desperation for a transplant, they are aware that the practice is illegal and that they and the vendor are liable to severe punishments, including jail sentences, if caught. We have heard some of our Pakistani patients mentioning that they are contemplating buying a kidney; it is quite possible that physicians in other countries have had a similar experience. In our opinion, national transplant associations should require physicians to disseminate information on the risks faced by patients seeking transplantations with vended organs, as well as the illegality of

this practice. This should be accompanied by clear expressions of disapproval and discouragement of such practices by physicians while dealing with their patients. A recent publication from Canada presents a policy statement which stresses the ethical responsibilities of transplant professionals and lists steps that will result in greater involvement of these professionals (40). While we are not in favour of denying care to patients who return critically ill after undergoing an illegal transplant, it should still be possible to take an ethical stand against this practice during interactions with such patients, as well as those suspected of planning to travel abroad for illegal transplants.

Responsibility for national self-sufficiency in transplant programmes: The international transplant community is unanimous that commerce in human organs is profoundly unethical and has been able to influence governments, as in Pakistan, to pass laws declaring it illegal. WHO, the Istanbul Declaration and other international accords also stress the importance of attaining national self-sufficiency in transplantation through robust living and deceased donor programmes based on altruistic donations (7,41,42). Transplant tourism remains a significant hurdle in achieving self-sufficiency, not only in the developing countries to which the tourists travel, but also in the countries from which they originate. We believe that transplant professionals and associations in countries that are signatories to international agreements have an ethical (and legal) obligation to take appropriate steps to prevent their citizens from travelling abroad for transplants.

We realise that it may be difficult to formulate one, uniform legal solution that can be applied across all countries to prevent citizens from travelling for transplants, or arrive at a uniform set of measures to make those returning with illegally transplanted organs accountable. However, we can at least reach a consensus that these practices are wrong and need to be addressed. The power of moral consensus within a group can often pave the way for legal steps.

Summary

Pakistan’s experience and its struggle to stem the exploitative trade and trafficking in kidneys bear many similarities with the situation in other impoverished countries. It took Pakistan several years to pass a transplant law criminalising such practices and many internal challenges had to be overcome in the process. The eventual success of the efforts can be attributed to the fact that members of the public, the judiciary and media joined hands with the healthcare professionals and associations concerned, and also, to collaborations with international transplant societies and organisations, such as WHO and the Istanbul Group against Organ Trade.

However, Pakistan’s battle against organ trafficking is not over yet. It is essential to develop robust deceased donor programmes to increase the number of organs available for transplantation, and to offer an alternative to desperate patients who resort to buying organs from the market. This will

require cohesive, well thought out and organised strategies to educate, mobilise and involve people from all sectors of society, from the public to the professional domains. Our studies reveal that there is considerable resistance among the public against the donation of organs following death due to myths and misconceptions arising out of religious and cultural beliefs. It will be difficult to sustain deceased donor programmes unless concerted efforts are made to win over the public by addressing their sentiments in a sensitive manner, and to convince them that such donation is a matter of the social responsibility of one citizen towards another rather than a “medical” issue.

While Pakistan must continue its efforts to improve the effectiveness of the transplant law and make its implementation more transparent, it is the moral responsibility of the international community to push the governments and healthcare professionals of “recipient” nations to consider ethical and legal measures to discourage their citizens from breaking their country’s laws against trade in organs, as well as those of the countries to which they travel to buy organs. Trade and trafficking in organs survives on the strength of transnational movement. Perhaps international steps similar to the laws curbing cross-border trafficking of humans could be considered. The absence of such steps are another hurdle for developing countries trying to achieve national self-sufficiency in organ transplantation through altruistic living and deceased donors programmes, an objective unanimously endorsed by the international transplant community.

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Deceased organ donation in India: where do we go from here?

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Abstract

Transplantation represents one of the best examples of the scientific achievements of medical science. However, its success has also led to some of the fiercest ethical challenges in modern medicine. Partly as a response to the uncovering of a flourishing clandestine kidney trade, the Central government promulgated the Human Organs Transplant Act (HOTA) in 1994. HOTA, along with its amendments, was a step forward in recognising concepts such as brain death. Nevertheless, there are numerous ethical challenges still to be resolved, particularly with regard to consent, incentives to donors and families, and equitable distribution of donated organs.

Introduction

Transplantation represents one of the best examples of the scientific achievements of medical science. However, its success has also led to some of the fiercest ethical challenges in modern medicine. The number of patients desperately needing a transplant far outnumbers the available organs, leading to a competition for organs which severely tests the principles of transparency and distributive justice. Transplantation is also unique in that it needs public sanction without which it will collapse. Although living donation is an option for some organs, the main source of organs is deceased donation which hinges on consent from family members. This consent is shaped not only by the perceived credibility of the process but also by other cultural, religious and political factors. On the recipient side, the ethical challenge is how to ensure justice in

allocating the few available organs to someone from amongst a large pool of patients on a waiting list.

The discourse surrounding organ transplantation covers a wide sweep of disciplines like sociology, anthropology, culture studies, public health, economics and politics. Central to the discussion, however, is ethics. Over the years this discipline has engaged with these debates in an intense and rigorous manner. Since its inception the pages of this journal have carried a wide variety of writings on this topic, about its global overarching dimensions as well as the Indian context. South Asia in general, and India in particular, has had to grapple with the specific issue of the enticement of the desperately poor to sell their organ for a price (1). The recent increase in cadaveric or deceased donation in India has been acclaimed by many in the lay media. In certain states it has also been argued that this has led to a reduction in commercial transplantation (2). But there has been a paucity of the social and ethical analysis necessary in a field where so much is at stake.

Organ transplantation in India has a relatively short history compared to the developed world. India's conceptual and scientific contribution to this specialty has been limited even as it has been at the epicentre of one of the biggest ethical controversies concerning transplantation. Kidney transplants in India were first performed in the 1970s. Though transplant activity picked up in the 80s and early 90s, it was largely restricted to live donor kidney transplants in selected urban centres. In the 1990s the establishment of more centres and the availability of trained staff, led to an increase in kidney