

The Long Road from the Kidney Bazaar: A Commentary on Pakistan's Progress Towards Self-sufficiency in Organ Transplantation

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Introduction

'Transplant tourism' may be defined as international travel for commercial organ transplantation, in which patients travel abroad to undergo transplantation involving purchased organs. The practice of transplant tourism emerged in the late 1980s with the advent of cyclosporine, an immunosuppressant drug that facilitated organ transfer between genetically unrelated individuals. In conjunction with increased surgical experience with living kidney provision, the possibility of matching patients with strangers in distant countries and planning procurement and transplantation of a kidney from one to another became feasible. It is thus likely that the majority of transplant tourists obtain kidneys provided by living kidney vendors,¹ although transplant tourists may also purchase partial livers from living vendors, or a variety of organs from deceased providers such as executed prisoners in China (Budiani-Saberi & Delmonico 2008: 927). In the last three decades, increasing global needs for organ transplantation have outpaced the development of deceased and living donation programs in many countries (Francis & Francis 2010: 284). Despite widespread prohibitions against trade

¹ To avoid ambiguity, I use the term 'provider' to refer to all individuals from whom organs are removed for the purpose of transplantation, rather than 'donor,' as the latter term implies both voluntariness and altruistic motivation. 'Donor' and 'vendor' will be used to distinguish between voluntary altruistic providers and voluntary remunerated providers.

in human organs in keeping with the policy of the World Health Organization (WHO 2010b), globalized networks of organ trafficking and travel for commercial organ transplantation have emerged and markets have flourished in numerous developing countries (Shimazono 2007).

Unmet needs for transplantation in wealthier nations encourage some patients to travel to countries with a plentiful supply of desperately poor vendors and absent or ineffective regulation of procurement and transplantation programs. In this paper, I draw on the history of transplantation in Pakistan to highlight the factors that contribute to travel for commercial organ transplantation and those that are influential in eradication of the practice. Following the introduction of the Transplantation of Human Tissues and Organ Ordinance in 2007 (Government of Pakistan 2007), Pakistan has evolved from a major 'hotspot' for kidney sales to a successful model for developing countries establishing transplantation programs (Persy *et al.* 2010: c125). I will argue that the example of Pakistan should inspire other countries in the region and throughout the world to renew their efforts to promote more effective and ethical access to organ transplantation through the pursuit of national self-sufficiency.

A brief review of global trade in organs

During the last decade Pakistan became infamous throughout the world as one of the best known and largest markets for human kidneys. In the absence of legislation governing organ procurement activities, as many as 1500 kidneys were sold annually to foreign patients (Rizvi *et al.* 2009). Research into the Pakistan market provides evidence of the impact of unregulated trade on kidney vendors and recipients, as well as highlighting the typical features of such markets. Vendors are drawn from socioeconomically disadvantaged communities and are often subjected to coercion, deception or fraud and inadequate standards of care (Naqvi *et al.* 2007 & 2008). As a result, they frequently suffer both physical and psychological complications, fail to obtain a benefit from their payment and may end up regretting their involvement in the practice (Moazam *et al.* 2009). Domestic patients who purchase kidneys as well as transplant tourists face higher risks of medical complications compared with those who receive organs from unpaid donors (see Rizvi *et al.* 2010; Alghamdi *et al.* 2010), and may also experience deception, fraud and exploitation (Shimazono 2007: 958).

Most countries have been touched by transplant tourism as either destinations or sources of transplant tourists. For example, India, the Philippines, China, Egypt, Iraq, parts of South America, and Turkey have all gained notoriety as organ suppliers for wealthy domestic patients and foreigners from all over the world, including Australia, the United States, Japan, Israel, Taiwan and Saudi Arabia (see Shimazono 2007; Budiani-Saberi & Delmonico 2008). The work of anthropologists such as Nancy Scheper-Hughes, a co-founder of OrgansWatch, journalists and human rights organizations such as the Coalition for Organ Failure Solutions has put a human face and voice to the disembodied organs sold on the market, sharing the narratives of countless kidney vendors from across the world and advocating on their behalf (Cohen 2003; Scheper-Hughes 2004 & 2011; Moazam *et al.* 2009; Budiani-Saberi & Mostafa 2010; Smith 2011). Whether in Moldova, South Africa, Nicaragua or Pakistan, the tale of an organ seller is often remarkably similar. Desperate poverty and naïve hope for a better future leads the young, healthy and ill-informed to sell kidneys to powerful brokers in circumstances that rapidly spiral out of the vendor's control. Hasty operations, inadequate payments and impaired health leave vendors deeper in debt, unable to return to work and socially isolated (Scheper-Hughes 2004: 49–52). Frequently, organ selling becomes a staple feature of local economies, with devastating consequences for communities (Moazam *et al.* 2009).

The WHO estimates that 10 percent of organ transplants performed worldwide involve transplant tourists, representing as many as 9000 a year (WHO 2007). Although recent data on current markets is lacking, there are ongoing reports of trade in some countries, including Egypt (IRIN 2011), South America (Smith 2011), China (Echevarría 2010), India (Carvalho 2011), the Philippines (Padilla 2009) and Pakistan ('Another Kidney' 2011). The trade persists despite the work of the WHO, individual countries and professional organizations that have helped to promote awareness of the issue, for example through the creation of the Declaration of Istanbul on Organ trafficking and Transplant Tourism (Participants 2008), to encourage and assist in the development of legislation prohibiting organ trafficking, and to prosecute those involved in illegal organ trading activities (see Smith 2010; Siddique 2011). Although at present only Saudi Arabia and Iran offer legal payments to organ providers or their families, and Iran formally prohibits transplant tourism (Ghods & Mahdavi 2007: 651), emerging support for the payment of organ providers by some medical professionals, policy makers and

bioethicists makes legal organ markets in a number of additional countries a real possibility in the future (Satel 2009; Steinbuch 2010; L. Smith 2011).

The endorsement of legal organ markets may undermine efforts to discourage less regulated markets by promoting the commodification of transplantation and organ providers. It also risks simply relocating the hazards of transplant tourism within national transplantation programs. In Iran, for example, studies suggest that organ vendors—like those in Pakistan—are disproportionately drawn from disadvantaged communities and face significant risks of harm (Zargooshi 2001; Malakhoutian *et al.* 2007). The poor comprise 84 percent of all vendors, but only 50 percent of recipients (Ghods *et al.* 2001). In Saudi Arabia, where expatriates comprise roughly 30 percent of the resident population, 54 percent of potential organ providers in 2009 were non-Saudis (SCOT 2009: 54), while only 16.5 percent of dialysis patients were non-Saudis (SCOT 2009: 37).² Inequities between potential organ provider and recipient populations are characteristic of all organ markets, whether illegal or regulated, domestic or international.

At the level of policy making, internationally and domestically, efforts to prevent transplant tourism have been marked by an emphasis on the prohibition of organ markets and the importance of establishing better access to transplantation services within countries, thereby minimizing demand for transplantation abroad. The WHO and numerous professional organizations have therefore highlighted the pursuit of national self-sufficiency in organ transplantation as a priority goal for policy makers. For example, as in The Declaration of Istanbul on Organ Trafficking and Transplant Tourism (Participants 2008), and in the recent updated WHO Guiding Principles on Organ, Cell and Tissue Transplantation (WHO 2008). The importance of this goal was emphasised at the most recent WHO Global Consultation on Organ Transplantation (Collaborators 2011).

² Although this discrepancy implies inequitable access to transplantation for expatriate workers in Saudi Arabia, it is difficult to interpret the figures in the absence of more explanatory data, for example regarding the prevalence of renal failure in the expatriate population. Additionally, some non-Saudis accessing dialysis may be from neighbouring countries such as Yemen, rather than resident expatriates. Unfortunately, no information is currently available regarding access to transplantation in Saudi Arabia for foreign residents, despite the fact they comprise a potentially significant proportion of the organ provider population.

The self-sufficiency model

The concept of national self-sufficiency dates from the mid 1970s when the World Health Organization first began to advocate the promotion of national blood supplies from voluntary unpaid donors, and to discourage commercial outsourcing that posed quality and safety risks for recipients and exploitation of the poor in foreign countries. Although the development of international trade in blood and plasma products has to some extent undermined the ideology of self-sufficiency with respect to blood procurement and regional—rather than national self-sufficiency—is now promoted in places such as Europe (Farrugia 2009: 126), it remains an important aspiration for many countries (WHO 2010a). Furthermore, despite the globalized nature of tissue banking for use in research and therapeutic products and the complex relationship between not-for-profit and for-profit entities engaged in the procurement, storage, modification and use of both human blood and tissue, societies maintain a strong interest in and responsibility for the treatment of their human biological materials (HBM). Within the borders of national healthcare systems, however porous, many nations will strive to meet their own needs for such materials for a number of reasons: it is the most effective, inexpensive or reliable way to do so; they wish to avoid unethical outsourcing practices; or simply because of a sense of national ownership of their bodies and any detached materials. The same concerns and principles identified in the history of national self-sufficiency in blood transfusion may now be applied to organ provision and transplantation.

Self-sufficiency with respect to any human biological materials such as blood, organs, cells or tissue refers to ‘the achievement by a population of an adequate supply of HBM and healthcare services, such that the needs of the population for therapeutic procedures involving these materials may be met using their own resources’ (Martin 2010: 386). While the achievement of true self-sufficiency in organ transplantation may remain a distant goal in many countries, adoption of this goal will guide more effective practical strategies and ethical policies concerning organ procurement and transplantation. The inherent reciprocity of the self-sufficiency approach—in which all members of a community are considered potential transplant recipients and potential organ donors—encourages public participation in efforts to minimize needs for transplantation and to optimize the availability of resources, thereby enhancing progress towards self-sufficiency. The prohibition of commercial organ provision in the self-sufficiency

model promotes social equity by removing incentives that would likely result in a disproportionate number of poorer individuals contributing to the organ pool. It also minimizes the risk of conflicts of interest among those responsible for the oversight and operation of procurement and transplantation programs by reducing commercialism within the programs.

The practical features of the self-sufficiency approach may be summarized as follows: (i) legislation; (ii) organization; (iii) healthcare infrastructure; (iv) registries and data collection; (v) public health and education; (vi) community consultation. A multifaceted approach to policy making that considers each of these elements enables the development of synergistic strategies that optimize the efficient use of resources. For example, public health campaigns can both minimize demand for transplantation by preventing diseases that contribute to organ failure, and encourage donation. The importance of each practical element, the role of government, professionals and community, and the ethos of equity, reciprocity and public ownership of transplantation, are manifest in the story of Pakistan's progress toward self-sufficiency.

Features of the self-sufficiency model in Pakistan

Legislation

In contrast to its former global notoriety as an international kidney bazaar, Pakistan is slowly but surely making progress towards self-sufficiency. Despite the enormous political, social and environmental challenges the country has faced in recent years, the combined efforts of Pakistani transplant professionals, policy makers and community members in conjunction with international support, have produced dramatic changes in the transplantation landscape. In 2007, The Transplantation of Human Tissues and Organ Ordinance was issued, formally prohibiting payment for organ provision, legalizing deceased organ donation and defining the role of national authorities in monitoring and regulating transplantation activities (Government of Pakistan 2007). Despite legal challenges from some individuals and groups who have sought to restore trade in organs, the Ordinance was upheld by the Shariat Court and the bill passing the legislation was ratified in March 2010 (Bile *et al.* 2010). Although its impact cannot be fully evaluated as yet, the criminalization of the organ trade has discouraged transplant tourism to Pakistan (Rizvi *et al.* 2009: 125). Perhaps more importantly, it has laid the foundations for the pursuit of self-sufficiency.

Organization and Infrastructure

The Ordinance resulted in the establishment of the Human Organ and Tissue Authority, which now accredits hospitals that may engage in organ procurement and transplantation (Bile *et al.* 2010). The identification of infrastructure required for safe and effective transplant programs helps to protect donors and recipients from inadequate care, while monitoring systems strive to ensure voluntariness and non-commercialism in donation. More general improvements in public healthcare programs and infrastructure in Pakistan will enhance existing transplant services and promote better access to transplantation.

Registries and data collection

Pakistani healthcare professionals have already highlighted the need to establish registries to evaluate programs and facilitate follow-up care of patients (Bile *et al.* 2010). At the WHO Third Global Consultation on Organ Transplantation held in March 2010, which focused on the development of strategies to promote progress towards self-sufficiency, the importance of registries and the value of comprehensive data collection were emphasized by a working group dedicated to this issue (Collaborators 2011: S75–S80). Such monitoring not only safeguards patients and facilitates identification and prevention of illegal practices, it provides policy makers and professionals with the information required to enable constant performance evaluation and improvement.

Public health programs and education

Recognizing the economic and social costs of organ procurement and transplantation, the self-sufficiency model strives not only to maximize the availability of organs and transplantation services, but also to minimize needs for transplantation through the prevention and treatment of diseases that may contribute to organ failure. In conjunction with education about organ donation, public health programs may be the most effective way to achieve progress towards self-sufficiency, particularly in the setting of scarce healthcare resources. Additional benefits of such programs include the opportunity to address more widespread healthcare needs in addition to those of patients with organ failure. In countries such as Pakistan, organ failure may not be foremost among healthcare priorities, and investment in public health represents an opportunity to address urgent healthcare needs while laying the groundwork for future transplantation and donation programs (see for example Persy, *et al.*, 2010).

Community consultation

Although deceased organ donation is now legal and supported by religious authorities, as the Shariat court decision demonstrates, only two deceased donors have provided transplants in Pakistan (Rizvi *et al.* 2010). Lack of the requisite healthcare infrastructure, as well as the need for public education and the evolution of social attitudes towards deceased donation mean that deceased procurement programs will take time. One study, for example, reveals that roughly one third of residents in Karachi believed organ donation was endorsed by religious authorities, one third believed it opposed, and a third simply did not know (Saleem *et al.* 2009) The study found that perceived religious support for organ donation, as well as socioeconomic status and education were the most important variables influencing willingness to donate (Saleem *et al.* 2009). Although there has been widespread support for deceased organ donation by Islamic religious authorities throughout the world, the issues surrounding end of life care for organ donors and organ procurement remain philosophically complex, both in Islam and other faiths, and may prove challenging in practice (Rady *et al.* 2009). In the meantime, living kidney donation offers many Pakistanis suffering end-stage renal failure the best, most cost-effective life saving treatment for their disease, and may be strongly motivated as a social responsibility or religious duty (Saleem *et al.* 2009). In the following section, I shall examine the importance of community in the self-sufficiency model using the example of the Sindh Institute of Urology and Transplantation (SIUT) in Karachi. The SIUT program of living kidney donation and transplantation reveals how community participation and engagement with transplantation contributes to self-sufficiency at both the local and national levels.

The ethos of SIUT

Despite the tragedy of rampant commercialism prominent in my account thus far, the history of transplantation in Pakistan is equally distinguished by an extraordinary example of excellence in healthcare. SIUT has not only lead the battle against organ markets and the evolution of transplantation policy in Pakistan, it provides an invaluable illustration of the self-sufficiency ethos for other provinces and countries throughout the world. Founded by Dr Adib Rizvi in 1991, SIUT began as a small dialysis unit in the urology department of the Civil Hospital in Karachi, which has become the largest public sector health care centre in the country, providing free medical care in urology and transplantation surgery, as well as dialysis to the poor (Rizvi *et al.* 2003; SIUT

2010). Only related live donors are permitted and payment for donation is prohibited. In addition to developing the institute, Dr Rizvi and his colleagues have also fought hard to discourage transplant commercialism and tourism by reporting on its impact on kidney vendors and by lobbying for the 2007 Ordinance.

In its mission statement, SIUT identifies the following goals:

- To provide free, comprehensive and modern medical facilities in urology, nephrology, liver disease, related cancers and transplantation;
- To train manpower in these specialties at all levels (i.e. doctors, nurses, technologist, technicians and others);
- To conduct comprehensive research in relevant areas of our specialties to increase the body of knowledge worldwide;
- To increase public awareness of prevention of diseases in these areas. (SIUT 2010)

SIUT now performs over 500 renal transplants and provides over 144 000 dialysis sessions each year (SIUT 2010). Largely funded by government and charitable contributions, it demonstrates how a non-commercial approach to transplantation and organ procurement can successfully meet public needs (Persy *et al.* 2009). It continues to grow with the creation of a new campus in northern Sindh province and has also helped to provide emergency medical relief camps for flood victims throughout Pakistan (SIUT 2010). Among the factors contributing to the success of SIUT is its emphasis on non-commercialism and public healthcare. Public funding and charitable support for the institute is undoubtedly motivated by the fact that it provides services to the poor. Although at present kidney donors are essentially limited to those able and willing to donate to relatives in need, it is probable that societal recognition of the value of SIUT services will encourage support for participation in deceased donation. If cultural beliefs and misconceptions regarding deceased donation can be addressed, the public trust in and support for services at SIUT will encourage efforts to contribute towards this community resource through donation.

Significantly, SIUT demonstrates that even poor living kidney providers can be successfully motivated by altruism and solidarity rather than commercial considerations. Donors within the SIUT program give kidneys to relatives or friends: members of their own communities rather than individuals rendered foreign by nationality or disproportionate wealth. This fact should prompt reflection by those who claim that, 'altruism has failed' and who argue that only the creation of markets can succeed in meeting needs for organs (see Satel 2009). The rate limiting factors for self-sufficiency

in Sindh province, as in many parts of the world, are primarily shortages of healthcare resources, lack of access to donation and transplantation services and the education and promotion of public participation in donation.

Learning from Pakistan

Pakistan's history of transplantation is one of extreme contrasts, from the miserable consequences of kidney selling noted earlier to the achievements of SIUT. It demonstrates the risks of those made vulnerable by extreme poverty and the progress that can be achieved in healthcare despite such poverty when professionals, governments and communities unite in pursuit of common goals. Pakistan faces enormous challenges if it is eventually to meet all needs for transplantation and to completely eradicate organ trading and transplant tourism, but it has made significant progress in recent years. It should serve as a warning and an inspiration to other countries engaged in transplantation activities both domestically and abroad.

Transplant tourism trades on existing international socioeconomic inequities, just as domestic organ markets rely on and may exacerbate injustice within national borders. Organ and transplantation commercialism fails to promote sustainable systems of organ provision and transplantation, in particular through the establishment of deceased donation programs, and contributes few, if any, lasting benefits to organ vendors and their societies. Those who argue that individuals should be 'free' to sell their organs must remember that those most likely to sell are also least likely to have access to transplantation, and that transplant tourists are not obtaining 'surplus' organs from foreign communities, but further diminishing the scarce transplantation resources of these communities. The pursuit of national or regional self-sufficiency, in the context of communities working together to meet common needs for transplantation, offers a comprehensive and ethical solution to the problem of organ shortages and transplant tourism. Although it requires effort, investment and commitment by governments, medical professionals and communities, the example of Pakistan confirms that such efforts are possible in the most challenging of circumstances, and that they will be rewarded.

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