Organ Trafficking and Transplant Tourism: The Role of Global Professional Ethical Standards—The 2008 Declaration of Istanbul

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By 2005, human organ trafficking, commercialization, and transplant tourism had become a prominent and pervasive influence on transplantation therapy. The most common source of organs was impoverished people in India, Pakistan, Egypt, and the Philippines, deceased organ donors in Colombia, and executed prisoners in China. In response, in May 2008, The Transplantation Society and the International Society of Nephrology developed the Declaration of Istanbul on Organ Trafficking and Transplant Tourism consisting of a preamble, a set of principles, and a series of proposals. Promulgation of the Declaration of Istanbul and the formation of the Declaration of Istanbul Custodian Group to promote and uphold its principles have demonstrated that concerted, strategic, collaborative, and persistent actions by professionals can deliver tangible changes. Over the past 5 years, the Declaration of Istanbul Custodian Group organized and encouraged cooperation among professional bodies and relevant international, regional, and national governmental organizations, which has produced significant progress in combating organ trafficking and transplant tourism around the world. At a fifth anniversary meeting in Qatar in April 2013, the DICG took note of this progress and set forth in a Communiqué a number of specific activities and resolved to further engage groups from many sectors in working toward the Declaration’s objectives.

Keywords: Declaration of Istanbul, Organ trafficking, Transplant tourism.

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By the middle of the first decade of the 21st century, the sale of human organs for transplantation, first reported in the 1980s (1), had metamorphosed from a hidden and limited activity in the back streets of a handful of developing countries to a widespread, and sometimes brazen, activity that involved potential recipients traveling to clinics around the world to receive a kidney from poor, and poorly paid, “donors.” Trafficking in organs and the persons from whom they were removed in India, Pakistan, Egypt, the Philippines, and Eastern Europe—or executed prisoners in China—came to

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have a pervasive, malign influence on transplant activities in many parts of the world (2). Growing numbers of transplant candidates with personal wealth or support from governments or health insurers were flying from the Gulf states, Israel, Europe, and North America to Eastern Europe, Asia, South Africa, and Latin America to obtain kidney transplants at for-profit hospitals and clinics they had found through brokers or online advertisements.

The growing rate of kidney sales over the preceding 20 years was driven by the needs of wealthy or well-insured recipients. The rationale for allowing the practice was provided by three groups: (a) philosophers who think that “donors” should be allowed to exercise their autonomy by selling their organs; (b) believers in neoclassic economics, who think that treating organs as a market commodity will increase the supply; and (c) nephrologists and surgeons whose eagerness to serve their patients’ needs have led them to flirt with “regulated markets” in kidneys and other organs (3). None of these positions stand up in the face of evidence or professional ethical standards. As to the first, decades of experience have shown that the sellers of organs everywhere are the poor or the vulnerable, whose actions reflect financial desperation and ignorance, not autonomous agency. The central bioethical principles of beneficence and justice are equally abused by organ sales, which crowd out altruistic donations, leave paid donors worse off, and exploit the poor to benefit the rich (4). Second, the transplant rates in countries with voluntary, unpaid systems exceed those in countries where organs are sold, and the number of available organs actually increases when sales are combated because the act of donating ceases to be mercenary and becomes a human gesture of solidarity and generosity. Third, it is wishful thinking to believe that creating a marketplace will provide more organs for their patients. Reliance on payments—including financial incentives and comparable monetary “rewards” for donors, or for families in the case of deceased donation—paints organ donation with the brush of financial vulnerability and sullies respect for human dignity. Unfortunately, the willingness of people in the third category to embrace the first two arguments has lent credibility to physicians and hospitals in developing countries that have profited financially from transplanting organs from the poor into wealthy and well-insured patients. By promoting explicit or disguised organ commercialism, these latter actors exploit the arguments of people in the third category who have called for “experimenting” with financially motivated organ donation (3), in an attempt to divert international attention from the history of destitution, injuries, and even death among paid organ donors who have been left to live with the legacy of exploitation.

In 2003, the World Health Organization (WHO), at the request of the governments of Colombia and Spain, began a study of the current global status of cell, tissue, and organ donation and transplantation to determine if a revision of its 1991 “Guiding Principles for Human Organ Transplantation” was warranted (5). A series of regional and global consultations over the following 4 years revealed that at least 10% of all transplants involved commercial organ sales (6), while also confirming that some governments had begun systematic efforts to bring such trafficking to an end.

Complementing these WHO activities, the two leading international professional organizations for transplantation and nephrology, The Transplantation Society (TTS) and the International Society of Nephrology (ISN), also reexamined organ transplant activities around the world. They concluded that unethical practices, particularly those involving living, unrelated kidney donation, were rampant, with transplant commercialism and human organ trafficking being commonplace in China, Colombia, Egypt, Pakistan, the Philippines, India, and Eastern Europe. The TTS and the ISN decided that efforts by governments and the WHO to curb unethical transplant practices needed to be augmented by a professional code of practice aimed at improving the ethics as well as the quality and availability of organ transplantation. To that end, the TTS and the ISN convened an international summit meeting on organ trafficking and transplant tourism in May 2008 in Istanbul that brought together more than 150 professionals with a variety of backgrounds from 78 countries. Istanbul was selected as the venue because it straddles Asian and European cultural and religious traditions. The text of the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (DoI) was published simultaneously in Transplantation (7), the journals of the ISN and American Society of Nephrology, and The Lancet (8). The DoI consists of a preamble, definitions of critical terms (organ trafficking, transplant commercialism, and transplant tourism), a set of principles to guide professional conduct and government policy, and a series of proposals applying those principles to particular problems in transplantation.

WHAT CAN ONE EXPECT OF A “DECLARATION”??

Although the implementation of international agreements among governments follows well-developed pathways, practical application of professional and academic guidelines and ethical codes is more variable. The DoI has been likened to another major statement designed to guide the behavior of physicians and healthcare institutions, the Declaration of Helsinki (DoH), which was first issued by the World Medical Association in 1964 (9). The DoI has been criticized for its lack of legal authority (10), but like the DoH, which has become a widely accepted statement of the obligations of investigators conducting research with human beings, the DoI gains authority both through the voluntary adherence by professional and governmental bodies to its principles and from being directly incorporated into national laws and regulations. In addition, the DoI works to address the needs of transplant candidates by promoting ethically acceptable living and deceased donation (7). One strong indication that the DoI is achieving such influence is the 127 endorsements it has received, not only from national and international professional organizations but also from governmental bodies (11).

To achieve a sinea qua non status for the DoI in organ transplantation comparable with that achieved over a half century by the DoH, the leaders of the TTS and the ISN decided to form a body with specific responsibility to promote and sustain the document. The Declaration of Istanbul Custodian Group (DICG) comprised representatives from the two organizations and other interested individuals (12). The chosen implementation pathways are to foster transparency in transplant practices, to promote education, to withhold

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academic recognition from professionals who do not adhere to the principles of the DoI, and to encourage the endorsing organizations to encourage adherence to the principles of the DoI. The DICG working groups (11) interact with endorsing professional societies, scientific journal editors, research funding agencies, and ethical review committees to develop and maintain global transparency of both acceptable and unacceptable practices, to promote understanding and knowledge, and to provide long-term support for its mission. Concrete examples of the withholding of academic recognition include the removal of abstracts from the content of an international transplant congress where the organ source was executed prisoners (12) and the retraction of articles from an academic journal where the organ source was commercially obtained living-donor kidneys in direct contravention of the journal’s adherence to the principles of the DoI (13).

Since the publication of the DoI, organ trafficking and transplant tourism, which have their greatest effect in developing countries, have been inhibited, as has the broader phenomenon of organ commercialism. Success in combating organ trafficking has been aided by the implementation of the protocol issued in 2000 by the United Nations as part of its effort to halt transnational organized crime, the United Nations Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, in which the “removal of organs” is recognized as a key purpose of human trafficking (14). In 2009, the Council of Europe and the United Nations jointly produced a study on organ trafficking and trafficking in human beings for the purpose of the removal of organs that concluded that specially adapted means should be used to combat each, including emphasizing voluntary donation and the absence of financial gain from the human body or its parts (15). In the UK, the Nuffield Council of Bioethics report on organ donation, to which the DICG contributed, concluded that altruism should continue to play a central role in ethical thinking about donation (16). In 2011, Spain made special mention of the DoI when modifying its Penal Code to provide sanctions for trafficking in organs or people for the purpose of the removal of organs (17). Further, in 2012, the Coalition for Organ Failure Solutions urged the U.S. Congress to incorporate human trafficking for organ removal under the rubric of the Trafficking Victims Protection Act (18). Such a measure need not interfere with a related practice, defined by the DoI as “travel for transplant,” such as occurs when a living related donor resides in a different country than his or her planned recipient or a recipient–donor pair have to cross a border to access transplantation expertise that is not available in their own community (7). Finally, in May 2010, the World Health Assembly (WHA) adopted a resolution encouraging the creation of systems of unpaid donation of organs from deceased and living donors and endorsing the updated WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation, which restate the 1991 principles and add two aimed at vigilance and safety in transplantation and at ensuring transparency in organ procurement and allocation. These steps by the WHA have encouraged countries to cooperate with one another and the DICG in ending all forms of organ commercialism (19). This alignment of activities is assisted by the status of TTS as a nongovernmental organization in official relations with the WHO.

WINDS OF CHANGE

In the past 5 years, major changes in policies and practices have occurred in countries that had previously been centers of organ trafficking and transplant tourism. Six of these former “hotspots” merit special mention because of the dramatic changes in policies and practices that have occurred—and are continuing—in each.

Pakistan

Over the past four decades, transplant programs in a number of Pakistani cities have performed many thousands of commercial transplants for foreigners using kidneys from the poor from villages throughout the country. In 2010, leaders of the Sind Institute of Urology and Transplantation in Karachi, backed by the DICG, led a successful effort for a new law criminalizing organ sales. The number of illegal transplants has since fallen, but constant vigilance must be exercised to prevent its resumption by the surgeons and hospitals that stand to profit. The DICG members have identified several illicit programs, which have been closed and prosecuted (20).

India

India was identified as a common destination for commercial transplants and transplant tourism in 1980s and 1990s. The Indian Parliament outlawed commercial transplants and recognized the concept of brain death through the 1994 Transplantation of Human Organs Act (21). The number of such transplants fell after the enactment of this law, although there remained widely publicized cases of its abuse. The law, however, allowed unrelated transplants motivated by love and affection provided these were cleared by a statutory “Authorization Committee” set up by the states. This committee itself provided an avenue for abuse (22).

In 2008, after the adoption of the DoI and the revised WHO Guiding Principles, the Indian government amended the Transplantation of Human Organs Act (21). The role and functioning of the authorization committees has been better defined, tests to ascertain relationship were prescribed, greater caution was suggested to prevent exploitation of females, a mandatory requirement for all foreign nationals to obtain clearance from the Authorization Committee and embassies of their home countries has been introduced, and the penal provisions stiffened. At the same time, the Government has put into place a mechanism to promote deceased donations. In the state of Tamil Nadu with a population of more than 70 million, a private hospital–public hospital partnership promoting deceased-donor transplantation has effectively eliminated commercialization in a manner that can serve as a model for other regions of South Asia and developing countries (23).

China

Chinese organ transplant activities have global implications. For the last decade or more, Chinese hospitals, aided by Internet advertising, have been major destinations for wealthy or well-insured transplant tourists from around the world. The conversion of the body of an executed prisoner into cash through sale of its organs and the exploitation of living kidney donors for foreign patients not only engenders
profound ethical concerns but also comes at the expense of the needs of the Chinese population.

The DoI specifically addresses the unacceptable nature of the Chinese practice of “donation by execution.” The DICG, the TTS (24), and other nongovernmental organizations, including Amnesty International and Human Rights Watch, have taken an unequivocal stance against this practice while promoting ethically acceptable alternatives (25). As urged by the DICG, several academic journals have placed barriers to the publication of data that involve executed prisoners, societies of transplant professionals have prevented the presentation at their meetings of clinical research involving executed prisoners, and pharmaceutical companies have limited clinical trials in China for the same reason. The firm stance by the DICG and other international groups, as well as the policies promoted by the WHO, are having notable effects. High-ranking Chinese government officials have themselves brought attention to the lack of acceptance by the international community of the practice of using organs from executed prisoners and of the corruption and commercialization that characterize living and deceased donation in China (26). Authorities have closed dozens of transplant programs, which violated new rules that severely limit transplant tourism. In the next cycle of reauthorization, Chinese transplant programs will be required to have in place alternative programs to the use of organs from executed prisoners (27). Progressive changes in China will have significant implications for countries from which a substantial number of transplant recipients have traveled in recent years to China to purchase organs. Nonethnic Chinese have been known to use assumed names and identities presumably to bypass the Chinese law that officially criminalizes such activities.

The Philippines

Fueled by poverty in the slums of Manila and an extensive network of organ brokers, the Philippines was a well-known destination for transplant tourists during the past decade; even programs that provided transplants for domestic patients relied on the profits from transplanting foreign patients. A presidential directive, issued on April 30, 2008, at the start of the Istanbul Summit, established a ban on foreign recipients receiving kidneys from Filipino living donors. Supplemental rules and regulations for the implementation of the organ trafficking provision of the Anti-Human Trafficking Law went into effect in June 2009 (28). The annual number of foreign transplant recipients fell from 531 in 2007 to 2 in 2011, and the number of deceased-donor transplants has increased threefold in the same period (29).

Egypt

Since the 1980s, Egypt has been the main locale for organ trafficking and transplant tourism in the Middle East (2). In February 2010, representatives of the WHO and the DICG obtained commitments from Egyptian transplant leaders and policymakers to end these practices; this culminated in the passage of the landmark Law on Human Organ Transplantation, which prohibits and penalizes organ trafficking and permits deceased donation in accord with the WHO Guiding Principles and the DoI (30). Unfortunately, political changes have shifted the focus, and most centers appear to be undertaking commercial organ transplants, including the use of trafficked donors, despite the 2010 law (31, 32). The reporting of Egyptian transplant data to a new registry under the auspices of the Middle Eastern Society of Transplantation may provide a much-needed source of transparency.

Colombia and Latin America

In the first decade of the 21st century, Colombia was a major provider of deceased-donor organs for wealthy foreigners. A concerted effort by the government to stop this practice and direct organs to citizens of Colombia and neighboring countries, through regional governmental agreements, led to a fall in transplants to noncitizens from 16.5% of the total (200 transplants) in 2005 to 1.37% (16 transplants) in 2010 (33). The presidents of every Latin American Society of Nephrology have endorsed the DoI (11), and the Society of Transplantation of Latin America and Caribbean (STALYC), during the first Latin American Forum in Ethics and Transplantation adopted the “Document of Aguascalientes,” which closely parallels the DoI (34). In February 2012, Brazil became the first country to include specific reference to the DoI in its national regulations regarding transplanting organs into nonresidents (35).

CHALLENGES IN DEFINING AND DEVELOPING NATIONAL SELF-SUFFICIENCY IN ORGAN DONATION

The WHO and the Spanish Organización Nacional de Transplantantes, supported by the European Commission and the TTS, convened a global consultation in 2010, which led to The Madrid Resolution on Organ Donation & Transplantation: National Responsibility in Meeting the Needs of Patients, Guided by the WHO Principles (36). The concept of national self-sufficiency in transplantation, identified in the DoI Principle 5, is that the members of a population who live within a country or region should share both equitable access to donated organs and responsibility for meeting those needs by participating in organ donation and in efforts to prevent organ failure. Translating these concepts into legal provisions is complicated by such questions as how each country would regard foreign workers, undocumented immigrants, and other noncitizens living within the country as to their legal rights to obtain organ transplantation services, and the extent to which a country should provide nonresidents access to the national organ transplantation system. The core concept of self-sufficiency, however, is simple: that poor countries should not allow organs from living donors to be sold to foreigners rather than provided to their own citizens and that wealthy countries should develop adequate transplant programs, including the use of deceased donation to the maximum extent possible, rather than allowing their wealthy or well-insured citizens to purchase a kidney transplant in a country where organs are sold. Progress has been made in this regard in a number of countries (37).

Israel

Although Israel had previously funded its citizens to obtain transplants in programs that relied on paid donors in Turkey, South Africa, and other countries, in 2008, a new Transplant Law was passed in parallel to the DoI (38). It

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prohibits insurance reimbursement for organ transplantation undertaken abroad that contravenes local laws and introduces criminal penalties for brokering organ sales. By removing funds for transplant tourism and thereby creating demand for transplants domestically, successfully prosecuting organ traffickers, introducing a systematic mechanism to reimburse living-donor expenses, and adopting a long-awaited brain-death law, Israel has both increased organ donations from living and deceased sources and reduced the number of transplant candidates seeking transplantation abroad (from 150 in 2006 to 35 in 2011) (39).

North America

A position statement adopted by the Canadian Society of Transplantation and the Canadian Society of Nephrology in 2010 describes the responsibilities of physicians and the healthcare system in promoting local organ donation and condemning organ trafficking (40). In the United States, the United Network for Organ Sharing has endorsed the Principles of the DoI, and the Department of Health and Human Services has accepted its definitions of organ trafficking, transplant commercialism, and travel for transplant (41). In keeping with the principles of the DoI, a new United Network for Organ Sharing policy requires all transplant waiting-list registrants who are noncitizens to state if the United States is their primary place of residence and whether they have traveled to the United States for the purpose of transplantation or for other reasons. The first 6 months of publicly available data reveal that only 241 (0.9%) newly listed candidates for deceased organ transplants were noncitizen/nonresidents of the United States and 83 traveled to the United States for transplant (42).

REVIEW OF THE DECLARATION

At a fifth anniversary meeting in Qatar in April 2013, the DICG took note of this progress but also set forth in the Doha Communiqué a number of specific activities (including, for example, the implementation in Qatar of The Doha Accord) and resolved to further engage groups from many sectors in working toward the Declaration’s objective of replacing transplant tourism, commercialism, and trafficking with ethical and sustainable programs of living and deceased donation and transplantation (see Appendix).

CONCLUSIONS

The promulgation of the DoI and the formation of an organization, the DICG, designed to effect and uphold its principles, have demonstrated that concerted, strategic, collaborative, and persistent actions by professionals can produce tangible changes both in medical practice and governmental policies. This experience also exemplifies the benefits that arise when such professional activities are undertaken in collaboration with international, regional, and national governmental organizations on matters of critical ethical importance. Although not yet established to the same degree as the DoH, the DoI has gone far in attaining the status of governing standards alongside the WHO Guiding Principles. Although much remains to be accomplished, the successes of the DICG in combating organ trafficking and transplant tourism should provide encouragement to others facing similar global challenges.

REFERENCES

APPENDIX

THE DOHA COMMUNIQUÉ OF THE DECLARATION OF ISTANBUL CUSTODIAN GROUP
(April 14, 2013)

On May 2, 2008, 150 representatives of scientific and medical bodies, government officials, social scientists, and ethicists from around the world adopted the Declaration of Istanbul on Organ Trafficking and Transplant Tourism to mobilize medical professionals against the exploitation of persons who are compelled by need or force to provide organs for transplantation to people within their own countries or to foreigners. To mark the Fifth Anniversary of the Declaration and to evaluate progress in implementing its Principles and recommended Proposals, 70 members of the Declaration of Istanbul Custodian Group (DICG) met in Doha, Qatar, from April 12–14, 2013. The participants were heartened by the steps taken by health authorities in many countries that have prohibited transplant commercialism and have greatly reduced the flow of transplant tourists to sites where organ trafficking, including from executed prisoners, occurs. The Doha participants also commended the adoption in many places of safe, effective, and accountable practices that facilitate meeting the needs of transplant patients while protecting the rights of donors, such as the creation of systems of follow-up care for donors and the development of successful deceased donor programs in a number of countries. It was recognized, however, that many challenges remain, and the participants therefore endorsed the adoption of means of reporting organ trafficking, the development of more complete registries of transplants of all organs from deceased and living donors, increased cooperation with law enforcement authorities combating human trafficking, and the use of international conventions to ensure that organs are obtained and used in an ethical, safe and transparent fashion.

The Doha Meeting Participants Resolved:

1. To re-affirm the Principles of the Declaration of Istanbul, which condemn transplant commercialism, organ trafficking, and transplant tourism, and to underline the urgency of putting the Principles into action in all settings where transplantation occurs.

2. To urge all member states of the World Health Organisation to adopt laws, regulations and practices consistent with World Health Assembly Resolution 63.22 and the Declaration of Istanbul, and in particular to enforce an end to transplant tourism and the use of executed prisoners as a source of organs for transplantation.

3. To develop and disseminate descriptions of the technical and organizational features of sustainable programs and systems that can be implemented in different countries to promote national self-sufficiency in organ transplantation, as elaborated in the Madrid Resolution in 2010, especially through the development of deceased donation and equitable regional cooperative arrangements.

4. To elaborate ethical approaches to acknowledging the generosity and humanity of donors and families in deceased organ donation programs.

5. To develop, and recommend implementation of, systematic ways for physicians to identify and report to appropriate registries (in a quantifiable but non-judgmental manner) patients returning with a donor organ from an “unverifiable source” or manifesting other indications of a vended organ.

6. To consider in detail the formats developed for the “xDoT” reporting platform.

7. To develop a “white paper” discussing professional responsibilities in responding to patients who travel or plan to travel abroad for a transplant that would be illegal in their country of residence, including professional and public policies on the access of such patients to short- and long-term treatment in the national healthcare and insurance systems.

8. To develop a “white paper” exploring issues in, and addressing principles of access to, organ transplant waiting lists.

9. To engage more effectively with the organizations which have endorsed the Declaration.

10. To propose to the Declaration’s endorsing organizations a global network of physicians to act as “National Focal Points.”

11. To cooperate with organizations that are examining the common and overarching issues in the procurement and medical use of all products of human origin.

12. To participate actively in the monitoring mechanisms of the Council of Europe Convention on Action against trafficking in human beings as it relates to human trafficking for organ removal (HTOR) and the...
Draft Convention against trafficking in human organs (THO).
13. To develop means of communicating with and educating law enforcement authorities, as well as with human rights monitoring organizations, regarding HTOR and THO.
14. To support adoption of a uniform coding system to improve traceability and vigilance for human organs.
15. To assist the preparation and publication of a report on the implementation of the Doha Donation Accord.
16. To thank the Hamad Medical Corporation and the Supreme Council of Health of the State of Qatar for sponsoring the Doha meeting and for sharing with the participants the progress made in implementing the Doha Donation Accord in a manner consistent with the Declaration of Istanbul.

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