The Dilemma and Reality of Transplant Tourism: An Ethical Perspective for Liver Transplant Programs

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Transplant programs are likely to encounter increasing numbers of patients who return after receiving an organ transplant abroad. These patients will require ongoing medical care to monitor their immunosuppression and to provide treatment when the need arises. Transplant societies have condemned transplantation with organs purchased abroad and with organs procured from executed prisoners in China. Nevertheless, transplant programs require guidance on how to respond to the needs of returning transplant tourists and to the needs of patients who may choose to become transplant tourists. This discussion presents a case that raised such issues in our program. It goes on to offer reasons for considering a program's responses in terms of the most relevant principles of medical ethics, namely beneficence and nonjudgmental regard. ***Liver Transpl 16:113-117, 2010.*** © **2010 AASLD.**

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This is the first in a series of case-based discussions of ethical dilemmas facing liver transplant programs and physicians. In caring for extremely ill patients with complex medical problems, liver transplant teams are on the front line when it comes to making difficult decisions. Many such decisions are made during meetings of the program's recipient review committee, a forum that seeks perspectives from a variety of professionals, including transplant coordinators, social workers, psychiatrists, and medical/surgical subspecialists. At times, however, a clear consensus on whether or not to perform transplantation for a patient may be difficult to obtain. What follows is such a case that we encountered at our center.

THE CASE

H.Q., a 46-year-old Chinese accountant, was placed on the liver transplant waiting list with a Model for End-Stage Liver Disease score of 18 and an O blood type. He had hepatitis C with refractory ascites requiring biweekly paracentesis, type 2 hepatorenal syndrome, and hepatic encephalopathy. He had no potential live donor and no close family living outside the New York City area, and he did not want to consider dual listing outside United Network for Organ Sharing (UNOS) region 9. After he had waited on the list for a year, his Model for End-Stage Liver Disease score had risen to 21, and he had received no donor calls despite several recent hospitalizations. H.Q. was then unable to be contacted for several weeks, and a family member subsequently told us that he had undergone liver transplantation in China. Friends had suggested that he travel to China, where he could obtain a liver transplant for a fee. He then investigated the option through relatives in China and made the necessary arrangements to stay with them. He received a liver transplant 2 weeks after arriving in China.

Three months after his liver transplant, H.Q. returned to our program, requesting follow-up care. He explained that he had received a liver transplant in China, but when questioned, he stated that he knew nothing about the source of the transplanted organ. He came with scant medical records and was about to run out of the immunosuppressive medication that he had been given by the transplant center in China.

Abbreviations: PRC, People's Republic of China; UNOS, United Network for Organ Sharing.

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Our program began to provide his follow-up care. Then, 2 months later, he developed septicemia due to diffuse intrahepatic biliary stricturing related to hepatic artery thrombosis. Although the patient recovered, he required 3 additional hospitalizations for biliary sepsis, with 1 due to a liver abscess. Retransplantation appeared to be the only viable option, but members of the team had different views about whether or not to proceed. H.Q. would meet criteria for a variance within our regional review board's purview and thus have some prioritization on the transplant list. He was medically a suitable candidate, but there was disagreement about whether it was morally right to provide him with a transplant.

What follows is a review of the current status of transplant tourism in the United States as well as a review of society position statements and bioethical principles that are most relevant to liver transplant programs dealing with transplant tourists.

THE UNITED STATES TODAY

A Scientific Registry of Transplant Recipients analysis published in August 2007 identified 173 wait-list removals, including 158 patients waiting for a kidney transplant, due to transplantation at foreign centers. The authors of this analysis estimated that an additional 200 to 335 patients had received transplants abroad for a total of 373 to 408 transplanted patients, with about 75% occurring between 2004 and 2006. Furthermore, it was estimated that more than 40% of these transplant tourists resided in New York and California, and it appears that this number is increasing. The majority of these patients traveled to the People's Republic of China (PRC), where organs from executed prisoners have been used for transplantation.[1,2]

SOME BACKGROUND INFORMATION ON TRANSPLANT TOURISM

Multiple reports have documented trafficking in human organs worldwide. For example, in December 2003, an international kidney transplant trafficking ring was busted. It was revealed that organ transplant recipients had paid $100,000 to the ring for a kidney transplant, whereas the living donors received only $800. It was also reported that a kidney could be had for $1000 to $10,000[3] and that a liver transplant from an executed prisoner in the PRC could be had for $94,000.[3,4] The revelations were followed by international condemnation of paid living donor transplantation in India, Pakistan, the Philippines, China, and South Africa. These denunciations and legal sanctions have driven some transplant tourism activities underground; it is assumed that they continue, but now without government oversight or regulation.[5] Although the majority of US transplant professionals frown on transplant tourism, the practice violates neither current US law nor the National Organ Transplant Act.[6] In addition, current UNOS policies allow a small percentage of each center's transplants to be allotted to foreign nationals,[7] in essence allowing for transplant tourism within the United States.

Transplant tourism has been associated with significant problems for those who sell their organs. The money that they are promised is paltry, and they are frequently swindled out of some of the procurement fee by middlemen and organ vendors. The surgery used to procure the organs and the posttransplant care may be substandard at some centers. Aftercare that should be provided is typically not made available.[8]

According to most studies, patients who receive organs as transplant tourists also experience significant medical problems. They too may be victims of substandard surgical techniques. In addition, their transplants may be compromised by poor organ matching, unhealthy donors, and posttransplant infections. Typically, organ recipients do not receive adequate patient education either pre-transplant or post-transplant, and there may be poor communication throughout the process because of language barriers. Patients may be discharged from the facility and encouraged to travel prematurely, and their immunosuppressive medication supply may be inadequate. When they return to their home transplant center, they often have inadequate records of what was done or no records at all. All of these problems compromise their health, their lives, and their transplanted organs.[9-17]

Combined, the practices associated with transplant tourism also translate into problems for the entire transplant community. Health professionals who work in transplantation worry that the transplant tourism industry could undermine our reliance on altruism for organ donation, undermine society's trust in transplant programs, and ultimately have a negative impact on future organ donation.

SOCIETY STATEMENTS AND GUIDELINES

The ethical challenges for transplantation become especially complicated when transplant tourism is involved and transplant centers have to sort out what, if any, medical care or additional transplanted organs they should provide to returning transplant tourists.[18] In the past few years, professional societies have begun to publish positions on transplant tourism. These public stances by professional groups, however, do not settle the matter because the opinions are not uniform and speak to somewhat different issues.

In April 2007, the International Society for Heart and Lung Transplantation issued a statement on accepting organs from prisoners. The Statement on Transplant Ethics of the International Society for Heart and Lung Transplantation argues that the practice

- Contravenes the principles of voluntary donation.
- Provides perverse incentives to increase the number of executions.
- Lays the judicial process open to corruption.

The society therefore concluded that members "should discourage patients from seeking transplan-

tation in countries where there is no external scrutiny" or assurance of ethical standards and declared that members "should not participate in, or support the transplantation of organs from prisoners." The statement goes on to hold out sanctions against those who fail to comply with this position. It states that "members who have been found to have contravened this ethical principle may have their rights and privileges as members suspended or removed." In conformance with its stand, the society now requires a personal declaration that the author adheres to these principles to accompany all submissions to the society's journal, the *Journal of Heart and Lung Transplantation*.[19]

Similarly, the American Association for the Study of Liver Diseases, the International Liver Transplant Society, and the editors of *Liver Transplantation* have endorsed a similar stance and created policies to uphold similar standards. They have taken positions against the exploitation of donors and recovery of organs from executed prisoners and have condemned the use of paid living donors. They have also mandated that original publications should explicitly exclude the use of executed prisoners or paid donors, but they do not prohibit basic research publications from transplant centers involved in such practices.[5]

Expressing a different position and emphasizing different aspects of the issue, the Transplantation Society has recently published a policy on interaction with China. It maintains that health professionals from the PRC should be accepted as registrants at meetings. Lecturing and sharing expertise in the PRC in order to promote ongoing dialogue and education are accepted, and training physicians from the PRC, either in a clinical or laboratory setting, is condoned as long as they comply with the society's policy and ethics statements.[20]

That said, the professional transplant societies that have addressed the issues, as well as most transplant professionals, express disapproval of some activities associated with transplant tourism. For example, the Declaration of Istanbul on Organ Trafficking and Transplant Tourism condemns transplant tourism and related practices, and that declaration has been endorsed by the American Society of Nephrology, one of the organizations sponsoring the Istanbul meeting that produced the declaration.[21] In the same vein, the UNOS board of directors issued a statement on transplant tourism in June 2007 that was supported by the UNOS ethics committee.[22] In it, they too condemn transplant tourism because the practice typically occurs without government oversight and in ways that undermine medicine's commitment to nonmaleficence. The UNOS statement does, however, acknowledge that transplant tourism exists because of a growing disparity between organ demand and supply. Therefore, it recommends that in emergent situations, patients who have received a transplant abroad should be evaluated and treated according to the standard of care. Although it does not affirm an obligation for individual physicians to treat such patients in nonemergent situations (whether they were previously known to the transplant center or not), the statement does maintain that the medical community has the obligation to provide medical care for these patients.

Interestingly, both the declaration and the UNOS statement stop short of offering further direction to transplant programs. The UNOS statement "recommends that emergent care be provided to such recipients" but also includes an exemption from the duty to provide nonemergent care for those "physicians who raise a conscientious objection." A similar declaration by the American Society of Transplantation avers that optimal medical care should not be withheld from those recipients who have chosen to receive transplants as "tourists" from abroad.[23] In sum, little guidance is provided for dealing with the specific problems of patients who choose to become transplant tourists.

EXPERIENCE OF THE MOUNT SINAI LIVER TRANSPLANT PROGRAM WITH TRANSPLANT TOURISM

Patients in our program who have been transplant tourists have learned about the option via word of mouth. From 2004 to 2008, 9 of our patients underwent liver transplantation in the PRC. Six of these patients were known to our program prior to transplantation. We took on the care of 3 additional patients post-transplantation because several transplant centers in our region do not render care to transplant tourists. Several of these transplant tourist patients have had biliary problems, and 2 of the 3 patients not previously followed at our program had been transplanted for hepatocellular carcinoma beyond the Milan criteria. Seven of the 9 patients have hepatitis B requiring prophylaxis with hepatitis B immune globulin. These patients had been provided with a limited supply of intramuscular hepatitis B immune globulin by the PRC transplant center to tide them over until they re-established their relationship with a US liver transplant center. In addition, we have cared for 3 patients who underwent renal transplantation in India and later developed liver failure, 2 from inadequately prophylaxed hepatitis B virus leading to virus reactivation and liver decompensation and 1 from acute hepatitis C virus acquired at the time of renal transplantation.

GUIDANCE FOR THE MORAL QUANDARY

Unfortunately, little guidance from societal statements and guidelines is given to transplant centers and the professionals in the trenches dealing with transplant tourists seeking care. Little is written as policy to answer the questions of whether a liver transplant program should inform its patients of the transplant tourist option, whether programs should take on the care of returning transplant recipients, and whether such patients should be retransplanted if the need arises.

In the clinical context, which transplant tourism–related practices should be refused and which should be provided by US transplant programs? What should

physicians consider in deciding what to do? We can draw on well-accepted principles of medical ethics to construct the guidance that clinicians need.

Physicians have a positive duty of beneficence, that is, a professional obligation to promote the good of patients.[24,25] This fiduciary responsibility to patients requires physicians to use the knowledge, powers, and privileges entrusted to them for the good of patients, even when that involves putting the good of patients before their own.

Furthermore, doctors have a professional responsibility to adhere to medicine's commitment to nonjudgmental regard. This professional responsibility requires physicians to render care to all patients who need it without being influenced by any judgment about the patient's worthiness. After all, enemy soldiers, prisoners, and even Tony Soprano are entitled to good medical care delivered with compassion and respect. The bottom line is that patients who are transplant tourists have not directly caused harm to anyone. In fact, patients who receive a transplanted organ abroad actually advantage other patients behind them on the list by removing themselves from the queue.

Taken together, the moral principles of beneficence and nonjudgmental regard direct us to treat potential or returning transplant tourists as we would treat other patients under our care by focusing on providing the medical treatment and support that they need.

A transplant center that provides ongoing care for patients prior to their transplantation abroad should not deny the patients post-transplantation care. For patients who were not known to the transplant center prior to undergoing transplantation abroad, the center has the obligation to provide at least emergent care and referral to another transplant center for long-term follow-up. Centers that programmatically refuse to take on the care of returning transplant tourists fail in their duties of beneficence and nonjudgmental regard and also overburden other transplant programs. When retransplantation is involved, this last issue becomes especially important. Once a transplant center has begun providing care, medicine's commitments to beneficence and nonjudgmental regard mean that the decision regarding retransplantation should be based only on medical urgency and medical appropriateness and not on the fact that the patient was a transplant tourist.

The principles of beneficence and nonjudgmental regard are also useful in guiding us through the quandaries that lay ahead. Because education and information are crucial components of good medical care, ongoing informed consent and patient/family education are mandated by Centers for Medicare and Medicaid Services and UNOS regulations at US transplant centers. Knowing that foreign transplant programs typically provide inadequate patient education and inadequate records, a US program should consider preventive measures and offer patients the education that they will need along with standardized forms to elicit and communicate relevant information to the home institution about the organ donor, the surgery, and the postsurgical treatment. These elements of the process should be initiated and implemented by the US transplant center. It is hoped that this would allow for a more seamless transition back to care within the United States post-transplantation.

We already know that some patients who return after transplantation have good results and others have poor results that probably are related to poor care. When future patients announce their intention to go abroad for an organ transplant, should a US program steer them away from institutions that seem to provide shoddy care? Should a US program offer information on the quality of foreign transplant programs as guidance for its patients? As there are numerous transplant programs that cater to transplant tourists, it is unlikely that US transplant physicians will be able to provide more than an anecdotal assessment of a specific program's results and reputation. Yet, medicine's commitment to serving patients and the commitments to nonjudgmental regard, beneficence, and fiduciary responsibility all point to a duty to inform as best we can. Patients will need to do their own research on these matters.

Taking this line of thought a step further will lead programs to consider the fate of their patients, some of whom can be expected to die for lack of a transplanted organ given the donor shortage and the current allocation system. Should such patients be informed about the possibility of transplant tourism when they are not eligible for a transplant in the United States or when they are likely to die before reaching the top of the transplant list? All transplant programs are mandated to inform their patients about the option of multilisting within the United States. Again, the medical responsibility to put a patient's well being before one's own, the commitment to beneficence, and physicians' fiduciary responsibility all dictate that the information should be provided to patients who could benefit from it. Although coverage of posttransplantation care by insurance carriers has not been a major issue (in fact, a few carriers now provide transplant tourism options for those patients in need), patients should be instructed to check their health insurance policy about obtaining a transplant abroad at a non–Medicare-approved institution so that they are not left in the lurch upon their return to the United States. In dealing with sometimes desperate patients and families, the transplant physician has to be as open-minded and as honest as possible in providing support and care. The patients should face no disparagement because of their need and desire to secure a transplant abroad. Although physicians may try to dissuade patients from going abroad for a transplant because of concern about the outcome or the quality of care, patients should not be threatened with abandonment by a center's refusal to provide care upon their return. Patients who do not meet reasonable criteria for liver transplantation (eg, hepatocellular carcinoma well beyond the Milan criteria or metastatic cancer to the liver) should be informed about the poor survival data associated with the diagnosis and dissuaded from seeking transplantation.

Because of the ongoing organ donor shortage, in-

creasing numbers of our patients may resort to transplant tourism. Liver transplant teams must be open to this idea and provide ongoing education and support for them. People with chronic liver disease already are suffering from a loss of self-esteem and independence, physical symptoms, financial pressures, anxiety, and depression. To consider leaving the transplant center that they have come to trust and traveling thousands of miles away from their families at great expense and thereby draining their savings is indeed stressful. Although none of us condone all of the practices associated with transplant tourism, it is our duty to provide patients who resort to it with the needed information and the compassionate care that we give to all of our transplant patients. Our responsibility is to care for these patients and uphold the principles of medical ethics that should govern our behavior as physicians.

OUR DECISION REGARDING H.Q.

After much discussion, our team ultimately accepted the primacy of the professional commitments to nonjudgmental regard, beneficence, and fiduciary responsibility. We decided that a transplant program must provide care for patients who need it and must treat patients on the basis of their need, regardless of what they might have done or how they secured their transplant organ. Agreement on the relevant principles of medical ethics enabled our team to make the decision to list and transplant patient H.Q. Although H.Q. had a long, complicated posttransplantation course, he is currently doing well.

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