



## Ethical Dilemmas in Patient Selection for a New Kidney Transplant Program in Guyana, South America

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### ABSTRACT

**Introduction.** We describe ethical/moral issues in patient selection in a new living donor kidney transplant program in Guyana, South America.

**Case Reports.** Over 3 years, we screened 450 patients with chronic kidney disease among which 70 were suitable for kidney transplantation. There were five patients whose evaluations raised possible ethical dilemmas: one had nonadherence to dialysis; two of Guyanese origin living abroad wished to have the transplant performed in Guyana; a minor wished to donate to her mother; and another subject was considering commercialization of the transplant process.

**Results.** Since inception of the renal replacement program in 2008, we have completed 13 living kidney transplantations, 17 peritoneal dialysis placements, and 20 vascular access procedures. In the five patients wherein faced ethical dilemmas, three were rejected for consideration despite having living donors: one was nonadherent, the second excluded due to an attempt to commercialize the process, and the third, a minor who wished to donate to the mother. The other two patients were considered Guyanese ex-patriots acceptable for the program.

**Discussion.** The consequence of kidney failure in Guyana prior to introduction of renal replacement therapy was a virtual death sentence. These cases illustrate ethical dilemmas serving to throw into stark relief the implications of decisions made in a developing country versus those in a developed country.

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**T**HIS MISSION STARTED when a Guyanese-American in Queens, New York, found a flyer asking for financial help for a 16-year-old young man in Guyana dying of kidney failure.<sup>1</sup> This, ultimately, led to a public-private partnership to provide medical and support services. United States doctors volunteered their services as part of an arrangement with the Health Ministry in Guyana to bring relief to the hundreds of Guyanese presently suffering from kidney failure. The cost of this initial venture was borne by US-based Guyanese-Americans. Later, the government agreed to supply generic immunosuppressive medications, use of operating rooms, hospital stay, and peritoneal dialysis (PD) fluid free of charge. However, long-term hemodialysis (HD) is not covered by the Government of Guyana.

Since the program's inception in 2008, we have performed 13 living donor kidney transplantations, 17 PD catheter placements and 20 vascular access procedures. To date, we have screened approximately 450 patients with various

stages of chronic kidney disease (CKD). This program has provided them with appropriate medical therapy including kidney biopsies, which have been read in the United States

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by renal pathologists. Critical tests, such as human leukocyte antigen tissue typing and crossmatching, are performed gratis by US-based laboratories. An educational program was launched to sensitize the population to the importance of organ donation and to the prevention of diabetes and hypertension by holding regular press conferences.<sup>2,3</sup> The medical-surgical-logistical-educational team goes to Guyana three to four times a year, each trip lasting from 6 to 9 days.<sup>4,5</sup> Video-conferences via Skype have been instituted to provide patient monitoring and consultation with local health care providers and selected patients.

In Guyana, the cost of HD is US \$200 for each session.<sup>6</sup> Comparative costs of HD for 1 year are US \$5000 in India, \$6240 in Indonesia, \$7500 in China, and \$7332 in Brazil. It seems that the cost of HD in Guyana is higher than in comparative developing countries, making it imperative to develop a kidney transplant program (Guyana Minister of Health, personal communication, January 5, 2008). The cost of kidney transplantation in the United States is about \$150,000<sup>7</sup> while in India it is approximately US \$60,000.<sup>8</sup> The real cost of a living donor kidney transplantation in Guyana cannot be accurately determined, since it is primarily borne by our sponsor. It includes transporting a team of six physicians and nurses to Guyana along with specialized disposable items and equipment. The government of Guyana pays a one-time amount of US \$5000 for each transplant procedure irrespective of the duration of the hospitalization and provides free lifelong immunosuppressive (generic) medications manufactured in and imported from India.

The number of patients requiring dialysis or kidney transplantation in the world is estimated to be about 1.4 million, is growing at a rate of 8% annually.<sup>9</sup> A number of factors may account particularly for the increase—diabetes, aging population, and hypertension. It may be difficult to estimate the burden of kidney failure in developing countries, as there is a lack of national registries. However, it is anticipated that the incidence of kidney failure is likely to increase due to the dramatic rise in the incidence of diabetic nephropathy. Developing countries also have a high incidence of infectious causes of kidney disease.<sup>10</sup>

The population of Guyana is estimated to be 751,223.<sup>11</sup> Extrapolating data from Singapore, a similar-sized population, which has a national registry for end-stage renal failure (ESRD); the incidence of new ESRD cases treated with dialysis was 96 per million in 1992 and 167 per million in 2000.<sup>12</sup> It would, therefore be reasonable to assume that approximately 200 new patients per year would need renal replacement therapy (RRT) in Guyana. The increased incidence of diabetes and hypertension throughout the developing world means that the number of patients requiring dialysis is likely to increase considerably.<sup>13</sup>

In India, less than 10% of all patients receive any kind of RRT; most are on HD with only a small proportion (<0.5%) on PD. About 60% are lost to follow-up within 3 months, primarily due to economic reasons. One could assume that “lost to follow-up” probably signifies death.

Furthermore, in India, although renal transplantation is a cheaper option due to reduced maintenance costs over time, only about 5% to 10% of patients with kidney failure undergo transplantation. From the various newspaper reports of people looking for help to travel abroad for kidney transplantation, it would seem that a similar situation exists in Guyana where probably only 10% of patients receive any type of dialysis therapy and only 5% to 10% of them, a kidney transplantation.<sup>14</sup>

With these realities as the backdrop, we herein have described ethical and moral issues that we faced in patient selection for kidney transplantation when resources are scarce in a developing country. We hope our experience will benefit others as they embark on RRT in the developing world.

## CASE REPORTS

### Case 1

A 24-year-old man who presented in June 2011 had developed kidney failure due to poorly controlled hypertension. He could not afford dialysis so he was being funded through our charity and the government. He was noted to have a murmur that turned out to be a vegetative growth on the mitral valve. He was told that his transplant would need to be postponed until this cleared; he was placed on PD. When we returned to Guyana 3 months later, it was evident that he had been nonadherent to both dialysis and antibiotic therapy. His pattern of nonadherence and frequent infections necessitated a review of his suitability. He was given a trial period of 3 months to prove his commitment and did not survive to his next scheduled review. Being good stewards of a limited resource and in protection of the donor (his mother) should the team have denied him transplantation?

### Case 2

With a successful program comes what can best be described as notoriety. As the word of this program spread, more ethical conundrums have come to the fore. The senior author received a letter from a physician in the nearby island nation of Antigua asking for consideration of a 17-year-old patient for transplantation. The Antiguan patient had run out of options in his HD treatment due to multiple vascular access problems. The patient's father, who was originally from Guyana, seemed to be a suitable kidney donor. The team had to consider whether care could be extended to this patient. Did this case fall outside our mandate from the host government under whose regulations we provide services? We were cognizant of the fact that we were there to benefit their citizens. While the referring physician informed us that, although this patient lived in Antigua, Antigua has an open-door immigration policy with Guyana, but no health care reciprocity arrangements or within the Caribbean basin. Second, did this case represent a form of medical tourism that should not be undertaken?

### Case 3

The next case was a 42-year-old Guyanese woman living illegally in the United States and undergoing HD. Her husband was also illegally in the United States, with three children under the age of 10 years. She originally came to the United States as a visitor to receive HD, as Guyana did not have any such facility. She had been

receiving Medicaid-sponsored HD for 10 years but now exhausted vascular and PD accesses. To continue to live, she needed a transplantation. She had a family member in Guyana who was willing to donate. If she left the United States, she might never be able to return. Her children are US citizens by virtue of being born in the States. Should she be accepted into the program to get her off the Medicaid roles? Should she utilize the scarce resources of Guyana for lifetime provision of medications to prevent rejection? If she is accepted and returns to her country of origin she may only see her husband and children when they can afford to visit her in Guyana. Should this motherly bond be broken for an improved chance of long-term survival of the mother? Is this a form of medical tourism in which we should not engage?

#### Case 4

At the preoperative evaluation 2 days before surgery (March 2012), the recipient, a 32-year-old man, informed us that the donor, who was a family friend was being paid a modest sum by the recipient's employer to compensate for loss of wages resulting from surgery and recuperation. The recipient is a valuable employee; the employer had offered to pay the potential donor without any involvement of the recipient. With respect to the recipient's context, "things that one needs are to be paid for." By our US standards, however, the exchange of money to compensate a donor is illegal. Yet in a country such as the United States, the friend would be eligible to receive sick time pay, use vacation time, or perhaps even receive short-term disability. Should the father, therefore, not get the transplantation, despite being at grave risk of dying? Moreover, the donor is a single father; his wife was reported to have died in childbirth. Should his child become parentless, by virtue of this standard? By proceeding with the transplant, the team was faced with the dilemma of possible participation in the commoditization of an organ. By canceling, we were allowing the recipient to face probable death, risking his child becoming parentless, and the employer losing the services of a valuable employee. Ultimately, the donor was turned down by the team and this patient did not receive a transplantation. Subsequently, his father donated a kidney and the patient is back to work.

#### Case 5

A 36-year-old single mother with two children aged 14 and 15 years was on HD but could not afford this therapy and was switched to PD. However, due to multiple episodes of peritonitis, dialysis was becoming less efficient. She had a job to clean houses and was barely able to manage but had succeeded in sending both kids to school who are doing well. The daughter who is 15 was willing to donate a kidney to enable her mother to survive and have a better quality of life. The age of consent in Guyana is 16 years. The age of consent was raised from 13 to 16 on October 31, 2005, by a unanimous resolution of the Guyanese parliament.<sup>15</sup> Although rare, children do serve as living donors, but these donations raise serious ethical issues. The American Academy of Pediatrics holds that minors can morally serve as living organ donors but only in exceptional circumstances when five specific criteria are fulfilled: donor and recipient are both highly likely to benefit; surgical risk for the donor is extremely low; all other deceased and living donor options have been exhausted; the minor freely assents to donate without coercion (established by an independent advocacy team); and emotional and psychological risks to the donor are minimized.<sup>16</sup> In our index case, the first four conditions were satisfied, but we were unable to obtain an independent evaluation of the

donor by an advocacy team given that there were no social workers or psychologists with transplant-related expertise in Guyana, we did not proceed with the donor workup. However, we were faced with the dilemma of letting a young mother succumb to her illness leaving two minors without family support. We continue to monitor this patient closely.

#### DISCUSSION

Bringing to fruition a medical program of this magnitude in the context of a developing country almost certainly throws into relief the stark differences between the developed and the developing world. Because of the vast inequity in resource availability, the consequences of decisions about resource allocation take on a gravity not faced in the developed world. The gravitas of the decisions seem to have the power to challenge the boundaries of ethical principles, begging deciders to formulate more nuanced or alternate paradigms to account for local conditions, which present a set of circumstances that invite breathing room for afflicted subjects and constrained by the need for more resources.

With respect to Guyana and the development of a RRT, we have described incremental progress in initiating and sustaining a comprehensive program. The program started with the first living donor kidney transplantation subsequently developing a full dialysis program, introducing PD, and performance of vascular access procedures. The authors favor PD in general, as it is a less expensive option in the context of received PD catheters in other developing countries.<sup>17-19</sup> Seventeen patients in Guyana were treated with PD with a mean age of 43.6 years; and a mean follow-up of 5.3 months. There were two deaths within 2 weeks of catheter placement due to multiorgan failure, while two patients were switched to HD due to inadequate clearance. Technical issues were noted in two patients and three subjects experienced peritonitis treated with intravenous antibiotics and one, an exit site abscess that was drained under local anesthesia. There were 0.36 episodes of peritonitis per patient year. Of the 17 patients, four patients received living donor kidney transplantation.<sup>10</sup>

Case 1 illustrates a common problem faced by transplant centers when placing dialysis patients on the waiting list for kidney transplantation.<sup>20</sup> Adherence must always be assessed to improve the likelihood of effectively utilization of these scarce resources. This also reflects the stewardship of the transplant program, one of the fundamental ethical underpinnings of the enterprise: a program does not want to give the "gift of life" only to have it squandered through nonadherence. A set of meticulous algorithms must be carefully followed to ensure graft durability. It has been clearly shown that patients who do not adhere to the pretransplant evaluation or this dialysis schedule are more likely to lose their graft or die after transplantation.<sup>21</sup> In fact, this young patient did not comply with the medications required to treat bacterial endocarditis, eventually succumbing to sepsis. Nonadherence has been shown to be more prevalent among patients between 20 and 30 years old, in lower socioeconomic groups, in women and in black

patients.<sup>22</sup> Case 1 fits a number of these features. Our program was willing to fund his treatment, but the patient chose not to adhere to scheduled use of antibiotics and continue with regular dialysis. A variety of multidisciplinary approaches have been used to understand and treat the underlying psychological processes leading to nonadherence: these include physicians, nurses, counselors, and social workers. However, these personnel were not available in the context of this program in Guyana. There was limited counseling for this individual; however, he failed to avail himself of this resource. Another approach that may work in the developed world is extensive formal psychotherapy,<sup>23,24</sup> which was nonexistent in Guyana at this time. These traditional approaches to the treatment of nonadherence are only partially successful. More research needs to be performed in the context of developing countries, including the use of complementary medicine approaches and behavior modification.<sup>25,26</sup> The concept of withholding transplant treatment in the context of a therapeutic plan of “bridge treatment” seemed justified for this patient. Unfortunately, he was not able to avail himself of this bridge treatment for whatever reasons. Nonetheless, adherence to good stewardship by the transplant team is justified in this case. This was not that dissimilar to the standard in the developed world, save for the lack of resources to help this patient overcome his inability to comply.

Case 2 on initial evaluation would be thought to reflect negative aspects of medical tourism, which the program does not support. In the Caribbean basin and other areas of the developing world, the existence of a program in one country creates the unintentional consequence of immediate inequity of that country over its neighbor. Those suffering in the neighboring country will try to gain access to the program. Again, the issue of resource allocation arises. So as not to overwhelm the program and render it nonfunctional, a clear policy of inclusion and exclusion to the waiting list for kidney transplantation should be formulated prior to initiating the program. This problem surfaces when programs become successful. However, in this case, a second set of criteria were at play. On closer inspection and in consultation with the government, another interpretation was considered relevant. In a Guyana program, one has to comply with the laws of that country. This patient from Antigua had a clear relationship to Guyana, as his father was originally from Guyana. Given Guyanese paternity, the program was allowed to consider him under the regulations set forth by the government of Guyana. Medical tourism was discounted in this case, as the patient was considered a Guyanese national and therefore could partake of the resources available to its citizens.

Case 3 also presents a case of a patient needing to migrate for treatment not available to her in her own country. Initially, she came to the United States for HD treatment not available to her in Guyanas. Now, she may travel back to her own country, putting her family cohesion in jeopardy to obtain treatments not available to her in the United States. Are resources in either country being mis-

used or misallocated? Is this a form of medical tourism? After consultation with the Guyanese government, it was made clear that the patient was entitled to receive care under the regulations set forth by the government of Guyana. In addition, the donor was Guyanese and resided in Guyana. Our team decided, after extensive counseling with the patient, that she understood the implications of leaving the United States and that she may only see her children when they can afford to visit her in Guyana. This patient was accepted for kidney transplantation. In these types of cases the team should be in close contact with the treating physicians to develop a coordinated plan: a meticulously detailed summary to the primary physician in the country of origin of the procedure, the evaluation, and the medications. Failure to provide this documentation and coordination can lead to unnecessary tests and lack of proper knowledge about the patient with a potential negative impact on the outcome.<sup>27,28</sup> This case was not deemed to be medical tourism, with the negative connotations associated therein. The patient was counseled such that she is making an informed decision, even though she may break up her family to obtain a transplantation and that the durability of the organ cannot be guaranteed.

Case 4 illustrates one of the most controversial issues faced in transplantation today: commoditization of the organ. Given that it is against international law, against the laws in the author’s country of origin, and considered unethical and unacceptable by the majority of the transplant community, the decision would seem to have been easy. The merits of the case were weighed, and a decision made to not proceed with this procedure. However, in the context of the developing world, the decision to not proceed was more difficult. One imagines the high likelihood that this unfortunate individual will die. The son of this single father will become parentless. The employer who was willing to provide donor compensation will lose a valued employee. In a commitment to preventing commoditization, have we diminished the overall good? What good have we done for our kidney failure patient who presented himself in good faith to us for help? In his worldview, people “pay for things.” So donor compensation made eminent sense and was, perhaps, the proper reflection of his appreciation.

Case 5 illustrates an unusual situation both in Guyana and in the west. Minors are more likely to be kidney transplant recipients. Although living children continue to be a rare source of solid organs in the United States, data from the United Network for Organ Sharing (UNOS) revealed that 60 children younger than 18 years occurred among 40,000 live kidney donors between 1987 and 2000.<sup>29</sup> Serving as a donor is clearly not in the minor’s benefit; however, there may be psychological benefits, in this case, maintaining an intact family unit. The risk of surgery, although small is still present. The minor may feel coerced and guilty if she refuses to donate. In our index case, the visiting team felt that the first four conditions were satisfied after extensive in-house discussion with the mother and

minor separately. However, we felt that the recommendation of the American Academy of Pediatrics that “the minor freely assents to donate without coercion (established by an independent advocacy team)” was not established. We therefore, did not proceed with the transplantation process with the caveat that we will revisit the issue at a later date.

Good stewardship by transplant teams anywhere needs to be exercised so that the patients can trust that we are making fair decisions with limited resources. This is a fundamental principle on which transplantation rests. In case 1, the team adhered to the principle of good stewardship while providing the patient with a bridge plan. The patient was never abandoned or left to fend for himself. Case 2 and 3 pose questions of “medical tourism,” although neither was ultimately considered to represent the negative aspects of this all too common practice. There is an increasing trend for patients from the Western countries to travel to various countries in the Eastern hemisphere for medical tourism.<sup>30</sup> Medical tourism often involves commercialization of body parts, in particular kidneys. This practice has existed for many years. We believe that it has increased, due to the larger waiting lists and longer waiting times. In the last decade, there have also come to be better hospital amenities in the countries of the Eastern hemispheres thus making medical tourism seem safer. Legislation and edicts from various transplant societies have failed to prevent this practice.<sup>31</sup> What would prevent other patients coming to Guyana as transplant tourists if they have a connection with the country? We have to be mindful of and make careful evaluation of each case, so as to avoid the exploitative features of this practice. Nascent programs as well as seasoned programs must develop careful vetting practices based on sound ethical and moral principles as well as judicial resource allocation.

In Case 4, we relied on the view that compensation to a donor is unethical. Opinion on even this concept is beginning to be reevaluated. The American Medical Association has recently come out in favor of a supervised trial of donor compensation. The recent court case of Flynn Holder allowed for donor compensation when the patient is donating “peripheral blood stem cell apheresis.”<sup>32</sup> Recently, an appeals court ruled payment to marrow donors acceptable.<sup>33</sup> Women who donate eggs are not only paid, but there are advertisements by MASS General Hospital and Columbia University Hospital to solicit egg donors. These women must undergo a potentially deleterious process to stimulate multiple ovulations to obtain a sufficient quantity of eggs.

Our team is well aware that ongoing negative medical, socioeconomic, and emotional impacts of CKD and ESRD upon patients and their families and the availability of financial incentives appear to be driving commercialization of organs for transplantation.<sup>34</sup> Our team was certainly sympathetic to the plight of the young father whose wife died in childbirth; the financial transaction was attributable to the patient’s employer. However, research suggests that medical, socioeconomic, and emotional outcomes for do-

nors who become vendors in the way it has been practiced around the world are poor.<sup>35,36</sup> The international consensus is currently against this practice as described in “The Declaration of Istanbul on Organ Trafficking and Transplant Tourism”<sup>37</sup> and The Fifty-seventh World Health Assembly, resolutions WHA40.13, WHA42.5, and WHA44.25 on organ procurement and transplantation.<sup>38</sup> Given the complexity of the circumstances, however, our decision was difficult for the team, as well.

Our team decision on case 5 reflects the current views of US pediatric transplant centers. Only 33% of responding centers would allow a monozygotic twin minor to donate a kidney to his or her twin, and even fewer (21%) would allow a nontwin minor to donate to a sibling. The great majority of responding centers (68%) require living donors to be at least 18 years old. These data indicated that most US transplant centers oppose using children as living kidney donors.<sup>39</sup> However, there are no studies of similar nature in developing countries with unique issues as identified in this report.

Ultimately, we strived to adhere to the highest standards in all aspects of care, so that none of our recipients or donors or physicians or the program itself can be challenged in its purpose. Our process and decision making has been one of transparency and informed consensus, guided by our ethics, fairness, and stewardship. We realize that despite the program now being more established, it will continue to be faced with difficult ethical/moral dilemmas and conundrums. These decisions will continue to be more difficult, in the context of administering a program in a developing country. Given the gravity of the consequences, these ethical and moral decisions must be carefully deliberated and given the fullest measure of consideration. It goes without saying that the highest standards of health care service should always be delivered no matter where one is in the world. However, until there is another paradigm that adjusts and accounts for these stark contrasts, we suggest that nascent programs adhere to the current standards of the developed world with respect to ethical and moral decision making.

An editorial in one of the newspapers in Guyana made the statement that it will be a great day when this program does not make “the news.” Success must be measured by seeing the return of the recipients and donors to living full and productive lives and not by the number of surgeries performed. Ethical situations will inevitably arise and must be resolved. There is no place for questionable ethical violations.

If an individual in the United States is turned down due to nonadherence, for example, she or he can seek another opinion at a different facility while continuing on lifesaving dialysis. Should the team make the same decision in a developing country, such as Guyana, the consequences of the team decision imply almost certain death for the patient. The gravity of the consequences, prompt careful deliberation, and the fullest measure of consideration to these ethical and moral decisions. Surely, these ethical and

moral realities make such decisions more difficult in this kind of environment; they challenge the clarity of our own definitions of “correctness” and “rightness.” Nonetheless, we have worked to establish transparency within the program, adhering to the ethical and moral standards of the United States, so that none of the recipients, donors, physicians, facilities, or the program itself can be challenged as to its’ purpose. It goes without saying that the highest standards of health care service should always be delivered.

We propose that, in the face of ethical and moral dilemmas, adherence to these ethical and moral standards is essential to the long-term viability of these types of programs. Until there is another paradigm that accounts for these stark contrasts, we suggest that nascent programs adhere to the current standards of the developed world with respect to ethical and moral decision making.

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