

Some Interesting Stories from the Iranian Model of Kidney Transplantation

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In this short communication we briefly discuss some aspects of organ shortage for transplantation with a brief characterization of the Iranian model of kidney transplantation, and we present 3 interesting stories related to this model.

Keywords: Kidney transplantation; ESRD; incentive payment; organ shortage

INTRODUCTION

Organ shortage for transplantation is an important dilemma for end-stage renal disease (ESRD) patients worldwide.⁽¹⁾ Several countries have developed different models of approach with respect to this issue. Iran has one of the most successful transplantation programs in the Middle East. Organ procurement in Iran includes allografts received from deceased donors, living genetically related, and living genetically unrelated donors. The latter group are either emotionally related (spouses, life partners, friends), or emotionally not related (incentivized donors or vendors).^(2,3) In 1988, a government regulated and funded Living Unrelated Kidney Transplantation (LUKT) program was established in Iran that is generally referred to as the “Iranian model of kidney transplantation” (IMKT).⁽³⁻⁵⁾ During the recent decades, organ transplantation and especially kidney transplantation has been developed and expanded in almost all regions of the country. At present kidney transplantation is performed in more than 30 centers in Iran with approximately 2500 kidney transplants being performed per year.^(4,6) However, the IMKT has not been fully recognized and credited as a successful model in the world and has been challenged by other organ transplant schools. Ethical questions on the issue of organ selling are among the most challenging aspects of IMKT program.⁽⁷⁾

While in the majority of cases of LUKT in Iran the motivation to donate (actually, to sell) is a financial need, however in some cases it could be a mixture of altruism and financial recovery, and there are still some kidney donors who wish to donate their kidneys as an altruistic humanitarian act. In this communication we would like to present the 3 interesting stories of living unrelated kidney donation from the IMKT program that we have personally encountered.

Case 1: Kidney donation leading to love and union in marriage

A 25-year old Iranian woman (lady T) with ESRD of unknown cause was undergoing regular chronic hemodialysis (3 sessions per week) for nearly one year. She was in a very poor economic condition and could not afford obtaining a kidney transplant. During her regular visits for dialysis she met a 27-year old man (Mr. A) who was visiting his sick mother in the same hospital. The young man inquired about Lady T’s situation from hemodialysis personnel and found out that she does not have any potential living related donor, and that she did not have financial means to afford paying for a kidney in the IMKT. Mr. A asked from dialysis personnel how he could become a kidney donor to her. He was referred to the local Patient’s Kidney Foundation office (referred to as “anjoman”) as a volunteer living unrelated kidney donor (LUKD) to Lady T. After thorough evaluation of his health history, physical examination and the required para-clinical studies he was found to be a suitable kidney donor for Lady T. The kidney donation and transplantation were performed successfully after few months of their accidental encounter. Two months after transplantation Mr. A visited the holy city of Mashhad (Imam Reza shrine), where he expressed his wish to marry lady T asking for guidance and support. He subsequently proposed to her, which was well received by Lady T and her family, and a wedding ceremony was established at that time. They got married and have been happily living together. The allograft functioned for almost 14 years. She went back on hemodialysis after 14 years. Her husband (Mr. A) remains in good health, and continues supporting her. Lady T is currently being listed for a second kidney transplantation.

Case 2: Kidney donation and continued financial support of allograft recipient by an altruistic unrelated donor

A 23-year old patient with ESRD caused by neurogenic bladder with past history of a failed nonfunctioning allograft was listed for a second kidney transplantation in the local anjoman. However, he was from a family in poor economic condition that could not financially afford compensating (rewarding the gift of kidney) an unrelated live donor. At about the same time, a 30-year old gentleman decided to donate his kidney to a dialysis patient who is in

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poor economic condition. He had good education, had a stable job, and was in no economic distress. He visited the same local anjoman to find a suitable ESRD recipient. These two people were introduced together, and after checking the blood group compatibility, they were sent to the designated transplant physician for further evaluation. After full evaluation, including the required laboratory and imaging tests it was noticed that the donor had paid for all of the expense, i.e., costs related to the physician visits, laboratory and imaging studies. Subsequently, kidney transplantation was performed successfully without any complications, and with good allograft function. To date, sixteen years later, the recipient is doing very well with good allograft function. The truly altruistic kidney donor is also doing very well with good kidney function. The donor has also been supporting the allograft recipient during these years.

Case 3: Buying kidneys for strangers across religious boundaries, initially motivated by religious belief, self-interest, and nationalism.

One of the present authors (BB) together with Ms. Sigrid Fry-Revere PhD, a medical ethicist and lawyer, in their 6-weeks fact-finding travel to Iran (November to December 2008), visiting around 10 transplant centers in 6 Iranian provinces, and recording more than 100 live interviews with LUKDs, recipients, health care and anjoman workers that lead to publication of a book and 4 article,⁽⁸⁻¹²⁾ encountered this very interesting case story. In a morning that we were recording our live interviews with some living unrelated potential donors and recipients in the anjoman in Tehran a well dressed and well groomed lady (Lady F) approached us asking if we were interested to hear her story. She said that she had come from Los Angeles, USA, to buy 2 kidneys for 2 young boys. This heightened our interest and curiosity to hear the whole story. She belonged to the Iran's Jewish religious minority. She had immigrated to the USA some 30 years earlier (around 10 years before the Iran's Islamic Revolution in 1979). She lived a good life with her grown up children and her grand children in LA, USA. One day they realized that her 13-year-old grand daughter was suffering from vesicoureteral reflux disease, and that it could lead to ESRD. She said, she made a "Nazr" (a promise to God) that if her grand daughter would be cured she would pay for a poor teen-age girl to receive a transplantation. Apparently after a new technique of gel injection (Deflux Injection) was tried the reflux disease was totally resolved and her grand daughter was considered cured. At this time, in order to fulfill her promise, she planned to come to Tehran, Iran, where her sister lived, to buy a kidney for a poor teen-age girl. Her close family members and friends in the USA had persuaded her to do this humanitarian act in Israel. Her response was that as an Iranian she wanted to serve a fellow Iranian. She said that after 3 days of frequent visits to the anjoman in Tehran she gave up finding a very poor girl around 13 years old girl with ESRD in need of a kidney. On the third day when she had disappointedly left the Tehran anjoman she heard being called from distance by the secretary of anjoman. She was informed that they had just located a very poor family living in Karaj (~1 hour drive from Tehran) who had a teen-age daughter with ESRD. The family was poor and could not afford paying for the rewarded gift of a living unrelated kidney, and indeed so poor that they did not have a phone at home, and anjoman person-

nel could not contact them. This was very happy news for Lady F who travelled next day with her sister to the address in Karaj. They found a simple house in a poor neighborhood. They encountered a middle-age lady who was curiously surprised of their unexpected visit. They noticed a pale thin chronically ill looking teen-age girl at the end of the hallway. When they explained the reason for their visit, i.e., paying for a kidney, the lady dropped herself at their feet thanking God for such a miracle coming true. Apparently the whole night before her sick daughter had been crying and complaining to God why she was created at all, and why she had to lose her kidneys, and why she was borne in a poor family that couldn't pay for a kidney for her, and so on, and now in the morning 2 strangers from a different religion, one of them travelling from a country thousands of miles away, had driven all the way from Tehran to their poor house in a different city to pay for her daughter's kidney. Incidentally, they noticed that the day was a religious mourning day ("Ashura") for the Shia sect of Islam, where masses of people had filled the streets mourning and lamenting for the martyrdom of their beloved third Imam some 1400 years earlier. With Lady F's gift of \$2,500 a 25-year-old man, who was in desperate need for cash for his imminent wedding, donated his kidney to the young girl with ESRD (Girl L). Five years later, Lady F told us that now Girl L remains off dialysis, living in good health, and is a sophomore student of economy in Karaj University. Lady F also showed us the pictures of the wedding ceremony of the young donor and his beautiful bride, and told us that in her visits to Iran she meets both families who feel much in debt to her past generosity. The reason for Lady F's present visit to the anjoman in Tehran was to buy 2 kidneys for two teen-age boys after she had made a "Nazr" (promise to God) for her very sick grandson to get well. But, then she added that this time I asked myself why am I always bargaining with God for some of my needs, this time I'll do it for the sake of goodness and kindness, whether or not my grand son will improve or not. That was her beautiful uplifting story. I contemplated then and now too, how acts of kindness with sincerity would transcend us to a higher level of spirituality and a deeper level of conscientiousness.

DISCUSSION

Due to the continued worsening in organ shortage at a global stage, the number of kidney transplantations from living unrelated donors (emotionally related or truly altruistic undirected donation) has increased in both economically developed and developing countries in the recent years.⁽¹³⁾ According to the Organ Procurement and Transplantation Network (OPTN) as of June 26, 2019 a total of 124,472 people were registered for a solid organ transplant in the USA, 103,011 of whom were waiting for a kidney, while in the year 2018 there were only a total of 21,167 kidney transplantations done in the USA (14,725 deceased donor and 6,442 living donations) and only around 21% of those in the wait list could get a kidney.⁽¹⁴⁾ At the same time in 2018 a total of 8,591 patients (~8.5% of those on the waiting list) were removed from wait list (4,111 had died while waiting, and 4,480 had become too sick to be transplanted).⁽¹⁴⁾ In the year 2017 of the 5,813 live kidney donations in the USA, 44% were genetically related, and 56% were altruistic genetically unrelated (39%

were spousal/life partner or friend, 12.5% were through paired donation, 4.5% were undirected anonymous donation).^(15,16)

In order to accommodate the large number of ESRD patients who had no living related donors, and because of the high cost of dialysis, economic sanctions against Iran, and lack of legislation for acceptance of brain death and deceased donor transplantation (legislation was passed later on April 2000) a government sponsored/regulated LUKT program was established in Iran in 1988.⁽³⁻⁵⁾ In this model that is known as IMKT, both the Iranian government and the transplant recipients compensate (incentivize) the LUKDs. Moreover, at the same time the number-of-transplant teams were increased from 2 to 25 teams in Iran. As the result of these 2 interventions by the year 1998 it was reported that the waiting list for renal transplantation was totally eliminated in Iran.⁽⁵⁾ In this model all eligible ESRD patients (the recipients) and the potential LUKDs are registered at their local Patient's Kidney Foundation office (referred to as "anjoman") that is in charge of matching donors with eligible recipients. Moreover, all kidney transplantations were to be performed in the university hospitals by faculty who had no personal financial gain of the procedure, and the Iranian government covered all transplant related expenses that occurred in hospital. Furthermore, it prevented foreign nationals buying kidneys from Iranian donors, thus preventing transplant tourism and rise in the price of a kidney for the locals. While at its conception it allowed foreigners to obtain kidneys from donors of the same nationality, however, because a number of abuses were discovered where some patients from other nationalities had faked Iranian identification cards and there was no means to regulate a fair and legally enforceable financial deal between the foreign donors and their recipients, transplantation of foreigners was totally abandoned in August 2014.⁽¹⁷⁾ The IMKT is considered a practical and reasonably fair solution for solving a local problem. A study by Ghods, et al., comparing socioeconomic characteristics and education level of LUKDs and their recipients found that more than half of both groups were males (90.2% of LUKDs vs. 63% of recipients), had high school or college education (69.6% LUKDs vs. 62% of recipients), and 84% of the LUKDs vs. 50.4% of the recipients were in the poor socioeconomic category.⁽¹⁸⁾ The IMKT intends to eradicate an underground illegal black market where both donors and recipients would be at loss, prevent transplant tourism, and provide a transparent system where the LUKDs and their recipients enter a reciprocal gifting relationship that is mediated by their local anjoman and is legally enforceable. In some instances a long-term relationship (emotional, economic or both) were observed between the LUKDs and their recipients. The IMKT has improved lives of many thousands of ESRD patients by providing them with life saving kidneys and reportedly eliminating the kidney transplant wait list in Iran, however, it has been surrounded with many ethical controversies and debates.⁽⁷⁾ While the motivation for a majority of LUKDs is to overcome some financial hardships, however, in some donors the financial reward could supplement their intention for a humanitarian act, and still in some the humanitarian act of kindness maybe the mere motivation to donate. It seems that providing adequate financial incentive and other social benefits to each LUKD by the government

and eradicating the direct dealing between donors and recipients, making the IMKT a non-directed government rewarded kidney donation program, whereby the donors and the recipients would not know each other, at least before transplantation, would overcome some of the short comings in this system.

In this short communication we do not intend to discuss pros and cons of the model, but would like to share with the transplant community 3 interesting stories that we had personally observed while dealing with these patients.

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