

COMMENTARY

# Safe and ethical living kidney donation in Qatar: A national health system's approach

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<http://dx.doi.org/10.5339/qmj.2017.3>

Submitted: 20 November 2016

Accepted: 6 June 2017

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Cite this article as: Asim M, Al-Maslamani Y, Al-Malki H. Safe and ethical living kidney donation in Qatar: A national health system's approach, Qatar Medical Journal 2017;3 <http://dx.doi.org/10.5339/qmj.2017.3>

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**QSCIENCE**  
دار جامعة حمد بن خليفة للنشر  
HAMAD BIN KHALIFA UNIVERSITY PRESS

## ABSTRACT

The increasing incidence of end-stage kidney disease in Qatar has led to growing demand for donor kidneys. The deceased donor kidney program has yet to achieve its full potential; hence, living kidney donation has been widely adopted as an appropriate alternative. The reliance on living kidney donors however, raises a number of social, ethical, and legal concerns surrounding informed consent, voluntarism, psychosocial evaluation, perioperative care, and long-term follow-up of living kidney donors. Many of these concerns become heightened in a multicultural, multilingual society within a Gulf country such as Qatar. This article provides an insight into the challenges that living kidney donation poses in a multiethnic society with significant socioeconomic divides. It also discusses the remedial measures that the Qatari government, healthcare authorities, and transplant community have adopted to address these issues.

Keywords: ethics, kidney donation, kidney transplantation, living donor, organ donation, Qatar

## INTRODUCTION

Enriched with multiculturalism, the population of Qatar is approximately 2.6 million,<sup>1</sup> of which noncitizens constitute over 80%. Many of them are manual laborers or domestic workers from central and south-east Asia who have migrated due to poverty in their own countries.

The incidence of dialysis therapy for end-stage renal disease (ESRD) in Qatar has increased from 82 per million population (pmp) in 2013 to 104 pmp in 2016. Although these incidence rates appear much lower than those reported in the United States,<sup>2</sup> the unique patterns of the worker immigrant population in

Qatar skew the population distribution – the population pyramid of 2014 illustrated that 83.6% of the population were from the ages of 15 – 64 years, whereas only 1.1% was above 65 years of age.<sup>3</sup>

The growing incidence of ESRD in Qatar has increased the demand for donor kidneys. Although many of the barriers to deceased donor transplantation related to legislation and infrastructure have been overcome, unfavorable public attitudes toward deceased organ donation still prevail, leading to desperately low consent rates for organ donation. In these circumstances, the living kidney donation program in Qatar promises hope to a growing number of patients with ESRD. Consequently, we have witnessed a steady increase in the number of prospective living kidney donors (LKDs) registering at our center in recent years (Figure 1).

Living kidney donation offers several advantages to transplant candidates – better patient and graft outcomes, avoidance of waiting time for a deceased donor kidney, and the unique opportunity for preemptive kidney transplantation. However, there are several concerns related to living kidney donation that have become more relevant in multicultural societies. First, equity of healthcare; morality calls for equal access and equal quality of care to all LKDs, regardless of their ethnic/socioeconomic background. Second, language and cultural barriers; these are known to adversely affect communication in healthcare encounters.<sup>4–6</sup> Since a LKD must undergo a medically unnecessary procedure for the benefit of others, ethics demands all LKDs receive sufficient unbiased information about living kidney donation, preferably in their own language, to make an informed decision. Third, social challenges; as most expatriates

are the chief breadwinners of their families, they worry about their long-term health and financial ramifications of kidney donation. Finally, transplant commercialism and organ trafficking; this can flourish in societies with significant socioeconomic divides.

In light of these concerns, governmental and nongovernmental bodies in Qatar have allocated resources to develop a transplant infrastructure and an operational framework for safe living kidney transplantation. This article discusses the aforementioned challenges of living kidney donation and describes the strategies that have been implemented in Qatar to protect the interests of LKDs (Table 1). In this article, the term 'LKD(s)' is used for both *prospective* living kidney donor(s) and *actual* living kidney donor(s).

### PROMOTING EQUITY, TRANSPARENCY, AND ETHICAL CONSISTENCY

Qatar has successfully integrated the migrated societies into its healthcare system. Public healthcare is managed by Hamad Medical Corporation's (HMC) network of hospitals. Kidney transplantation services are provided at Hamad General Hospital – a 600-bed tertiary care facility of HMC. Health services are largely subsidized for expatriates such that they pay only a nominal fee for medical consultations, admissions, or laboratory tests. For LKDs, even these charges are waived. Hence, equal access to transplant services (consultation visits, transplant work-up, surgery, and subsequent life-long follow-up) is offered to all residents, regardless of their social background. Free expert medical care and immunosuppression coverage is extended to all transplant

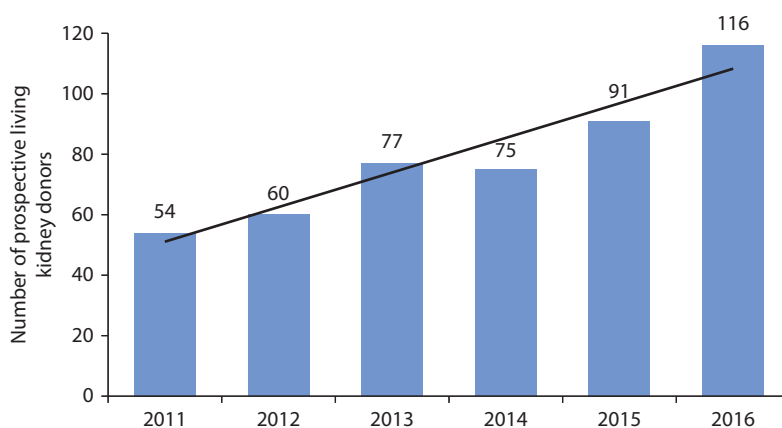


Figure 1. Number of prospective living kidney donors registered for donation work-up at our center from 2011 to 2016.

**Table 1. Key strategies implemented to protect the interests of living kidney donors (LKDs).**

Development of policies and clinical guidelines to promote equity, transparency, and ethical consistency
Recruitment of ethnicity-matched healthcare professionals to close cultural and linguistic gaps
Education of LKDs to facilitate informed consent for living kidney donation
Creation of an organ donation fund to avoid financial disincentives for living kidney donation
Establishment of legal and policy frameworks to combat organ trading while encouraging solidary/altruistic donation
Evaluation of LKDs and transplant candidates by separate healthcare teams to avoid any conflict of interest
Provision of care by qualified healthcare professionals to ensure patient safety
Establishment of clinics dedicated to life-long follow-up of all LKDs in Qatar
Implementation of quality improvement programs to enhance patient care and clinical outcomes of LKDs

recipients as long as they are resident in Qatar – measures shown to improve graft survival among lower-income patients.<sup>7</sup>

The transplant program has developed clinical guidelines that address all phases of the living kidney donation process. The program also documents LKD selection criteria that conform to the laws of the Qatari government and the principles of medical ethics. Compliance with these consensus guidelines and policies ensures that ethical behavior is maintained and there are no disparities in the evaluation process, evaluation time scales, selection criteria, or perioperative care of LKDs in a culturally diverse population.

### MANAGING CULTURAL AND LINGUISTIC DIVERSITY

Our program recognizes the importance of language and culture in healthcare services. Many LKDs are not proficient in Arabic or English – the two official languages of the hospital. This can be a barrier to equity in healthcare. Discussing sensitive issues in organ donation (e.g., obtaining informed consent) with LKDs who do not share a common language/culture with the healthcare professionals can be challenging. Cultural values, beliefs (including myths and superstitions regarding organ donation), and family influences may also have a significant impact on the decision to donate.<sup>8</sup> HMC's patient and family's bill of rights outlines the institution's responsibility to

ensure the LKD's right to information in a language he/she understands.<sup>9</sup> Although the hospital employee language bank offers linguistic services, relationship-building can be hampered with interpreter-mediated communication. To facilitate effective bidirectional communication, our program has employed multi-lingual healthcare professionals from immigrant backgrounds who speak Hindi, Urdu, Malayalam, or Tagalog in addition to English or Arabic. They are able to fully engage, comprehend, and discuss in depth organ-donation-related issues in the LKD's native language without third-party involvement. This helps foster enhanced relationships with the LKDs.

### ASSISTING LKDS IN MAKING INFORMED DECISIONS

We believe that educating the LKD is the most vital component of the donor work-up. A multidisciplinary team (MDT) strives to provide sufficient information to LKDs and their families to enable them to make an informed decision about living kidney donation. Education starts at the very first (pre-registration) visit to the living kidney donation coordinator. Verbal information is reinforced by educational materials written in simple English and Arabic for optimal comprehension.

At the time of registration for kidney donation, the LKD signs a form declaring that he/she has read the educational material and is willing to donate, free from coercive inducements and consents to proceed with

the evaluation process for living kidney donation. The LKD must be 18 years of age or older in order to make a competent informed decision. Two witnesses co-sign the consent form, confirming the identity and consent of the LKD. Benefits and risks associated with living kidney donation are discussed in detail during the comprehensive psychiatric and medical evaluations that the LKD undergoes after signing the declaration form. Thus, informed consent for kidney donation turns into a dynamic educational process that takes place during several interactions between health professionals and the LKD.

To maintain confidentiality and assess willingness to donate, the LKD is seen in person without the presence of any family member/transplant candidate, in at least one consultation. The following two aspects of kidney donation are specifically addressed:

#### **a) Misconceptions about kidney transplantation:**

Many LKDs hold the misconception that living kidney transplantation is the only treatment option for ESRD, thus exaggerating the urgency for living kidney donation. They are made aware of alternative treatment modalities for ESRD, such as dialysis or (waitinglist for) deceased donor kidney transplantation. They are also informed that a kidney transplant is not a cure for ESRD, as the transplant does not last for an indefinite period of time; many patients develop recurrence of their native kidney disease and graft failure requiring more than one kidney transplant in their lifetime.

#### **b) Potential psychological, medical and obstetric risks related to living kidney donation:**

Psychological risks are determined primarily by a psychiatrist. LKDs are informed about the risk of postdonation depression (especially if outcomes are unfavorable), anxiety, or relationship problems. Potential perioperative complications (ranging from bacterial infections to death) and long-term risks (including hypertension, proteinuria, and reduced kidney function) are discussed by a nephrologist. Evidence on long-term kidney and maternal outcomes after kidney donation has evolved with time; our goal is to ensure that all LKDs receive up-to-date information in these areas so that they are able to make an informed decision. LKDs are educated about permanent loss of 25 – 35% of kidney function after

donation, which increases their long-term risk for ESRD, cardiovascular disease, and mortality as compared to a selected population of nondonors who would have met the criteria for donation.<sup>10,11</sup>

Similarly, female LKDs of child-bearing age are informed about an increased risk of gestational hypertension and preeclampsia.<sup>12</sup>

Donors are informed that they are under no ethical obligation to donate and that they can freely withdraw consent at any stage before surgery. We use two LKD 'cooling off' periods, one after the signing of the declaration form and another after the psychosocial and noninvasive medical evaluations; this ensures that adequate time is given to the LKDs to reflect on their decision to donate. In our experience, it is not rare for LKDs to withdraw from the evaluation process after initial consent; we consider such cases a reflection of an effective 'informed' decision-making process. Sometimes LKDs do not keep clinic or laboratory appointments, raising suspicions of hesitancy to donate. In these situations, the appointments are rescheduled; however, the LKDs are informed that two consecutive uninformed absences will be taken as an indication that they are not prepared to continue with donation work-up. Further appointments are not arranged unless the LKDs themselves make contact with the coordinator for resumption of the evaluation process.

### **REMOVING FINANCIAL DISINCENTIVES TO LIVING KIDNEY DONATION**

Socioeconomic and future health concerns haunt many LKDs, especially if they are the sole breadwinners for their families. Studies indicate that LKDs incur many direct and indirect costs attributable to kidney donation and recovery from surgery.<sup>13</sup> They also face difficulties obtaining health or disability insurance after donation.<sup>14</sup>

Providing financial support for the LKDs is a crucial part of our program. We believe that they should be granted every opportunity to give to society without bearing any financial detriment. Hence, LKDs are exempt from expenses incurred as part of donor evaluation, hospitalization, and surgical or medical follow-up. The social worker makes an assessment of the financial risks posed by donation and arranges sources of monetary assistance. One of these sources is the Organ Donation Fund established in 2001, which is financed by charity organizations and

reimburses any lost wages associated with LKDs' time off work during medical evaluation and perioperative phases of care.

All LKDs consciously accept the perioperative risk of medical complications – albeit it being small, for the benefit of others. A comprehensive health insurance is provided in order to offset the morbidity risk. Eliminating the financial risks of kidney donors and their families is not only ethically just, but might also encourage more LKDs to pursue their altruistic ambitions.

### ENSURING THAT LKDS ARE DRIVEN BY THE RIGHT MOTIVES

Living kidney donation is only morally acceptable if it is made for solidary or altruistic reasons.<sup>15</sup> Human solidarity is the main driving force of most intrafamilial kidney donations, where the donor and recipient have a genetic or spousal relationship – LKDs derive psychological self-benefit from their loved one's improved health. However, even close family bonds do not necessarily exclude coercion.<sup>16</sup> In Middle Eastern and South Asian communities, family is central; one's individual situation is usually of secondary importance to that of the family. When a number of family members are evaluated, those who are found to be medically fit may feel obligated to donate. In such situations, a prospective donor's autonomy is put in jeopardy. These communities also tend to have strongly hierarchical cultures,<sup>17</sup> where men and elderly occupy a more authoritative status. Although women are gradually gaining more recognition, the male head of the family often takes the decision regarding important healthcare-related aspects. Therefore, it is advantageous to have language and ethnic matching of LKDs and healthcare professionals, as this allows for effective and meaningful discussions regarding complex donation issues. Our multiethnic team has been able to uncover cases of LKDs experiencing overwhelming emotional pressure from other family members to donate. If coercion is detected, the transplant candidate is informed that the evaluation has revealed conditions, based on which it is inadvisable to proceed further. If required, a medical alibi is given to LKDs who come forward to be evaluated after yielding to family pressure.<sup>18,19</sup>

Acceptance of non-directed unrelated LKDs (where the LKD has neither a genetic nor a preexisting emotional relationship with the transplant candidate) has increased in recent years.<sup>20</sup> Although organ

donation for the sake of charity and social solidarity is morally justifiable, 'altruistic' nondirected donation raises significant concerns with regards to an LKD's psychological status, motivation, and knowledge of the donation process or recipient outcomes.<sup>21–24</sup>

Some of these LKDs come forward in response to emotional organ donation appeals in the media. They may be unaware that patients with ESRD can live for many years on dialysis; some even fare better on dialysis than with a kidney transplant. Therefore, nondirected unrelated LKD's psychological status, risk factors for a poor psychosocial outcome, the concept of altruism, and comprehension of the potential complications of kidney donation are analyzed in depth by a qualified psychiatrist and an independent donor advocate. They are also informed, before their medical evaluation, that the institution will determine the transplant candidate.

### COMBATING COMMERCIAL EXPLOITATION OF THE VULNERABLE

Natural gas and oil has given Qatar a per capita GDP that ranks among the highest in the world.<sup>25</sup>

However, there are significant socioeconomic divides within its population. Most immigrants are sponsored by their employers and recruited on a fixed-term agreement such that they cannot change jobs before the contract expires. Hence, these workers represent a vulnerable group with regard to organ donation and become susceptible to commercial exploitation.

To combat organ trading, the Qatari government has enforced a law, which prohibits commercial dealings in human material and describes punishments of criminal offenders, including heavy monetary penalties, imprisonment for up to 10 years, and for healthcare personnel – temporary retraction of their right to practice. In addition, the court may also order temporary closure of the facility in which illegal transplantation was carried out.<sup>26</sup>

All LKDs are required to sign a declaration form to affirm their intention to donate as a personal choice without any financial considerations or material gain. They are then evaluated by the Ethical Committee, which comprises of an independent donor advocate, clinical psychiatrist, social worker, and a community representative. The committee evaluates the ethical, psychological, and social aspects of living kidney donation and plays a major role in combating commercial exploitation of the vulnerable. LKDs are interviewed, and evidentiary documents provided by

the LKD and transplant candidate are reviewed. If the nature of the relationship between the LKD and transplant candidate suggests a significant socioeconomic disparity or imbalance of power in such a way that the LKD is from a poorer socioeconomic/disadvantaged class, then this raises a strong suspicion of organ trading and transplantation is denied.

Spousal donations are accepted only after adequate proof of a genuine relationship is provided. Non-spousal, unrelated, directed living kidney donation (where the LKD has no biological or familial relationship with the transplant candidate) mostly raises the suspicion of commercialism. In developing countries, there is evidence of unrelated donors masquerading as friends approaching the transplant program. We do not allow nonspousal, unrelated, directed living kidney donation unless adequate proof of their vital socioemotional connection of more than three years is provided and the committee finds no evidence of commercialism or coercion. To discourage the import of LKDs from low-income countries, the policy requires LKDs to be Qatari citizens or legally resident in Qatar for more than three years. Even if the three-year-residency criterion is met, the Ethical Committee examines the nature of any socioemotional connection between the LKD and transplant candidate during this time as well as their social statuses in order to determine eligibility.

### AVOIDING CONFLICT OF INTEREST

Transplant teams may run the risk of conflict of interest as they strive to promote organ transplantation and shorten the waiting list. At HMC, separate clinical teams of physicians, coordinators, nurses, and social workers are dedicated for the work-up of transplant candidates and LKDs. The medical records of LKDs and transplant candidates are also stored separately. Although this arrangement requires sufficient available staff educated in living kidney transplantation, it maintains confidentiality and allows optimal advocacy for the LKD. The two medical teams, however, do interact and share relevant information during the MDT meetings, thus coordinating the transplant process without jeopardizing the independence of either the LKD or the transplant candidate. Incorporation of the living donor advocate further augments the independence of LKD evaluation. The living donor advocate promotes the best interest of the LKD and is empowered with full veto-authority if they believe that the donation is ill-advised.

### CERTIFYING MEDICAL HEALTH

A comprehensive medical evaluation is conducted once psychosocial assessment ensures there are no issues that might impede donation. Medical assessment is conducted by a nephro-urology team experienced in living kidney donation that have up-to-date knowledge of HMC's policies and protocols. This team plays a key role in continuing care during the preoperative, intraoperative, and postoperative phases should the donation proceed.

The assessments are carried out according to an agreed protocol, although the sequence (and pace) of evaluations may be influenced by factors relating to individual LKDs as well as the number of LKDs who come forward for a given transplant candidate. The goal of these assessments is to ensure that the LKD is immunologically compatible with the transplant candidate, has excellent general and kidney health, and does not have any conditions that may adversely affect his/her long-term health. Another aim is to confirm that the LKD has no malignant or infectious disease that may be transmitted to the recipient.

As organ donation is considered to be of top priority in our institution, LKDs are fast-tracked for imaging investigations, which generally have lengthy waiting periods, such as abdominal ultrasound and CT-angiogram. Similarly, LKDs are given consultation priority if referral is made to other specialties.

We have defined a minimal acceptance and exclusion criteria for living kidney donation. All LKDs are discussed at a MDT meeting that convenes fortnightly. This team comprises of nephrologists, transplant surgeons, immunologists, and transplant coordinators. Complex medical donor issues are discussed and a final decision is made about the donor's suitability. In cases where there is a lack of consensus about the suitability of an LKD, additional advice is sought from local/international experts in the field. Appropriate counseling and follow-up is organized for those LKDs who are deemed unsuitable for donation.

### CREATING A HEALTH INFRASTRUCTURE AND WORKFORCE FOR SAFE LIVING KIDNEY TRANSPLANTATION

Living kidney donation is priceless; our program recognizes its moral responsibility of providing the best possible care to both the LKD and the transplant recipient in a setting conducive to a safe and

successful transplantation. The program is equipped with qualified and credentialed staff, surgical theatres, ICU facilities, pharmaceuticals, and ancillary services required for transplantation. Serologic, molecular, and flow cytometric assays for human leukocyte antigen typing, cross-matching, and antibody screening for transplantation are performed in an internationally accredited immunology laboratory. A dedicated transplant infectious diseases and microbiology team provides collaborative support to prevent donor-derived infections in the transplant recipient.

We place high value on patient safety and the integrity of procured organs during the provision of care. Joint Commission International accreditation of our institution and its living kidney donation program certifies that the program meets international patient safety goals,<sup>27</sup> protects the basic rights of LKDs,<sup>27</sup> and is compliant with WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation.<sup>28</sup>

### GUARANTEEING POSTDONATION FOLLOW-UP; BUILDING LONG-TERM RELATIONSHIPS WITH LKDS

We honor our ethical obligation of maintaining a long-term postdonation follow-up with all LKDs in Qatar. We have established dedicated post-kidney donation clinics to monitor LKDs' kidney function as well as diagnose and treat relevant comorbidities. One of the strengths of our program is that we maintain continuity of care such that the same coordinator and members of the medical team who were involved in the donors' initial education and evaluation continue to follow them after donation.

At the time of discharge from hospital, the transplant coordinator discusses the follow-up schedule with the patients. All kidney donors are seen in the clinic twice during the first month after discharge from hospital to make sure that they make a good postoperative recovery. Subsequently, they are reviewed at least every six months during the first year and then yearly to look for the development of risk factors for chronic kidney disease or ischemic heart disease. Consultations are provided with other specialty services depending on the needs of the kidney donor. Considering the increased risk of gestational hypertension and preeclampsia among LKDs,<sup>12</sup> a closer nephrology and maternofetal follow-up is provided during pregnancy. To minimize any financial burden, all the follow-up visits and laboratory testing are offered free of charge.

### IMPLEMENTING QUALITY IMPROVEMENT PROGRAMS IN LIVING KIDNEY DONATION

We have recently implemented two quality improvement programs to improve the care and clinical outcomes of LKDs. One of these focuses on increasing the LKDs' involvement in the consent process by improving their understanding of the information presented. To confirm comprehension, the LKDs are asked to 'teach-back' the associated benefits and risks of living kidney donation. The independent donor advocate also makes an independent assessment of the LKD's understanding of the process of donation and the elements of informed consent.

Another quality improvement program has been established to improve postdonation follow-up of all LKDs in Qatar. Reminder telephone calls and SMS text messages are sent out to alert the kidney donors before their scheduled outpatient visit. Regular postdonation follow-up not only offers long-term healthcare to kidney donors, but also provides an opportunity to collect data on long-term health outcomes of LKDs.

### CONCLUSIONS AND FUTURE DIRECTIONS

We believe that LKDs are a unique group of people who should be carefully and respectfully evaluated to determine their suitability for donation. HMC offers a culturally and linguistically tailored living kidney transplant program that focuses on protecting the rights and best interests of the LKDs. The program's legal and policy framework prohibits organ commercialism whilst providing a safe, supportive, and compassionate environment for those who come forward with solidary/altruistic motives.

Challenges still exist. ABO/HLA incompatibility is the most significant barrier to optimizing living kidney donation – 30% of the LKDs are immunologically incompatible with their intended recipients.

To circumvent this problem, the program is developing protocols for desensitization therapies for both ABO-incompatible and HLA-sensitized patients. Kidney paired donation (KPD) has emerged as an attractive option for donor – recipient pairs who are not immunologically compatible with each other. It would be interesting to study and unravel any cultural or religious concerns that multiethnic societies might have, and to assess their willingness to participate in such a program. Establishment of a national KPD registry and perhaps a unified registry in the Gulf

region will have the potential to maximize living donor transplant rates. Collaboration with international societies such as Transplantation Society, International Society of Nephrology, and European Society for Organ Transplantation would facilitate the establishment of desensitization and KPD programs to

optimize living kidney transplantation in Qatar. Successful implementation of these programs will invariably require resources and expertise – in return, it will ensure that maximum number of LKDs achieve their noble ambition.

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