# The doctor-patient relationship in living donor kidney transplantation

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## Purpose of review

A therapeutic and effective doctor – patient relationship and patient–doctor relationship is at the core of all successful medical care. The medical and psychological evaluation of a potential kidney donor serves to protect the long-term health of both the donor and the potential recipient. Careful assessment of risk and donor education is at the core of donor evaluation and the decision to progress with donation requires refined clinical judgment by the medical team and critical thinking by the donor.

#### **Recent findings**

Increasing pressure to increase the numbers of living donor transplants and suggestions by some that the process should be commercialized make it timely to consider the nature of the relationship between the doctor and the patient in the unusual circumstance of living donation. A high rate of complications in recipients of purchased kidneys and a lack of knowledge of the fate of paid donors have been reported.

## Summary

Commercialization of transplantation undermines the therapeutic doctor-patient relationship and threatens the healthy development of the international transplant endeavor.

#### Keywords

commercialization, ethics, transplant donation, transplantation

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## The doctor-donor relationship

Concern that living donor transplantation might compromise the physician-patient relationship were expressed by a renowned nephrologist, the late John Merrill, to the surgeon, Joseph Murray, at the time of the first successful living donor transplant performed at Harvard in 1954. Murray went on to receive the Nobel Prize for his work whose impact we continue to feel. Both Murray and Merrill were concerned that in their eagerness to perform the transplant for the welfare of the terminally ill recipient, Richard Herrick, they might neglect, or take for granted, the welfare of John, his identical twin donor [1]. Fifty years later, at a celebration of this momentous event, John, who was the only participant who was well enough to attend, expressed no regrets. In fact his life had been much enriched by his expression of love for his sick brother who had died some years earlier.

Living donor transplantation, by its very nature, stresses the physician-patient relationship. The physician is being asked to assess the appropriateness of a potentially morbid, surgical procedure, with both short and longterm consequences, that an individual does not need. Primum non nocere ('first, do no harm') – a core value of medical practice - is at stake each and every time living donation is considered. The physician must be constantly aware that the moment the donor evaluation process commences the donor becomes his or her patient and, by definition, the physician becomes the patient's health advocate. With these constraints in mind the physician evaluating an informed and educated potential living donor must assess both the risk of the procedure and its benefits. And benefits there are, as will be discussed below. To ensure the primacy of the responsibility of the physician to the potential donor, and to prevent conflicts of interest, it has been repeatedly recommended that the physician not be part of the recipient's transplant team or not be simultaneously responsible for the care of the recipient.

The decision to progress with donation requires refined clinical judgment by the medical team and critical thinking by the donor and the medical evaluation of overtly healthy donors and radiographs. Two recent reviews [2,3] of the donor evaluation process attest to the complex and nuanced nature of the process that also includes a psychosocial or psychiatric evaluation to assess, among other things, for the presence or extent of coercion, overt or covert depression, and unrealistic expectations. Much critical information regarding the risks of donation for both the donor and the recipient require the honesty, cooperation, and goodwill of the donor and cannot be obtained by medical testing alone. Such information includes family history of kidney disease; use of blood pressure medications; history of kidney stones; family history of diabetes; history of gestational diabetes; exposure to infectious agents; distant history of malignancy; high-risk sexual activity; history of recreational drug abuse; history of psychiatric illness. A thorough and satisfactory donor evaluation therefore requires honesty, trust, and transparency between the potential donor and the physician performing the evaluation. In traditional voluntary or altruistic donation trust can generally be presumed because of the mutual interest for a favorable outcome for both the donor and the recipient. In this respect the donor evaluation process is no different from any other physician-patient interaction. Altruistic living donor transplantation is indeed associated with very low medical risk for the donor; with excellent outcome for the recipient; and with measurable gains in terms of the psychosocial health of the donor. A systematic review of the psychosocial health of over 5000 donors revealed that the great majority reported stable or improved relationship, improved self-esteem and high quality of life. Anxiety and depression were uncommon [4<sup>•</sup>]. These gains are most gratifying, though they should not be taken for granted [5].

What impact might commercialization of living donation have on the process just outlined? Not surprisingly, reliable outcome data for both the donors and the recipients of commercialized donation are sparse and fragmentary. Unethical and even criminal exploitation of vulnerable donors is well documented and it is unlikely that these unfortunates ever had the benefit of a recognizable doctor-patient relationship [6,7]. Recipients of vended kidneys have been repeatedly reported to suffer a high rate of infectious complications not all of which could have been easily prevented by routine evaluation [8,9]. The absence of trust and honesty cannot be compensated for by laboratory tests. The inclusion of major financial rewards for donation could also place tremendous pressure on transplant doctors to act against their best medical judgment. It is not difficult to imagine such scenarios: might a donor surgeon, faced with a kidney with multiple vessels, elect to perform nephrectomy when he or she might otherwise have declined to do so because of the knowledge that the donor desperately needs the vending money? Might a nephrologist feel similarly pressured to approve a donor with mild hypertension, or borderline proteinuria, or a history of kidney stones? In a vending system, where regard for the recipient is divorced from the motivation for donation, there would

be powerful financial incentives for a donor not to be forthcoming about critical information that could affect both their own health and that of the recipient. If donors are being coerced or blackmailed to sell their kidneys, are they likely to spontaneously provide this information? Medical decision-making is already difficult enough without its distortion by large financial rewards. Physicians are not trained to be police detectives or prosecuting attorneys and they should not take this role upon themselves. If kidney vending were to be permitted it would seem that specially trained investigators would need to be included in the transplant team to ensure the accuracy of the paid donor's history and to ensure public safety.

Can the positive balance between the intrinsic risks of donation and its psychosocial benefits for the altruistic donor be maintained in a commercialized environment? Available evidence suggests that it cannot. It has been argued that the evils and dangers of the procedure so benignly termed 'transplant tourism' could be obviated by a so-called 'regulated' vending system [10]. This may be true to some extent but available studies from countries where kidney selling is permitted or uncontrolled suggests that the lump sum that the paid donors receive has little impact on their long-term financial security and that many end up worse-off, financially and otherwise [7]. A detailed report [11] of the paid and regulated living donation program practiced in Iran commented little on the fate of the donors themselves but indicated that 84% of over 15000 paid donors were poor and that the program 'neither has enough lifechanging potential nor has enough long-term compensatory effect, resulting in long-term dissatisfaction of some donors'. A more detailed report [12] on the quality of life of 300 paid kidney donors in Iran revealed a highly negative effect on psychosocial health. Family conflict, isolation, and depression were described by 70% of paid donors, many of whom had actually concealed their donation. Deterioration in employment status and overall financial status was reported by 65% of donors. These data are in stark comparison to similar data obtained from altruistic donors that have been previously described. There is no reason to believe that kidney venders in the Western world would be protected from this or a similar outcome. With this experience in mind paid donation can hardly be considered to be an example of primum non nocere and the term 'healthy doctor-patient relationship' becomes an oxymoron in this circumstance.

# The doctor and the paying recipient

Iran is the only country where paid donation is officially sanctioned and encouraged [11]. For the rest of the world, in the current environment, paid donation typically implies 'tourism' to countries where paid donation is openly or tacitly permitted and the outcome for the donors is of little concern. China, where the source of donated kidneys has been from prisoners executed for reasons that are not openly documented, has been a venue of many thousands of paid donations. In addition to the impact of paid donation on the actual donor, paid donation also undermines the national development of altruistic or voluntary donation [13<sup>•</sup>], and serves to export the problems of one country to another, more vulnerable one.

With this in mind, how should physicians respond to patients who seek their counsel regarding the wisdom of purchasing a kidney abroad? Physicians cannot and should not shrink from discouraging patients from engaging in behavior they deem to be unethical or even criminal. Neither should they withhold from patients their knowledge of the additional medical risks patients may be taking upon themselves. If, despite these admonitions, patients elect to progress with their plans and request medical records, there appears to be little option but to provide them since autonomous patients are entitled to their medical records. Physicians should not accept payment for providing medical records since this puts them in the position of gaining financially from an unethical and potentially morbid procedure.

A physician, faced with a patient who has returned to his or her country of origin after a paid donation, should provide or at least facilitate the optimal care of that patient whatever his or her personal feelings of abhorrence might be. A healthy doctor-patient relationship would require a professional, nonjudgmental attitude with the physician, once again, maintaining an advocacy role. The role of insurance carriers, who have not approved of the paid donation, is more problematic [14]. In the United States, patients who return home after a paid donation have not been declined coverage, even if the their posttransplant course has been complex, as it often is.

### Conclusion

The dilemma of a patient with advanced kidney disease who does not have the option of an altruistic living donor, and is anticipating a prolonged wait for a transplant, is indeed a profoundly difficult one. The physician is obliged to make every effort to minimize morbidity and maximize quality of life while the patient waits. Transferring the problems of one patient to another is neither a rational nor an ethical response. Physicians should support the innovative programs for increasing both deceased and living donation that have been instituted in several countries. Successful organ transplantation requires a sophisticated medical infrastructure and cannot flourish in a medical vacuum. The last two decades have seen organ transplantation become one of the great medical gifts to humankind and hundreds of thousands of patients have benefited as a result. For this to happen an extraordinary degree of trust has developed between the public and their transplant teams that must not be taken for granted. Commercialization of kidney transplantation might seem like a tempting solution to the organ shortage but, by its very nature, it risks bringing destruction and not relief. A bright future for organ transplantation requires that we foster altruism and not stifle it, and strengthen doctor-patient relationships and not undermine them.

#### References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

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- of outstanding interest
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