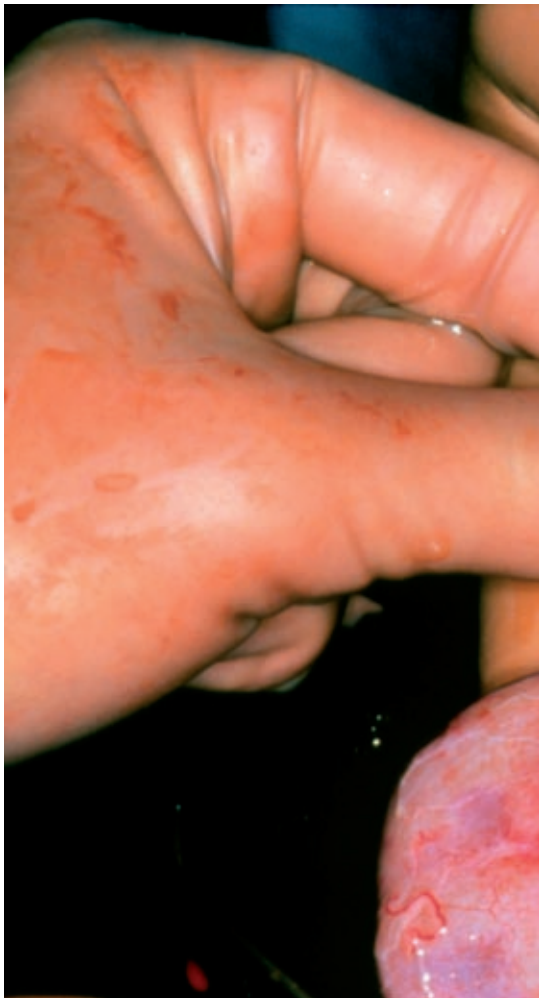
Did Iran eliminate its waiting list for kidney transplants? And if so, where are the kidneys coming from? **Anne Griffin** investigates

KIDNEYS ON DEMAND



When a Toronto based transplant surgeon and bioethicist wrote last year that Iran had eliminated its waiting list for kidneys, the lay press listened. Abdullah Daar made the claim in *Nature Clinical Practice Nephrology* while arguing for a regulated system of living kidney sales.[1] An approving editorial in the *Economist* shortly after declared: "Governments should let people trade kidneys, not convict them for it."[2]

But not everyone agrees that the claim is true. "It depends on how you define waiting list," Behrooz Broumand, a past president of the Iranian Society of Nephrology, told the *BMJ*. Javaad Zargooshi, a urologist at the Kermanshah University of Medical Sciences, goes further. "The elimination of the waiting list has never occurred in Iran. It is merely a Goebblesian lie repeated over and over by the commercial programme's spin doctors," he said.

Dr Daar backs his claim with a reference to a paper by Ahad Ghods.[3] For data on Iranian transplants Dr Ghods's paper references only his own work, and the original source is unclear: The results of a large academic hospital in Iran are given "as an example for the whole country."[4] So what is the truth about transplantation in Iran?

The history

After the 1979 Iranian revolution, materials for dialysis were in short supply and there was no system of cadaveric donation. If you lost kidney function, you either went abroad for transplantation or died in Iran. The Ministry of Health set up two renal transplantation teams in the mid-1980s, the first of which was headed by Iraj Fazel, a surgeon who trained in the US and subsequently became minister of health and medical education.

He told the *BMJ* that he started to transplant patients "strictly from live related donors, with very limited support and facilities." Demand rose swiftly, and a surgeon in another institution started to use organs from emotionally related donors and altruistic strangers, he said. Soon rumours developed that money was being exchanged. In the late 1980s the government put in place a regulated programme to support recipients who could not afford to pay for organs. A cadaveric kidney donation system was not started until 2000.

Iranian system

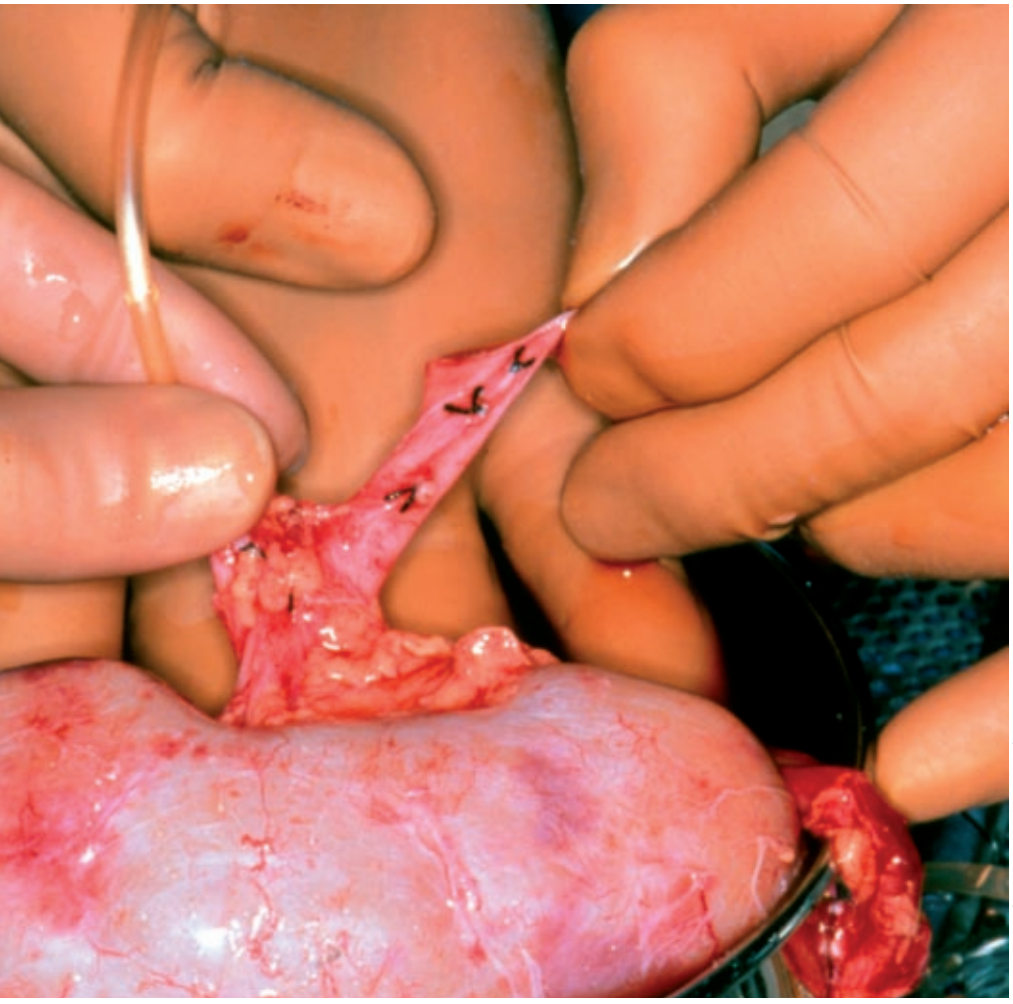
In Iran, a candidate for transplantation can get a kidney from a cadaver, a living relative, or a living stranger. However, in contrast to most countries, 76% of kidneys come from strangers; only 12% of kidneys are from deceased donors. For comparison, in the US in 2006, 65% of transplanted kidneys were from deceased donors and less than 1% were from anonymous living donors.[5]

The reason so many strangers in Iran are giving up a kidney is money. Whether or not Iran is the first country to eliminate its waiting list, it is certainly the first government to pay donors. It pays living unrelated donors the equivalent of about €900 (£600; $1200), and in most cases, donors legally receive additional compensation from the kidney recipient.

"Living unrelated transplant is all most people know about transplant," Mitra Mahdavi, the director general of Iran's Transplantation and Special Disease Centre, told the *BMJ*. The living related programme is not considered a separate programme, and while Dr Mahdavi has patients who have donated kidneys to family members without accepting money, in some cases relatives do get paid.[4]

To prevent transplant tourism, the donor and recipient must be the same nationality. This means that although an Afghan refugee living in Iran can be transplanted for the same costs as an Iranian, the kidney must be donated by another Afghan.[6]

Iran's cadaveric kidney donation system is similar to that of many other countries. It



BRAD NELSON/CUSTOM MEDICAL STOCK/SPL

Iran's regulated system of living kidney sales

Donors must:
Be same nationality as the recipient
Be aged 20-35
Be healthy
Have written consent from a spouse or parent

Donors receive:
€900 from government
One year of free health insurance
Additional compensation from the recipient, in most cases

National patient led charity coordinates:
Preoperative assessment
Medical consent
Introduction of donor and recipient
Negotiation of extra compensation for donor

is centralised under the Ministry of Health and removal of organs requires either a donor card signed by the deceased or family consent. [7] Organ procurement organisations and brain death identification units identify potential donors and procure organs, ensuring transparency in the process of matching donors and recipients. In university hospitals, each case of brain death is determined by five physicians, one of them being a specialist in forensic medicine appointed by the Ministry of Health. The cadaveric programme is "purely altruistic" according to the Transplantation and Special Disease Centre, with no money given to families, except funeral expenses in a few cases.

Standard medical criteria are used to select potential donors and recipients. Although specific tests such as HLA typing, are not done routinely, kidneys transplanted in Iran last nearly as long as in other countries. The graft or kidney survival rates for all kidneys transplanted—from living and deceased donors—is 89% at year one according to the Transplantation and Special Disease Centre. Data published in 2003 suggested that although graft survival rates at one year were lower than in other countries, they were similar at five and seven years.[8]

Whenever we have life on one side and money on the other side, we have the potential for very good and very bad endings

Members of the transplantation team have no role in identifying potential donors. The Patient Kidney Foundation matches living donors and recipients and deals with transactions of money, medical assessment before transplantation, and consent. The foundation, which was formed in 1980, is run mostly by dialysis and transplant patients who are affluent enough to volunteer their time. Although the foundation is a registered non-profit organisation, it gets at least part of its funding from the Ministry of Health. Some nephrologists volunteer time to help out with the consent process, but otherwise healthcare providers are not involved. A nephrologist will write a letter of introduction for a recipient and the foundation takes care of the rest up to transplantation.

Recipient

Once a potential recipient registers with the foundation, it usually takes 2-3 months to find a kidney donor and have the transplantation, said Dr Mahdavi, who is also the foundation's representative for international relations. The recipient's insurance pays 90% of the fee and the Ministry of Health 10%. Anyone who needs dialysis or transplantation is provided with a special government subsidised insurance. Although "many patients going into end-stage renal disease never have to have dialysis" because of the living unrelated programme, there are also many who remain on dialysis or wait for a cadaveric kidney, said Dr Mahdavi. Recipients who register in the living donor system can also register with the cadaveric system, but only if they are already on dialysis, a rule which was devised, at least in part, to counterbalance inequity.

Donor

The donor can be of either sex and must be healthy and aged 20-35 years. Although

this might seem young, the median age in Iran is 24.2 years compared with 38.8 in the United Kingdom. The donor must also have the consent of his or her next of kin and both the donor and the relative are required to provide identification to the foundation. Advertising of living donation is officially banned (although not unheard of), but there is a surplus of willing donors. With greater supply than demand, would-be donors sometimes attempt to bypass or accelerate the system—for example, by giving their phone numbers to patients at the dialysis clinic. Clinic staff are aware that this is banned and refer donors to the foundation.

As well as a fixed payment from the government, donors get a year of free health care and a negotiated payment from the recipient. The foundation introduces the donor and recipient but its exact role in brokering is not well defined. In general, donor and recipient are provided with a private space on-site to agree on a price. The foundation does not keep records of the amount of money exchanged, said Dr Mahdavi.

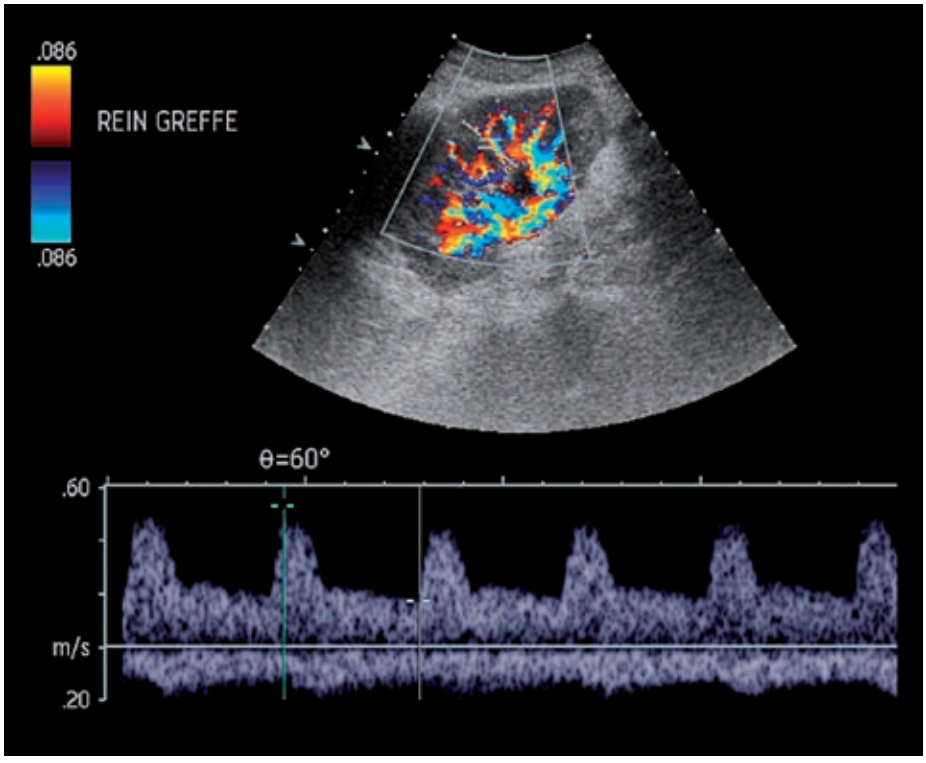
The foundation can act as a check on negotiations and also as a guarantor. If a potential donor asks a member of the foundation for advice on whether to accept a recipient's offer, it might indicate that there are other donors who would accept such a price. In some cases, the foundation holds the money before the transplantation so that the donor can be assured the money is forthcoming and the recipient knows that the donor will not disappear if paid ahead of time.

"Whenever we have life on one side and money on the other side, we have the potential for very good and very bad endings," said Dr Mahdavi.

Although many branches of the foundation match private benefactors with needy candidates for transplants, those who cannot afford to pay for organs have to stay on dialysis or wait on the cadaveric list. Recipients of cadaveric kidneys do not pay for the surgery or the kidney, and presumably they are among the poorest patients.

Who sells their kidneys?

Both the World Health Organization and the World Medical Association oppose payment for organ donation.[9 10] A letter written by WHO to the Transplantation and Special Disease Centre after a visit to Iran three years ago emphasised that Iran had no national registry of donors, according to Alireza Heidary-Rouchi, a senior expert at the centre.



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Although there is still no long term donor follow-up, for the last two years a national task force has been studying the outcomes of living kidney donors. The report of the task force will be published shortly.[6]

Right now, however, published and unpublished data are not consistent. But this much seems true: nearly all the donors are desperately poor men who don't want to be identified after they have received their money, and women are more likely to be donors than recipients, especially if they are unemployed.[11] Long term, economically and health wise, it is unclear whether donors are better or worse off and whether they would do it again.[12]

"Less than 5% of over 1000 donors who we invited to follow up responded," Dr Heidary-Rouchi said of a study the Transplantation and Special Disease Centre attempted a few years ago. They are young, healthy, busy young men, he explained. One problem is that young men are not as interested in going to the doctor as others, but donors also face societal stigma; many Iranians consider selling your kidney to be shameful and wrong.[13]

Iranian proponents of the system, like Dr Ghods, have shown that recipients can be as poor as their donors: one study of 1000 donors and recipients found that while 84% of donors were poor, so were over 50% of recipients.[14] But the researchers' definition of poverty may have been too broad to lend meaning to these numbers: poverty is defined as not being "able to afford average housing and food and college training for children." Those who live hand to mouth are different from those who can afford below average housing.

Dr Heidary-Rouchi showed the *BMJ* an unpublished study conducted by the Transplantation and Special Disease Centre of 300 living kidney donors that doesn't hide the dismal socioeconomic status of donors: 79% of donors were uninsured. Only 30% were employed full time and only 6% were either at university or had a degree. Ninety five per cent of the donors in this study expressed absolute satisfaction with their decision, but this was at the time of discharge from the hospital.

A study by Javaad Zargooshi, an opponent of unrelated donation, suggests the satisfaction may not last. He studied 100 donors 6 to 132 months after donation: 76% of donors agreed that kidney sales should be banned

and if there was another chance they would prefer to beg (39%) or get a loan (60%) instead of selling a kidney.[15] The research on both sides of the argument has been criticised.

Better than a black market?

Organs Watch has been working in Iran for over 10 years, and although it is against the sale of organs, comes the closest to being an independent observer there: "Regulation in Iran has not ended the black market, it has simply made it an official policy," according to Nancy Scheper-Hughes, director of Organs Watch.

"Medical critics of the system say that easy access to the bodies of poor people has prevented the development of a deceased donor system in Iran and has eroded living kidney donation among loving family members," she continued.

Francis Delmonico, medical director of New England Organ Bank, said: "The Iranian physicians are trying to do the best for their patients and they are genuine in that effort without seeking financial gain for themselves. The experience in Iran and elsewhere is that the poor remain poor following a vendor sale and then with one less kidney."

Dr Delmonico also points out that the system is not truly regulated: "What has become evident is that the government is not the source or final arbiter of payments. Market forces ... determine the under the table price—in some instances based upon gender, blood type and age. Thus, the Iranian system is (not surprisingly) far from regulated."

Many agree that the regulated system of living sales has undermined the cadaveric programme. "Reacting to the undermining of altruistic donation by paid donors, Iran started encouraging living related donation and is currently progressing in increasing donations from deceased donors. The latter is probably the real model for the region," Luc Noel, clinical procedures coordinator at WHO, told the *BMJ*.

While the annual rate of organ transplantation from deceased donors has increased from 0.3 per million population in 2000 to 1.7 in 2004,[16] it seems unlikely that donations from deceased donors will become the main source of kidneys any time soon. When given a choice, and when they are told about the better outcomes associated with living donors, most people would choose a living donor rather than a deceased one, according to Drs Heidary-Rouchi and Mahdavi.

If you have access to the health system in the first place and can pay extra money to a kidney donor, the wait is definitely over

So has Iran eliminated its waiting list for kidney transplants? The short answer is no. "The waiting list for cadaveric kidney transplants is currently about 300," Dr Heidary-Rouchi told the *BMJ* in late January. When the *BMJ* shared these findings with Dr Daar, he declined to comment.

The waiting list may be larger still: "The Iranian prevalence of renal failure may not be completely assessed," said Dr Delmonico. We do not know the total numbers who are in need but not able to afford to buy a kidney.

Dr Broumand, had the same insight two years earlier: "Although there has not been a waiting list for kidney transplantation since 1999, one should consider the fact that many dialysis patients are still not scheduled for renal transplantation and continue chronic hemodialysis."[7] Other research suggests that women, in particular the unemployed, are less likely to be listed.

In November 2006, Dr Ghods qualified his claim that the waiting list has been eliminated. In the *Clinical Journal of the American Society of Nephrology,* he and his coauthors acknowledge the prevalence of patients with kidney failure in Iran is much lower than in developed countries: "A major cause of this is the many patients who are from villages and small towns and do not receive a diagnosis and are not referred for dialysis ... The low prevalence of patients with end stage renal disease results in fewer numbers of transplant candidates. This is the main reason that the renal transplant waiting list was eliminated quickly and successfully in Iran."[17]

"Living unrelated donation may be a temporary solution for developing countries, but it's not a long term one," Dr Broumand told the *BMJ*. He sees two main advantages to living unrelated donation: to increase facilities and manpower and to create the situation where we no longer need brokers. "We went from having two dialysis centres to having 22." Although he was initially strongly against living unrelated donation, for him the ends may justify the means: "If we did not have enough transplant centres and transplant surgeons how could cadaveric transplantation have expanded?"

So were the *Economist* and all the other authors wrong? Yes, but not entirely. If you have access to the health system in the first place and can pay extra money to a kidney donor, the wait is definitely over. The waiting list for kidney transplantation in Iran has improved more than in any other country in the world, but not for everyone who needs one and quite literally at a price.

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