

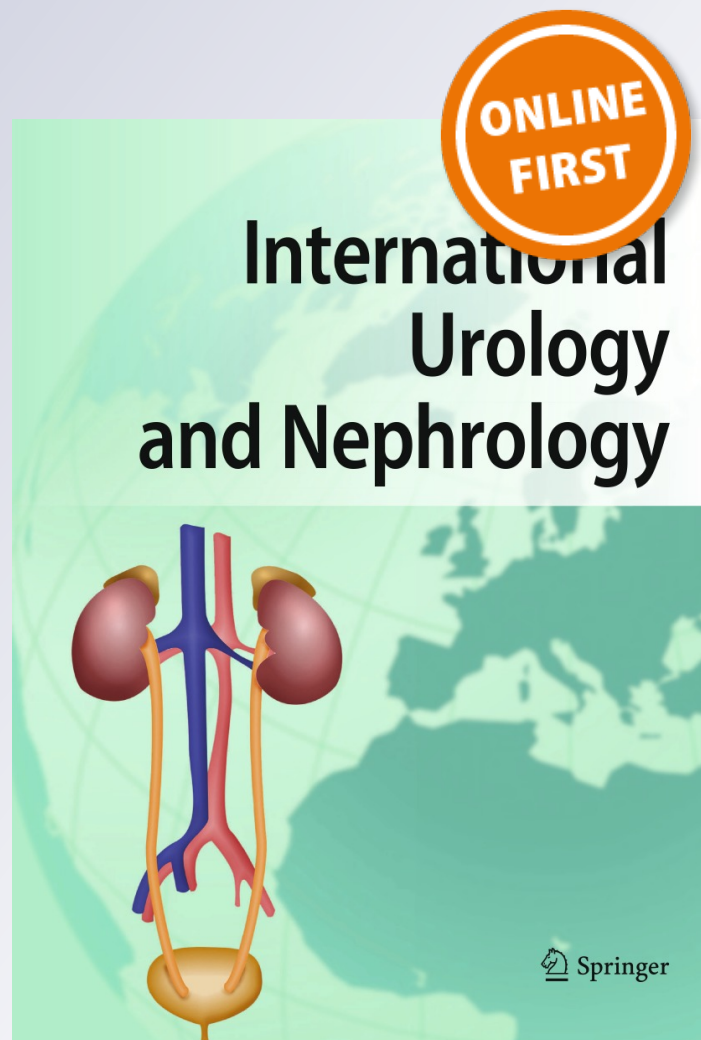
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**Sigrid Fry-Revere, Deborah Chen, Bahar
Bastani, Simin Golestani, Rachana
Agarwal, Howsikan Kugathasan &
Melissa Le**

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Coercion, dissatisfaction, and social stigma: an ethnographic study of compensated living kidney donation in Iran

Sigrid Fry-Revere¹ · Deborah Chen² · Bahar Bastani³ · Simin Golestani⁴ · Rachana Agarwal⁵ · Howsikan Kugathasan⁶ · Melissa Le⁷

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Abstract

This article updates the qualitative research on Iran reported in the 2012 article by Tong et al. “The experiences of commercial kidney donors: thematic synthesis of qualitative research” (Tong et al. in *Transpl Int* 25:1138–1149, 2012). The basic approach used in the Tong et al. article is applied to a more recent and more comprehensive study of Iranian living organ donors, providing a clearer picture of what compensated organ donation is like in Iran since the national government began regulating compensated donation. Iran is the only country in the world where kidney selling is legal, regulated, and subsidized by the national government. This article focuses on three themes: (1) coercion and other pressures to donate, (2) donor satisfaction with their donation experience, and (3) whether donors fear social stigma. We found no evidence of coercion, but 68% of the paid living organ donors interviewed felt pressure to donate due to extreme poverty or other family pressures. Even though 27% of the living kidney donors interviewed said they were satisfied with their donation experience, 74% had complaints about the donation process or its results, including some of the donors who said they were satisfied. In addition, 84% of donors indicated they feared experiencing social stigma because of their kidney donation.

Keywords Living kidney donation · Ethics · Paid organ donation · Law · Iran · Ethnographic study · Human rights · Social justice · Transplantation · Bioethics · Exploitation · Donor satisfaction · Poverty · Medical ethics · Transplant ethics · Living organ donation

Background

Study origin

In 2012 Tong et al. published “The experiences of commercial kidney donors: thematic synthesis of qualitative research,” which reviews the work of seven researchers on compensated organ donation. That review includes the work of two researchers who wrote about the Iranian system of kidney donation: Dr. Zargooshi, who wrote in 2001 [2, 3], and Dr. Tober, who wrote in 2007 [4]. Those studies were based on living donor data collected, respectively, in 2000 (from donors who donated from 1989 to 2000) and 2002 (from donors who donated in 2002). Both of these researchers did their studies *before* the Iranian government fully implemented its 1997 laws subsidizing and regulating compensated kidney donation [5].

In 2008, Dr. Fry-Revere and Dr. Bastani spent 2 months in Iran gathering interviews for a documentary film on compensated kidney donation in Iran. That material was donated

Authors are listed in the order in which they joined the project. The affiliations listed are the relevant affiliations the authors had while working on this article.

✉ Sigrid Fry-Revere
Sigrid@alodf.org

¹ American Living Organ Donor Network, 40357 Featherbed Lane, Lovettsville, VA 20180, USA

² Center for Ethical Solutions, Madison, WI, USA

³ Saint Louis University School of Medicine, Saint Louis, MO, USA

⁴ University of Texas, Austin, TX, USA

⁵ Harvard University, Boston, MA, USA

⁶ Fisk University, Nashville, TN, USA

⁷ University of Virginia, Charlottesville, VA, USA

by the project's sponsor, the Center for Ethical Solutions (CES), to the U.S. National Library of Medicine (NLM) in 2017 [6]. The raw video footage available at NLM includes almost 100 h of video, which provides a treasure trove of information about the Iranian system of organ donation and includes interviews with medical staff, organ recipients (of both living and cadaveric organs), dialysis patients, living organ donors, those making inquiries into becoming living organ donors, and the staff of the non-profit charities that match donors and recipients (i.e., the *Anjoman*). Also available as part of the NLM collection are the interviewees' consent forms and Dr. Fry-Revere's field notes. We reviewed all these materials as well as Dr. Bastani's field notes and the notes from Dr. Golestani's five follow-up phone interviews. All the paid donors interviewed had donated under the new laws governing living organ donation in Iran and were offered the benefits and protections created under that new system of regulations. We looked specifically for insights into how Iranian living kidney donors felt about the system in which they participated.

Iran has long been of interest to living organ donation researchers because it is the country with the highest average per-million rate of living organ donation in the world for at least the last 20 years [7]. It is also the only country in the world where it is legal to compensate living organ donors for more than their expenses (and more than just token gifts of appreciation), and where the government actively regulates and subsidizes the paying of donors for their participation [8]. Despite all the interest, it is hard to get data on the Iranian system of organ donation because Iran is a closed society that is generally hostile to foreign researchers. Until now, the three studies referenced by Tong et al. were all that was available [4]. We hope to remedy that situation by publishing this article reporting on the Iran organ donation data recently made publically available at the NLM [6].

After reviewing all the CES material available at the NLM, three themes stood out as particularly relevant: coercion and the pressures motivating donation, dissatisfaction and the causes thereof, and what forms of social stigma donors feared. These three themes struck us as relevant given the growing interest in the USA, and other countries, in considering whether incentivizing organ donation, and in particular the paying of donors, is a good idea [10].

Before other countries implement policies that pay living organ donors to donate [9], it makes sense to try to get as clear a picture as possible of how incentivization affects living organ donors in Iran, where such incentives have not only been accepted government policy for 20 years, but also have been actively promoted through national laws that help pay donors and protect their rights to the money and benefits they are promised. It is with the goal of studying this regulated system on which to date there are no ethnographic

studies available in the West that we began our review of the data reported here.

Some general background on the Iranian system

Unlike most countries, Iran has never passed laws prohibiting or restricting the compensation of living organ donors. Since the 1980s, living kidney donors have been compensated by organ recipients. But not until 1997, did the national legislature formalized a program that grants donors one year of health insurance, exemption from Iran's two-year mandatory military service, and a financial gift ("*issar*") of one million tomans (approximately \$4000 in buying power¹ in 2008 when the first CES interviews were done and \$1000 in 2017) [5]. While the original intent was to replace the recipient contribution with a national one, recipients began to supplement the national *issar* with a gift of their own almost immediately [8]. In addition, the *Anjomans* (the non-profit organizations that match organ donors and recipients), transplant centers, and local governments also began supplementing the *issar* with additional benefits such as extra compensation from charity organizations, additional health-care coverage, job counseling, household goods, education vouchers, and interest-free loans [8]. In 2008, the central (i.e., Tehran) *Anjoman* endorsed 4 million tomans as a reasonable cash contribution (because of inflation that recommendation is 6 million tomans at the time of this writing). Local *Anjomans* basically follow this endorsement, but compensation may vary for several reasons, such as the recipients' ability to contribute and the availability of charity funds [8]. The underlying policies that drive the whole Iranian system, however, are the benefits available at the national level—which have remained static for two decades—and the financial incentives that are provided by the organ recipients, which are to some extent open to negotiation [8]. So, unlike in any other country, for the last 20 years, Iran has had a nationally sanctioned system of incentivized living organ donation, supplemented by a legal—albeit heavily regulated—market in living organ donor services.

Other research on Iranian-living organ donors (studies reviewed by Tong et al.)

The only researchers who have done similar work on Iranian living organ donor attitudes to what we present in this article are Dr. Zargooshi and Dr. Tober [2–4], but unfortunately their data were collected before Iran's laws governing

¹ Note that "buying power" is a different concept than "exchange rate". A detailed explanation of why "buying power" is a better measure for understanding what living organ donors are paid in Iran is provided in *The Kidney Sellers* (p. 212) [7].

organ donation were fully implemented, with most of Dr. Zargooshi's donors having donated even before the laws were passed. In 1997, Iran passed laws, for the first time and without revision since, to regulate its kidney market [5]. These laws created a national subsidy for the payment of donors and also providing for other national level benefits such as exemption from military service and one-year health insurance for donors.

Methods

Our goal was to show how living kidney donors in Iran felt they were treated under the new post-1997 system. An obvious limitation of the work done by Zargooshi and Tober is that the donors they interviewed didn't enjoy the benefits, rights, and protections that were passed in 1997, so their work doesn't apply to what is commonly called the "Iranian Model" which is understood by most to be the regulated market described above. If Zargooshi's and Tober's raw data were available, we could have coded for the things we looked for in this study and done a comparison, but unfortunately, their recordings (if any ever existed) and field notes are not publically available. The donors used for this study all donated after the new regulated system was implemented. All donors in this study, for example, had the national government's *issar* as part of their compensation (see Table 2 "General Donor Data," sec. b).

We reviewed approximately 100 h of video available through the U.S. National Library of Medicine (NLM) which was taken in Iran during November and December 2008 [6]. The NLM collection was originally intended for a documentary film on kidney donation in Iran by the Center for Ethical Solutions (CES). That film was never made, and CES donated the project footage and interview consent forms to the NLM in January 2017. We also reviewed Dr. Fry-Revere's field notes which are also part of the NLM collection [6]. In addition, we were given access to Dr. Bastani's field notes from the 2008 documentary film project and Dr. Golestani's report on five follow-up phone interviews done in 2011 that are not included in the NLM collection. We reviewed this material for evidence of coercion or other pressures that motivated donation, dissatisfaction and its causes, and donors' fear of social stigma.

Original data collection methodology

In November and December 2008, Dr. Bastani and Dr. Fry-Revere interviewed transplant medical staff, transplant program administrators, *Anjoman* staff, dialysis patients, organ recipients and their family members, organ donors and their family members, and people applying to be organ donors. They obtained their donor interviews at

24 institutions (transplant wards, follow-up clinics, and *Anjomans*) in six provinces (see Table 1 for more details). They received consent from everyone interviewed and comprehensive releases from everyone who completed an interview. Some of the consents were verbal, but most were written consents on a form that gave CES permission to publish the interviews (see Table 1, sec. f). These forms also included permission to use the interviewee's name, voice, and image, but some forms have handwritten notations indicating that interviewees did not want their names or images used (see Table 1, sec. f).

Since this study focuses primarily on living organ donors, the remainder of this section describes how the film team collected living organ donor interviews and not other interviews which we only use for background and cultural context. Dr. Bastani and Dr. Fry-Revere collected data randomly but in a methodical manner to avoid any selection bias by medical or *Anjoman* staff. At transplant centers, they went down the hall in the transplant ward and interviewed every living organ donor who was awake. Some of these donors were about to donate, and some were about to be discharged. At the post-op clinic and *Anjomans*, they interviewed every consenting living organ donor who walked in the door, unless the donor came and went while the filmmakers were interviewing another donor. Only two donors at the *Anjomans* and one donor at a hospital refused to be interviewed. The interviews were usually conducted by Dr. Bastani, with Dr. Fry-Revere videotaping the interview, with eighteen un-taped exceptions: six donors did not want to be videotaped but allowed Dr. Fry-Revere to be present and seven interviews were done by Dr. Batani alone, five of these were at hospitals or *Anjomans* where Dr. Fry-Revere was not present, one was performed at a family gathering where the donor was a guest, and one was done on the phone after the recipient gave Dr. Bastani her donor's phone number. The remaining five interviews were done by Dr. Golestani, who did follow-up interviews in 2011 by phone. Her interviews were of donors who had been interviewed on videotape in 2008. Unfortunately, 90% of the donors could not be reached so only five follow-up interviews were collected. In addition to the videotaped interviews, Dr. Bastani, Dr. Fry-Revere, and Dr. Golestani all took notes on the interviews in which they participated.

Most of the interviews were conducted in the interviewee's native language, since both Dr. Bastani and Dr. Golestani are fluent in Farsi. In addition, Dr. Bastani is a nephrologist and knows the relevant medical terminology needed for reading donor's medical charts and understanding their conditions (see Table 1, sec. c). Two of the physicians interviewed did their interviews in English, and in four instances, an interpreter was used when the donor spoke Turkish or another non-Farsi dialect that Dr. Bastani could not understand.

Table 1 Comprehensiveness of reporting

Sample size and general study characteristics (sec. a)	
Number of interviews	217
Background (e.g., organ recipients, medical and <i>Anjoman</i> Staff)	158
Total number of donors interviewed	59
Living organ donors (paid)	53
Altruistic living organ donors (didn't seek payment)	6
Number of paid living organ donor interviewees included in this study	50
Number of people who refused to be interviewed	6 ^a
Interviewees compensated for participation	0
Number of follow-up interviews	5
Incomplete interviews	3 ^b
Data collection (sec. b)	
Hospital	79
<i>Anjoman</i>	73
Clinic	30
Dialysis center	12
Other	23
Average length of interview (min)	17
Language (sec. c)	
Interviewees native tongue	210
Farsi (not native tongue)	7
Interpreter used	4
Format of interview documentation (sec. d)	
Video only	0
Field notes only	18 ^c
Both video and field notes	199 ^d
Interviewers (sec. e)	
Dr. Bastani and Dr. Fry-Revere	205
Dr. Bastani alone	7
Dr. Golestani alone	5
Bystanders (sec. f)	
Medical or <i>Anjoman</i> staff present	12
Organ recipient present	3
Methods and materials (sec. g)	
Protocol for data preparation and transcription	Yes (all)
Use of software	Excel (all)
Native speaker translation and transcription	Yes (all)
Translation verified by at least one additional native speaker	Yes (all)
Total codes	55 (all)
Codes applicable to current analysis	15 (all)
Number of themes	10+ (all)
Themes applicable to current analysis	3 (all)

Table 1 (continued)

Methods and materials (sec. g)	
Code and themes verified by multiple authors, including two Iranian American authors	Yes (all)
Description of cultural context informing analysis	Yes (all)
Consents obtained (sec. h)	
Written	197
Verbal	20
No restriction on use of interview	
Paid donors	38
Others	155
Restrictions expressed	
Paid donors	15
Others	3
Exclusion criteria (sec. i)	
Interviewee was not a living organ donor	158
Living donor interview interrupted prior to data collection completion	3
Second hand source, i.e., instances where donor was not reporting own experience ^e	22
Totals (sec. j)	
Total living organ donor data reference points used for this study's analysis	90
Number of paid living organ donors included in this study	50

^aThree men and three women. Three were donors (one man and two women) and three were other types of interviewees

^bAll three incomplete interviews were of donors (two men and one woman)

^cSix donors allowed Dr. Fry-Revere to be present while Dr. Bastani did an interview but did not allow videotaping. Other interviews (7) were done by Dr. Bastani when Dr. Fry-Revere was not present. And, five interviews were conducted as follow-up interviews by phone by Dr. Golestani in 2011

^dNote this number does not correspond to the number of interviewees because some people were interviewed more than once

^eAll donors described their own experiences, but some also described the experiences of other donors they knew. Any description of other donors (second hand descriptions) were not included in this analysis. Only donors descriptions of their own experiences

Dr. Bastani and Dr. Fry-Revere used a specific list of questions to elicit information from donors about their experiences. The questions most relevant for this article were some variation of the following: "Did you feel pressured to donate?", "Are you happy with your donation experience" or "Are you happy with how your donation is

proceeding?”, and “Are others treating you differently or badly because you donated?” or “Do you fear social stigma because you are donating?”

Between 2009 and 2014, CES translated and transcribed all the video interviews and Dr. Bastani’s notes, which were in Farsi. The translation was done by volunteers who were all native Farsi speakers living in the USA, most of whom were medical students. Each translation was then checked by another translator, and many were also checked by Dr. Bastani. Dr. Golestani was one of the medical students who helped with translations and did the initial translation of over half the donor interviews. Dr. Fry-Revere, who has a background in medical ethics, then did the original coding of the interview transcripts in preparation for making the documentary film, which was checked by Ms. Chen who has a background in psychology.

Methodology for the current study

In 2017, the study that leads to this article was conceived, and Dr. Agarwal was asked to join the project because of her background in anthropology and clinical psychology. All interviews were recoded to fully explore the themes of coercion, satisfaction, and stigma. All authors had access to translated transcripts and field notes, which they consulted as needed to verify the synthesized results. Mr. Kugathanan, who has a background in mathematics, and Ms. Le, who has a background in biostatistics and medical anthropology, were the final additions to our project team. They joined to help verify our data synthesis and the accuracy of our data reporting.

We adjusted our coding and theme criteria several times during the analysis phase of our study. For example, specific responses to the questions Dr. Bastani asked about “coercion or pressures,” “satisfaction,” and “social stigma” were not the only evidence that donors felt pressure, social stigma, or dissatisfaction. While there was no evidence of coercion in the common sense of the term (Merriam-Webster defines “to coerce” as (1) “to compel to an act or choice,” (2) “to achieve by force or threat,” (3) “to restrain or dominate by force”), we found evidence of less extreme but potentially disturbing kinds of pressure. We began to look beyond the responses to Dr. Bastani’s direct question about whether donors were forced to donate to see if other factors might indicate disconcerting forms of pressures. Knowing that the bioethics literature is replete with discussions over whether “vulnerable populations” can donate voluntarily [11], we looked for evidence of the use of vulnerable populations such as children, the elderly, prisoners, etc. (see Table 2, sec. a), and we also began to look at more subtle indications of pressure in donors’ accounts of why they donated (Table 2, sec. e, sec. f).

We also had to adjust our coding for donor satisfaction to account for donor complaints (see Table 2, sec. g). When asked directly whether they were satisfied, almost half of

donors responded “yes” but then some also went on to complain or otherwise indicate that they were unhappy with some part of their experience.

Finally, Dr. Bastani asked about stigma directly using the word “stigma” or asked if the donors had felt or feared they would be thought of in a negative manner because they donated. The first thing we noticed is that more donors feared stigma than actually experienced it. We also started to code for factors that may be evidence of a fear of stigma which donors brought up even before Dr. Bastani got a chance to ask about stigma. Those factors included donors wanting to keep their names and images private (Table 1, sec. f) and wanting to hide that they donated or that they donated for money (Table 2, sec. i).

After each analysis phase, we tracked each factor in a spreadsheet and coded each interview to indicate relevant factors. The resulting data are reported in Tables 1 and 2 in the results section. We also coded the interviews for evidence of our three themes: (1) Do donors feel pressured to donate? If yes, in what ways? (2) Are donors satisfied with their donation experience? Regardless of whether they say they are satisfied or not, what are their complaints? and (3) Do donors fear social stigma? If yes, what types of impressions worry them? Those results are reported in the results section of Table 3 “Themes (Coding Phase II)”.

Results

There was no evidence of coercion or the use of physical force to get people to donate, but 68% of the paid donors interviewed felt pressure to donate due to extreme poverty or other family pressures (see Table 2, sec. i; Table 3, sec. a). Note some donors experienced more than one kind of pressure, so the number of incidents of pressure is greater than the total number of donors who felt pressured. Even though 27% of the living kidney donors interviewed said they were satisfied with their donation experience, 74% mentioned some form of complaint about the donation process or its results, including some of the donors who said they were satisfied. Eighty-four percent of donors also gave some indication of fearing one form or another of social stigma, that is, a negative impression others might have of them because they donated.

Discussion

Coercion, undue influence, and other motives for donation

Among the 50 donors included in this analysis, there was no evidence of physical coercion. The only vulnerable population that was evident was the poor. There was no evidence

Table 2 General donor data (Coding Phase I)

General donor characteristics (sec. a)	
Gender	
Male	44
Female	6
Age	
Under 18	0
[18–60]	50
Over 60	0
Unknown	0
Marital status	
Single	6
Married	32
Engaged	1
Divorced	3
Unknown	6
Level of education	
Finished college	1
Finished high school	5
Less than high school	28
Unknown	15
Donor has children	
Yes	27
No	15
Unknown	8
Profession	
Blue collar	33
White collar	5
Unknown	12
Compensation (sec. b)	
Cash	
Issar only	5
Issar and recipient	45
No cash received, only other benefits	0
Non-cash benefits	
National government provided	
Exemption from military service	1
One-year health insurance	50
Regionally provided through Anjoman	
Extra health benefits for donor	4
Extra health insurance for donor's family	3
Free dental clinic	3
Tuition for local university	0
Business loans	1
Job services	2
Donated household items	0
Provided by organ recipient or recipient's family	
Gifts (clothing/household items etc.)	2
Place to stay after donation	0
Participation in family meals, and events such as weddings	2

Table 2 (continued)

Relationships (sec. c)	
Donor related to recipient by blood, marriage, or adoption	2
Donor friend or acquaintance	3
Strangers	45
Timing of interview (sec. d)	
Pre-donation	
Contract details finalized	13
Contract details not-finalized	9
Post-donation	
≤ 1 month post-nephrectomy	18
≥ 6 months ≤ 1 year post-nephrectomy	0
≥ 1 year post-nephrectomy	10
Whose idea was it to donate? (sec. e)	
Donor's	33
Family member's	2
Other	0
Unknown	15
Reason for donation (sec. f) (some donors indicated more than one reason for donating)	
Good deed	39
Family pressure	7
Financial pressure (debt and/or unemployed)	27
Threat of debtors' prison	3
Exemption from military service	0
Employed with no debt but wants money to improve life	3
Other	4
Total number of donors who experienced extreme pressure to donate ^a = 34 (see Table 3 for a more detailed thematic breakdown)	
Donor satisfaction (sec. g) (some donors indicated more than one complaint)	
With information received	
Yes	22
No	12
Unknown	16
With Anjoman staff (contract negotiations, responsiveness to inquiries, final agreement)	
Yes	16
No	19 ^b
Unknown	15
With medical staff	
Yes	6
No	7
Unknown	37
With medical outcome	
Yes	20
No	15
Unknown	15

Table 2 (continued)

Donor satisfaction (sec. g) (some donors indicated more than one complaint)	
With social reaction to donation	
Yes	4
No	22
Unknown	24
Total number of donors who said they were satisfied = 22 Total number of donors with complaints, including six who had said they were satisfied = 37 (see Table 3 for a more detailed thematic breakdown)	
Does immediate family approve? (sec. h)	
Spouse or fiancée approves	23
Fiancée does not approve	1
Had to convince spouse or fiancée	9
Fiancée does not know	1
Parents approve	9
Parents do not approve	4
Had to convince parents	3
Parents do not know	13
Unknown	11
Donor wants to hide the fact of donation or that donation was for money (sec. i) (some donors fell into more than one category)	
From fiancée	1
From parents	11
From neighbors	4
From other acquaintances	7
Donor does not want name/and or image shared	17
Donor lies about getting more than <i>issar</i> or about not being related to recipient	9
Total number of donors who gave indication of fearing social stigma: 42 (see Table 3 for a more detailed thematic break- down.)	

^aNote that this total only includes donors who felt they had no choice but to donate to solve their problem

^bThe single most common complaint (12 donors) was that donors felt pre-donation costs (which are sometimes taken out of their payment) were higher than represented. Eight donors felt pressured to donate for less money than they needed. And, six donors complained other contract terms were misrepresented. Note total is 19 because several donors had more than one complaint against *Anjoman* staff

of any other vulnerable populations being taken advantage of: the oldest donor was 57, the youngest was 20, and there were no prisoners, no employee/employer relationships, no mentally impaired donors, and no evidence that women were unjustly targeted as potential donors. At least not that we could tell from the videos or field notes available from the CES project (Table 2, sec. a and sec. f). Eighty-eight percent of the donors interviewed were male, and while two of the three donors who refused to be interviewed were female²

² All the quotes and details about donors are about men unless the donor is specifically identified as a woman.

our study included a higher percentage of female donors (12%) than the percentage of women reported as participating in living organ donation in Iran (on average, only 9% of all living organ donors in Iran between 1986 and 2006 were female [11]). Note, even if there is some pressure exerted on women to donate in Iran that wasn't evident in the data at our disposal, there aren't enough women donors in Iran for the coercion of women to be a significant factor in how that system functions.

More than half the donors interviewed were extremely poor, as evidenced by the fact that 30 out of 50 (60%) stated that their main reason for donating was that they were in debt or unemployed (Table 2, sec. f). All but one of these donors were so deeply in debt that they felt they had no alternative but to donate, and three were in such severe debt that they were on the brink of being sent to debtors' prison. (One donor said he had alternatives: He could sell his house or continue as he was each month paying only the interest on his loan. He was donating his kidney so he could pay off the principle on his loan.) While financial distress is not physical coercion, it was clearly a negative pressure that motivated over half of the interviewed donors. The most common reasons for indebtedness were unemployment, a failed business, marriage, divorce, or the birth of children.

Nineteen (38%) of donors complained about pressure from *Anjoman* staff, all of whom were among the previous group of donors who were desperately poor, i.e., donating because they were unemployed or in serious debt. Eight (16%) complained that *Anjoman* staff pressured them to donate for less money than they needed to solve their financial problems. One of those donors described how *Anjoman* staff put him in a room to wait where the potential kidney recipient's wife was crying. That donor complained with a resigned look on his face, "What could I do after that?" Another tactic that could be considered a form of pressure was to misrepresent the details of either the donation contract or the donation process and recovery. Six donors (12%) said that *Anjoman* staff misrepresented the terms of their contracts, making it seem as though the donors were getting more money than was actually the case. One donor got the impression that donating would help his son (who was born with a kidney deficiency) if he eventually needed a kidney, only to find out 3 years later that it is extremely hard to find living donors for children and that there were no potential donors who could donate to his son. Two donors complained that *Anjoman* staff underrepresented the time it would take before they could go back to work, and 12 (24%) of donors complained that they knew pre-donation testing costs would be deducted from their payment but that those costs were much higher than they were told. While such behavior by *Anjoman* staff may not rise to the level of "coercion," it is arguably a form of undue influence which many policy makers would find objectionable. None of the seven complaints

about medical staff (Table 2, sec. g) were about pressure to donate and will be discussed later.

Other pressures described by donors included four cases of potential family pressure. One donor's father and the recipient were religious leaders ("Rohani") together. The father wanted his son to help the father's friend, and at first the son tried to find someone else to donate. Seven potential donors came forward who didn't qualify to donate before the son felt obligated to help his father's friend by donating his own kidney. Another donor was interviewed in the presence of two of his sisters, one of whom said, "He donated to make up for bad things he has done." In two additional cases, the donor was raising money to prevent a family member from going to debtors' prison or to get him out of debtor's prison. Even if there was potentially objectionable family pressure in any of the cases described above, the donors also seemed emotionally committed to helping the organ recipient. In none of these cases did donors actually say they were pressured by family members, but these are the only cases where there might have been such pressure given the circumstances described. It is worth noting that none of these donors said they donated primarily to solve their own financial troubles, but the troubles of others.

There are also seven cases where the donor was potentially pressured by the organ recipients or their families. The six cases where the *Anjoman* introduced potential donors to the recipient or recipients' families to pressure them to donate could also be understood as cases where donors were pressured by recipients and/or their families. We also found one case where the donor specifically spoke of being pressured by the recipient independent of any action by the *Anjoman*. That donor complained, "Here I was trying to give him a part of my body and he was fighting with me. He was trying to give me less because I was from Tehran and not from the south like he was."

Finally, there are motives for donating that are worth mentioning specifically because we feel no potentially objectionable form of pressure was involved: almost all donors expressed helping a person in need, pleasing God, or serving humanity or their country as one of their motives, but only six of the paid donors expressed such altruistic motives as their only or primary motive. The CES data included 59 donors in all, six of those donors didn't seek payment (Table 1, sec. a): four were donating to family members and two were donating to strangers. These six were clearly not motivated by money, but in addition to these, there were another six paid donors who could be considered altruistic donors because they were donating to help another person financially. Two donors, who were already mentioned, were donating to keep or get a family member out of debtors' prison. Two others were donating to pay for the medical operation of a loved one. A fifth, also mentioned above, was donating in the hope that his sick son would be given priority

for a kidney should he need one. And a sixth donor was raising money to allow his orphaned nephew to start his own business.

We also found five cases where donors were helping themselves but weren't in dire financial straits. All these donors also spoke of doing a good deed. These donors were neither unemployed nor in serious debt. One female donor wanted money to complete an addition on her house. Her husband didn't have a consistent income because of recurring back problems, and an addition on the house would allow them to take in a boarder who would provide them with a steady revenue stream. Another donor was starting his own business rather than continuing as an apprentice. A third was expanding an existing business. A fourth decided to donate to create an emergency fund. He had started the donation process while unemployed but then found a job, eliminating the urgency to donate. A fifth donor, mentioned above, had been paying the interest on a loan, but he wanted to pay it off completely with the money he earned by donating a kidney.

In total, 34 donors (68% of the paid donors interviewed) felt pressured by extreme poverty and/or pressure from their families.

Donor dissatisfaction and complaints

As discussed in the method section above, we began by focusing on whether donors reported they were satisfied and found that many of the donors who said they were satisfied nevertheless reported complaints [22 donors out of 50 (44%) said they were satisfied, but 6 (27%) of those 22 also had complaints] (see Table 2, sec. g), as did many donors who didn't specifically say that they were either satisfied or dissatisfied. Because of this finding, we changed our focus from general satisfaction to identifying the complaints donors were reporting. It is worth noting that only two donors specifically stated that they felt Iran should stop allowing people to sell kidneys. One of these donors went so far as to say, "Better to steal than donate a kidney." All other donors who commented on the Iranian system didn't want to abolish it but rather improve it so it would be fairer to donors. Often, they spoke of educating the public to prevent social stigma.

The most common complaint was that *Anjoman* staff favored recipients in payment negotiations (19 donors, 38% of paid donors interviewed). These donors complained that the *Anjoman* were focused on getting the organ recipient the "best price" at the expense of donors. One example of this is the donor already mentioned who was sent to a room with the recipient's crying wife to persuade him to accept less money than he needed to pay off his debts. Five others described less dramatic scenarios of the same tactic where they were introduced to recipients and their families so the donor would take pity on the recipient's family and demand

less money. One donor summed up the problem: “The government wants to contribute the least amount of money possible to take somebody’s kidney out of their body and then take care of the patient [recipient] and that’s it.” Another said, “If I had known this is all I would get, I would not have come, but once I was here, I couldn’t back out.” When further questioned, he said the recipient was a “good man” and that he had made a promise to help before he knew how little money he would get. Two donors even said that after all donation-related costs, they ended up receiving nothing for their donation. One of these donors grumbled, “I didn’t know people could negotiate.... I got a big hat pulled over my head [an Iranian expression meaning he had been deceived].” He was in debt and decided to donate to help someone while helping himself, but in the end the donation actually left him deeper in debt.

Other complaints about *Anjoman* staff included slow responses to inquiries about whether a match had been secured (four donors) and when payment would be received (three donors). One female donor said, “The government promised me something, but I have no idea about the time. I don’t know when they are going to give it. We are happy, we are happy about our government. I don’t want to get myself or my father in trouble by complaining.”

Two donors complained about how soon they could go back to work. One said that he was still in a lot of pain a month after donating and, although told otherwise before he donated, he was as yet incapable of returning to his job as a manual laborer. Another expressed concern that he hadn’t found out until after surgery that he couldn’t go back to his job as a trash collector for at least 6 months due to restrictions on heavy lifting.

There were only seven complaints about medical staff. Four donors complained that nurses and doctors were slow in responding to their calls for assistance at the hospital (two of these donors also complained about *Anjoman* staff). One donor stressed, “They mostly pay attention to the recipient.... If the recipient was asking them to do something, they would quickly do it for him. But this is not the case for the donor.” Others voiced similar complaints: “They care for the patients [recipients] quite a bit and not so much us.” The other three donors expressed annoyance with the patronizing statements they would get from medical staff when they asked about potential future health issues, like “Don’t worry, you will be fine.”

Since both medical staff and *Anjoman* staff should be answering questions about recovery time and complications, it is hard to know who failed in their duty to inform the 15 donors who complained of unexpected medical consequences. Nine of these donors had medical or psychological complaints including more pain than expected, high blood pressure, exhaustion, or depression. Another four donors were anxious they would fall ill or lose their other kidney. As

one female donor explained, “I don’t think anyone who has donated a kidney is not worried about the future—about the day they may need a kidney.” Two donors complained that the healing process was taking longer than expected; one developed kidney stones after his donation and complained that he had no way to pay for the treatment he needed, since the government-provided insurance would only cover a small portion of the treatment. “I have no rights,” he complained. “I mean, it was as if I sold a shirt and that’s it. I am gone.” Two donors complained that potential employers ignoring their applications for employment because they were living organ donors. One donor shared, “I went to look for a job; as soon as they knew I have only one kidney, I was refused that job.” Lastly, one of the donors who complained about how hard it was to get work also complained that his best friend abandoned him and his fellow college students looked down on him once they found out he had donated a kidney. He bemoaned that “society and friends look very low at those who donate or sell.”

The total number of donors who had one or more complaints was 37, 74% of the living organ donors interviewed (see Table 2, sec. g; Table 3, sec. b).

Social stigma: the impressions donors fear

Several of the reasons above for donor dissatisfaction overlap with the types of social stigma donors feared they would face—for example, job discrimination or being treated with less respect by medical professionals than organ recipients. Some donors had a general sense that people had negative impressions of donors. One donor pointed out, “When people find out that you have donated, they start looking at you in a different way. They start keeping their distance.” Another donor explained what he thought was going through people’s heads: “Oh, he sold his kidney, he’s not a good person.”

Other donors feared more specific negative impressions: only one donor reported that someone thought he was a drug user because he had donated, but four donors feared that impression. While no donors mentioned family members, friends, or others thinking of them as weak or sickly, two donors said they had been discriminated against in their search for a job, and 13 donors (26%) expressed a fear that they would be considered disabled. One donor put it this way: “People think that if you remove a kidney, donors will be disabled and can no longer have a good life.” Another donor suggested his recipient didn’t ask family members to donate because of similar fears. He said, “The recipient had four brothers, but he didn’t want to ask, since none of them were married. He didn’t want there to be problems further on.”

Another thirteen donors expressed a fear of being deemed inadequate providers, and 29 (58%) had a related fear that they would be considered poor. One donor said he wouldn’t

Table 3 Themes (Coding Phase II)

Coercion/other pressures (sec. a) (some donors felt more than one type of pressure)		
	Instances where donor said "yes" to feeling pressure or interviewers found evidence of pressure	Instances where donor said "no" to feeling pressured and interviewers found no evidence of pressure
Was there any evidence that donor was physically forced to donate?	0	50
Possible pressure by family	4	46
Possible pressured by <i>Anjoman</i> staff	19	31
Possible pressured by medical staff	0	50
Possible pressure by recipient or recipient's family	7	43
Financial pressures	30	20
Total number of donors who felt at least one type of pressure =34		
Potentially vulnerable populations		
Children	0	
The mentally impaired	0	
The elderly	0	
Prisoners	0	
Employees donating to employers	0	
The poor or unemployed	15	
Women	6	
Other dependent populations (e.g., adult-child still living with parents)	0	
Dissatisfaction (sec. b) (some donors felt more than one form of dissatisfaction)		
Incidents where donor complained of unfair treatment by others		
By own family		1
By recipient or recipient's family		2
By <i>Anjoman</i> staff		19
By medical staff		7
By employer or potential employer		2
By neighbors		0
By colleagues or other acquaintances		1
Indicators of dissatisfaction		
Donor wanted more money or more benefits than agreed upon		14
Donor complained that s/he didn't get what was promised or expected		9
Donor had unexpected post-donation physical or psychological complaints		6
Donor was in more pain than expected		3
Donor's return to work was delayed		2
Donor had anxiety about falling ill or losing other kidney		4
Other		0
Total number of donors who had at least one complaint = 37		
Social Stigma (sec. c) (some donors feared more than one type of stigma)		
Donor brought up negative social stigma without being prompted		18
Donor indicated "yes" when asked if s/he felt or feared social stigma		13
Other evidence of fear of social stigma		29
Negative impressions feared by donors		
Poverty		29
Cannot provide for family (e.g., inadequate spouse or parent)		13
Drug addiction		4
Damaged (weak, sickly, unattractive, barren)		13
Other		1
Total number of donors who feared at least one kind of social stigma = 42		

tell his fiancée about his kidney donation because he didn't want her to know he was desperate for money. When interviewed 3 years later, he said his wife still thinks his scar is from an appendectomy. A second donor said, "When I spoke with my mother and the rest of my family and told them that I wanted to donate a kidney to someone, they wouldn't accept it. Because I was poor, they thought that I was going to go sell my kidney." He assured them that he was only going to get enough money to cover his donation-related expenses, and his mother consented to the donation. He complained 3 years later that people didn't believe him when he told them he hadn't been paid to donate: "Their view of kidney donation is not good. When I donated my kidney, people said that I had sold my kidney for money." A third donor, who planned to buy a car to start a taxi service, explained, "My hope for the future is that I am able to earn a decent living for my family, so I don't need to ask anybody for help. In this society, I need to earn bread for my wife and kids so I am not ashamed of myself in front of people."

One donor surprised us: she feared people would think of her as greedy. This was the donor above who needed money to complete an addition on her house. While she needed the money, she wasn't desperate and thought people might find her selfish for taking the opportunity to donate away from someone who needed the money more. This concern exists because in most places in Iran there are more people waiting to donate than those who need kidneys. Since the *Anjomans* can afford to be selective, some try to find donors whose problems they can actually solve so they don't have to deal with unhappy, complaining donors—so in Iran it is actually possible to be too desperate to be allowed to donate. While it is hard for us to believe that any donors would be branded as greedy as feared by this one donor, a donor population that is 60% unemployed or in severe debt makes it understandable why people might think most donors are desperately poor.

Even altruistic donors expressed anxiety about stigma. One such donor said, "There is a world of difference between me and these other donors [those who sell their kidneys]" He stressed that he was helping a friend out of goodness and that he doesn't want to be thought of like those other donors—the ones who are desperate enough to scribble their phone numbers on walls with "call here to get a kidney" or "kidney for sale."

Thirty-one out of 50 (62%) of the donors interviewed openly expressed fear of experiencing one or more of the forms of social stigma mentioned above. Eleven additional donors (22%) who did not bring up stigma or discuss stigma in their interviews nevertheless gave some indication of fear of stigma, such as not wanting relatives or neighbors to know they donated, lying about whether they were related to the recipient or that they were being paid to donate, or not wanting their name or face shown in the documentary film without explaining why not. When this

latter group of donors is included, the number of donors who feared some form of social stigma goes up to 42 or 84% of the donors interviewed.

Some stigma feared by donors could be reduced with education: for example, the public could be educated to understand that Iranian transplant policy no longer accepts drug users as donors and that living organ donors, once they recover from surgery, are no more sickly or weak than the general population. But it will be much harder to eliminate forms of stigma grounded in fact. As one donor put it, "Because many people donate because they are bankrupt or because they have to pay off a tort judgment, people automatically assume that those who donate are poor or some sort of criminals." Only five of the donors included in this study said they were bankrupt and only one was donating to pay off a tort judgment, but perhaps more importantly, 68% of the donors interviewed were extremely poor, and 84% overall admitted to being at least in part motivated by a need for money (see Table 2, sec. f; Table 3, sec. c).

It is also worth noting that almost none of the donors interviewed mentioned any of the non-cash benefits *Anjoman* and medical staff frequently mentioned in their interviews. No donor mentioned the exemption from military service as a reason for donating, and only one donor even qualified for the exemption. Only one donor mentioned wanting to take advantage of the small business loans available through most *Anjomans*. Only two donors mentioned healthcare benefits as one of their reasons for donating, but both donors were promised a considerable amount of additional coverage on top of the usual 1 year voucher booklet provided by the national government: one donor was promised 5 years, and another was promised 7 years of coverage for her and her immediate family. Another donor mentioned extra health insurance as part of his compensation, but didn't include it as a motivation for donating. Other incentives mentioned by medical and *Anjoman* staff such as reduced college tuition, free dental care, and job services, were never mentioned as a reason for donating, only in passing by a few donors as something included among their donation benefits: three donors got dental care, one got a small business loan, and another two got help with finding a job. No one mentioned wanting to go to college.

All this goes to affirm that the main benefit sought by living donors in Iran is money, and all other motivations, even the altruistic ones (e.g., to please God or help another human being), and all other incentives (e.g., exemption from military service, healthcare coverage, educational benefits) are of secondary importance. Given these facts, it is understandable that donors fear the general public will think they are motivated by money or are desperate for money, because most donors are.

Limitations

The greatest limitation to this study is its small sample size. But given that Iran is a closed society where it is difficult for foreigners to do research, the data presented here is a valuable contribution to existing research. Hopefully in the future, a larger study will be possible. Another limitation is the age of the data. The fact that the majority of the interviews took place 9 years ago is not ideal, but Iranian policies regarding compensated kidney donation have not changed in the last two decades so the age of the data used here is less significant than the even older data used in the Tong et al. article which was collected before the national laws regulating living organ donor compensation were passed and/or implemented.

Another limitation is that this study relied on data collected from only six out of 31 Iranian provinces. It is possible that including data from the remaining provinces would alter the results. Note, however, that the six provinces where the CES data were collected are six of the largest transplant regions in Iran and some provinces have no transplant programs at all. Future studies may wish to divide data by the different types of regional policies: most regions follow the “Tehran model” described in this article which most articles on the Iranian system of compensated kidney donation simply call the “Iranian Model”. Under that model there is a fixed subsidy provided by the national government but also some leeway to negotiate how much recipients and their families contribute to the final total received by donors. But it is worth noting that Shiraz does not follow this model. In Shiraz, donors and recipients have to sign sworn affidavits that state donors are not being paid and, if the rules are followed, donors get no money beyond the nationally provided *issar*. It is possible that other variations in the basic model exist in other provinces and that those variations may increase or decrease whether donors feel pressured, satisfied, or social stigma.

Conclusion

In 2012, Tong et al. published an article analyzing the work of seven researchers on compensated living organ donation, including the results from three studies done on living organ donors in Iran (two by Dr. Zargooshi with data from 1889 to 2000 and one by Dr. Tober with data from 2002). All the data on Iran were collected before the new Iranian national system of subsidized organ donation (passed in 1997) was fully implemented. We have provided an analysis of compensated living organ donation in Iran based on data that reflects the newer and currently active regulatory system. Our analysis is valuable because it more accurately reflects the living organ donor experience in Iran than the Zargooshi

and Tober studies relied upon by Tong, et al. In particular, donors in our study are not nearly as unhappy as the donors in Zargooshi's and Tober's studies, but nonetheless, we found some significant negative findings. The majority of compensated kidney donors in Iran face severe financial pressures, have numerous complaints about how the system is administered, and fear social stigma. More research is needed, but we wonder if some of what we found implies that certain problems such as the stigma of poverty may be inherent in any system that is incentivized through financial compensation, no matter how well regulated.

Compliance with ethical standards

Conflict of interest None of the authors have any conflicts of interest.

Human and animal rights No animals were used in the study.

Ethical approval An IRB letter that indicates that IRB approval is not needed for this qualitative ethnographic study is attached.

References

1. Tong A, Chapman JR, Wong G et al (2012) The experiences of commercial kidney donors: thematic synthesis of qualitative research. *Transpl Int* 25:1138–1149. <https://doi.org/10.1111/j.1432-2277.2012.01534.x>
2. Zargooshi J (2001) Iranian kidney donors: motivations and relations with recipients. *J Urol* 165:386–392. <https://doi.org/10.1097/00005392-200102000-00008>
3. Zargooshi J (2001) Quality of life of Iranian kidney donors. *J Urol* 166:1790–1799. <https://doi.org/10.1097/00005392-200111000-00040>
4. Tober DM (2007) Kidneys and controversies in the Islamic Republic of Iran: the case of organ sale. *Body Soc* 13:151–170. <https://doi.org/10.1177/1357034x07082257>
5. Ruznamehi RJII (1997) The bill on kidney donors. The Official Gazette of the Islamic Republic of Iran: Byelaw on Kidney Donors. No. 15146
6. Center for Ethical Solutions (CES) (2008) Documentary footage from Iran. U.S. National Library of Medicine Historical Audio-visuals Accession #2017-04 (2017)
7. IRODaT. In: IRODaT—International Registry on Organ Donation and Transplantation. <http://www.irodat.ORG/>. Accessed 7 May 2017
8. Fry-Revere S (2014) *The kidney sellers: a journey of discovery in Iran*. Carolina Academic Press, Durham, North Carolina
9. Bolton L (UNOS Policy Department) (Open for public comment Jan. 23, 2014–March 24, 2017) A white paper addressing financial incentives for organ donation, Organ Procurement and Transplantation Network / United Network for Organ Sharing Public Comment Proposal
10. Shivayogi P (2013) Vulnerable population and methods for their safeguard. *Perspect Clin Res* 4:53. <https://doi.org/10.4103/2229-3485.106389>
11. Ghods AJ, Savaj S (2006) Iranian model of paid and regulated living-unrelated kidney donation. *Clin J Am Soc Nephrol* 1:1136–1145. <https://doi.org/10.2215/cjn.00700206>