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QUALITY OF LIFE OF IRANIAN KIDNEY "DONORS"

JAVAAD ZARGOOSHI*

From the Department of Urology, Kermanshah University of Medical Sciences, Kermanshah, Iran

ABSTRACT

Purpose: The quality of life of Iranian kidney vendors was clarified.

Materials and Methods: A questionnaire was completed by 300 kidney vendors 6 to 132 months postoperatively (median 61). Interviews and living conditions were videotaped. In addition, the 300 vendors and 100 controls that underwent nephrectomy for benign disease completed the RAND 36-Item Health Survey (SF-36).

Results: Poverty prevented 79% of vendors from attending followup visits, and vending caused negative effects on employment in 65%. Of the families 68% strongly disagreed with vending, which caused rejection of 43% and increased marital conflicts in 73% of vendors, including 21% who divorced. There were 70% of vendors isolated from society, and 71% had severe de novo postoperative depression and 60% anxiety. Vending caused somewhat (20%) to very (66%) negative financial effects. It also had negative effects on the physical abilities in 60% of vendors who were mainly unskilled laborers, and 80% were dissatisfied with postoperative physical stamina, which was decreased mostly by depression. Of the vendors 37% concealed the truth of kidney sale from anyone, 14% disclosed it only to spouses, 43% to first generation relatives and 94% were unwilling to be known as donors. The mental preoccupation with kidney loss was usually (30%) to always (57%) present and interfered negatively with vendor life, and 62% reported negative effects on sense of being useful. Effects on general health were somewhat (22%) to very (58%) negative. When thinking about vending, the majority cited negative feelings. They responded that if they had another chance 85% would definitely not vend again, and 76% strongly discouraged potential vendors from "repeating their error." Half the vendors were ready to lose greater than 10 years of life and 76% to 100% of properties to regain kidneys. Compared to controls, vendors had significantly lower scores on all SF-36 scales ($p < 0.001$).

Conclusions: Our sample is a good representative of Iranian kidney vendors, with the majority having psychosocial complications. Globally, the medical community should focus more attention on motivations, quality of life, health and opinions of kidney vendors.

KEY WORDS: kidney, kidney transplantation, living donors, quality of life, commerce

INTRODUCTION

The importance of patient opinion regarding medical procedures has been accepted unanimously. However, with vendor nephrectomy, the lack of communication with patients is evident. There are plenty of ethical philosophical discussions but without empirical support or study. Paid, living unrelated renal vendors constitute greater than 90% of kidney "donors" in Iran. We have shown elsewhere that 97% of these "donors" are kidney sellers (vendors), there is no hint of vendor-recipient "emotional relatedness," and our sample is a good representative of a whole population of paid, including related and unrelated, vendors in Iran.[1] Internationally, quality of life has been studied in kidney donors, and reviewed literature generally shows satisfaction of donors and excellent quality of life.[2–7] However, there is no study of kidney vendors. To address this lack of information regarding vendor quality of life, we evaluated the issues and psychosocial repercussions of "donation" in 307 "donors" in Kermanshah, Iran. Of these donors 300 (97.7%) regarded themselves as vendors explicitly. To our knowledge based on a MEDLINE search from 1966 to January 15, 2001, this is the first report of kidney vendor quality of life in scientific literature.

MATERIALS AND METHODS

We visited 310 "donors" who had undergone surgery from 1989 to 2000 at a public medical center in Kermanshah, Iran.

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* Requests for reprints: zargooshi@yahoo.com.

From the beginning of the transplant program in mid 1989 to June 21, 2000, 594 "donor" nephrectomies have been done. Of these procedures 565 (95%) were paid vendor transplants. Of the 310 patients evaluated 3 refused to participate in the study, and so we continued with the remaining 307. Informed consent was obtained from all participants. There was no difference in demographic characteristics of patients whose place of residence was or was not known. Of the patients 49 were included in Project 76012 at our university, and the motivation for vending and relationship with the recipients were reported.[1]

Of the 307 patients 300 (97.7%) clearly regarded and called themselves kidney sellers (vendors). Characteristics of the vendor sample are presented in table 1. A total of 290 patients were unrelated and 17 were related to the recipient. Of the related "donors" 10 were vendors and their answers were not different from other vendors. Experiences of the 7 related donors who were not vendors were markedly satisfying and are not mentioned further. All data refer to the 300 vendors only. Of the family members we interviewed there were 50 spouses of vendors who had entered the vending process seriously but were rejected by the nephrologist because of blood group incompatibility, angiographic findings, diagnosed urological disease, or prevention from vending by the spouse or relatives, or their own later refusal to vend.

Vendors completed a questionnaire that was the product of working with vendor focus groups, WHO guidelines[8] and other studies of living related renal donors.[3] The questionnaire was self-administered if respondents were sufficiently

TABLE 1. *Demographic characteristics of vendors*

% Men/women	71/29
Mean vendor age ± SD (yrs.)	33 ± 15
Mean mos. postoperatively ± SD (range)	63.6 ± 33.3 (6–132)
Median mos. postoperatively	61
% Currently married	81
% Insured	4
% Drug abuser	3
% Employment status at interview:	
Unemployed	27
Home duties	18
Part-time	42
Full-time	13
% Education:	
Illiterate	35
Less than high school	60
High school degree	5

TABLE 2. *Mean SF-36 scores plus or minus SD of vendors and controls*

	Vendors	Controls
General health	35.2 ± 7.5	77.3 ± 12.5
Physical functioning	62.5 ± 9.3	87.4 ± 11.1
Role physical functioning	48 ± 11	82.7 ± 9.4
Role emotional functioning	30.1 ± 10.9	80.9 ± 13.7
Social functioning	34.8 ± 7.7	83.9 ± 15.4
Bodily pain	64.9 ± 8.2	82.1 ± 16.8
Vitality	37.9 ± 4.5	69.3 ± 9.9
Mental health	43.3 ± 13.5	75 ± 17.2

able to complete it, otherwise, interviewer assisted or administered forms were used.[8] In addition, we videotaped the interviews and living conditions of the participants. Based on WHO guidelines, the questions focused on respondent "perceived" quality of life rather than the objective measurement of health and functional status. Nonetheless, we checked the accuracy of vendor statements regarding financial difficulties, loss of work or postoperative complications by interviewing independent observers and referring to hospital records. The questions were in regard to perceived objective, self-reported subjective and importance of behavior, state or capability.[8] No interval was included in the questions, and many questions were not multiple-choice.

The questionnaire was tested in a pilot study and modified accordingly before being used in the final phase. The pilot and final studies were performed by visiting the vendors. Vendors and a matched group of 100 controls that underwent nephrectomy for benign disease also completed our own Persian translation of RAND 36-Item Health Survey (SF-36). SF-36 data are presented as mean plus or minus standard deviation (SD). Differences in mean values between vendors and controls were analyzed by a 2-tailed unpaired t-test, and significance was defined at the 0.05% level. The author has no relationship to the transplant program.

RESULTS

Survey results. Our survey results are presented in the Appendix. Our findings contained markedly negative effects of and a high rate of dissatisfaction with vending on physical abilities, which were important to vendors. There was an extraordinary lack of information about preservation of the remaining kidney, difficulty making the decision to vend, markedly negative effects on employment status, general disagreement with family members about vending, and negative effects of vending on family, marital and, especially, social relationships. An unwillingness of the vendor to be known by society, concerns about the future and their mental preoccupation in this regard, high rates of self-reported de novo depression and anxiety after vending, and generally negative effects of vending on health and life existed. Finally, they regretted their decision as expressed in the response to willingness-to-pay for health improvement and time tradeoff questions, low rate of reaffirming the decision to vend, high rate of discouraging potential vendors and a range of bitter feelings when thinking about having only 1 kidney. Compared to controls, vendors had significantly lower scores on all 8 SF-36 scales ($p < 0.001$, table 2).

Qualitative results. Some of the vendor statements from our recorded interviews were:

Mowlood S. M.: Despite working hard during all of my life, if I not work a single day we should sleep hungry. Here is heaven for thieves, brokers and hypocrites, and prison for toilers. Meat consumption of our whole family is 0.5 kg. weekly. When one has no capital, he should die or live miserably.

Fatolaa F.: Like a cigarette end we have been thrown out. We are crushed by poverty and exploited by parasitic mercantile capitalism that press us to sell our only remaining belongings—our kidneys—only to lose. Our life is a closed circuit. My children are tortured by poverty. My 8-year-old girl gave her earring to me to be given to our house owner in place of house rent (weeping) . . . I was struggling with myself for 3 months preoperatively, to persuade myself to undergo operation and vend my kidney. During this period, my condition was worse than a prisoner waiting execution.

Leilaa A. M.: My husband persuaded me to sell my kidney, and I paid all of my kidney money to indemnify my husband car accident damages. I thought that my husband would appreciate and respect what I did for him. However, I was mistaken, and even before stitch removal, he struck my operated flank and kicked my wound twice during quarrels. After vending, his behavior with me was as if I am useless and dying.

Jalaal Sh.: Kidney vending destructed my life. A loan shark lent us money at exorbitant rates of interest and we will never rescue from him.

Mahmood G.: Before vending, I was using my horse to bring smuggled goods from border. After vending, I lost this way of living because of my flank pain and my vulnerability to being captured as I lost my quickness, adaptability and versatility before vending that gave me the opportunity for escape in case of danger . . . it is now 8 years that I have not bought a single new clothing for my children. The only lasting effect of my kidney vending has been that all those informed of it has changed my name to Mahmood the kidney seller.

Ghadam Kheir R.: We are at zero level. This life does not deserve living.

Hamid Rezaa Kh. (while showing us a hand grenade): I always keep this grenade for exploding myself if my remaining kidney get trouble because I am sure of my inability to buy a kidney and I do not bear lifelong dialysis . . . at least 3 times weekly in my dreams I see my kidneys intact. I am in a constant state of grief for my kidney, akin to my state soon after death of my close relatives . . . my boss was relative of the recipient and immediately after becoming certain of rejection of the kidney, threw me out of work.

Soltaan Ali K.: God know that the last time we ate meat was 6 months ago, and that meat too was provided by someone who had a vow (nazri). Our sole food is bare bread . . . I have a symptomatic hernia for 10 years and I am unable to pay for its operation.

Behrooz R.: Preoperatively, to persuade and deceive me my very rich merchant recipient claimed "You are like one of my sons. I will buy a car and a house for you, and if you give me your kidney, I ensure lifelong support and employment." However, several weeks postoperatively, after I submitted the entire 200,000 Tomans of kidney price directly to usurers, when I returned to him to lend me 5,000 Tomans (approximately $6 United States [$1 United States equals 800 Tomans]), even in exchange for a check Hajji replied harshly

"You wasted a bag of money, so what can you do with 5,000 Tomans?" and rejected me. . . my family attempted to kill my recipient upon being informed of my vending the kidney. . . doctors say half of the truth. We learn the other half ourselves later by our own experiences. . . . Seeing a beggar, I always think that he is fortunate enough to select a better way than kidney vending. I felt myself responsible for enlightening potential vendors about what they should expect of their vending a kidney.

Mehdi K.: I will kill myself with my gun in case of becoming dialysis dependent.

Hojatolaa R.: Relatives of my wife severely objected me for my wife vending her kidney, stating "We gave our girl to you to remove her kidney?"

Farhaad A.: Never in my life has I been generous, merciful and altruistic. No altruism involved, only poverty.

Ali Rezaa K. G.: I sold my kidney to pay my wife's medical expenditures. However, upon being cured of the disease, she divorced and left me forever.

Faride A.: Heavy traffic of creditors created the impression in our neighbors that I am a prostitute and the visitors are my patrons. To defend my honor, there was no way other than to sell my kidney. . . after vending, during a fight, our neighbor cried "You kidney seller! If you were good people you would not sell your own body (the kidney)." Ebraahim A., the husband of Faride A., also sold his kidney.

Farmaan M.: I crush and feel embarrassment when someone talk of kidney and dialysis. I feel that the speaker has an eye to me and try to torture me by recalling me what I did. I feel that the speaker has accompanied me in all steps of vending, although the speaker is a stranger. . . . After vending, my recipient rejected my request to lend me a refrigerator, even in exchange for a check. He said "By default, all of the vendors' checks are discredited checks." Masoome K., the wife of Farmaan M., also sold her kidney.

Gholaam Rezaa Sh.: Unable to pay a 130,000 Tomans ($162.5 United States) debt, during the last 3 months I have not had the courage to go out of home, fearing exposure to my creditors. . . . There is nothing to link us to life and we wish dying each night. After 3 days of total starvation of my family, I ate poison to kill myself, but unfortunately my children who saved me returned me back to this miserable life.

Ali Asghar Sh.: I wish for my recipient endless trouble and difficulty because he deceived me with his unrealized promises. . . . The cause of all of our problems is that we have no capital, and capital owners left no way for us other than to sell our kidneys, in addition to our work force, only to live in this miserable conditions. We are the victims of oppression of capitalism.

Ahmad M.: Being a bedridden cripple is preferable to being a vendor, considering intolerable effects of vending on our nerves and social interactions.

Batool A.: People see me as a cripple, and treat me as if I have leprosy. In a clash with my neighbor she shouted "If you touch me, I do what I can to you!"

Aaref F.: I think that one should not damage his body and should return his body to God as healthy as was given to him. Because of infringement of the contract between God and us through kidney vending, we do not receive any piece of good fortune from kidney's money.

Jasim N.: I sold my kidney under my brother's pressure who dictated kidney sale to pay his 50,000 Tomans ($63 United States) debt. . . . It is now years that we spent 250 Tomans for meat (125 gm.) every 2 weeks, and eat 1 fruit serving each 20 days. (1 kg. of sheep meat in Kermanshah costs 2,000 Tomans [$2.5 United States.])

Karim P.: As you see, the entire contents of my falling home are a small heater, a worn out carpet, several spoons and dishes, and a bed. It is now 6 months since we last ate meat and rice, and the last time we ate fruits was 2 months ago. In multiple occasions I tried suicide but saved unfortunately. I will kill myself as soon as a suitable opportunity is prepared.

Mohamad M.: After eating our last bread, and after there was not even a single bit of bread to eat, I poisoned myself to reach to the comfort and relaxation of dying but unfortunately, I was saved. . . . I do not return to hospital for checkup because after vending, I hate hospitals and their personnel.

Nowrooz Ali M.: Despite being a manual laborer for many years, at the end, my wife is a beggar and I am a vendor.

Soleimaan H.: I has become obsessive about my remaining kidney. I think I have edema and doctors find no edema.

Nasrin D.: I constantly feel my empty flank.

Shamsodin D. B.: I wish I would give my kidney to a dog to eat than giving it to Seifolaa M. (the recipient) because of his hateful ingratitude. He is a millionaire, but ripped off my 50,000 Tomans ($62.5 United States). I sold my kidney to bring my wife back to home. The wife left home because of abject poverty and multiple days of absolute hunger.

Ebraahim K.: Immediately before vending, we were dying of starvation. . . after vending, I provided water and electrical power for our home and bought foodstuff of several months. After vending, I regularly see painful dreams. . . . All of our properties do not cost 100,000 Tomans ($125 United States), so, how can I buy a kidney if needed?

Fardin A. R.: The husband of the recipient said that he had sworn an oath that give "all of his belongings" to the kidney donor of his wife. However, after his wife received my kidney, he offered none of his properties, and laughing at me he stated "I only said something you liked to hear." I lost my work after vending, as my absence during convalescence was not regarded as a medical leave because I decided to hide my surgery and kidney vending.

Gol Bahaar Z.: All of our marital conflicts are due to poverty, that make us irritable, unhappy, bad tempered, and morose. . . 4 days after vending, and while I had severe postoperative pain, my mother come to visit us. To prevent disclosure of my kidney sale, I performed household duties as before, despite severe pain to not sensitize my mother that there occurred a problem.

Hosein H.: After vending, I have no relish and gusto for work. My former work place is a prison for me and I have no appetite and zest to work. (This was also one of the most common statements made by other vendors.)

Yahyaa A.: Mental concern does not leave me even when driving. . . . We are trapped in a blind alley.

Khadije F.: I sold my kidney for my husband's hemorrhoid operation. However, the operation failed.

Eftekhaar Saadaat T.: My brothers bitterly protested that your kidney vending degraded and broken us forever, and left me. (She had divorced and his former husband prevented her from visiting their children, all of them were ordered to live with their father, so she was in total isolation and severely depressed after vending.)

Badri A.: I wish I had several kidneys to sell all of them except one. In case of urgent need for money, the only way before us is to die, as there are absolutely no resources to depend.

Tayebe A.: After vending, to guarantee paying laboratory expenses following a blood test (a creatinine check), I left my identity certificate in the laboratory but never returned to reclaim it again because there was no money to pay in exchange for the certificate. Also, after a visit, I was unable to pay for the prescribed drugs and did not get them. We eat very irregularly, on average only one meal per day. My husband left us forever, being unable to provide basic needs for the family.

Pari M.: After vending, after 6 months of flank pain, I finally visited a doctor. He ordered a laboratory test and a

sonography. I was unable to pay for these tests and returned home without any treatment.

Mohamad Hasan B.: My wife satirize and humiliate me and say "these useless properties in our home were bought by your kidney money; otherwise you was too incompetent to provide them by more prestigious ways. I am selling my home equipment (television, refrigerator, etc.) for daily living, and I projected to be a beggar in future.

Heshmat R.: Dying is far better than our living. We have no future. (This vendor came from Ilam province. The rate of suicide in this province in the Persian year 1376 (1997 to 1998) was 68/100,000 people, and suicides were characterized by a high rate of seriousness [50% death rate], dominance of young female victims, and setting themselves on fire as the method of choice.[9])

Mohamad Amin M.: If I had enough money, I had certainly had to buy a kidney to replace my lost one, the torture of its absence never leave me.

Ahmad E., Rasool H. and HamidRezaa Kh., among others, were repeatedly questioned by neighbors and authorities whether they were addicted because of their pale faces and weakness. The vendors refused to explain the cause of their problems, including postoperative complications and malnutrition, and the neighbors became certain that their impression was correct.

Soheilaa G. H.: If my brothers know my secret of kidney sale, they press me to divorce from my husband because he was unable to provide our basic needs with resultant obligation for me to sell my kidney.

Fereshte M.: It is now 10 years that we are paying the interest of a 100,000 ($125 United States) loan borrowed from a usurer. (We visited her "house" bought by kidney money, that is a 3 m. little shop in middle of other working shops, devoid of bath, refrigerator and electric power.)

Anbar R.: My husband is drug addicted. Our whole put aside money is not even 1,000 Tomans ($1.25 United States). If you saw my kidney money, I too saw it. My husband paid all of the money to his creditors. His monthly income is 15,000 Tomans (approximately $19 United States).

Heshmat W.: I sold my kidney to pay my debts to my brother.... After vending, a stone was diagnosed in my remaining kidney but I declined crushing it because I have no money to pay. I live with that stone now.

Kobraa R. (while weeping bitterly): After several months of being unable of buying meat, I lend 2 hens only for Noe-Rooz (the greatest Iranian festival, which is The Persian New Year celebration that has been celebrated for at least 5,000 years) and only because I felt guilty before my children if not celebrate Noe-Rooz. I swear to God that my children and I do not eat meat for many months, eat fruit only in others' parties and eat wild plants of mountains. I came here with a bus ticket and I have no another ticket to return home. I exempted my girl from attending school at all because we are unable to pay the school... life is a constant torture for us, and any minor improvement is akin to the medical care that the tortured persons receive to live longer only to withstand further tortures before being killed. Mohamad K., the husband of Kobraa R., also sold his kidney.

Rezaa Gh.: I asked the teacher of my schoolchildren to exempt them from doing homework exercises because we were unable to buy notebooks. (In separate interviews with no opportunity for coordination of statements his children and the teacher of his children validated his statements.)

Molook A.: I continuously reassure myself that my lost kidney is present inside my body to deny the depressing effects of the reality.

Naiime O.: If people know my secret of vending my children will be subjected to irony and stigmatized as being grown by kidney's money.

Ali T.: Owner of my house said "I let house with hope of obtaining rental. You have even no bread to eat, so how you pay your rental?" and thrown us out. All ways are closed to us. There is no support at all.

Of the vendors who were mostly uninsured wage laborers 38% lost their jobs due to absence from work because of postoperative pain and disability. At the interviews, a minority of these vendors resorted to part-time work for low wages, begging or home duties. In 19 families the wife and husband sold 1 kidney each. Despite living in the same miserable conditions as vendors, the remarkable finding in 50 potential vendors was the extraordinary lack of psychosocial difficulties, suggestive of their accommodation to and acceptance of wretched living conditions. Of 50 potential vendors only 3 (1.5%) reported severe de novo depression and 4 (2%) severe de novo anxiety. None was socially withdrawn. None, including the spouse, was informed by the 37% of vendors about the secret of kidney vending. All of these patients except 3 were male. In such cases vendors told their spouses that they were going on a trip, and after returning home, they presented such excuses as being traumatized in quarrels or car accidents, undergoing surgery for urolithiasis, nephrectomy for medical disease and so forth to justify the scar.

There were 39% of vendors who stated that they would certainly and unavoidably leave their present residence in case of disclosure because of intolerable pressure, stigmatization, and rejection by family and relatives for committing an inexcusable wrongdoing. Of vendors 84% stated that in case of disclosure people regarded them as unable to earn money by other, more respectful ways. Also, 81% stated that people would sarcastically say that vendors are so ruthless that they did not have mercy and leniency on their own body, so how could they have mercy with any one else, including the recipient and their own children. There were 60% who expected to be dialysis dependent and die of the inability to preserve the remaining kidney, considering their certain inability to pay and attend followup visits. Many vendors resorted to pseudo jobs and were stressed from concealed unemployment. The usual scenario for those vendors who did not give their entire kidney money to usurers immediately postoperatively was to expend it during unpaid convalescence.

Several vendors had dreams of being dialysis dependent. Others stated that they saw themselves in their dreams as having their lost kidney intact with no scar in their flanks and awaken happily only to realize the depressing reality of having only a single kidney. Painful dreams were also common. The patients struggled with flank pain in dreams. Preoperatively, many vendors were so confident in medical professionals that they believed that if there were any complications they certainly would be informed. However, postoperatively most of the vendors lost confidence in the medical profession, observing their unexpected postoperative complications. Many vendors based their knowledge of effects of kidney loss on observations of single cases of nephrectomy in their neighborhood.

Many swore that they did not eat fruit and meat for several weeks, and their weak bodies and pale faces were clearly supportive of their statements. The average frequency of eating meat and fruit in our series, according to vendors and families, was 2 meals monthly and 1 serving weekly, respectively. By far, the single most common foodstuff consumed by the vendors and families was bare bread eaten with tea only, unaccompanied by any other food. The average monthly income of the studied vendors was 12,000 Tomans ($15 United States), average debt 400,000 ($500) and average total hoard 35,000 ($43.7). Typically, the home of the visited vendor was a single, wet dark basement densely populated by numerous children.

Many vendors had used analgesics daily but sought no medical visits, and stated that this was because of the inability to pay the fees. However, a minority stated that they were so depressed and hopeless that they hated life and wished to

die, and that they would not go to doctors to die and be disposed of their tortured life. In many cases those vendors who attended early examination declined to continue merely because they were given the assurance that there was no problem during these examinations. In some cases the vendors thought that taking analgesics may be harmful and, thus, tolerated severe pain without treatment. The minority of vendors who had no mental preoccupation or worry about kidney loss stated that the reason was the enormous daily living difficulties and survival struggles that left no time to think of the kidney rather than the absence of vending related problems.

Of the 9 addicted vendors 6 were addicted postoperatively. There were enormous multiple somatic complaints, including but not limited to palpitation, tremor, chest pain, dyspnea, nervousness, headache, knee pain, backache, easy fatigue, dizziness and faints, mouth dryness, generalized pruritus, anorexia, nausea, impaired memory, and emotional instability and irritability. We did not find such a high incidence of somatic complaints among controls or potential vendors. Some vendor fears were unfounded. However, these unsupported phobias had contributed significantly to their limitations of physical activity or social functioning.

The vendors lived in a hostile, harsh environment, with many physical fights over trivial problems or small amounts of money. Several of them received kicks to their remaining kidneys or flank that was operated on during these exchange of blows. Fear of sustaining injury to the remaining kidney with the inability to defend themselves in these fights was disadvantageous. Also, many female vendors were hit by their husbands postoperatively, some even before stitch removal. In fights with strangers the most common cussword stated by almost all vendor opponents was "you kidney-seller!" Almost all vendors who received this curse thought that opponents were entitled, and they had no compelling reply and were humiliated. Of the 6 vendors who reaffirmed the decision to vend 5 stated that they were willing to vend the remaining second kidney and to be dialysis dependent only to reduce the financial hardships even temporarily. All 5 vendors had heavy debts to usurers.

Many vendors had tried to contact their recipients postoperatively but they refused. In other cases when vendor multiple visits with recipients remained unanswered, they discontinued further attempts. Many said that their recipients refused to give their telephone number and/or gave false addresses. Vendors stated that the main reason was that the recipients believed that in case of a continuing relationship, the vendor may ask for money or some other help. It was noteworthy that to confirm statement accuracy, the majority of vendors insisted that we should not limit ourselves to their accounts and should check their statements by referring to independent sources.

Some vendors felt guilty and thought that they had been punished for their presumed sins. To explain why the money the vendors received had not changed their lives, some believed that the kidney money was prohibited (haraam), and no one could enjoy a lucky thing and a piece of good fortune (kheir) from this money. Some women resisted the pressure of the husband not to vend. Husband pressures were mainly due to such cultural traits as considering the woman as "weak" and "in need of support" from the traditional husband role as provider for the family. Also, fear of objection by the parents of the wife was involved. However, a minority of wives stated that husbands "persuaded," "convinced" or pressured them to sell their kidneys, while preventing disclosure of the secret to be immune to parent objections and actions. Many vendors stated that they genuinely wished they died because of intolerable poverty.

DISCUSSION

Quality of life has gained increasing importance in medicine, and urology has not been an exception. It has also been studied in kidney donors, and all such studies have shown generally excellent quality of life in them. Johnson et al sent a questionnaire to 979 American donors, and of the 60% who responded the vast majority had excellent quality of life.[2] As a group they scored higher than the national norm on the SF-36. Jacobs et al studied 524 donors who had a higher quality of life than the general population, and an overwhelming 96% would donate again.[4] A total of 104 Canadian donors were reported on by Vlaovic et al, and less than 5% of them said that renal donation severely affected any aspect of life.[5] For the 55 kidney donors evaluated by Corley et al all quality of life scores were high.[6] Of the 167 donors in the study by Schover et al 90% would make the same choice again and 83% would strongly encourage others to donate.[3] Westlie et al examined 494 Norwegian donors and concluded that the quality of life is better than that in the general population.[7]

Our results are in sharp contrast with the aforementioned because our participants are vendors and not donors. They had no altruism to depend on or get support from to enrich their miserable lives. We have no objective information about the preoperative psychosocial condition of vendors. However, based on our own observations of vendor living conditions, and interviews with vendors and independent and key informants we found no reason to believe that they were less than truthful. In fact, the vendor insistence on checking their statements against those of independent sources supports our impression that if they were less than truthful they would be unsatisfied with our contact with others to check for accuracy. Being a select group of the general population, one expects that they had no significant problems preoperatively. Regardless, in quality of life studies the optimum source of information is the patient and not anyone else. It is not the duty of quality of life studies to prove or disprove patient statements and views.

All pain is affected to some degree by an emotional state and psychosocial factor. Considering the high rate of depression, it is not surprising that some patients had pain. Certainly, division of intercostal nerves during nephrectomy may also cause pain. Of the vendors 79% had no followup visit after removal of stitches, and almost all reported that it was due to the inability to pay the fees. The remaining vendors cited such excuses as an unawareness of the need for followup, willingness to die and distance from the city. Vendors were pathetically uninformed about how they could optimize preservation of their remaining kidney. The most common way of "protecting" the kidney was to wear a sash around the waist to prevent "kidney cold." Many vendors were athletes and forced to end sports permanently because of pain and physical limitations, risk of exposure of the scar or fear of injury. These effects severely limited leisure time activities and contributed to depression according to vendors.

Vending, especially the psychological complications, severely affected employment potential. Many vendors predicted eventual renal failure and with the lack of any social support if that happened, they lost the energy and impetus to work. In some instances such fears were clearly unfounded but nonetheless contributed significantly to failure to fulfill potentials. Some were frightened of injuring their remaining kidney during work and, thus, abstained from working. Also, being uninsured wage laborers, many vendors lost work against their will because of absence from the workplace postoperatively during convalescence. Of those parents who became aware of impending vending 68% strongly disagreed with it and pressured vendors to cancel the procedure. Whenever attempts failed they punished the vendor with rejection, isolation and coldness, which resulted in a high incidence of

disrupted family relationships, and marital relations were affected negatively with frequent quarrels and conflicts. The 21% divorce rate is higher than the 15% average in Iran.[10]

Despite objection of kidney vending, parents were unable to offer any significant financial help to dissuade vendors. In some cases vendors had borrowed small amounts of money from family members, mainly brothers. The brothers then pressed them to sell their kidneys to pay the debt. In fact, in several cases the sole reason for vending was pressure from the brother. These cases illustrate the dilution and disappearance of humanitarian and family ties, and sympathies by abject poverty. Of vendors 78% considered the decision to vend difficult, and many canceled the operation repeatedly even over the operating table before finally undergoing surgery. Indeed, the escape of vendors from the ward the night before surgery was quite routine and occurred despite the fact that the majority of them, including women, stated that they vended under the pressure of poverty, and no one had a significant influence on their decision.

One of the most devastating effects of vending was damage to social relationships, with 70% who became isolated, irritable and hated social contacts. Many vendors had been so sensitized and felt humiliated when someone talked about any general topic, such as kidney or dialysis. They believed that the speaker was aware of their vending when talking about such matters. Also, many abstained from their favorite sports, and this increased isolation. Although receiving $250 (earlier vending) to $1,250 (recent) United States equivalent for kidneys, vendors lost much more financially for many reasons. Postoperative, mainly psychogenic, disabilities prevented many vendors from resuming work, and many uninsured wage laborers lost jobs because of absence from work.

Few recipient preoperative promises, including providing material gifts and/or employment, materialized. Money was rapidly worthless due to increasing inflation rates, and many paid the entire money to the usurers immediately postoperatively. Considering the fact that the main or sole reason for donation was financial,[7] it became clear that in the absence of altruistic motivations on which the vendors could depend, financial losses became intolerable and depressing.[1] Accuracy and reliability of vendor statements regarding financial and/or employment problems after surgery were confirmed in 95% of cases by independent observers and objective data, including documents. For the remaining 5% of vendors, 70% to 90% of statements were confirmed and those disputed were trivial details. Our personal videotaped observations of miserable living conditions were also supportive of vendor honesty, the vast majority of vendors deprived of the most elementary necessities of life.

In other Iranian cities the vendors have more opportunity to maneuver and negotiate with brokers and recipients to obtain more money in addition to the standard 10,000,000 Rials (approximately $1,250 United States) that is given to all vendors.[1] However, vendors in Kermanshahian are so poor that they are content with the standard fee, and several of them did not take any extra money from the recipient. According to officials, of the 28 Iranian provinces Kermanshah is the twenty-eighth in average income and first in unemployment.[11] These officials announced that there is 30% overt and 45% covert unemployment in Kermanshah, and 95% of the population has financial hardship.[11] Although most pronounced in Kermanshah, increasing poverty is not limited to this province. Economic research has shown that from 1984 to 1997 (Persian years 1363 to 1379) a 64% increase, in consumption of flour and macaroni and 41% decrease in consumption of meat in Iranian cities occurred, indicating that people resorted to grain in place of meat.[12] Although official figures for poverty in Iran are 70,000 Tomans ($87.5 United States) monthly for towns and 48,000 ($60) monthly for villages, economists state that those officials who announced these figures know fully how far the figures are from the real poverty line.[13]

Economic research shows that the real poverty line in Iran is an average of 130,000 Tomans ($162.50 United States), with 200,000 ($250) for large cities like Tehran, 170,000 ($212.50) for moderately large cities, 120,000 ($150) for small cities and 100,000 ($125) for villages.[13] It also demonstrates that 80% of the Iranian population is poor.[12] Of this 80%, 30% is in absolute poverty and 50% relative poverty. While 33% of Iranian population was below poverty line in the Persian year 1356 (1977 to 1978), this has increased to 60% in Persian year 1379 (2000 to 2001).[12] Economic research has shown that during a 15-year period, expenditure by urban families on foodstuff has decreased by 41%.[12] During the last 20 years the income of Iranians decreased by 30%.[14] Although 15% of the population gets 30% of the gross national product[15] and greater than 70% of Iranian wealth belongs to 3% of the population,[16] the Health Minister announced that almost 11.5 million of the Iranian population are unable to pay medical expenditures in case of disease.[17] The deputy minister of health announced that 20% of the Iranian population is unable to feed itself, 15.4% (800,000) of children younger than 5 years have moderate to severe nutritional short stature, 10.9% of children have moderate to severe low birth weight, and rates of pediatric growth retardation, iron deficiency anemia, and iodine and vitamin A deficiencies are increasing.[18]

As part of the whole Iranian population recipients are generally not rich, although there are many who are, and considering the fact that currently the majority of vendors ask for extra money, these rich recipients clearly are in an advantageous position to give such extra monies and obtain a kidney than those who are poor and unable. The price of a kidney is not the same in various Iranian cities and the cheapest is found in Kermanshah.[19] The poor recipients should compete with the rich recipients for such vendors as the poor Kermanshahian ones so that in the future the number of relatively rich recipients will increase. It is anticipated that these rich recipients will constitute by far the majority of the Iranian recipient population in the near future, if it has not already occurred. The "Kermanshahian kidneys" are also probably the cheapest in the world, considering the Iranian low currency ($1 United States equals 8,000 Rials). When someone telephones the brokers, they announce kidney prices for various blood groups, the cheapest being AB positive.[19] The brokers state that "You (potential buyer) should not have any concern about (kidney) buying. We find the vendor and reach an agreement with him/her. It is only sufficient for you that your recipient be ready for transplant operation."[19] Each day in Tehran only, 100 vendors refer to authorities asking that their kidney be bought.[19]

Effects of vending on physical ability were out of proportion to what one expects from nephrectomy. This result was probably related to the high incidence of depression and disappointment that markedly decreased vendor stamina, reserve and driving motivation for fulfilling physical potentials. We found no other differences between vendor nephrectomy and nephrectomy for benign disease other than higher frequency of rib resection and generally longer flank incisions. All vendor nephrectomies were done through generous extraperitoneal flank incisions. In almost all cases the 12th rib was resected. Being mainly unskilled laborers, the effects on physical ability were devastating for vendors. The vendors did every thing they could to remain unidentified and hide the scar. They considered the scar stigmatizing and hated it. Some married female vendors said that to prevent disclosure of their kidney sale, they performed household duties as

before not to let visiting parents know that a problem occurred, despite severe early postoperative pain.

The majority of vendors were apprehensive of the future. There were 37% who expected job loss due to disability, 83% predicted shortened life, and 60% anticipated renal failure and premature death because of the certain inability to protect the remaining kidney and pay medical expenditures in case of disease. Once again, some of these fears were unfounded but, nevertheless, damaged quality of life. The mental preoccupation with having 1 kidney was common. Vendors stated that this preoccupation interfered significantly with pursuing daily activities. Some stated that they were in a constant state of grief, "akin to ones' state soon after death of a very loved relative." Depression was the most common mood, followed by anxiety. The majority (6 of 9) of addicted vendors became addicted after vending, suggesting possible causative effects of vending. One may consider the lack of information regarding the preoperative psychosocial condition a limitation. However, in quality of life surveys patient views are the optimum outcome measure and final arbiter, and there is no need to "prove" or challenge patient statements.

The interviewed vendors reported on suicide completion by at least 5 vendors, including 3 who set themselves on fire after becoming severely depressed because of their unchanged miserable living conditions and inability to provide the most basic necessities of life for their families despite losing 1 kidney. Many of the present vendors were suicidal. In response to time tradeoff and willingness-to-pay for health improvement questions, almost half the vendors agreed to their life being shortened by greater than 10 years and properties lost by 76% to 100% in return for their preoperative condition and recovery of kidneys. Considering their depressing preoperative living conditions, one can realize how deep their sense of regret is over the decision and how real their judgment was that organ selling was against their interest. Despite living in awful conditions preoperatively, postoperative complications were so intolerable and unexpected for the vendors that they were ready to lose many years of their remaining life and the majority of their properties only to be returned to their wretched preoperative conditions. Losing 1 kidney affected the sense of being useful negatively, and most vendors regarded themselves as useless cripples. The effects of vending on general health were negative, and when thinking of people with 2 kidneys, 80% considered quality of life as somewhat to markedly decreased. Overall effects of vending on life were somewhat (38%) to markedly (55%) negative.

When asked about their feelings, the respondents cited a long bitter list. There were 85% of vendors who stated that with current information, if they had another chance they would definitely not donate, and 76% would discourage potential vendors strongly from "repeating their error." In fact, many vendors acted as campaigners against unrelated donation and stated that they "lost all of their belongings for obtaining nothing." Rare vendors who reaffirmed their decision stated that even with the high risk of dying they would donate again because there was absolutely no other way to provide short-term support for their urgent financial need. The lack of psychological social difficulties in 50 potential vendors who were in almost all aspects except sex matched with their vendor spouses further support the notion that the development of these complications is due to vending and no other confounding factor.

The SF-36 was first made available in a developmental form in 1988 and standard form in 1990.[20] In 1996 version 2.0 of the SF-36 was introduced. To date, experience with the SF-36 has been documented in greater than 1,000 publications. The usefulness of it for estimating disease burden is illustrated in articles describing greater than 130 diseases and conditions. Of the SF-36, 47 translations are the subject of 148 publications, and 1 or more articles compare results from it with those of 225 other generic and disease specific instruments.[20] It has been stated correctly that conventional translation strategies, including duplicating the originals as closely as possible, of health related quality of life questionnaires are limited because they preserve the deficiencies of the original questionnaire and do not permit modifications that reflect differences in culture and values.[21] The solutions suggested are to duplicate the process used to construct the original English language questionnaire if the investigator has considerable time and resources or, alternatively, omit irrelevant items, include new items, and modify the wording of questions and response options if there are limited resources.

We only modified the wording slightly to help the vendors understand the questions and responses. Needless to say, our own disease specific questionnaire is nonstandard. However, it provides information about and includes some vendor problems that are not even addressed in any present standard quality of life questionnaire because up to now, there are absolutely no reported quality of life studies of vendors to develop appropriate standard questions for coverage of their unique problems. The vendors had significantly lower scores on all SF-36 scales. However, in our view the SF-36 only supplements our own disease specific questionnaire. There is no normative data on the general Iranian population to allow a norm based interpretation of our SF-36 data or perform meaningful reliability validity tests.

It is with uncertainty that we think that many of the vendors studied met the International Classification of Diseases-10 diagnostic criteria for enduring personality changes not attributable to brain damage and disease subcategory of enduring personality change after catastrophic experience.[22] By 1995, 10% of the transplants in the United States were from living unrelated renal donors and living unrelated donors represented the fastest growing donor source in the United States.[23,24] Considering this surge in living unrelated renal donor transplantation, there is also a need to objectively study the American unrelated donor motivation and quality of life. The results may be considered when studying unrelated donors and the donor selection process.

CONCLUSIONS

The majority of vendors stated that what they obtained from vending did not compensate them for what they lost. None were able to remove themselves from poverty and debt or change their lives radically. Quality of life was impaired in all aspects. In addition, SF-36 scores were significantly lower than controls. Rejection by family and friends, and attempts to remain unidentified indicate the disapproval of organ sale by the Iranian society. Our sample is a good representative of Iranian, living unrelated renal donors, the majority having psychosocial complications. The medical community should focus more attention on paid, living unrelated renal donor motivations, quality of life, health and opinions.

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APPENDIX: SURVEY RESULTS

Multiple-choice questions are labeled with asterisks, and the remaining questions were sorted by response. Vendors chose more than 1 answer to some questions, so the sum is greater than 100% on some items, which are labeled with a bullet sign (•).

1. Do you have chronic postoperative pain?
   - No 40%
   - Yes, at the operated flank 27%
   - Yes, at the nonoperated flank 13%
   - Yes, general aches 20%
2. My surgery and recovery were *
   - as painful as expected 3%
   - less painful than expected 5%
   - more painful than expected 92%
3. After stitch removal, did you have followup visits? If yes, how many times?
   - Not at all 79%
   - 1 Visit 10%
   - 2 to 5 Visits 7%
   - 6 to 10 Visits 3%
   - Greater than 10 visits 1%
4. What was the length of postoperative conva lescence?
   - 1 Week or so 4%
   - 2 Weeks 10%
   - 3 to 4 Weeks 49%
   - 1 to 2 Months 20%
   - 2 Months or greater 17%
5. What were the effects of nephrectomy on your physical abilities?*
   - Markedly negative 60%
   - Somewhat negative 15%
   - A little negative 14%
   - No effect 11%
   - Positive 0%
6. How satisfied are you with your current level of physical abilities?*
   - Very satisfied 3%
   - Almost satisfied 7%
   - Somewhat dissatisfied 10%
   - Very dissatisfied 80%
7. How important are the physical abilities to you?*
   - Very important 83%
   - Somewhat important 11%
   - A little important 5%
   - Not important 1%
8. You can best preserve your remaining kidney by •
   - protecting the kidney from cold 92%
   - avoidance of lifting heavy weights 45%
   - drinking ample fluids 25%
   - dietary precautions 36%
   - avoidance of trauma 7%
   - rest 10%
   - more walking 4%
   - wearing masks 3%
   - attending followup visits 6%
   - talking less 0.6%
   - Do not know 8%
9. How easy or difficult was it to make the deci sion to vend your kidney?*
   - Easy 22%
   - Somewhat difficult 35%
   - Very difficult 43%
10. What were the effects of vending on your leisure time?
    - Positive 0%
    - Somewhat negative 19%
    - Very negative 81%
11. How would you rate the effects of vending on your employment status?*
    - No effect 5%
    - Mainly positive 10%
    - Somewhat negative 20%
    - Markedly negative 65%
12. What was the opinion of your family mem bers about your kidney vending?*
    - Agree strongly 3%
    - Agree somewhat 12%
    - No opinion 8%
    - Disagree somewhat 9%
    - Disagree strongly 68%
13. Before you vend your kidney, how would you rate your overall closeness with your family?*
    - Close and warm 60%
    - Somewhat close 23%
    - Distant and harsh 17%
14. What was the effect of vending on your rela tionship with the family?
    - Causing cold and harsh relations and rejection by parents 43%
    - Vendor concealed the kidney sale from anyone, so little change 37%
    - Reproach and constant conflict but not rejection 18%
    - Positive effects 2%
15. Currently, how would you rate your overall closeness with your family?
    - Close and warm 25%
    - Somewhat close 13%
    - Distant and harsh 62%
16. How would you rate your satisfaction with your current level of closeness with your family and overall relationship?*
    - Very satisfied 7%
    - Satisfied 18%
    - Somewhat satisfied 15%
    - Somewhat dissatisfied 7%
    - Dissatisfied 30%
    - Very dissatisfied 23%
17. How important is the family relationship to you?*
    - Very important 85%
    - Important 11%
    - A little important 4%
    - Not important 0%
18. Vending a kidney had the following impact on my marriage
    - I had no spouse at the time 14%
    - No impact 9%
    - Positive impact, made me closer to my spouse 4%
    - Negative impact, created conflict and tension with my spouse 52%
    - Was a major factor or sole reason for break ing up my marriage 21%
19. How would you rate the importance of marital relationships?*
    - Very important 80%
    - Somewhat important 12%
    - A little important 8%
    - Not important 0%
20. What were the effects of vending on your social relationships?
    - Became isolated and irritable, wish to be alone, losing self-esteem 70%
    - Became somewhat more distant than before 20%
    - Somewhat improving the relationships 9%
    - Markedly improving the relationships 1%
21. How would you rate your satisfaction or dis satisfaction with your postoperative social re lationships?*
    - Very satisfied 2%

Almost satisfied 8%
Somewhat dissatisfied 12%
Very dissatisfied 78%

22. How would you rate the importance of social relationships?*
Very important 80%
Somewhat important 13%
A little important 5%
Not important 2%

23. How would you rate the financial effects of vending?*
Very positive 0%
Somewhat positive 11%
No effect, that is almost equal financial loss and gain 3%
Somewhat negative 20%
Very negative 66%

24. In regard to lost work time, medical bills not covered by insurance or other personal expenses the financial consequences of vending were
very important 96%
somewhat important 4%

25. Who is informed of your kidney vending?
No one, even the spouse 37%
Only the spouse 14%
Only first generation relatives 43%
Family and some other relatives 2%
Family, relatives and some friends 1%
Many people 3%

26. What is your opinion about others being informed of your nephrectomy?
Not willing 94%
Indifferent 4%
Willing 2%

27. Why are you unwilling of others being informed?•
Kidney vending is a form of prostitution 73%
Rejection by the family and relatives if they know the truth 50%
The fear of reproach by others 43%
The fear of irony 40%
People evaluate the act badly 59%
The fear of bringing the marriage to an end 32%
In case of disclosure I should leave here 39%
The fear of discredit 79%
People regard me as incompetent to earn money by better ways 84%

28. In your opinion what is your possible outcome considering having only 1 kidney?•
Expect normal life 7%
Expect loss of job due to disability 37%
Expect decreased life expectancy 83%
Expect to be dialysis dependent and die 60%
Unable to predict the future 3%
Not thinking of future at all 1%

29. I worry about having only 1 kidney *
Not at all 1%
occasionally 3%
fairly often 9%
usually 30%
always 57%

30. If any how would you rate your new onset depression after vending?*
No new onset depression 5%
Minor 7%
Moderate 17%
Severe 71%

31. If any how would you rate your new onset anxiety after vending?*
No new onset anxiety 11%
Minor 9%
Moderate 20%
Severe 60%

32. If it was possible you agree to lose how many years of your remaining life to regain your lost kidney?*
0 to 1 5%
2 to 5 25%
6 to 10 20%
Greater than 10 50%

33. If it was possible you agree to lose what percent of your current possessions to regain your lost kidney?*
0 to 25 6%
26 to 50 18%
51 to 75 23%
76 to 100 53%

34. Compared to your status before vending, how would you rate your usefulness to yourself, family and society after vending?*
Very positive 0%
Somewhat positive 6%
No effect 4%
Somewhat negative 28%
Very negative 62%

35. Vending has had *
a positive impact on my health 1%
no impact on my health 9%
a little negative impact on my health 10%
somewhat negative impact on my health 22%
very negative impact on my health 58%

36. Compared to others who are in all aspects similar to you except they have 2 kidneys, how would you rate your quality of life?
Markedly decreased 59%
Somewhat decreased 21%
A little decreased 13%
The same as before and as others 7%
Increased 0%

37. Vending has had *
positive effects on my life 0%
no effect on my life 4%
a little negative effect on my life 3%
somewhat negative effects on my life 38%
markedly negative effects on my life 55%

38. What are your feelings when you think about your vending a kidney and having only 1?•
No feeling 3%
Exasperation 90%
Sadness and depression 90%
Apprehension and anxiety; fear of health deterioration with time 84%
Fear of shortened life span 87%
Lonesomeness 92%
Feel tortured 36%
Humiliation 70%
Embarrassment and shame 81%
Miserliness 90%
Painful feelings 83%
Irritation and nervousness 79%
Inferiority feelings 94%
Debilitated and loss of stamina 80%
Regret 97%
Feel deceived 97%
Self hate 25%
Worthlessness 70%
Hate towards medical professionals 61%
Feel oppression of own body 71%
Emptiness 40%

Disappointment and frustration 91%

39. With current information, if you had another chance would you reaffirm the decision to vend?*
    - Definitely 2%
    - Probably 5%
    - Do not know 2%
    - Probably not 6%
    - Definitely not 85%
40. What advice would you give to someone who was considering being a kidney vendor?*
    - Encourage strongly 4%
    - Encourage a little 9%
    - Discourage a little 11%
    - Discourage strongly 76%

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