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The experiences of commercial kidney donors: thematic synthesis of qualitative research

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Summary

Commercial transplantation has expanded because of the shortage of kidneys for transplantation. This study aims to synthesize qualitative studies on the experiences and perspectives of living commercial kidney donors. We conducted a comprehensive literature search in electronic databases to April 2011 and consulted experts to identify unpublished studies. Thematic synthesis was used to analyze the findings. Seven studies involving over 676 commercial kidney donors were included. Three major themes were identified: desperation (the participants' decision to sell their kidney was forced by poverty, debt, or to fulfill a family obligation); despair (destroyed body integrity, shame and secrecy, dehumanized and dispirited, loss of livelihood, heightened sense of vulnerability, disappointment, and regret); and debasement (deception by brokers and recipients, victimized by the hospital, stigmatized by community, and rejected by family). Commercial kidney transplantation is reported to result in ramifications for the donors' mental, physical, and social well-being. Not only do they remain in poverty, they lose dignity, sense of purpose, respect, relationships, and livelihood. Review of this published literature supports the need for effective implementation of the WHO guiding principles and legislated regulation to deter potential recipients and healthcare providers from pursuing commercial transplantation.

Introduction

Worldwide, there is a shortage of organs for transplantation. Waiting times to receive a kidney can exceed many suitable patients' life expectancy. As a consequence of the drive by patients to be transplanted, transplant commercialism and tourism has become a growing problem in many countries [1–4]. It is estimated by the World Health Organisation that organ trafficking accounts for 5–10% of kidney transplants performed annually throughout the world [1].

Transplant commercialism is “a policy or practice in which an organ is treated as a commodity, including by

being bought or sold or used for material gain” [5]. The Declaration of Istanbul on Organ Trafficking and Transplant Tourism states that organ trafficking and transplant tourism “violates the principles of equity, justice and respect for human dignity and should be prohibited” [5]. Still, patients travel overseas, namely to China, India, Pakistan, Iran, and the Philippines, for organ transplantation [3,6–8]. Not only is the mortality rate for commercial transplant recipients reported to be seven times higher compared with legal transplantation [9], commercial transplantation has a measurable impact on donors. Published research with commercial donors consistently report that “kidney vendors” suffer a deterioration in

health, depression, chronic pain, death, a sense of worthlessness and shame, and social problems [2,10–12].

Qualitative research can offer rich narrative data to provide an in-depth understanding into people's experiences and perspectives. Thematic synthesis of qualitative studies offers a high-level analytical abstraction of findings derived from primary qualitative studies of living commercial kidney donors' perspectives. A review on the state of international organ trade is available, but it does not synthesize qualitative data from commercial donors [13]. This study aims to synthesize published qualitative studies on the experiences and perspectives of commercial kidney donors. A broader understanding of the perspectives of commercial donors can inform strategies to safeguard against the potential ramifications of commercial transplantation.

Materials and methods

Data sources and searches

Medical Subject Headings and text words for living donation and kidney transplantation were combined with subject headings terms and text words for psychological, social, quality of life concepts, and qualitative research terms (Appendix A). The searches were conducted 11 April 2011 in MEDLINE (1948 to Week 5 2011), PsycINFO (1806 to April week 1 2011), Embase (1980 to Week 14 2011), and CINAHL (1982 to Week 5 2011). We also searched reference lists of relevant articles, Google Scholar, and contacted researchers and experts in the field for potentially relevant studies. We screened the titles and abstracts and discarded those that did not meet the inclusion criteria. Full texts of potentially relevant studies were retrieved and examined for eligibility.

Study selection

Qualitative studies using interviews, focus groups, or observations to explore the experiences and perspectives of commercial living kidney donors were included. Studies on deceased organ donation, potential donors, or non-kidney donation were excluded. Non-English articles were excluded to prevent linguistic bias in translations. Papers were excluded if they used structured surveys and reported only quantitative data. Nonprimary research articles such as editorials, reviews, and commentaries were excluded.

Data extraction and quality assessment

We assessed the explicitness and comprehensiveness of reporting of each primary study. We used a framework that was developed for reporting qualitative studies,

which included criteria specific to the research team, study methods, context of the study, analysis, and interpretations [14]. This can provide contextual details for readers to assess the trustworthiness and transferability of the study findings to their own setting. Two reviewers (AT, PB) independently assessed each study and resolved any disagreement by discussion.

Data synthesis and analysis

We used the technique of thematic synthesis described by Thomas and Harden [15]. For each paper, we extracted all the participant quotations and text under the "results/findings" or "conclusion/discussion" section of the article. These were entered verbatim into HyperRESEARCH (ResearchWare, INC.2009, version 3.0), software for storing, coding, and searching qualitative data. We performed line-by-line coding of the findings of the primary studies, identified descriptive themes, and then developed analytical themes. For each paper, we coded the text and recorded concepts that focused on the motivations and postdonation experiences and perspectives of commercial kidney donors, and identified common and divergent concepts and ideas. Subsequent papers were analyzed similarly, and we translated the concepts from one study to another by adding coded text to existing concepts or created a new concept when necessary. We identified relationships between themes using Freemind 0.9.0 Beta 14 (Source Forge Inc., Mountain View, CA, USA) to develop a new analytical framework to extend the findings offered by the primary studies.

Results

Literature search

Our search yielded 2491 articles. Of these, 2348 did not meet the inclusion criteria after title and abstract review. Of the remaining 143 articles, 136 were excluded because no commercial donors were included in the study, or they were nonresearch articles, focused on deceased donation only, were epidemiological studies, or used quantitative surveys only. Seven studies involving more than 676 participants were included in the review, of which three studies did not report the number of participants (Appendix A and B). The study characteristics are provided in Table 1. The seven studies, including one PhD dissertation thesis, were conducted in the Philippines, Pakistan, Bangladesh, India, Iran, Brazil, and South Africa. Of these seven studies, five were ethnographic studies undertaken by anthropologists where the findings were embedded within a critical analysis and in-depth description of the legal, cultural, social, philosophical, and religious context of the community in

Table 1. Characteristics of the included studies.

Study ID	Country	n	Donor age range (yr)	M:F	Donor type	Identification of relevant community	Participant selection strategy	Data collection	Conceptual methodological framework	Topic
Awaya 2009 [18]	Philippines	311	–	292:19	Paid nonrelated kidney donors	Media coverage, key informant statements	Snowballing	Face-to-face interviews	–	Economic and social consequences
Cohen 1999 [31]	India	–	–	–	Paid kidney donors	–	–	Face-to-face, open-ended interview	Ethnography	Donor experiences and perspectives
Moazam 2009 [17]	Pakistan	32	19–42	28:4	Commercial donor	Contacts through nongovernmental organizations	Purposive	Face-to-face, open-ended interviews	Ethnography	Experiences and perspectives of commercial kidney donation
Moniruzzaman 2010 [16]	Bangladesh	33	–	–	Commercial donor	Key informants	Snowballing	Face-to-face, in-depth interviews	Ethnography	Ethics of commercial transplantation
Scheper-Hughes 2000 [32]	Brazil, South Africa, India	–	–	–	Commercial donor	–	–	Face-to-face, open-ended interview, observations	Ethnography	Social context of transplant surgery
Tober 2007 [33]	Iran	–	–	–	Commercial donor	–	–	Face-to-face, semi structured interview, observation	Ethnography	Islam discourse and organ sale
Zargooshi 2001 [19]	Iran	300	–	–	Paid related and unrelated donors	Public medical center	Comprehensive	Face-to-face, structured interviews	–	Quality of life

N, number of participants; M, male; F, female, (–), not stated; snowballing, to identify participants by soliciting names of potential participants from those participating in the study; ethnography, to discover and describe individual social and cultural groups by collecting in-depth information through extensive fieldwork; thematic analysis, concepts and theories are inductively derived from the data.

which the research was conducted. Interviews and observations were used to collect data.

Comprehensiveness of reporting

Comprehensiveness of reporting was variable with studies reporting details on 8–23 of the maximum 31 items included in the framework for assessing reporting of qualitative studies (Table 2). Six of the seven studies included, six provided a comprehensive description of the cultural, political, and historical context in which the study was

conducted. Four studies described the participant selection strategy and three specified the participant characteristics. The researchers mostly relied on local contacts and snowballing strategies (where researchers ask participants to nominate potential individuals for the study) to identify and access participants who were usually difficult to reach. Of the four studies reporting on audio-visual recording, three explicitly stated that audio-taping was not permitted or conducted due to ethical considerations and the sensitive nature of the topic. No studies reported on the procedural aspects of data analysis including the

Table 2. Comprehensiveness of reporting.

Items	Study reference						
	[18]	[31]	[17]	[16]	[32]	[33]	[19]
Personal characteristics							
Interviewer/facilitator identified	–	•	•	•	•	•	–
Occupation	–	•	•	•	•	•	–
Gender	–	•	•	•	•	•	–
Experience and training	–	•	–	•	•	•	–
Background and context							
Description of cultural, political, historical context	•	•	•	•	•	•	–
Relationship with participants							
Relationship established prior to study commencement	–	•	•	•	–	•	•
Participant selection							
Method of participant selection	•	–	•	•	–	–	•
Sample size	•	•	•	•	–	–	•
Number and/or reasons for nonparticipation	–	–	•	•	–	–	•
Setting of data collection	•	•	•	•	•	•	–
Presence of nonparticipants	–	–	•	•	–	–	–
Description of participant characteristics	–	–	•	•	–	–	•
Participant reimbursement	–	–	No	Yes	–	–	–
Data collection							
Interview guide or topics provided	–	–	•	•	–	–	–
Repeat interviews/observation	–	–	•	•	–	–	–
Audio/visual recording	No	–	No	No	–	–	Yes
Field notes	–	–	•	•	–	–	–
Duration	–	–	–	•	–	–	–
Language	–	•	•	•	–	–	–
Use of interpreter	–	Yes	NA	NA	–	–	–
Data (or theoretical) saturation	–	–	•	–	–	–	–
Data analysis							
Number of data coders	–	–	–	–	–	–	–
Description of coding tree	–	–	–	–	–	–	–
Derivation of themes	–	–	–	–	–	–	–
Protocol for data preparation and transcription	–	–	–	–	–	–	–
Language in which coding and analysis was completed	–	–	–	–	–	–	–
Use of software	–	–	–	–	–	–	–
Description of the cultural context informing analysis	•	–	•	•	–	•	–
Participant feedback or member checking	–	–	–	–	–	–	–
Reporting							
Participant quotations provided	Yes	Yes	Yes	Yes	No	Yes	Yes
Thick description to provide in-depth insight into the experiences and perspectives of commercial donors	No	•	•	•	No	No	•

(•), this item was reported by the authors; (–), not stated; NA, not applicable.

process of translating raw data, coding, and interpretation. However, four embedded a description of the cultural context influencing the analysis.

Synthesis

We identified three major themes: desperation, the participants' decision to sell their kidney was forced by poverty or the need to repay a debt or to fulfill a family obligation; despair (including subthemes of destroyed body integrity, shame and secrecy, dehumanized and dispirited, loss of livelihood, heightened sense of vulnerability, disappointment and regret); and debasement (including subthemes of deceived by brokers and recipients, victimized by the hospital, stigmatized by community, rejected by family). To illustrate each theme, selected participant quotations and the results and interpretations offered by the authors from the included studies are provided in Table 3. The conceptual links between themes are depicted in Fig. 1.

Desperation

Almost all participants sold their kidney out of financial desperation and poverty. Selling a kidney was perceived as the only means for survival, to repay debts they owed, or to assist a family member in financial need.

Forced by poverty

Selling a kidney was believed to offer relief from poverty. The participants were offered money or a better job and for many, selling a kidney was seen to be the only means for survival.

Repaying debt

Many participants felt compelled to sell their kidney to repay debts or to pay dowries for children's weddings.

Fulfilling a family obligation

Some participants felt duty-bound and sold their kidney to fulfill an obligation to family members who needed to pay debts or healthcare service fees.

After selling their kidney, most participants came to a realization that the commercial kidney transaction provided false hope and their expectations of financial gain and a better life were not realized (Fig. 1).

Despair

The participants across all studies felt that losing a kidney permanently disrupted their sense of body wholeness and

integrity. Commercial kidney donation was described as shameful and they felt dehumanized and dispirited about life. They regretted selling their kidney, many suffered a loss of livelihood, and described constant anxiety about their health.

Destroyed body integrity

Losing a kidney was described by the participants as rendering them "incomplete," "empty," or "half a man."

Shame and secrecy

The participants believed that commercial kidney donation was widely deemed as socially heinous and morally wrong thus describing that they lived in constant fear of judgment and rejection by their family and the community. Many were burdened by the necessity of keeping their nephrectomy a secret, which was made difficult by a scar "sweeping from their back to their belly" [16]. Some participants were also worried about subjecting their family to shame because of their decision to sell their kidney. If the recipient died, participants felt at fault, believing they had given an inferior kidney and that it had been a "total waste."

Dehumanized and dispirited

The participants described feeling that they lived in a state of hopelessness such that for some life was not worth living and they expressed a wish to die. They lost their motivation and zeal to work and felt worthless. In one study, a female participant believed that by selling her kidney, she had "auctioned" herself [17]. Disappointment was frequently expressed by the participants because selling their kidney had not resulted in long-term financial improvement nor did it resolve their debt crisis. The disappointment was greatly intensified if the recipient died. They deeply regretted "sacrificing something as important as a kidney" [18].

Loss of livelihood

After the transplant surgery, many participants became incapacitated by weakness, fatigue, and pain. They became unable to work, especially in physically demanding occupations, and could not earn as much as they had prior to donation. The participants felt grief for being unable to provide for their family.

Heightened sense of vulnerability

The participants believed that with only one kidney, they were at an increased risk of health problems. The sense of

Table 3. Illustrative quotations.

Themes	Illustrative quotations
Desperation	
Forced by poverty	<p>"I sold my kidney for 32,500 rupees. I had to; we had run out of credit and could not live." [31]</p> <p>"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." [19]</p> <p>"No altruism involved, only poverty." [19]</p> <p>"Poor Bangladeshis believe that selling a kidney is their only hope for changing their 'wheel of fate.'" [16]</p> <p>"I was weaving sari at Mirpur, Dhaka. Like many other handlooms, my was closed due to rapid industrialization. I tried but was not able to get any satisfactory job without high school education and other expertise. On the other hand, I could not live as a rickshaw puller or a garment worker due to my social status. So, I decided to sell my kidney, which helped me arrange a bribe to get a job." [16]</p>
Repaying debt	<p>"Decisions to sell a kidney appear to have less to do with raising cash toward some current or future goal than with paying off a high-interest debt to local moneylenders." [31]</p> <p>"She said selling a kidney is not a good thing but majboor see (they had no choice) as they wanted to free their children from the zamindar." [17]</p> <p>"However, all donors were of low socio-economic status and, when probed further, indirectly expressed a need for money to pay off their debts." [33]</p> <p>"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." [19]</p> <p>"Among the 33 sellers I interviewed, most were compelled to sell their kidneys to pay off debts and dowries." [16]</p> <p>"After borrowing money at high interest rates to support a growing business, my research population fell into onerous debt mostly due to unexpected circumstances. For example, a peasant started a poultry farm after borrowing money, but later was ruined by <i>ranikhet</i>, an epidemic; a small businessman opened a variety store, but was unsuccessful due to a colossal amount of unrecovered credit; a contractor borrowed money to start a business, but had to bribe the police to keep quiet when one of his workers died on the job. These types of business loss force many Bangladeshis to sell a kidney in order to pay off their debt." [16]</p> <p>"One widow, who had been struggling financially since her husband's death in 1990, sold her kidney in order to arrange dowries and weddings for her four daughters." [16]</p>
Meeting a family obligation: imposed a responsibility	<p>"I sold my kidney under my brother's pressure who dictated kidney sale to pay his 50,000 Tomans (\$63 United States) debt." [19]</p> <p>"I sold my kidney for my husband's haemorrhoid operation. However, the operation failed." [19]</p> <p>"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." [19]</p>
Despair	
Destroyed body integrity	<p>"Pointing to the left half of his body, one vendor told us that mehsos hota hay kay khalee jaga hay (I feel that there is an empty space here), and that he was now an adhoora banda (incomplete or half a man). This curious sense of feeling "half," being "empty," somehow having been transformed into an "incomplete" person, was among the most common statements we heard. One young man pointed to the uncapped pen in a researcher's hand and said that he was now adha (half) like that pen; replacing the cap back on the pen, he said he was "like that" before surgery." [17]</p> <p>"One man said that if someone uchi awaz nal bolay (speaks to me in a loud voice) he became terrified, adding that fikr say adha kay ikon gurda (fear that I have only one kidney has made me half the man I was)." [17]</p> <p>"Different phrases were useddil pay bojh (weight on my heart), chaubees ghantay fikr kay hun ikon gurda, maira saath kee hoyay ga (I worry twenty-four hours that I have only one kidney, what will happen to me), dil ghabaranda (my heart is restless, not at peace), and following nephrectomy hun himmat nahin rae (I have no strength/will left). One man said that if someone uchi awaz nal bolay (speaks to me in a loud voice) he became terrified, adding that fikr say adha kay ikon gurda (fear that I have only one kidney has made me half the man I was)." [17]</p> <p>"Being a bedridden cripple is preferable to being a vendor, considering intolerable effects of vending on our nerves and social interactions." [19]</p> <p>"We are living cadavers. By selling our kidneys, our bodies are lighter but our chests are heavier than ever." [16]</p>

Table 3. continued

Themes	Illustrative quotations
Shame and secrecy	<p>"Some subjects expressed remorse connected to a religiously grounded perception that there was an intrinsic "wrongness" in selling an organ. One man described the kidney as a naimat (blessing) from God, and others said that selling a kidney was Allah tala kaa gunnah (sin in the eyes of Allah), a buraa (wrong, evil act), or accha kaam nahin (not a right/good act). One vendor described the money obtained from selling a kidney as haram (something strictly forbidden in Islam)." [17]</p> <p>"One of them had told his wife that he had surgery for a kidney stone and was convinced that she would leave him if she discovered the truth. He had also not told his parents, for fear that the biradari (extended family) would find out, and he was miserable because sub say dhoka kiya hay (I have deceived everybody). In the case of the second vendor, his large extended family blamed his wife's influence on him and openly expressed their animosity toward her when she was present. The vendor himself was contrite that his act had resulted in shame for the entire family, and he added that people in the community made fun of those who sell kidneys." [17]</p> <p>"If people know my secret of vending my children will be subjected to irony and stigmatized as being grown by kidney's money." [19]</p> <p>"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!" [19]</p> <p>"No wife would accept her husband bringing food with this money. A wife can live with her husband even under a tree and can sell their home if their debt is increasing. However, they would not live with a bodiless husband. If my wife finds out about it, she would be senseless. If my family finds out about my action, they would have never touched the gifts I brought them. I will never disclose it, ever." [16]</p> <p>"We live in a society, but I have a black hole inside. I failed to keep my body intact, so I feel embarrassed and disgusted at my actions. I always feel very small inside. How could you tell someone about this disgusting action? I would rather die with this secret." [16]</p>
Dehumanized and dispirited	<p>"He said that marnay ko dil chahda ay (my heart feels that I should die) and that he no longer experienced any khushee kay lumhat (moments of happiness/pleasure) in his life." [17]</p> <p>"One man who sold his kidney without informing his wife who said she would have stopped him informed us that he felt hun zindagee dee koi lor nahin; na wajood raya na sihat (now I have no need for life; I have neither my body left nor my health)." [19]</p> <p>"Some said they regretted the decision because they felt no economic improvement in their lives even after sacrificing something as important as a kidney." [18]</p> <p>"One has only one kidney to give, but the conditions of indebtedness remain. At some point the money runs out and one needs credit again, and then the scar covers over the wound not of a gift but of a debt." [18]</p> <p>"Sellers are frequently back in debt within several years." [31]</p> <p>"They proclaimed kidney selling to be the biggest loss of their lives; if they had a second chance in life, they would not sell their kidney." [16]</p>
Loss of livelihood	<p>"Many also complained of tiredness, generalized kamzori (weakness), chukkar (dizziness), and shortness of breath while working. All expressed an inability to work as hard as before, a perception confirmed by family members with whom we spoke. One vendor explained his tiredness by saying that jism may khoon nahin hay (my body has no blood in it). A common complaint was hun wazan uthanay day naal dard (lifting anything heavy now gives me pain), a significant issue for those involved in manual labor." [17]</p> <p>"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." [19]</p> <p>"I lost my kidney as well as my job. Now I cannot engage in heavy lifting or work longer; what kind of life is this? If I had strength in my body, I could work at anything and could easily earn that little sum I received for selling." [16]</p> <p>"I was much healthier when I worked days and nights and lifted 60 kilograms of weight on my head, but now I cannot even carry 10 kilos. I become tired more quickly and always get scared if I need to carry weight. My body was like a strong tree trunk, but now it is like an old banana tree that anyone can stab with a finger." [16]</p> <p>"Before, I sold meat in the market for seven days, but now I can only go there for two days. I cannot work hard and I feel weak chopping the meat into pieces, so I hired an employee and I just weigh the meat and collect the money." [16]</p>

Table 3. continued

Themes	Illustrative quotations
Heightened sense of vulnerability	<p>"Another described himself before and after he had sold a kidney <i>pehlan mein sher san, hun mein bakri an</i> (before I was like a lion, now I am like a she-goat)." [17]</p> <p>"Different phrases were used <i>dil pay bojh</i> (weight on my heart), <i>chaubees ghanatay fikr kay hun ikon gurda, maira saath kee hoyay ga</i> (I worry twenty-four hours that I have only one kidney, what will happen to me), <i>dil ghabaranda</i> (my heart is restless, not at peace), and following nephrectomy <i>hun himmat nahin rae</i> (I have no strength/will left)." [17]</p> <p><i>"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."</i> [19]</p> <p><i>"I will kill myself with my gun in case of becoming dialysis dependent."</i> [19]</p> <p>"Some felt that the doctors and hospital staff did not want them back and many were advised by their respective brokers to never go back to the transplant hospital." [18]</p> <p><i>"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."</i> [19]</p> <p><i>"Now I cannot pump tube-well for my daily shower or wash my clothes by hand. I always need to ask someone to help me. So, I take someone else with me if I plan to go somewhere. I do not even drink water from someone's glass, fearing that I might get sick."</i> [16]</p> <p><i>"The village doctor confirmed that I would survive five or six years at the most, as my body is half and I am already half dead." This seller was so anxious that he deposited the entire kidney payment in the bank and signed an affidavit for his daughter, believing that he could die soon and nobody would help his family.</i>" [16]</p>
Debasement	
Deceived by brokers and recipients	<p>"A loan shark lent us money at exorbitant rates of interest and we will never rescue from him." [19]</p> <p><i>"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> [19]</p> <p><i>"However, instead of supporting me, they deceived me brutally. In addition, my kidney is gone and I will never get it back."</i> [16]</p> <p><i>"The recipient and her family mistreated me, so much that even a dog would not want to keep in touch with them. They did not treat me as a human being, so why should I treat them in such a way? They did not even let their maid talk with me. From their point of view, I was a bad person who does not have any dignity as I sold my kidney for money. Thus, poor sellers cannot be welcomed by the rich recipients; they can never stand in the same row as the rich do."</i> [16]</p>
Victimized by medical professionals	<p>"One man bitterly described the hospital as <i>sub karobar hay</i> (it is all a business) and said he would never return. He characterized those connected to the hospital as <i>kasaae</i> (butchers) and said he hated the place because <i>sub jhootay hein</i> (they are all liars)." [17]</p> <p>"Hospitals and staff were described variously as <i>sub choree da kaam ay</i> (in a business of theft), <i>sub daqa shahi ain</i> (all are the kings of thieves), <i>dhokay baz</i> (those who deceive others) and <i>destroy lives like phansee ka phanda</i> (a noose for hanging people). One female vendor described her experience in the hospital as one in which they <i>khoon choos litta; murda bana kay ghar bhajj dainday hein</i> (sucked out all my blood; they send us home after turning us into corpses)." [17]</p>
Stigmatized by community	<p><i>"During a fight, our neighbour cried "You kidney seller! If you were good people you would not sell your own body (the kidney)." "</i> [19]</p> <p><i>"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!" "</i> [19]</p> <p><i>"Wherever I go, the villagers call me a kidney man. I do not know how much longer I can carry this shameful burden."</i> [16]</p>
Rejected by family	<p><i>"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."</i> [19]</p> <p><i>"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."</i> [19]</p> <p><i>"It was terrible when I told my wife that I had sold one of my kidneys. I do not know how the words came out of my mouth. I had to disclose it because she saw the scar. She started behaving like a crazy person; she repeatedly asked me why I did it. I told her that I donated my kidney to save a dying person. My wife did not buy my argument and asserted that she would not eat in this home and would leave immediately."</i> [16]</p>

NB. Italicized text indicates quotations taken directly from participants of the original studies.

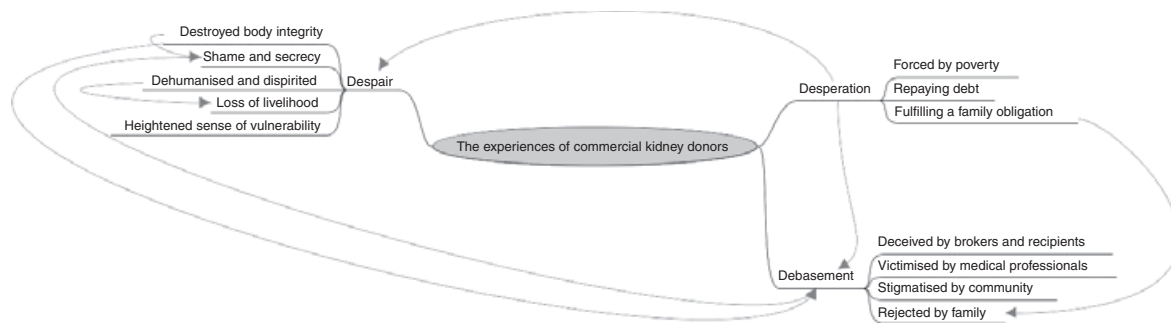


Figure 1 Thematic schema of the experiences and perspectives of commercial kidney donors.

vulnerability was exacerbated by their inability to access and pay for follow-up care or medical treatment for health problems such as kidney stones. Some also believed they had an increased risk of premature death. They were petrified about the possibility of losing their remaining kidney and having to go on dialysis. In one study, some participants threatened suicide by grenade or shot gun if they ever needed to go on dialysis in the future.

Debasement

Across all studies, the majority of participants felt they had been deceived by brokers, recipients, and healthcare providers. They experienced stigmatization from their community and outright rejection from their family and friends.

Deceived by brokers and recipients

The participants had initially believed in the promises of money and support by brokers and by transplant recipients. However, as participants came to realize they had been misled and misinformed, they felt disappointed and demeaned. The participants stated that payments were withheld. They reported their recipients claimed they had no money and in some cases were callously told by their recipient “I only said something you like to hear” [19]. Some participants tried to negotiate with their broker or recipient to retrieve the payment they were promised but were met with abuse, contempt, and disregard. In rare cases, participants reported receiving the full payment promised and aid from their recipient.

Victimized by medical professionals

After the surgery, the participants felt in hindsight that the doctors had given false reassurance about their health. They described beliefs that they were victims of deception. Participants also described the hospital staff as “thieves” and “butchers” and in one study, a participant

stated that the hospital “sucked out all my blood; they send us home after turning us into corpses” [17].

Stigmatized by community

The participants believed that they suffered humiliation and torment by the community. Kidney sale was considered by their community to be an immoral and atrocious act. Kidney donors, who were identified as having sold their kidney, were mocked and called derogatory names in public.

Rejected by family

Some participants sold their kidney with the intention to bring benefits for their family. However, many still faced rejection and abuse from their family members. In one study, a participant sold a kidney to pay for her husband’s car accident damages but was eventually abused and deemed by him to be “useless and dying” [19]. In another case, one husband who sold his kidney was rejected by his wife who eventually left him.

Discussion

The commercial kidney providers described in these qualitative studies had unexpected ramifications for their mental, physical, and social well-being. Commercial kidney “vendors” were motivated by financial desperation and poverty. After donation, in contrast, they lost physical and mental capacity to make a living and many described becoming financially worse off than they were prior to donation. There was no apparent gain among commercial vendors. They felt “victimized,” lived in fear of their future health, and bore a sense of emptiness, shame, guilt, regret, and depression. Commercial vendors felt they were regarded as having committed a reprehensible act and were deemed useless. They faced rejection and persecution from their families and by their community.

In this review, we performed a comprehensive search and contacted experts in the field of transplantation to identify relevant studies. We used software to code the data and record an auditable development of themes and developed a new analytical framework that incorporates a wide range of concepts relating to the experiences and perspectives of commercial living kidney donors. However, there are a number of limitations. We did not access original transcripts or observation notes since this is not standard practice due to ethical restrictions. The number of eligible studies potentially missed cannot be accurately determined as publications on this topic have been banned by government authorities [19,20]. The experiences of donors in more extreme circumstances, such as those who progressed to end-stage kidney disease, or were displaced from their communities, may not have been captured. On the other hand, those who were “satisfied” with their nephrectomy, health, and payment may not have participated in the studies, and thus, it must be acknowledged that there is little data about the proportion of kidney sellers who are dissatisfied or regret their decision to be a kidney vendor. Finally, we recognize the results may reflect the study authors’ motivations, personal biases, and values regarding commercial kidney sales.

Our findings reflect quantitative studies which have found that the majority of commercial donors have sold their kidney to pay financial debt; and after nephrectomy, experience no long-term economic improvement and a deterioration in general health status [7,11,12,21]. A quality-of-life survey conducted among kidney vendors demonstrated that kidney vending increased marital conflicts, social rejection, depression, and impaired physical stamina, with the majority regretting their decision to be a kidney vendor [19].

Commercialization of live donor kidneys breaches the fundamental ethical principles and in most countries also breaches the law. Current international guidelines on living kidney donation state that donors should provide informed, voluntary consent and be free from coercion [22,23]. Our study indicates that commercial donors were forced by financial desperation and family obligation and were unaware of the health risks, and the psychological and lifestyle impact of donation. Guidelines also recommend that donors should have adequate social support and medical follow-up [24]. In contrast to altruistic kidney donors, many of whom receive gratitude, support, and recognition [25]; commercial vendors did not access medical follow-up care, being either unwilling, fearful, or unable due to financial inability and discrimination [13,17].

As organ trafficking and transplant tourism remain a reality [1,11], some argue in favor of a regulated organ market [26], such as those reflected in the Iranian model of kidney transplantation, with the justification of saving

lives, patient autonomy, and improving the economic well-being of the impoverished [27]. However, findings from our review and the incomplete, conflicting, mixed survival, and quality-of-life data [7,19,21,28,29] suggest that commercial transplantation, even in the context of a regulated system, is not justifiable for both health and ethical reasons. While global initiatives exist, such as the Declaration of Istanbul [30] and WHO Guiding principles and the existing legislated regulation in almost all countries, effective policing strategies at both international and local levels are urgently needed to deter potential recipients and to protect the unwitting, vulnerable, and impoverished communities that are the known sources for commercial transplantation.

In-depth qualitative research conducted with commercial kidney vendors are scarce and are predominantly composed of ethnographic studies not identified by standard search strategies in health and medical literature databases. Potentially, these studies may then be less readily accessed and therefore clinicians and policy makers might not be widely cognizant of the perspectives and experiences of commercial donors. The data contained in these studies accentuate the need for broader awareness about the likely detrimental consequences of commercial transplantation to the lives of kidney vendors among the professional medical community, policy makers, potential recipients, and the “hidden” communities of potential kidney vendors. The concerns and anxieties uncovered by these studies add emphasis to the calls for active efforts by the professional transplant community to identify actual commercial kidney vendors to provide follow-up and supportive care.

Commercial kidneys vendors suffer significant loss as a result of their nephrectomy. Not only do they remain in poverty, they lose dignity, sense of purpose, respect, relationships, and their livelihood. Interventions that deter commercial transplantation and protect the health, wellbeing, and livelihood of individuals who have resorted to selling their kidney for commercial transplantation are warranted.

Authorship

AT: designed the study, collected and analyzed the data, and drafted the manuscript. JRC: co-wrote the manuscript and reviewed the manuscript for important intellectual content. GW, NBC, and JCC: reviewed the manuscript for important intellectual content. PB: collected and analyzed the data.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix A. Search strategies.

Appendix B. Search results.

Please note: Wiley-Blackwell are not responsible for the content or functionality of any supporting materials supplied by the authors. Any queries (other than missing material) should be directed to the corresponding author for the article.

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