

## REVIEW

## Care for commercial living donors: the experience of an NGO's outreach in Egypt

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### Introduction

The movement to combat organ trafficking has begun to make strides in recent years, particularly in the enhancement of legal frameworks in several key host countries including China, the Philippines, Pakistan and most recently Egypt. Still, the organ trade flourishes and, especially within societies of host countries, concepts about transplants are closely associated with the ills of this trade. The Amsterdam [1,2] and Vancouver Forums [3] are efforts to improve standards for follow-up clinical care for living organ donors. Various schemes for the provision of follow-up care exist in transplant settings where the living donor is altruistic and commercialism does not characterize transplantation. Yet this care is insufficient and only a fraction of organ donors actually receive it [4]. Follow-up care is

### Summary

Follow-up care for living organ donors is inadequate in countries with advanced transplantation systems based on altruistic donation. In cases where financial incentives drive an organ donation, care for the live 'donor' is largely absent. Care must be provided not only to living altruistic organ donors but especially to victims of organ trafficking who are often not suitable candidates for a donation and subject to poor surgical practices and conditions. Such follow-up is essential not only as a basic right, but also as an important reconciliatory step to regain public trust in transplants where they have been characterized by commercialism. Yet, the question, *who will provide care for the commercial living donor?* persists. In the absence of public or private commitments to this care, the Coalition for Organ-Failure Solutions (COFS) conducts outreach programmes that include identifying victims of organ trafficking, assessing their consequences and arranging support services. This paper presents studies on consequences for commercial living donors (CLDs), describes the case of organ trafficking and COFS' care provision in Egypt and discusses why follow-up care for CLDs is not an appropriate ingredient for advancing regulation proposals but should be considered an essential component of the movement to end organ trafficking.

largely absent in cases of organ trafficking where victims are amongst the world's poorest and most destitute. Despite the call for follow-up care in the Amsterdam and Vancouver Forums and more recently in the Istanbul Declaration [5], there are not commitments to the provision of care for individuals who are trafficked within the variety of conditions that this occurs. This care provision is especially challenging in developing countries where advanced medical services like transplants are conducted but universal health care is but a dream and primary health care services are inadequate for the majority of the population. Care must be provided to these individuals as a basic right as well as an important step towards reconciliation and to obtain public trust in transplants.

The Coalition for Organ-Failure Solutions (COFS) was established in 2005 as a result of research that the first

author began in 1999. COFS is a nonprofit international health and human rights organization committed to combating organ trafficking and advancing altruistic deceased donation. COFS combines prevention, policy advocacy and survivor support through a comprehensive approach to combat organ trafficking. In addition to prevention projects, COFS' outreach programs work to identify victims of organ trafficking/commercial living donors (CLDs),<sup>1</sup> assess their consequences and arrange long-term support services via a coalition of civil-society partners. Egypt is a country in which COFS has, since its founding, conducted field research and outreach service programs for victims of the organ trade.<sup>2</sup> Egypt also, like other key countries that host organ trafficking, has a large underclass that is poor and deprived of basic human rights. In this paper, studies on CLDs' consequences in various countries are reviewed and Egypt is discussed as a relevant case. The findings however represent the broader phenomena of CLDs' consequences that are not confined to Egypt. It is the abuse of power upon the poor and destitute that demands the outreach that COFS works to provide. A description of COFS' outreach programs in Egypt is presented and it is argued that follow-up care for CLDs is not an appropriate ingredient for advancing regulation proposals but should be considered an essential component of the movement to end organ trafficking.

### Lived consequences of commercial living organ donors

Studies on CLDs that have emerged in recent years indicate similar findings about the consequences they have experienced as a result of the procurement of a kidney for a commercial transplant. Negative health, economic, social and psychological consequences for CLDs have become evident from these studies. CLDs have consistently reported a gen-

eral deterioration in their health status—86% in India, 60% in Iran, 98% in Pakistan and 48% in the Philippines [6–9]. The study in Iran included specific enquiries about CLDs' desires for health improvement. Half of the CLDs would have preferred to lose more than 10 years of their lives and to lose 76–100% of their personal possessions in return for their preoperative condition.

These studies also indicate that a kidney sale does not relieve poverty or solve economic crises for the desperate poor who resort to them. In fact, despite payment for a kidney, the economic situation of CLDs tends to decline as a majority has reported the inability to return to labour-intensive work and thus compromised capacity to generate income following the donation. In India, CLDs reported that average family income declined by one-third after the nephrectomy and 75% of CLDs remained in debt; in Iran CLDs reported that kidney vending caused somewhat (20%) to very (66%) negative financial effects; in Pakistan 88% reported that the sale made no economic improvement in their lives; and in the Philippines 93% of CLDs reported that the kidney sale did not help their economic hardship, whereas 21% reported that the donation negatively affected their capacity to work. Thus, with the supply of desperate people exceeding the demand of kidney patients, prices for a kidney sale could not provide a sufficient remedy for a poor donor, who continued to live in poverty after the donation.

Commercial living donors reported that a financially motivated organ donation also caused social and emotional harm. The majority of CLDs reported feeling negative social consequences such as isolation and felt that there was stigma attached to the commercial organ donation. In Iran, 68% of CLDs' families strongly disagreed with vending, which increased marital conflicts for 73% of vendors, including 21% who divorced (as compared with a divorce rate of 1.39% in Iran in 2006). Seventy percent of Iranian vendors felt isolated from society and 71% had severe postoperative depression. Thirty-seven percent concealed the truth of kidney sale from anyone and 94% were unwilling to be known as CLDs to strangers. Finally, CLDs expressed psychological distress and regret about the organ donation and discouraged others from making a commercial donation. In India, 79% percent would not recommend that others sell a kidney. In Iran, preoccupation with kidney loss was usually (30%) to always (57%) reported and 85% of CLDs would not vend if they had it to do over again. Seventy-six percent of CLDs in Iran strongly discouraged potential vendors from 'repeating their error.' In Pakistan, only 35% of CLDs encouraged future vending to pay off debts and to gain freedom from bondage. In the Philippines, 24% stated regret for selling a kidney and others reported feeling shame for being known as a kidney seller or getting bad

<sup>1</sup>COFS uses the term 'commercial living donor' as a parallel to the term 'commercial sex worker' to demonstrate the financial incentive that drives the act. We also use the term 'victim' not to diminish a sense of agency of these subjects but rather to emphasize the structural forces at play, the inducement, that this was an act of desperation and last resort and to include cases of organ theft. We also employ the term to share its use in the human trafficking discourses that recognizes similar processes of the abuse of power on vulnerabilities.

<sup>2</sup>COFS facilitates prevention projects in various countries and, in addition to Egypt, is engaged in conducting outreach programmes in countries such as India. COFS has arranged follow-up medical services for 300 victims of organ trafficking in Chennai and 500 victims in Erode, India in 2010, for which data are still preliminary.

'karma' or punishment, including a decline in their health and difficulty in finding a job.<sup>3</sup>

### The case of Egypt

Since the first live-donor kidney transplantation in Egypt in 1976, there has been an absence of an entity to govern allocation or standards for transplants. Until recently, the Medical Syndicate was the single authority to issue licences for transplants with the loosely monitored rule that the donor and recipient must be the same nationality. Although there is a history of other vulnerable groups such as Sudanese serving as CLDs in Egypt, the vast majority is Egyptian for Egyptian patients and thus most commercial transplants in Egypt are via internal organ trafficking rather than for transplant tourists.<sup>4</sup> Also until recently, Egypt has been one of the few countries that prohibited organ donation from deceased donors and has relied entirely on the living. Accordingly, the market has been the distribution mechanism and CLDs have served as the key source of organ suppliers, with only a minority of organ donations from related living donors. CLDs in Egypt include those who have sold a partial liver or a kidney. We restrict our discussion here to the larger number of those who have sold a kidney.

Estimates suggest that Egypt performs approximately 500–1000 transplants per year (source: Dr. Hamdy Sayed, Director of the Medical Syndicate, November 2009) and that between 80% and 90% of living kidney donors in Egypt are unrelated/commercial donors [10,11]. The passing of a national law on transplantation in Egypt in February 2010 provides a framework for the prohibition of organ trafficking and the permission to transplant from deceased donors. The law has started to curb the trade but not yet implemented full surveillance and when and how transplants via deceased donations will commence is still uncertain.

<sup>3</sup>The outcomes from these studies may be a result of poor donor selection criteria to include individuals who should not part with a kidney. Even in the best circumstances, these surgeries involve risks and longitudinal research on the long-term effects of live organ donation in any country is scarce. Parting with a kidney is significantly more difficult when donors do not have clean water or sufficient nutrition and rely on labour-intensive work to generate income. Risks are especially high for a partial liver donation from a live-donor.

<sup>4</sup>The first author has conducted an extensive study on how the unanimous fear of organ theft amongst Sudanese asylum seekers in Egypt has led them to avoid Egyptian clinical services. COFS is now conducting a research project that includes only Sudanese CLDs, most of whom are asylum seekers from Darfur.

In-depth interviews with Egyptian CLDs have been conducted as a study between July 2004 to December 2006 and September 2008 to November 2010 to assess consequences of their commercial organ donation.<sup>5</sup> Data are collected as a longitudinal, ongoing, action-based research project to develop and enhance COFS' outreach services. COFS' field researchers are from areas in greater Cairo that is in or neighbour to those where CLDs reside. They are trained in research methods, certified by the Collaborative Institutional Training Initiative (CITI) and included as research personnel on the protocol for this study. In addition to their research, they also play the role of social workers and donor advocates to CLDs. The aims of this research are thus to address CLDs' concerns in their immediate problematic situation and to further the goals of social science simultaneously.

COFS identifies CLDs from transplant centres where COFS has been granted research clearance (those centres with the most transparency) as well as via a snowball technique in which CLDs tell us of other CLDs they know. Interviews in this study include those subjects who participated in the complete interview ( $n = 96$ ) and do not include those who receive COFS' services but opted out of the study (10%) or opted out of portions of the interview (15%). Two researchers conducted interviews in Arabic primarily in CLDs' homes or occasionally in a neighbourhood coffee shop (*ahwa*) when participants preferred this location. A consent form explained that participation was voluntary and that identities would remain confidential. Verbal consent was then obtained from each participant and interviews were not recorded in order to assure trust and protect confidentiality as many CLDs in Egypt fear being criminalized. No monetary compensation was provided and the researchers made it clear that medical follow-up care would be provided regardless of their decision to participate in the interview.

The questionnaire included closed-questions to collect demographic data and open-ended questions to illicit narratives about their lived-experience of the kidney sale and how it affected their lives. The relatively small number of participants in this study is a reflection of the lack of transparency in many transplant centres' practices, the widely dispersed places of residency of CLDs in Egypt (albeit most are in and around Cairo, they are increasingly from the city's stretching outskirts), the intense field work that is required to access them and COFS' limited resources to facilitate more extensive work.

The results from interviews in this longitudinal study reveal similar findings about CLDs and their conse-

<sup>5</sup>The University of Pennsylvania hosts the IRB for this study, protocol numbers 801824 and 808752.

quences of a commercially motivated organ donation with those studies in India, Iran, Pakistan and the Philippines.<sup>6</sup> The participants in this study include those who made a commercial organ donation in private and public centres and via licenced and unlicenced transplants. The majority (72%) of CLDs in Egypt were male, the median age was 32 years, 40% were married and only one individual was insured. 62% of participants in this study were illiterate and 68% were unemployed.

In Egypt, 82% of the CLDs reported a deterioration in their health condition regardless of where the transplant was performed and if they felt they received 'good' or 'poor' treatment before and after the surgery. This is likely a result of factors such as insufficient donor medical screening for a donation, pre-existing compromised health conditions of CLD groups and that the majority of employed CLDs reported working in labour-intensive jobs. Many spoke at length about the pain they continued to experience at the site of the incision, an inability to lift heavy objects as prior to the surgery and general fatigue. It is noteworthy that of the transplant surgeries that the first author observed in Egypt ( $n = 24$ ), 92% involved the removal of a rib for the nephrectomy.

Similar to findings highlighted elsewhere, in Egypt CLDs described economic consequences as a result of the sale of their kidney- looming debt was the most frequent reason reported for resorting to a kidney sale and 81% spent the money within 5 months of the nephrectomy to pay this debt. All participants reported that the organ sale did not enhance their economic situation. A long-term financial disadvantage is evident from the reported compromised ability to generate a prior income level.

Egyptian religious and cultural beliefs that the body belongs to God were repeated in the narratives of open-ended interview questions. This led many to discuss their fears that they would not go to heaven because they sold a part of their body. It is also noteworthy that in peer support groups of CLDs, there were efforts to comfort one another on this matter with explanations that *Allah* (God) is merciful and would forgive this act. Accordingly, 71% of Egyptian CLDs did not tell anyone about their donation, 90% felt socially isolated about concerns related to their donation and 81% were unwilling to be known as organ sellers. Further, in Egypt, 94% of CLDs felt regret about their donation and their inability to get further assistance from those involved with their donation including the recipient, broker, labs, or transplant centre. The extensive narratives in the open-ended interviews and

peer support groups reveal that compromised health and economic consequences are a part of the burden CLDs experience as a result of the sale of a kidney. Shame, psychological isolation, guilt and fear are also salient features of their long-term experiences.

### Care for commercial living donors

Studies to assess CLDs' consequences from a commercial organ donation have largely consisted of single interviews. Researchers have also generally not included arrangements for care provision after obtaining findings.<sup>7,8</sup> COFS

<sup>7</sup>An exception to this is the following study: Farhat Moazam, Riffat Moazam Zaman and Aamir M. Jafarey, 'Conversations with Kidney Vendors in Pakistan: An Ethnographic Study,' *Hastings Center Report* 39, no. 3 (2009): 29–44. This study included qualitative interviews with 32 'kidney vendors' followed by blood pressure readings and a 'dipstick' urine examination to test for the presence of sugar, protein, bilirubin and blood. Of the vendors, who were referred to a physician for proteinuria and/or haematuria (3) or referred for psychiatric assessment (20), none participated in the follow-up. The authors attributed this to the cost of travel and/or the inability to take time off from work.

<sup>8</sup>COFS' investigations to assess CLDs' experiences are built on the aims to: i). understand the exploitative practices around commercial transplants, ii). understand the consequences for poor and vulnerable groups, who serve as CLDs, iii). provide long-term outreach to these victims of the organ trade who are largely abandoned after a commercial transplant and iv). where commitments to ethical frameworks in transplant systems are being made and maintained (particularly in countries where such practices have characterized transplantation), work towards rebuilding public trust in transplantation through these reconciliation measures of caring for the victims of organ trafficking. Such public trust is an essential ingredient to shift from the reliance upon CLDs and develop altruistic and deceased donation. The discussion in this paper is focused on the second and third of these aims. The first aim of understanding exploitative transplant practices not only reveals findings about solicitation and the parties involved but also indicates much about the social networks that develop to foster organ trafficking, beyond just that of the criminal brokers. For example, we could recognize patterns of parents who sold a kidney who later encouraged their children to sell a kidney, as well as husbands who sold who also encouraged their wives to sell. We are also able to further our understanding of how individuals are victim to multiple forms of human trafficking. For example, cases of Darfurian men who were solicited to come to Cairo for jobs, worked without compensation, accumulated rent debts and were then lured into selling a kidney to pay these debts.

<sup>6</sup>As a result of COFS' limited resources, this number is regrettably a small fraction of the estimated thousands of victims of the organ trade in need of outreach services in Egypt.

commenced its work in Egypt in 2005 to respond to CLDs' needs as assessed in the first author's preliminary research in preceding years. Outreach services have thus been developed according to the findings about the CLDs' consequences from their commercial nephrectomies and include: clinical follow-up services, health education on living with a single kidney, counselling and peer support, income generation/employment assistance and referral to legal services. COFS-Egypt has organized a coalition of partner health, human rights and development non-governmental organisations (NGOs) and a network of volunteer doctors and low-cost charitable clinics to provide these services.

Although several centres that conduct commercial transplants offer follow-up care to organ donors, CLDs and the centres report that CLDs do not return to these centres for follow-up care. COFS' beneficiaries consistently explain that they do not feel comfortable returning to the same centre for follow-up visits, particularly if they felt they did not receive good treatment during their stay there for the commercial organ 'donation.' Further, they often cannot afford the fees for this care at the centres, where the transplant was conducted or via most other clinical care options.

In contrast, COFS' outreach services are based on building trust with these victims. COFS' social workers/donor advocates are individuals from local or neighbouring communities where CLDs reside and who developed the motto: 'Consider us the friends you never told.' They are trained to conduct the interviews with CLDs and they coordinate their clinical follow-up exams immediately postnephrectomy, after 1 month, 6 months, 1 year and then annually for life. The protocol of clinical services was developed by the network of doctors who partner with COFS to provide this care provision. Considering that we meet CLDs at various periods of time after their commercial organ donation, the schema of follow-up visits is applied accordingly after an initial exam. Each exam includes a clinical assessment, urine analysis.<sup>9</sup> Blood tests (to assess blood urea, serum uric acid and serum creatinine) and the examinations that occur immediately postoperatively and 1 year after the nephrectomy also include an ultrasonic determination of the kidney size. Through an extended referral network of care providers, COFS arranges the provision of health care services for ailments that can be attributed to being a direct result of the nephrectomy. In addition

to these clinical services, the examining doctor conducts brief health education discussions with the CLDs about living with one kidney, emphasizing the need to assure safe drinking water (a necessity not readily available to many who reside in very low-income settings in Egypt), a nutritious diet and to avoid the consumption of alcohol and cigarettes.

Coalition for Organ-Failure Solutions -Egypt's social workers/donor advocates conduct peer support groups with partial participation of a trained psychiatrist and coordinate appointments for private appointments upon request or the psychiatrist's recommendation. These sessions are often the first opportunity that many CLDs in Egypt have to meet with a group of other CLDs to discuss their experiences, consequences and fears about the commercial organ donation each has made. These sessions also serve as an important venue for CLDs to further address questions about their concerns. CLDs often discuss their fears about ailments, life expectancy and fertility and women ask if they will be able to bear children after a nephrectomy.

Considering that many CLDs report an inability to return to labour-intensive jobs, COFS partners with economic development NGOs to arrange employment opportunities for its beneficiaries that do not involve heavy labour. Finally, COFS arranges legal services for CLDs. This last service has not yet been utilized as there have not yet been adequate avenues for legal recourse for victims in Egypt. Despite the new law against organ trafficking, thus far victims still fear being blamed for their involvement in a commercial organ donation if their case is brought to the attention of authorities and there are not yet paths for reporting cases of abuse.

### **Proposed regulated compensation as a solution to combat organ trafficking**

Proposals that suggest that a regulated market in organs could solve the problem of organ trafficking are removed from the desperate lives of those who financial incentives target, whether in a regulated, semi- or un-regulated market or in developed or developing countries [12].<sup>10</sup> The inevitable reliance upon the poor, the global economic forces that would not make stringent regulation possible, the difficulties of assuring good standards in donor selec-

<sup>9</sup>The urinalysis is complete, including measurement of pH, specific gravity, protein, glucose, RBCs, nitrites and WBC esterase by dipstick reagents and analysis for cells, casts and crystals.

<sup>10</sup>Iran is the only country to have a state-supported compensation system and, similar to black market organ sales elsewhere, has not avoided a reliance on the poor for the advantage of relatively rich patients.

tion criteria when driven by financial incentives and the erosion of altruistic and deceased donation that commercial donation causes are identified as key faults of these proposals.

Follow-up care for organ donors is another consideration in the debate on material versus altruistic incentive structures for organ donation. Regulationists suggest that a CLD in a regulated market would receive better medical care during and following the organ sale/compensated 'donation.' While this improved care may be offered in a regulated arrangement, this argument disregards the challenges of assuring that organ donors actually receive this care in both altruistic and commercial scenarios. Further, our experience in Egypt includes CLDs, who were in a range of private and public settings and received a range of 'descent' and 'bad' care during their stay at a transplant centre for the organ donation. CLDs who were offered follow-up care where they donated a kidney refused to return to that centre for such care as they were convinced that the centre did not serve as an advocate of their best interests. It is likely that CLDs in a regulated market would share similar convictions.

Despite several prominent Egyptian proponents of a regulated organs market, the recent law in Egypt stands in opposition to such a system. Yet, this is a critical moment for Egypt to regain public trust in transplants in order to advance altruistic and deceased organ donation. The extent to which it remains committed (versus moves to remove the ban on commercial donorship in the Philippines) and enforces the new prohibition on transplant commercialism, will shape the success of its trust-building project and eventually the goal of national self-sufficiency in organ supplies.

Coalition for Organ-Failure Solutions' experience thus continues to propel support for the World Health Organization (WHO) Guiding Principles and Istanbul Declaration that oppose material incentives for an organ donation globally and for the draft Madrid Resolution that calls for government commitments to meet the needs of patients while avoiding the harms of transplant tourism and commercial living donation. Such principles are required to protect the vulnerable from the lure of financial incentives in any schema in which they are offered.

### **Movement to combat organ trafficking**

The movement to end organ trafficking has gained momentum in recent years. It includes a diverse set of actors to address the multi-faceted character of the organ trade. By conducting case investigations, individual social and health science researchers and media

investigators have made essential contributions of creating awareness of the criminal operations behind organ trafficking, parties involved and the victims' consequences.

Two NGOs (i.e. COFS, Asia ACTS Against Child Trafficking, Philippines) have worked to identify victims, provide medical follow-up and other outreach services, conduct systematic studies and report findings. In aims of prevention, they have also worked to establish or improve national legal frameworks on transplantation, protect potential victims and advance altruistic and deceased donation.

The WHO has utilized findings and international expert consultations to update the Guiding Principles on Human Cell, Tissue and Organ Transplantation in 2008, which urges Member States to implement the Principles in the formulation and enforcement of legal frameworks on human cell, tissue and organ donation and transplantation [13]. In official partnership with the WHO, the Transplantation Society (TTS) and the International Society of Nephrology (ISN) developed the Istanbul Declaration in 2008 as another key instrument to define the problem and make recommendations for solutions. These Societies, primarily composed of transplant professionals, have made strides to oust peers engaged in 'bad' transplant practices from participation in these societies and from publishing in various related journals. They have also pressured governments to adopt and enforce stricter laws on organ trafficking and pharmaceutical and insurance companies to make commitments against fostering the organ trade.

Various human rights groups (Laogai Research Foundation, Human Rights Watch), anti-human trafficking initiatives and several UN bodies (the United Nations Office of Drugs and Crime, Joint Council of Europe/United Nations) have also begun to take greater interest in the movement against organ trafficking and have an essential role to play in further investigating and reporting cases and calling for accountability from multi-level authorities.

Each party is situated uniquely and each is committed to the mission of ending abuses around organ donation. Each also entails its strengths and limitations. Greater alliances must be built to recognize and compliment the contributions of these parties to assure success of the movement.

### **Conclusion**

The Istanbul Declaration makes an essential advance in giving special recognition to CLDs and affirmed that this care as a 'critical responsibility of all jurisdictions that

sanctioned organ transplants'.<sup>11</sup> Yet neither public nor private commitments (i.e. government services in jurisdictions that have universal health insurance and private suppliers where this insurance is absent) exist to assure the provision of this care.

The movement to end organ trafficking must develop strategies that secure care for the live organ donor, including victims of organ trafficking. A third party who recognizes the grim realities of the lived experiences of the victim of organ trafficking is required to serve an advocacy role for the living organ donor and assure the provision of follow-up care.

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<sup>11</sup>The Istanbul Declaration suggests the following recommendations for follow-up care to ensure the protection and safety of living donors:

'Provision of care includes medical and psychosocial care at the time of donation and for any short- and long-term consequences related to organ donations

a. In jurisdictions and countries that lack universal health insurance, the provision of disability, life and health insurance related to the donation event is a necessary requirement in providing care for the donor;

b. In those jurisdictions that have universal health insurance, governmental services should ensure donors have access to appropriate medical care related to the donation event;

c. Health and/or life insurance coverage and employment opportunities of persons who donate organs should not be compromised;

d. All donors should be offered psychosocial services as a standard component of follow-up;

e. In the event of organ-failure in the donor, the donor should receive:

i. Supportive medical care, including dialysis for those with renal failure, and

ii. Priority for access to transplantation, integrated into existing allocation rules as they apply to either living or deceased organ transplantation.'