

ORGAN RECIPIENTS WHO PAID FOR KIDNEY TRANPSLANTATIONS ABROAD:

A Report

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- 1. Trafficking in human beings for the purpose of organ removal: a comprehensive literature review (December 2013).
- 2. Organ recipients who paid for kidney transplantations abroad: a report (November 2014)
- 3. Trafficking in human beings for the purpose of organ removal: a case study report (November 2014)
- 4. Indicators to help data collection and identification of trafficking in persons for the purpose of organ removal (August 2015)
- 5. Recommendations to improve non-legislative response (August 2015)

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1. Introduction

Worldwide, there is a mismatch between the increase in the number of those waiting and the increase in those identified as potential donors. Kidney transplant wait lists grow most prominently (1). By the end of 2013, 49.266 people were waiting for a kidney transplantation in the European Union, whilst only 19.227 transplantations were performed that year (2). Eurotransplant's wait list has an average waiting time of 3-5 years. About 15-30% of the patients die before receiving a kidney (3). Also in other parts of the world such as in the United States of America (USA), the number of candidates on the kidney wait list is increasing. Between 1980 and 2009 the list increased by 600% (1). Yet, the number of annual donors between 2004 and 2011 remained relatively stagnant at 13.000, making the gap between organ supply and demand even larger (1). The list in the USA now has a median wait time of over 4 years (4). The activity of organ transplantation worldwide is less than 10% of the global need (5). Furthermore there are substantial disparities in access to transplantation, not only globally (6), but within countries as well (7). Organ recipients travel across the world for transplantation, the most common being live kidney transplantation (8-13). Although travelling abroad does not imply an illegal transplant purchase, it is commonly perceived to be an illegal and/or immoral endeavour involving health risks (14-16).

Several qualitative studies have been performed among patients who purchase kidneys (17-22). Some of these studies reveal that patients bring back little or no information about their operation, such as the origin of their kidney, the transplantation costs or where and by whom the transplantation was performed. The limited amount of data about transplantations abroad makes it difficult to draw firm conclusions about its scale, nature and potential illegality. Also, little knowledge exists about the motivations, experiences and characteristics of patients travelling abroad.

Purpose of study

The main conclusion of the HOTT project's first report, '*Trafficking in human beings for the purpose of organ removal: a comprehensive literature review*' (23) (hereafter: literature review), is that a literature study provides limited information and knowledge about the nature and incidence of the crime. The underlying report aims to fulfil gaps of knowledge highlighted in the literature review by presenting the results of interviews with patients who travelled abroad for paid kidney transplantations. The purpose of this study is to describe *the process* of the transplantation (how, where and by whom it was facilitated) and the perspectives, experiences, behaviors and motivations of these patients.

Research questions

The research questions are as follows:

- 1. Do patients travel abroad for paid kidney transplantations?
- 2. How, where and by whom were their transplantations facilitated?
- 3. What are patients' motivations, experiences and characteristics?

Countries

This study was carried out in Sweden, Macedonia and The Netherlands by research teams of the following institutions:

- Lund University, Sweden (ULUND)
- University of St. Cyril and Methodius, former Yugoslav Republic of Macedonia (UCM)
- Erasmus MC University Hospital Rotterdam, The Netherlands (EMC)

Scope and use of terms

The underlying report adheres to the definitions and terms that are presented in the HOTT project's literature review (23). The study focuses on kidneys and not on other organs. Kidneys are increasingly transplanted from living suppliers and are the most commonly traded organs. The number of transplants per million population (pmp) and patients on the waiting list in 2013 in Sweden, Macedonia and The Netherlands were as follows:

Number of transplantations and number of patients waiting for a kidney transplantation in 2013

SwedenTotal number of kidney transplantations pmp: 43,7Number of deceased kidney donations pmp: 28Number of deceased kidney transplantations pmp: 28Number of living kidney donations pmp: 15,7Number of kidney patients on waiting list: 650Acceptance of living donations from indirect and unspecified suppliers¹ (24): yesSource: The Swedish Council for Organ and Tissue Donation 2000-2013 (25); The National Board of Health andWelfare's report 2013 (26)

Macedonia

Total number of kidney transplantations pmp: 18 Number of deceased kidney donations pmp: 0 Number of deceased kidney transplantations pmp: 0 Number of living kidney donations pmp: 18 Number of kidney patients on waiting list: 400 Acceptance of living donations from indirect and unspecified suppliers : no *Source: Nephrology Clinic, University of St. Cyril and Methodius*²

The Netherlands

Total number of kidney transplantations pmp : 56,8

Number of deceased kidney donations pmp: 15.9

Number of deceased kidney transplantations pmp: 25,8

Number of living kidney donations pmp: 31

Number of kidney patients on waiting list (31 December 2013): 710 (or 735 kidney + pancreas/liver)

Acceptance of living donations from indirect and unspecified suppliers : yes

Source: Annual report of the Dutch Transplant Foundation (27) & Organización Nacional de Trasplantes (2)

¹ Indirect donation means that a person donates indirectly to his or her intended recipient or to a specified recipient through an exchange program. Unspecified donation is donation to an anonymous and unspecified recipient (e.g. donation to the waiting list) (23). ² The Nephrology Clinic at UCM is the only center in Macedonia that performs transplants.

2. Methods and sources

2.1 Study design

This study consisted of in-depth interviews with recipients who travelled abroad for kidney transplantations.

2.1.1 Questions and themes

The interviews took place in correspondence with a semi-structured list of questions that addressed 6 topics.

Торіс	Description
Patient characteristics	Age, place of birth, schooling, family situation, living situation, nationality.
Anamnesis	Experiences of illness and treatments in the home country prior to going abroad for transplant, life on dialysis, waiting time, (living) transplant possibilities.
Pre-transplant stage	Motivation, preparation and facilitation of the transplant abroad, role of health insurance companies.
Transplant stage	Organization of the transplant, operation team, contact with physicians.
Post-transplant stage	Aftercare, complications, contact with supplier and physicians, quality of care, satisfaction of transplant abroad.
Ethics	Patient's (moral) point of view about: getting a kidney from a (unknown) supplier, commercialization, awareness of suppliers' situation, solution of organ shortage.

EMC and ULUND performed the interviews in an in-depth and semi-structured manner. They were performed by using the topic list. The interviews by EMC and ULUND were tape-recorded. UCM held the interviews in a structured way by posing the questions listed in Appendix 1. The interviews by UCM were not tape recorded; answers were written down during the interview.

2.1.2 Study population

Patients with renal disease who travelled for a kidney transplant from Sweden, Macedonia or The Netherlands were included in the study.

2.1.3 Ethical approval

ULUND and EMC applied for approval to perform the study. ULUND submitted an application to the board for ethical approval of research involving humans in Sweden. The board's approval of the study is registered under Nr 2013/769, dated 11 December 2013. EMC submitted a proposal to the medical ethical committee of the hospital. The hospital's approval of this research is registered under MEC-2013-577, dated 10 December 2013.

2.1.4 Approach of the participants

ULUND

Finding respondents was rather difficult in Sweden. For the recruitment of respondents ULUND mainly relied on a list of patients provided by one of the transplant clinics in Sweden. There were 12 persons on the list, a number which by no means indicate the total number of patients from Sweden having travelled abroad for transplantation³, since this is the list from only one transplant unit. The information about the patients on this list was scarce. After contacting the patients, we realised that only one (Leila) of the 5 patients we could get hold of fit the criterion of the study.

The patients were all first contacted by mail. The letter they received contained information about the study, an inquiry into their willingness to participate and an informed consent sheet for them to sign and return to us if they were willing to participate. A week later, the patients who had conveyed their willingness to participate were contacted by phone in order to make arrangement. The remaining patients were also contacted by phone in order to make sure that they had received and understood the information and to orally inquire about their willingness to participate.

Due to the low proportion of these patients, we also included 3 interviews (Ahmed, Mohammed, Amir) that we conducted in 2010, as a part of a previous research project (18). These interviews fit the criteria since the respondents were all transplanted abroad while living in Sweden. Moreover, these interviews were performed with a methodology and interview protocol similar to that of the HOTT-project. In the end, we also recruited one patient (Ali) through another transplant professional. This patient gave his informed consent to his treating physician who then contacted us in order to make the practical arrangements for the interview.

UCM

UCM approached 10 patients⁴ who are regularly followed on out-patient basis in the University Clinic of Nephrology, and gave them a detailed explanation of the study. All patients agreed to participate in the study and signed the informed consent sheets. The patients were informed that the data would be used anonymously and that their personal data would be kept strictly confidential.

EMC

The researchers asked transplant doctors in EMC to identify patients (who are treated in this hospital) who went abroad for transplantation. In total, the doctors identified 13 patients⁵ and asked them if they were willing to be interviewed. The patients were informed that their information would be used anonymously and that their personal data would be kept strictly confidential. They also were asked permission to provide their contact information to the researchers. Then, the patients were sent an information form and contacted for an appointment. In total, 7 patients agreed to be interviewed. Each patient signed an informed consent form.

³ An informal list compiled by physicians in Sweden indicates approximately 40 patients who most likely have travelled abroad for organ transplantation, for which they have paid different amounts of money.

⁴ Thirty-five patients are known at UCM who travelled abroad to buy kidneys, predominantly in Pakistan, India and Egypt.

⁵ The total number of patients who travel(led) abroad from the Netherlands to purchase kidney transplants is not known.

2.2 Other data sources

EMC and UCM used medical background information of patients as supplementary data. ULUND did not have access to such files. At UCM, the data mainly concerned surgical and medical complications for which patients were treated in the University Clinic of Nephrology and Urology after their return from the transplant abroad. The written medical report, if present, was used as well. EMC searched patients' Electronic Health Records (hereafter: EHR). This data was collected with approval of the patients. Most of the patients' medical history (such as the etiology, renal replacement therapy and previous transplants) and information from the hospital abroad is based on data retrieved from the EHR.

2.3 Interviews with organ recipients

The number of respondents per country are presented below.

Country	Number of interviews
Sweden	5
Macedonia	10
The Netherlands	7
Total	22

2.3.1 Interpreters

During 2 interviews held by UMC, an interpreter was present. EMC asked an interpreter to translate during one interview. ULUND also used an interpreter in one occasion.

2.3.2 Data analysis

ULUND and EMC transcribed and encoded the data of this study manually, which led to summaries based on the recurring and relevant themes that were identified. These summaries were then used as the empirical background to the presentation of the results. UCM used the written answers and notes made during the interviews to analyze the data.

3. Results

3.1 Sweden

Sweden – ULUND		
Gender	4 male	
	1 female	
Year and place of birth	Amir: Born 1950 in Iran	
	Ahmed: Born 1959 in Lebanon	
	Mohammed: Born 1961 in Iraq	
	Leila: Born 1949 in Iran	
	Ali: Born 1974 in Iraq	
Marital status	All married	
	4 have children	
Education	4 with university degree	
	1 unknown	
Employment	2 employed	
	1 unemployed	
	2 retired due to illness	
Year of transplantation,	Amir: 2006 in Iran (deceased supplier)	
destination and supplier	Ahmed: 2005 in Pakistan (living related supplier)	
	Mohammed: 2005 in Pakistan (paid supplier)	
	Leila: 2007 in Iran (paid supplier)	
	Ali: 2007 in Iraq (living unrelated supplier)	

Motivations

The motivations that the respondents stated for travelling abroad for transplantation varied. What motivated the majority of them were the complications they experienced when undergoing dialysis. But they also stated other reasons. Deficiencies and discrimination in the health care they receive in Sweden was one motivational factor. Ahmed, for example, decided to go abroad for transplantation when he was moved to the bottom of the wait list as a consequence of him terminating the evaluation of his sister. The reason he terminated the evaluation process was that he felt sorry for his sister who had to stay in Sweden for months since his doctors could not decide whether or not to allow her to donate to her brother. No one, however, had told him that this would mean that he lost his place on the waiting list. Another motivational factor was knowledge about and contacts established within the transplantation society of one's country of origin. When undergoing dialysis in Sweden, Amir frequently went to Iran where he consulted a physician and where he was awaiting a transplant. On a similar note, Leila told us that it felt safe to go to Iran since she was aware of the skills of the doctors there. She would not have gone to another country, she said.

All respondents, except Leila and Ali, investigated the possibility of receiving an organ from a living related supplier prior to going abroad for transplantation. However, Amir's sister was deemed unfit, Mohammed's sister failed to receive a visa for Sweden and, as mentioned earlier, Ahmed terminated the evaluation process of his sister since it dragged on for so long. Thus, no one succeeded in finding

a suitable living supplier. In their narratives, Mohammed and Ahmed clearly ascribe this outcome to the discriminatory structures of the Swedish society.

Practical arrangements

The practical arrangements that preceded the transplantations abroad also varied between the respondents. All but Amir and Leila mentioned the involvement of family members in assisting them to find suppliers or establish contacts with hospitals and transplant professionals abroad. While Amir relied heavily on the contact he had established with the doctor in Iran, Leila posted an ad in a local Iranian newspaper with the aim to find a person willing to sell a kidney. Few of the respondents mentioned the involvement of an organ broker. The majority seemed to have been in direct – or indirect through family members – contact with the transplant clinic. Ahmed was the only one who mentioned money being paid to a contact person, but it was not clear what function this person had. The medical evaluation and matching that preceded the transplantations were in most cases performed at the hospital where the surgery took place. Amir, for instance, told us that the Iranian doctors retook almost all of the tests that the Swedish doctors had already taken. Ahmed, however, was able to bring all the documentation that had been made on him and his supplier in Lebanon to the hospital in Pakistan where the transplantation finally took place.

When Amir, Ahmed, Leila and Ali went abroad, their transplantations were yet to be fully organized. Amir underwent all the necessary tests in Iran and then stayed there for 7 months before the transplantation took place. Likewise, Leila went to Iran to stay with her sisters and only while living there she started the process of looking for a supplier. Four months later the transplantation took place. Although Ali just went to Iraq to visit his relatives without intentions to undergo transplantation, he quickly received an organ. Ali was under the impression that undergoing a transplantation in Iraq was highly dangerous, but his parents convinced him that this was not the case and provided him with a supplier from within their own clan. Two weeks later Ali was transplanted. Mohammed also describes the process as fast. After 3 days in Pakistan a person willing to sell an organ to him was found.

Payments

All of the respondents made payments in association with the transplantation. Not all however paid for the organ per se, but for the services. Only Leila and Mohammed openly said that they paid for the organ, that is, made payments to the supplier. Leila paid 10 million Iranian real (approximately €280 in today's monetary value). Mohammed did not mention the amount of money that he paid but said that he needed the help from his brother to finance the purchase. Amir paid for the surgery and the associated services. This cost approximately 120.000 Swedish crowns (approximately €13.000 in today's monetary value). Ali also paid for the surgery and associated services, which cost approximately US\$10.000. But there were also other costs not directly associated with the medical procedure. For example, the relatives that accompanied Ali to Bagdad for the operation had to be housed in a hotel. In the end, these indirect costs amounted to another US \$10.000. Ali's father, who was the owner of a hotel, covered these costs. Ali mentioned giving a gift to the supplier, but it is unclear whether the gift was of symbolic or financial nature. Regarding Ahmed, things were even more unclear. Since his mother managed the financial transactions, and financed the surgery by selling a plot of land, Ahmed claimed that he did not know how much was paid and who was paid what.

Suppliers

All but Amir, who received a deceased supplier organ, met their suppliers. Leila went together with her supplier to the state agency that organizes the sharing of organs in Iran. At the time of the interview, she was still in contact with the supplier and his family and regularly sent money to them. Mohammed went against the recommendations of the Pakistani doctors and demanded to get to meet and pay his supplier. But since this meeting they have not been in contact. Ali's supplier was a member of the same clan as him (Iraq is a distinctive clan society), but he did not meet him until 4 or 5 days before the operation. Today they have no contact.

Openness about their actions

It is unclear whether all the respondents told their Swedish caregivers about their intentions to go abroad for transplantation. Mohammed was open about his intentions to go abroad but lied about the destination of his travel, saying the USA instead of Pakistan. Amir was completely open about his intentions, to which the caregivers reacted with bafflement. But they did not discourage him to go, he says. Upon their return to Sweden, the reaction of the Swedish caregivers differed. Mohammed was asked a lot of questions when he returned to Sweden, but he answered them openly, a fact that he believes improved the care he received. Ahmed, however, felt that the Swedish doctors overreacted when he returned. He sensed that they assumed that he had bought a kidney and that he, as a result, had become infected with various diseases. Since Ali returned to Sweden with the organ that he received in Iraq, his doctor has actively dissuaded him from going abroad for a transplant again. For the sake of his health, his doctor argues, he should remain within the Swedish health care system.

Post-transplant outcomes

All respondents, except Ali, seem to have had no or minor complications after the transplantation. Whether Ali received an infected kidney or whether the chronic virus that he was affected with in his early childhood caused the violent rejection that he experienced is unclear. But 2 months after the transplantation he started to experience severe complications and returned to Sweden immediately. At the airport in Stockholm an ambulance waited for him and subsequently he spent 3 months in the hospital. All of the other respondents received functioning and uninfected kidneys. Mohammed left the hospital in Pakistan already after 2 weeks. However, it took one year before he was fit enough to start working full time again. Amir experienced some complications. Only 3-4 weeks after the transplantation he came down with a fever, which turned out to be caused by a kidney stone. But the doctors managed to remove the stone without damaging the graft. When it comes to the care that the respondents received in the destination country, the majority of the respondents highlight the skill of the surgeons but also point out that they worried about the lack of hygiene.

Ethics

When it comes to ethical issues associated with transplantation abroad and the commercialisation of organs, the respondents often struggle to align the principle level with the individual level. Leila, for instance, tells us that the implementation of a regulated market in organs would be good for those in need of a transplant. But if one takes into account the totality of what this means, she does not think it is favourable. On a similar note, Mohammed tells us that he is not "the kind of person who wants to buy from others", but he says that his situation forced him to do so.

3.2 Macedonia

Macedonia - UCM		
Gender	8 male	
	2 female	
Year and place of birth	Basri: Born 1984 in Kosovo-Albanian	
	Nijazi: Born 1968 in Kosovo-Albanian	
	Nazife: Born 1953 in Kosovo-Albanian	
	Ismet: Born 1985 in MKD-Albanian	
	Zeliha: Born 1962 MKD-Bosnian	
	Bajram: Born 1963 in MKD-Albanian	
	Muidin: Born 1961 in MKD-Albanian	
	Agim: Born 1952 in Kosovo-Albanian	
	Refik: Born 1957 in Kosovo-Albanian	
	Nusret: Born 1981 in MKD-Albanian	
Marital status	All married	
	9 have children	
Education	6 primary school education	
	2 high school	
	2 university degree	
Employment	5 employed	
	5 unemployed	
Year of transplantation,	Basri: Transplanted 2002 in Russia (no information available)	
destination and supplier	Nijazi: Transplanted 2006 in Pakistan (20-years old boy)	
	Nazife: Transplanted 2007 in Pakistan (young girl)	
	Ismet: Transplanted 2007 in Pakistan (22-years old boy)	
	Zeliha: Transplanted 2007 in Pakistan (no information available)	
	Bajram: Transplanted 2006 in India (no information available)	
	Muidin: Transplanted 2007 in Pakistan (young man)	
	Agim: Transplanted 2006 in Pakistan (25/26-years old person)	
	Refik: Transplanted 2007 in Pakistan (30-years old man)	
	Nusret: Transplanted 2007 in India (no information available)	

Pre transplant stage and motivation

The practice of transplant tourism is very well known among the Balkan countries especially in the last 20 years. Common destinations are India, Pakistan, Russia and Egypt. The motivation to go abroad and to buy a kidney is caused by a lack of regular transplant activity in most of the Balkan countries. Unfortunately there are many other important reasons such as recent civil wars, a full economic collapse after the introduction of a market economy and change of the political system. Regarding the motivation of the Chronic Kidney Disease patients to go abroad to buy a kidney it can be concluded that there is a lack of regular transplant activity in most of the Balkan countries. For example in the recently founded Republic of Kosovo there is still not any transplantation as a medical procedure. Therefore, for the Kosovo patients no options were suitable to get a kidney. Although the conditions in Macedonia are different, the number of transplants per year is far from sufficient. It can be also one of the reasons for patients to go abroad and to get a kidney.

Most of the patients describe the time of dialysis as very depressing, complicated and hopeless. Especially when taking into account other everyday additional living problems such as unemployment and mostly catastrophic economic situation in the country. Anyway, the decision to go abroad was supported by the members of the closed families despite the confidence in the local health system and dialysis conditions. Among 10 transplants performed in Pakistan and India, 2 were pre-emptive (Refyk and Nazife) and 8 (Basri, Zeliha, Nusret, Ismet, Bajram, Agim, Muidin, Nijazi) were regular living paid supplier transplantation after 1 up to 12 years of dialysis time. Except 2 patients from Kosovo, there was no support from the local medical staff.

Regarding education there are 3 patients with a university degree (Zeliha is high school teacher, Muidin is Muslim theology and priest-hodja and Refyk is economist and university professor). Six patients had a primary school education. Four patients from Kosovo are unemployed with very bad social and living conditions. Only one patient (Bajram) is unemployed among the patients from Macedonia. All other patients are employed according to their qualifications. Most of the unemployed patients in Kosovo receive social monthly help (up to ξ 50,-) whereas Bajram (unemployed from Macedonia) got ξ 75,-. Most of the unemployed patients received some help from the relatives who work abroad (such as from Germany and Switzerland).

All interviewed patients are Muslims (9 Albanians and 1 Bosnian) and 7 of them were transplanted in Pakistan, 2 in India and 1 in Russia. The information for the possibility to go abroad and buy the kidney usually came from the patients that were already transplanted in those countries.

Four patients tried to get a kidney from their relatives but it was not possible because 2 suppliers were ABO incompatible and another 2 faced serious health problems. Two other patients had no suitable supplier and 4 did not want to "sacrifice" their family members for living donation. Six patients (Refyk, Bajram, Nusret, Agim, Nijazi, Muedin) got a telephone number from a doctor in charge: 4 in Pakistan (3 in Jinnah Hospital, 1 in Lahore) and 2 in New Delhi. Four patients had brokers or intermediaries (Zeliha, Ismet and Muedin in Lahore) and Basri (Moscow). Only one patient (Nazife) used internet as a communication to contact the hospital in Karachi.

Practical arrangements

All patients were accompanied by members of families or friends: Zeliha – brother, Muedin – wife, Ismet – father, Nusret – father, Nijazi – brother, Basri – brother, Nazife – son, Agim – friend, Bajram – friend and Refyk – nephew. Three patients (Zeliha, Ismet and Muedin) were accompanied also by their broker. Seven patients organized the trip by themselves. Eight visas were issued in Belgrade after the confirmation letter from Pakistan, 1 in Sofia (Bulgaria) and 1 in Ankara (Turkey). Visas were issued without any problems.

The trip to Pakistan (Karachi, Lahore and Rawalpindi) for Muedin, Nijazi, Zeliha, Nazife, Refyk, Agim and Ismet was well organized, predominantly by Turkish Airlines. The destination New Delhi was complicated by several days stay in Turkey for Bajram and Nusret and relatively easy for Basri in Moscow. There were no border and customs problems for most of the patients. Usually for the hospitals in Pakistan there was always a guide at the airport who transferred the patients directly to the hospitals. The guides usually had the name of the patient on the list.

Hospitals and suppliers

The reception in the hospitals was quite good and the staff was polite. Most of the patients who were transplanted in Pakistan were alone in the room, sometimes with their accompanying persons. Nobody shared the room with the supplier. Six recipients saw their supplier directly but only 4 held some conversation with them. Refyk and Nazife describe the very bad situation of their suppliers and, because of that, they paid some additional money directly to their suppliers. The suppliers were usually young, between 20-30 years; most of them were men and there was only one young girl of 20 years. Jinnah Memorial Hospital in Rawalpindi and Rashed Hospital in Lahore performed some additional investigations regarding recipients. The transplantation started usually from 7 to 10 days after the reception in the hospital.

Payments

The payment was predominantly done directly to the doctor in charge (Nusret, Bajram, Agim, Refyk, Nijazi), 3 patients paid a broker (Muedin, Zeliha, Ismet), 1 by Bank – Transfer (Basri) and 1 to the hospital (Nazife). The amount of money was as follows:

Basri (Moscow)	- € 45.000 + travel costs
Zeliha (Lahore)	- € 22.000 + travel costs
Ismet (Lahore)	- € 22.000 + travel costs
Muedin (Lahore)	- € 26.000 + travel costs
Niazi (Rawalpindi)	- € 10.000 + travel costs
Refyk (Rawalpindi)	- € 11.000 + travel costs
Agim (Rawalpindi)	- € 12.500 + travel costs
Nazife (Karachi)	- € 26.000 + travel costs
Bajram (New Delhi)	- € 22.000 + travel costs
Nusret (New Delhi)	- € 22.000 + travel costs

Post-transplant outcomes

Four recipients felt good after the operation (Agim, Nazife, Ismet, Zeliha) and did not show any further surgical or medical complications. Two patients were with sepsis (Nijazi, Muedin) and 3 were re-operated (Basri, Nusret and Bajram). Two had delayed graft function (Refyk, Nusret). Most patients had urinary tract infection. The surgical correction was done locally (Moscow – Basri) and 2 other in Skopje and Prishtina (Nusret and Bajram). The clinical follow up was done in University Clinic of Nephrology in Skopje.

Transplanted patients in Pakistan were usually dismissed up to 10 days if there were not any complications. Three patients transplanted in Lahore (Muedin, Zeliha and Ismet) had a detailed written report while another 3 in Rawalpindi carried only one simple page without any details about the procedure, immunosuppression, complications etcetera. Basri also had a detailed written report from Moscow. Bajram and Nusret did not bring back any information from New Delhi.

Eight patients were not satisfied with the conditions in the hospitals and hygiene; only 2 had no remarks. Regarding the staff, most said that the staff was polite. Recipients met their doctors before the operations. Seven patients were alone in the room after the surgery, 2 recipients were in the room with 3-4 other patients and 1 patient was in ICU for 5 days.

Ethics

Regarding ethical aspects, only 3 recipients (Refyk, Zeliha and Muedin) showed some reflections and "guilty conscience" about the morality and justification of the act of paid donation and use of the poverty of the suppliers. But all agreed that in the moment there was a solution for their desperate and hopeless situation. Unfortunately there was no any other option in that moment. All of them found the health system and government responsible because of the lack of introduction of a real transplant program in their country.

3.3 The Netherlands

The Netherlands - EMC		
Gender	7 male	
Year and place of birth	Amir: Born 1982 in Somalia (1999)	
(migrated to the Netherlands)	Angelo: Born 1969 in Curacao (1989)	
	Chao: Born 1973 in China (1983)	
	Dilip: Born 1967 in Sri Lanka (1992)	
	Fahad: Born 1955 in Pakistan (1991)	
	Tahir: Born 1967 in Pakistan (1992)	
	Salim: Born 1972 in Pakistan (1993)	
Marital status	5 are married, 1 is cohabiting, 1 is divorced	
	6 have children	
Education	1 no education	
	2 high school	
	4 college degree	
Employment	2 employed	
	2 unemployed	
	3 retired due to illness/since transplantation	
Year of transplantation,	Amir: Transplanted 2007 in Pakistan (living unrelated supplier)	
destination and supplier	Angelo: Transplanted 2001 in Colombia (deceased unrelated supplier)	
	Chao: Transplanted 2000 in China (deceased unrelated supplier)	
	Dilip: Transplanted 2000 in India (living related supplier)	
	Fahad: Transplanted 2007 in Pakistan (living related supplier)	
	Salim: Transplanted 2007 in Pakistan (living related supplier)	
	Tahir: Transplanted 2009 in Pakistan (living related supplier)	

Motivations

Patients' primary motivation to go abroad was the long wait time for a deceased donor kidney. Four patients (Angelo, Dilip, Fahad and Tahir) were on the wait list and underwent dialysis. Their experience of having dialysis influenced their "feeling of waiting". The time during which they underwent dialysis varied from 1 to 6.5 years. They experienced this period as heavy and difficult (a lot of nausea, fatigue and pain). Amir, Chao and Salim were not on the wait list when they travelled abroad. Three patients (Dilip, Fahad and Tahir) initially went abroad to celebrate holidays; the idea to undergo transplantation seemed to emerge there. After hearing that Dilip was placed on the wait list and had to undergo dialysis in The Netherlands, Dilip's family decided to explore the possibilities of

donating a kidney to him in India. Fahad and Tahir became ill during dialysis in Pakistan and they grasped the opportunity to undergo transplantation there. Tahir and Salim's reasons to go abroad, in addition to the long wait time, was because they thought that the procedure to bring a supplier to the Netherlands would take too long.

Practically all patients talked at an early stage of their disease with their Dutch physicians about domestic solutions, such as a transplantation from a deceased or living kidney supplier, and dialysis. Amir was the only patient who did not really talk about this beforehand. His nephrologist said he could try to go abroad for transplantation, although he advised Amir that it was better to be transplanted in the Netherlands. Although they had discussed possibilities with his physician, Chao's parents knew about transplant possibilities in China and they immediately went abroad. None of the patients tried to get a kidney from a relative in the Netherlands. The decision about a transplant abroad was made despite their confidence in the quality of medical care in the Netherlands. Overall, the patients were satisfied with the Dutch health system.

Practical arrangements

The arrangements preceding the transplants varied between the respondents. Dilip and Tahir heard in the Dutch hospital from other patients on dialysis about the possibility of buying organs in Sri Lanka and India. Whereas Salim and Dilip performed most of the research themselves, the others received help from family or friends (including a physician and policeman) to facilitate the transplantation. Their support consisted of finding a suitable clinic or hospital and connecting patients to the "right" people. Family and friends established contacts with transplant professionals. Especially in Pakistan it was useful to "know" people, in order to ensure lower costs and a faster transplant procedure. None of the patients mentioned the Internet as a source to find a supplier or a transplant clinic. No one mentioned the involvement of an organ broker, although the exact role of Chao's contact person (in China) was not really clear. None of the patients' family or friends directly assisted them to find suppliers; these were found by the clinic or by the transplant professionals.

Dilip, Fahad and Tahir took information abroad about their dialysis treatments from the Dutch hospital. Salim brought his medical record with the most recent data. The others did not bring records from the Netherlands and did not ask their physicians for help to go overseas. Amir, Chao and Dilip arranged a visa in the Netherlands. Fahad, Salim and Tahir had a so-called "origin card", which allowed them to travel in and out of Pakistan. For Angelo a visa was not necessary. Whereas Angelo travelled alone to Colombia and stayed there without friends and family, the others went abroad with family members or they travelled alone but met with their friends or family upon arrival. Physical examinations (e.g. blood, kidney, heart and lung) were performed in the hospitals abroad. All transplantations were performed within 4 months.

Hospitals

Angelo went to Hospital San Vicente de Paúl in Medellín (Colombia), Chao to the First Affiliated Hospital of Qingtian (near Wenzhou, China). Dilip went to Madras in India (name of the hospital unknown). Four patients went to Pakistan; 2 went to Lahore and were transplanted in Adil Hospital (Fahad) and Surgimed Hospital (Tahir). Salim was transplanted in Islamabad, in the Military Hospital, and Amir in the Jinnah Memorial Hospital, in Rawalpindi.

Most patients mentioned that the transplant procedure required proof of connection between them and their suppliers; they had to be family or they had to prove that there was a strong emotional relationship. For this, the hospital verified their family names, blood, DNA, their birth certificate and identification documents. Fahad said that his supplier was questioned about his motivations for donation. Salim had to sign a document that no money was paid. Based on the new law in Pakistan, the hospital had to write a letter (with a description of the patient's health situation, the need for transplantation, information about the supplier and proof of the connection between them) for the judge who needs to approve the transplantation. However, some patients hinted that this law procedure could be circumvented if you had money or connections.

Payments

The paid amounts differed between patients, as well as the reimbursements that they received from their health insurance companies. Some patients said that they paid the hospital directly (Salim paid an invoice from the hospital). From the others it is unknown to whom their payments were made. Two patients paid a package deal. The 4 patients who went to Pakistan mentioned that they had to pay (separately) for all services: for the hospital stay, surgery, physicians and nurses, food, medicines and examinations. Especially the medicines were very expensive. The more these patients paid, the better the treatment they received: "it was all about money". Except for Salim, the 3 other patients who went to Pakistan could negotiate the prices. In China, Chao and his family could choose which "kidney type" they wanted: the better the match, the higher the price. They chose the best match and thus the most expensive one. Salim gave his supplier around \notin 600,- out of gratitude, an amount for which, according to Salim, one has to work 3 months in Pakistan. None of the other patients mentioned whether they directly paid their supplier. The amounts were as follows, converted at the current exchange rate⁶:

Chao (China)	- € 25.000,- (medical costs ⁷)
Angelo (Colombia)	- € 11.500,- (package deal)
Dilip (India)	- € 5.000,- (package deal; probably excluding hotel costs)
Tahir (Pakistan)	- € 7.500,- (all costs)
Salim (Pakistan)	- € 8.000,- (all costs)
Fahad (Pakistan)	- € 9.000,- (all costs)
Amir (Pakistan)	- € 6.000,- (including travel costs)

Some patients received (partial) reimbursement from their health insurance company in the Netherlands. The health insurance company of Angelo and Fahad reimbursed the whole amount. Angelo's reimbursement was arranged directly between the coordinator of the hospital in Colombia and his health insurance company. Three patients were compensated a part of the costs: Dilip received \leq 1.850,- (flight costs excluded), Salim \leq 3.000,- and Tahir \leq 6.000,-. They got paid, provided that official and stamped invoices were attached (flight costs were never paid). Both Amir and Chao did not receive anything. Chao's family did not know that refund was possible; they did not notify their insurance in advance that they went abroad for transplantation and thus did not receive a reimbursement. Some patients received financial support from family to cover the transplantation

⁶ Some patients mentioned an amount in another currency than Euro. Chao (2000): 200.000 RMD; Angelo (2001): \$15.000; Tahir (2009): 1000.000 Pakistani rupee; Fahad (2007): 700.000 RMD and Amir (2007): \$8.000,-.

⁷ The Chinese hospital made a distinction between the medical costs (including surgery, doctors, medicines and room) and the hospital costs (food and cleaning) in addition to the amount of € 20.000,- Chao had to pay for food and cleaning.

costs; Chao's brother paid all the costs in China and Dilip's parents paid everything as well. Salim was supported financially by his church in the Netherlands.

Transplant experiences

All patients met their physicians and surgeons right before the operation abroad. They were satisfied with their physicians, describing them as "intelligent specialists" and similar to Dutch physicians. The care of the nurses was also described as "good". Many physicians in Pakistan have studied in the United Kingdom or the United Stated of America. The spoken and written language in Pakistan was English, in Colombia they spoke Spanish (records were written in English) and in China they spoke Chinese. Fahad heard that his nephrologist and his surgeon performed transplantations outside their normal job in another hospital in the same country, to earn extra money. Most patients had a private room. Both Dilip and Salim moved to a shared room after a couple of days. None of them stayed in the same room as their supplier. All transplants were performed without problems. Amir and Fahad (transplanted in Pakistan) mentioned the lack of hygiene in the hospital. The others said that the hygiene was comparable with Dutch hospitals.

All patients saw other foreign, hospitalized transplant patients. According to Angelo, patients came from all over the world because the care was good and quick; he mentioned patients from Venezuela and Bonaire. Chao mainly saw foreign patients: 2 were Dutch and the others came from abroad but were of Chinese origin. Dilip saw 2 patients from India. All other foreigners came from Europe (e.g. Germany, England and France). Amir saw a patient from Somalia, Libya and Oman. Salim saw a Dutch patient and 2 patients from Italy and Scandinavia. Fahad saw foreign patients as well but did not talk with them ("it was not my business").

Post-transplant outcomes

Fahad was not really satisfied about the care that he received; there was too little attention for patients. The others described the care as "good" or "sufficient". The duration of the hospital stay varied from 1 week until 1.5 months. Salim and Fahad mentioned issues around medicines: there were many fake medicines on the market (as well as trade in medicines), there was a shortage of certain medicines and the drugs were very expensive. Salim became ill before he returned to the Netherlands. He experienced kidney rejection within 2 months after the operation. Dilip experienced kidney rejection as well within 1.5 years and Chao experienced rejection after 8 years. Dilip had to dialyze again until he received a deceased donor organ and Salim had to start dialysis until he received a kidney from an unspecified⁸ supplier. Chao is still on dialysis in the Netherlands; a suitable supplier has not yet been found. Amir got an infection within 6 months after returning to the Netherlands, but he recovered well. The others have a good renal function without problems.

Suppliers

All patients had contact with their suppliers after their transplantation, except Angelo and Chao who received a kidney from a deceased supplier. Fahad and Salim received a kidney from a (distant) cousin, Tahir from his brother and Dilip from his mother. Amir said he did not know the supplier, but thanked her afterwards for giving him her kidney. In most cases the information about the transplant provided by the hospital abroad to the patients was limited or even non-existent. For instance, there

⁸ See footnote 1.

is neither information about Chao's supplier nor is there information that supports Dilip and Fahad's accounts. Some patients' Electronic Health Records (EHR) provide information about their suppliers, however this information is based on what the patients told their doctors after they returned to the Netherlands. For example, Salim's EHR states that his supplier was "possibly a living related, cousin". Amir's EHR states that his supplier was an acquaintance, although his record from Pakistan mentions "a young suitable supplier". The records that Tahir (Pakistan) and Angelo (Colombia) took back with them support what they said during the interviews.

Ethics

All patients except Chao and his family said that they are against the illegal purchase and sale of organs. However, most of them agree with paying for an organ transplantation, if the system would be legal and fair for both the supplier and the recipient. Some patients do not agree with selling (parts of) a body based on religious reasons, however they approve of donating out of altruistic reasons. Angelo would go abroad for transplantation if it would be necessary. He said, "If I have the means, I will go there again. I can highly recommend it. It suited me well." He believes that organ trade is impossible to stop, at least as long as there is an organ shortage. Chao needs another transplantation and his family is now looking for possibilities in China. The Chinese culture is used to paying for every service. According to them "in China, it is really all about money, you can buy everything. Everything!," including purchase of organs, "you just pay to receive something, that is normal in China. That is just the culture. It is still going on, if you can pay." The others would not go abroad for transplantation a second time; they prefer to undergo transplantation in the Netherlands. Two patients heard of clinics or hospitals in Pakistan where it still seems to be possible to buy organs.

4. Conclusion

Through this study, the research team was able to collect data that would have been difficult if not impossible to collect through desk research. The authors were able to fill gaps that were highlighted in this project's literature review (1). The purpose of this study was to describe *the process* of the transplantations abroad (by whom, how and where it was facilitated), as well as the perspectives, experiences, behaviors and motivations of patients. We aimed to answer the following questions: Are patients travelling from Sweden, Macedonia and the Netherlands to other countries for a paid transplantation? How, where and by whom was the transplantation facilitated? What are the motivations, experiences and characteristics of patients travelling abroad for transplantation?

Characteristics and motivations

The patients shared some common features. The vast majority are men (19 of 22) and most of them are married with children. From this one can infer that patients who assume the traditional role of the "breadwinner" are more likely to travel abroad for transplantation. A characteristic that was shared by patients in Sweden and The Netherlands was that they were born in another country. In fact, none of the patients that travelled from Sweden and The Netherlands were born there. Not all however travelled back to their country of origin for transplantation. But a slight majority (7 of 12) did and 2 travelled to neighboring countries. Among the Macedonian patients, 5 were natives of Macedonia and 5 originated from Kosovo. Pakistan was by far the most common destination country. Thirteen of the 22 patients underwent transplantation there. This does not mean however that Pakistan was and still is the most common destination country for all commercial transplants. But it was a popular destination. Besides these shared features, common characteristics are hard to find. The patients' age varied between 29 and 65, also their level of education and work situation varied.

The motives patients gave for travelling outside Europe for transplantation also differed. In Sweden and The Netherlands long wait times for deceased donor kidneys and a desire to get away from dialysis were the main motivating factors. In Macedonia the lack of regular transplant activity was the chief reason given by patients for travelling abroad. But they also mentioned major events on a sociopolitical level such as civil wars, economic crisis and political instability. Among the Swedish patients, experiences of discrimination and deficiencies in the domestic health care system were also mentioned as motivating factors. Some patients had examined the possibility to receive a living donor kidney in their country of residence, but none had succeeded. The failure to do so was for some patients a motivating factor. Interestingly, a number of patients were motivated to go to a particular country because it was their country of origin and/or because they were familiar with and had established contacts with health care professionals there. For others, undergoing transplantation was not the chief reason to go abroad. Rather, the transplantation alternative appeared while they were on vacation or in their country of origin visiting relatives.

Practical arrangements

When it comes to the practical arrangements that preceded the transplants abroad, what united the vast majority of the interviewed patients was their reliance on assistance from family and friends. Very often this assistance consisted in providing contacts with hospitals and transplants professionals

in the country of destination. Some patients, however, informed themselves about the possibilities and practicalities of going abroad through fellow patients. A minority used the Internet. A majority did not rely on an organ broker, but arranged the trip themselves with the help of family and friends. Four of the Macedonian patients and possibly one in Sweden and The Netherlands were in contact with and, on 3 occasions, travelled with some sort of intermediary. Two of the Dutch patients bought package deals that included for instance the hospital services, transplantation, surgery, travel and accommodation costs. A majority did not bring any medical documentation with them to the destination country. Instead, physical examinations and evaluations were performed at the hospital where the transplantation was to take place.

Payments

How much patients paid and what their payments included was not always possible to establish. It is clear however that some patients only paid for the services and others for the services and the donor organ. In many cases it is also unclear what amount and if suppliers were paid at all. On some occasions patients paid the supplier themselves, but mostly they did not reimburse the supplier. The most common procedure was to pay the hospital or doctor in charge directly. Three of the Macedonian patients made payments to a broker. The amount patients paid varied significantly, from ≤ 280 ,- to ≤ 45.000 ,-. A number of patients received financial support from family members. In The Netherlands some patients received (partial) reimbursement from their health insurance company.

Transplant experience and post-transplant outcomes

The vast majority of the patients were satisfied with the care they received in the country of destination. Many, however, were discontented with the level of hygiene at the hospital. None of the patients shared a ward with their supplier, but several saw and/or spoke to other patients, who often came from a vast array of countries. Patients were generally dismissed from the hospital after 1 week to 1,5 months after the operation. Most patients had no or minor complications afterwards. Four experienced rejections.

Suppliers

Most often suppliers were recruited by the hospital or the broker. But the vast majority of the patients who received a living donor kidney met their supplier. Some received an organ from a relative. A couple of patients spoke about the destitute conditions that the suppliers were in and paid or gave them gifts out of gratitude. The vast majority have not remained in contact with their supplier. In general, the information the patients received about their supplier was scarce. The documentation they brought back with them also revealed little about their suppliers.

Ethics

Most patients questioned the ethics of their choice to purchase a kidney abroad. Not all had actively reflected on this though. Those who did were generally opposed to the implementation of a legal market in organs, but explained that in the particular situation they were in, going abroad for transplantation was their only choice. Interestingly, some legitimized the organ purchase by reference to the different cultural and moral mindset of the destination country. In Macedonia many patients held the national transplant system and the government responsible for their actions.

Patient interviews and establishing trafficking in human beings for the purpose of organ removal

Our study demonstrates that patients' accounts about transplants abroad constitute a valuable source of information about the international trade in organs. Since the documentation that patients bring back from abroad is often incomplete, what they tell about their experiences is crucial to gain a better understanding of their motivations and the way their transplantations were facilitated. The interviewed patients provided information about the origin of their transplanted kidneys, the transplant costs, why, how and where they went and which persons were involved in facilitating the transplant. This information contributes to the acquiring of knowledge about paid transplants abroad and to efforts preventing illegal transplant activities.

Patient interviews provide little (if any) information about whether their organ suppliers were exploited. Even if patients told us everything they knew or wished to share, this information remains limited. Furthermore, the question remains to what extent the patients' stories and/or medical records are credible. There is also discrepancy between what the medical records show (if available) and what the patients say. Thus, it is difficult if not impossible to establish whether trafficking in human beings for organ removal took place. In order to assess whether this crime occurred, patient interviews should be complemented by interviews with their organ suppliers, brokers, transplant doctors and other facilitators of the transplantation.

Recommendations regarding paid transplants abroad will be published under the auspices of the HOTT project in 2015.

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