ORGAN TRADE

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Organ Trade Orgaanhandel

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INTRODUCTION
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INTRODUCTION

Organ trade constitutes the sale and purchase of organs for financial or material gain [1,2]. Although prohibited since the 1980s, an increasing number of reports indicate its proliferation across the globe [3,4]. Defined as a form of human trafficking [5], the prevailing discourse on organ trade is that of an organized crime, driven by mafia-like networks that exploit the poor for their organs [6-8]. In 2007 the World Health Organization estimated that 5-10% of all organ transplantations are conducted illegally each year [9]. Ranking the organ trade in the top 10 of most lucrative transnational organized crimes, Global Financial Integrity estimated in 2011 that the trade's annual profits lie between $615 mln. and $1.2 bln [4].

These claims however, are made in the absence of thorough, empirical research. The empirical literature on organ trade comprises mostly of studies performed amongst donors who sell their kidneys on the black market and who report a deterioration in physical, psychosocial and financial well-being [10,11]. Yet, practically no knowledge exists on the scale of patients who are reported to buy organs for transplantation, and how and where they purchase organs. Most patients are reported to purchase organs abroad and are generally assumed to obtain these organs illegally because of a lack of available (legally procured) donor organs in their countries of residence. Yet, this does not explain why some patients buy organs and why others do not. Only three empirical studies exist that describe patients' motivations and experiences in buying organs. However, these present small samples and offer limited information on the potential illegality of their transplants [12-14].

In addition, no studies exist on the role of health care professionals who treat patients who buy organs. What is unknown, for instance, is whether these professionals know if their patients bought organs, how often they encounter the issue and how they respond to their patients if they find out they are going to, or have purchased organs. In the absence of this knowledge, no information exists on factors that may help sustain the trade. For instance, the trade may persist because professionals are reluctant to report, or prohibited from reporting suspicions of organ trade, and/or because organ trade is (morally) tolerated in certain cultures despite its prohibition.

There is also limited knowledge on the modus operandi of organ trading networks [15]. Any explanation for the persistence of the trade requires an understanding of the criminal networks involved. Yet, the limited number of convictions has hampered the performance of case study research that could enable the collecting of information on how these networks operate. In addition, this has hampered research into how police and prosecutors detect and convict cases and what possible obstacles and successes they encounter. Possible hurdles in enforcing organ trade cases may explain why the crime is rarely prosecuted.

AIMS AND OUTLINE

The overarching objective of this thesis is to fulfil the abovementioned gaps in knowledge by presenting the results of five empirical studies. Adopting a range of qualitative and quantitative research methods (a systematic literature review, a national survey and interviews), this thesis addresses the following aims:

1 Provide insight into the scale of patients who buy organs for transplantation and describe why, where, how and from whom they purchased organs (chapter 3)

2 Acquire knowledge and understanding of the experiences, attitudes, behaviors and needs of transplant professionals who treat patients before and/or after they buy organs (chapter 4)

3 Examine the modus operandi of those who facilitate illegal transplantations and study the investigation and prosecution of organ trade networks (chapter 5)

4 Assess the possible implications of a punitive, legislative approach (chapter 6)

5 Propose alternative strategies that may deter organ trade more effectively (chapter 7)

Adopting a multidisciplinary approach, the objective is not only to acquire a better empirical understanding of organ trade, but to use this knowledge to explore and encourage strategies that may eliminate—or regulate—the trade more effectively with lesser risk of harms.

Although in the literature numerous terms are used to denote the trade's various practices such as 'organ trafficking' [16], 'trafficking in human beings for the purpose of organ removal' [15], 'transplant commercialism' [17] and 'transplant tourism' [18], in the underlying thesis, the term 'organ trade' is largely used as an umbrella term to cover these activities. Because kidneys are the most commonly traded organ [3], this thesis focuses predominantly on kidneys. The outline of this thesis is as follows:

Chapter 2 provides the background of the studies presented in this thesis.
Chapter 3 provides insight into the scale of patients who buy organs for transplantation and describes why, where, how and from whom they purchased organs.
Chapter 4 acquires knowledge and understanding of the experiences, attitudes, behaviors and needs of transplant professionals who treat patients before and/or after they buy organs.
Chapter 5 examines how illegal organ transplants are facilitated and studies the investigation and prosecution of networks.
Chapter 6 assesses the possible implications of a strict prohibition of organ trade.
Chapter 7 proposes strategies to regulate and deter organ trade.
Chapter 8 provides the conclusion and discussion of the findings.

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2

BACKGROUND

I

ETHICAL AND LEGAL ASPECTS OF KIDNEY DONATION

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P.J. Morris and S.J. Knechtle, (eds.) *Kidney Transplantation. Principles and Practice.*
7th Edition. UK: Elsevier; 2014. p. 715-72 (adapted and updated)

World Health Organization (WHO)	The United Nations specialized agency that coordinates international public health
Specified direct donation	When a person donates directly to his or her intended recipient [1]
Specified indirect donation	When a person donates indirectly to his or her intended recipient or donates to a specified recipient through an exchange program [1]
Unspecified donation	Donation to an anonymous and unspecified recipient such as donation to the waiting list or to the recipient of an exchange couple in the case of domino-paired exchange [1]
Principle of nonmaleficence	This principle stems from the Latin phrase, 'primum non nocere', which means 'first (or above all) do no harm' [2]
Hippocratic Oath	Requires doctors to do what they consider beneficial for their patients and to 'abstain from whatever is deleterious and mischievous' [3]
Volenti non fit iniuria	When the person concerned consents, no injury is done [4]
Informed consent	Medical doctors provide a patient with all relevant information about a proposed procedure or treatment prior to obtaining the consent of the patient to carry out the procedure. Ensures that the autonomy of the individual is respected [5]
Paternalism	Neglecting a competent person's will or even acting against it [6]
Altruism	A moral act intended to promote the happiness of others
Subsidiarity	Removal of organs or tissue from a living person may be carried out where there is no suitable organ or tissue available from a deceased person [5]
Home based education programmes	Patient and family education on transplantation and donation in the patient's own environment [7]
Pre-emptive transplantation	Transplantation that takes place prior to commencement of dialysis
Black market of organs	Illegal market that coexists to meet the demand that altruistic systems fail to fulfil [8]
Organ trafficking	The recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation [9]
Transplant commercialism	A policy or practice in which an organ is treated as a commodity, including by being bought or sold or used for material gain [9]
Travel for transplantation	The movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes [9]
Transplant tourism	Travel for transplantation that involves organ trafficking and/or transplant commercialism or if the resources (organs, professionals and transplant centers) devoted to providing transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population [9]
Monopsonistic market	A market with multiple vendors but only one purchaser [10]

table 1 Definitions

INTRODUCTION

In organ transplantation growing emphasis is given to ethical and legal aspects. The main reason for this, is the increasing organ scarcity [11]. The range of ethical and legal considerations in relation to organ donation that is focused on in scholarly literature is considerable. This chapter introduces ethical and legal principles that arise in contemporary, everyday medical practice concerning living organ donation (LOD) and transplantation. In particular, this chapter presents ethical and legal considerations that arise in the expansion and encouragement of living kidney donation (LKD) and commercialisation of organs. Because organ trade largely comprises of trade in living donor kidneys, the focus of this chapter is on live kidney donation and transplantation. Ethical and legal aspects concerning deceased donation are therefore not addressed.

EXPANSION AND ENCOURAGEMENT OF LIVING KIDNEY DONATION

NEW DONOR-RECIPIENT RELATIONSHIPS

Due to the shortage of deceased donor kidneys, living kidney donation has become the most important alternative to fulfil the need of the increasing amount of patients with end-stage renal disease (ESRD) in need of transplantation.

World Health Organization

In 1991, the WHO, drew up Guiding Principles on Human Organ Transplantation. The aim of the Guiding Principles was to provide 'an orderly, ethical and acceptable framework for regulating the acquisition and transplantation of human organs' [12]. Principle 3 stated that organs for transplantation 'should be removed preferably from the bodies of deceased persons'. Adult living persons 'may donate organs, but in general should be genetically related to the recipient' [12]. Thus, for many years living donation was commonly restricted to genetically related adults.

Expansion of the donor pool

However, due to the organ scarcity, strong advancements in transplant technology and excellent results in LKD, the donor pool has expanded over the last three decades from genetically related donors to spouses [13], friends, acquaintances and even anonymous donors [14]. The need to expand the living donor pool has been recognized by transplant professionals and international organizations worldwide. By 2015, genetically unrelated donors accounted for 2726/5773 (47%) of LKD in the US [15], 688/1322 (52%) in the Eurotransplant area [16], and 315/513 (61%) in The Netherlands [17]. In 2008 the WHO updated its Guiding Principles.

Principle 3 now states, 'living donors should be genetically, legally or emotionally related to their recipients' [18].

Spouses, friends, acquaintances and other non-genetic related donors are often referred to as 'unrelated' donors, to distinguish them from genetically related donors. Yet, many of these genetically unrelated donors have an emotional relationship with their recipient. The use of the term, 'unrelated' is thus said to be 'inappropriate' [1]. The introduction of new schemes such as paired exchange programmes has contributed to the complexity of donor-recipient relationships.

Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT)

For this reason, a Working Group of the European Platform on Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) developed a new classification for living organ donation [1]. The group distinguishes between specified and unspecified donation. Specified donation, in turn, can consist of direct and indirect donation through an exchange programme. This classification is presented in table 2.

table 2 New ELPAT classification for living organ donation (*Transplantation* 2011; 91:935-938)

Specified donation	Direct donation When a person donates directly to his or her intended recipient Donation to genetically and emotionally related recipient (e.g., to one's child, parent, or sibling) Donation to genetically unrelated but emotionally related recipient (e.g., to one's spouse, friend, or acquaintance) Donation to genetically related but emotionally unrelated recipient (e.g., to an estranged child, parent, or sibling) Donation to genetically and emotionally unrelated recipient, but the recipient (or the group to which he/she should belong) is specified (e.g., to persons younger than 18 yr or a specific person in need of a transplantation, who was interviewed by the media)
	Indirect donation When a person donates indirectly to his or her intended recipient Donation to a specified recipient through an exchange program
Unspecified donation	Donation to an anonymous and unspecified recipient (e.g., donation to the waiting list or to the recipient of an exchange couple in the case of domino-paired exchange)

Alternative living donation programmes

Examples of successful alternative living donation programmes [19] are national kidney-exchange programmes [20-22] ABO incompatible programmes [23], desensitization in HLA-incompatible recipients [24] and domino-paired anonymous donation [25,26]. National kidney exchange enables incompatible couples to donate and receive a kidney indirectly through exchange with another incompatible couple. This is also referred to as indirect specified donation (table 2). ABO incompatible programmes make it possible to transplant patients despite ABO incompatibility when, after adequate immunoabsorbent and immunomodulating treatment an adequate decrease in anti ABO titer can be realized. Desensitization involves the use of preconditioning, either with high-dose intravenous immune globulin or with plasmapheresis plus low-dose intravenous immune globulin to enable transplantation across HLA barriers [24]. In a domino-paired anonymous donation, the anonymous

donor donates to the recipient of an incompatible couple, while the potential donor of this couple donates to a patient on the waiting list (dominodonor) or to a recipient of another incompatible couple [19]. This is referred to as unspecified donation (table 2). The contribution of exchange programmes to the overall number of LKD has been significant.

THE WELFARE AND PROTECTION OF THE LIVE DONOR

The principle of nonmaleficence

The expansion of specified and unspecified LKD raises ethical and legal considerations. One of the most frequently mentioned considerations is that LOD violates the principle of non-maleficence. This principle stems from the Latin phrase, 'primum non nocere', which means 'first (or above all) do no harm' [2]. The origins of this phrase however are unknown. It is not a literal translation of the Hippocratic Oath, which requires doctors to do what they consider beneficial for their patients and to 'abstain from whatever is deleterious and mischievous' [3]. The oath does not mention anything about 'first or above all do no harm' [3].

The Hippocratic Oath, although a prominent principle in medical practice, is not absolute [2]. It is a prima facie obligation—one that can be overridden if there are compelling counter obligations. Indeed, many medical procedures cause harm even as they benefit the patient [27].

Risks versus benefits

In LOD, the health of one individual is put at risk in order to benefit another [27]. The justification for LOD, especially LKD, thus lies in the expectation that the benefits outweigh the harms [28]. Thus, if the benefits to the donor (psychological and moral) override the risks to the donor (physical and possibly psychological), then LOD is morally permissible [14,28]. Therefore, arguments given against LOD on the claim that it violates the physician's responsibility not to do harm are unconvincing [28].

Donor risks in living kidney donation

The foregoing implies a need of understanding of the physical and psychological risks for the donor. The protection of live donors from these possible harms is emphasized in various national and international (legal) rules and regulations. The EU Directive on Standards of Quality and Safety of Human Organs intended for Transplantation states that 'the highest possible protection of living donors should be ensured' [29]. The WHO underpins that 'live donations are acceptable when the donor's informed and voluntary consent is obtained, when professional care of donors is ensured and follow-up is well organized' [18].

Even though LKD transplantation has acquired an outstanding record worldwide, LKD involves risks including morbidity and mortality for the live donor. Nevertheless, these risks are very low. One study reported that the risk of donors developing ESRD was 0,47% [30]. Another study found this risk to be 0,1% [31]. Despite these varying results, the reported incidence of ESRD among living donors remains lower than in the general population [32]. The risk of death is cited as 1 in 3000 (0,03%) and the risk of postoperative morbidity is

2-4% [33,34]. It is conceivable that the more widespread use of laparoscopic nephrectomy techniques will decrease morbidity in the coming years [35].

Psychological harms of the donor may involve coercion. Arguably, there is always coercion in LKD, especially when the person suffering is a loved one. Pressure may be put on people to donate, leading those who are hesitant to do so to feel coerced [36].

Elliott has argued that to minimize the likelihood of coercion or other psychological harms of the live donor, LKD should be restricted to relatives [37]. This belief is shared by Glannon, who also states that the risk in nephrectomy is justified because of shared emotions amongst family members, but that these factors are lacking when the donor is not a relative [27]. The argument here is that the suffering of another person is perceived to be felt more intensively if the person concerned is a relative. If, for example a mother offers to donate her organ to her daughter, her explanation that her donation occurs for the sake of her child will be deemed sufficient. On the contrary, if an altruistic or Samaritan donor offers to donate his organ to a stranger, the motivation is often not well understood [38]. Furthermore, these donors do not have the opportunity to witness and enjoy the benefits from the donation. Hence, it is perceived to be more acceptable to benefit from the donor's selflessness when he or she is a relative rather than a stranger [37].

Coercion may also arise as a result of the expansion of alternative living donation programmes. With the increased reliance on exchange programs, for example, comes the increased number of potential, suitable organ donors. In the past, when persons were eventually reluctant to donate, transplant doctors were willing to identify a plausible medical excuse, so that the person could 'bow out gracefully' [36]. In alternative LD programs the possibility of a medical excuse for unwilling donors no longer exists [39]. In a study performed by Kranenburg et al. amongst 48 donors and recipients, the question was asked whether they felt additional pressure or coercion into donating within the exchange donation program. All except two responded that this was not the case [39].

Legal restrictions in Europe

The possible physical and psychological risks underlie the justifications given for restrictions in de law regarding donor-recipient relationships. In Estonia for instance, LOD is allowed only for the benefit of the donor's descendant, spouse, cohabite, parent, grandparent or their descendants. In the Czech Republic, Finland, Germany, Hungary, Italy, Poland and Sweden, in addition to the listed relationships, additional donor-recipient relationships are possible due to an open clause. Denmark, The Netherlands and Switzerland, by contrast, do not have any regulations addressing whether donor and recipient have to be related, or whether any specific procedure must be followed [5].

National kidney exchange problems are legal in the countries that do not require a defined donor-recipient relationship (Belgium, Denmark, England, Latvia, The Netherlands, Portugal, Scotland, Spain and Switzerland). On the contrary, in Germany, Bulgaria, Estonia, Finland, Hungary and Lithuania, cross-over LOD is illegal [5].

Indeed, the differences in these national legal regulations are reflected in the wide disparity in numbers of LKD across Europe [40].

Equal donor risks in direct, indirect and unspecified living organ donation

Lopp [5], Van Dijk and Hilhorst [6], and others [14,28,33,41] argue that none of the arguments used to justify restrictions in donor-recipient relationships (based on possible harm inflicted on the donor) are convincing.

First of all they point out that the donor's risks are equally high in direct, indirect and unspecified LOD [28,42]. Practice and research show that there is no important difference between specified and unspecified LKD in terms of motivations and outcomes [43,44]. Motivations and reasons to donate to strangers, for instance, are found to be equally understandable as donations to relatives. Medical evaluations of unspecified donors have shown these donors to be truly generous and selfless [44,45].

In fact, when comparing the donation to benefit a stranger to the donation to benefit a relative, the unspecified donation could be regarded as the highest expression of altruism [5]. Indeed, altruism may 'receive its highest expression in the absence of personal relationships' [41]. The special relationship between a donor and recipient, according to Van Dijk and Hilhorst, is 'not the morally relevant key feature that provides a justification for LKD' [6]. Both specified and unspecified donation, Lopp argues, should be treated equally [5].

Donor autonomy

The same authors claim that these restrictions violate the donor's right to autonomy. When the donor voluntarily decides to take part in the surgery, he exercises his or her right of autonomy and thus cannot be considered to be harmed. This argument is also referred to as the 'volenti non fit iniuria principle' [4]. This principle means that in case the person concerned consents, no injury is done [4,5].

The concept of informed consent is closely related to the right of autonomy [5]. Informed consent ensures that the autonomy of the individual is respected [5]. Deception and coercion are mitigated by consent procedures, which is why such procedures have become standard requirements in most countries. Reasons to refuse the donation that refer to the donor's best interests can be called paternalistic, that is: 'neglecting a competent person's will or even acting against it' [6].

The principle of autonomy is applicable to all donors, be they specified or unspecified. From this perspective it has been argued that 'if a competent adult wants to act altruistically and offers to donate his organ to a stranger unconditionally, and the adult understands the risks and benefits of the procedure, and gives informed consent to the procurement, then his or her wishes should be respected' [28].

Besides moral arguments to support organ donation by indirect or unspecified donors, there is also a pragmatic reason. Indeed, as illustrated above, there is increasing support for unspecified and indirect donation to relieve the ever increasing demand for organs [14,38].

Subsidiarity

Considering the excellent results in LKD, some transplant professionals have raised the question whether 'health care professionals should encourage LKD' [33,42]. This question touches upon the question whether LKD should be 'subsidiary' to deceased donation.

The Additional Protocol to the Biomedicine Convention concerning Transplantation of Organs and Tissues of Human Origin (Article 9) declares that 'Removal of organs or tissue from a living person may be carried out [...] where there is no suitable organ or tissue available from a deceased person' [46]. Many countries, such as Austria, the Czech Republic, Estonia, Finland, Germany, Hungary, Lithuania, Moldova, Portugal and Slovakia follow this proclamation and prohibit the performance of LOD when an organ from a deceased person is available [5].

Other countries such as England, Italy, Latvia, The Netherlands, Norway, Poland, Scotland, Slovenia, Spain, Sweden and Switzerland do not regulate the relationship between LOD and post-mortem donation. In these countries both deceased and living donation are considered equal [5].

ENCOURAGING LIVE KIDNEY DONATION

Van Dijk and Hilhorst write that good medical and ethical reasons exist to promote the many options of LKD [42]. The advantages of LKD over cadaveric donation are manifold: LKD helps patients to circumvent the waiting list and relieves them of the burden of dialysis. Furthermore, the kidney survival rates for living kidneys are significantly better (50% still functioning after 20 years; for post-mortem organs this is only 10 years). Many patients prefer living to cadaveric donation [47]. Transplant care professionals may therefore feel an obligation to bring these facts to the attention of patients and their relatives [42].

Cronin argues that given the low risks for the donor it is not unethical for doctors to encourage healthy adults to donate their kidneys, even to strangers. Demonstrating that such encouragement is unethical, requires a powerful argument against it [33].

Home-based education programmes

There are a number of approaches to patient and family education on living donation. One is the so-called 'Norwegian approach' where the doctor discusses potential living donors with the patient and then personally contacts these individuals and invites them for evaluation [48]. Another approach (done in the US) is home-based, where a psychologist gives transplant education to the (pre) dialysis patient and family and friends in the patient's home [7]. This programme has proved successful in increasing knowledge and willingness to communicate about living donation and in decreasing living donor transplant concerns [49].

The home-based programme by Massey et al. (The Netherlands) is similar to the US 'house-call' but offers the educational meeting earlier in the clinical course to include the option of pre-emptive transplantation [49]. Pre-emptive transplantation, that takes place prior to commencement of dialysis, offers optimal graft and patient survival when compared

to transplantation after dialysis [49]. Massey et al. state that the 'interference in people's lives' is justified if a number of criteria are fulfilled. The criteria that they propose include that the patient decides whom to invite, the invitees have the right to withdraw at any point and confidentiality should be maintained at all times [49].

In the foregoing chapter, we addressed the ethical and legal issues that arise in expanding living kidney donation. The following chapter focuses on the various considerations that arise in the debate on commercialization of organs.

COMMERCIALISATION OF ORGANS

This section is based, in part, on own, previously published work: Ambagtsheer F, Weimar W, Zaitch D. The Battle for Human Organs. Organ Trafficking and Transplant Tourism in a Global Context. *Global Crime* 2013;14(1): 1-26

THE RISE OF ORGAN TRADE

Organ scarcity

Transplantation is becoming a victim of its own success, with demand for organs being far higher than supply. With the aging of populations and growth in heart and vascular diseases, demand for transplantation is increasing exponentially [50]. In the United States (US) for instance, in 2015, 17,878 donor kidneys were reported to the Database on Donation and Transplantation [15]. As of the end of October 2016, 99,382 kidney patients were on waiting lists for transplantation [15]. In the Eurotransplant region which covers 8 countries, 10,797 patients were waiting for a kidney at the end of 2015. In this region, a total of 4780 kidney transplants took place in 2015 [16]. An estimated 10 people in the European Union die every day waiting for an organ. Annual mortality rates range from 15% to 30% [51].

Organ markets

Despite strategies to increase the donor organ pool such as adopting presumed consent systems, broadening deceased donor criteria and increasing the number of living (mainly kidney) donations, the worldwide organ shortage persists. Under these circumstances patients seek strategies to obtain organs from outside their home countries. With organs' increased value comes their increased potential profitability, causing some people to trade and sell. Hence, next to altruistic procurement systems of organ supply, black markets exist to meet the demand that altruistic systems fail to fulfil [8].

Trends and patterns

Recurring trends and patterns of organ trafficking generally occur around a group of 'donor-exporting' countries (Egypt, China, India, Pakistan and The Philippines), 'demand' countries (US, Canada, Israel, UK and some other European countries) and countries where the transplants take place including the US, Israel and South Africa [52,53].

Organ trade does not only involve organised, cross-border networks. It may also involve milder, more voluntary forms. In a survey performed by Van Buren amongst 250 living kidney donors in Rotterdam, The Netherlands, some donors reported that they had received 'rewards' or 'gifts' from their recipients. Examples were weekly meals, exotic vacations, a race car, jewellery, a racehorse and a painting [54].

THE CONDEMNATION OF ORGAN TRAFFICKING, TRANSPLANT COMMERCIALISM AND TRANSPLANT TOURISM

Universal prohibition

Organ trade is prohibited worldwide. The United Nations (UN) Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children supplementing the UN Convention against Transnational Organized Crime is the first international legal instrument to define and prohibit trafficking in human beings for the purpose of organ removal. In this definition, organ trade is viewed as a form of organised crime and defined in the context of trafficking in human beings [55].

The WHO first prohibited transplant commercialism in 1987, claiming that such trade is inconsistent with the most basic human values and contravenes the Universal Declaration of Human Rights [56]. Its Guiding Principles declare that organs should be 'donated freely, without any monetary payment or other reward of monetary value' [18]. The reason given is that 'payment for organs is likely to take unfair advantage of the poorest and most vulnerable groups, undermines altruistic donation, and leads to profiteering and human trafficking. Such payment conveys the idea that some persons lack dignity, that they are mere objects to be used by others' [18]. The belief is that altruism and financial motivation cannot coexist. Although trafficking in human beings for organ removal and transplant commercialism are separate crimes, commercialism is perceived to *lead to* trafficking.

Organ trade is also forbidden by the Council of Europe in the Protocol concerning transplantation of organs to the Convention on Human Rights and Biomedicine [46]. Article 21 declares that 'the human body and its parts shall not, as such, give rise to financial gain or comparable advantage'. It also states that 'advertising the need for, or availability of, organs or tissues, with a view to offering or seeking financial gain or comparable advantage, shall be prohibited' [46]. Article 22 states that 'organ trafficking shall be prohibited' [46].

The Declaration of Istanbul

In 2008 the Transplantation Society and International Society of Nephrology convened in Istanbul to establish the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (the Declaration) [9]. This is the first document, established by transplant professionals, that defines and condemns organ trafficking, transplant commercialism and transplant tourism.

table 3 The Declaration of Istanbul on Organ Trafficking and Transplant Tourism (*Transplantation* 2008;88(8):1013-1018)

Organ trafficking is the recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation.
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.
Travel for transplantation is the movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes. Travel for transplantation becomes **transplant tourism** if it involves organ trafficking and/or transplant commercialism or if the resources (organs, professionals and transplant centers) devoted to providing transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population.

The Declaration, although legally nonbinding, has proven to have significant influence. Over 100 transplant organizations endorse it. Whereas the Declaration's aim is to influence transplant professionals and societies, the WHO is aimed at governments. Both act in concert to address growing problems of transplant commercialism, transplant tourism and trafficking by strict prohibition and penalization [57]. As a result of the universal prohibition, almost all countries have implemented the prohibition into their domestic laws.

REWARDED GIFTING

The Iranian model

Iran is an exception. Iran allows the sale of kidneys through a government-related, regulated, organ procurement system. Because of low deceased donation rates, the government in 1988 introduced a model of 'rewarded gifting' to promote live kidney transplantation [58]. People who wish to donate can refer to a government institution who matches them to a prospective recipient. Middlemen and brokers, it is claimed, remain uninvolved [59]. All donors receive a payment (the equivalent of $4,000) and a 1-year health insurance from the government. A large number of donors also receive an award or gift from the recipient. This reward is considered a private matter that is not interfered with [60].

The 'Iranian model' is scrutinized by many [61-63], yet others claim that incentives for donation could—and should—be explored in other countries to increase the number of donations [64]. Rewards or incentives can be applied to deceased organ donation and to LKD. A 'reward' is defined as a 'gesture of gratitude for someone's trouble' [10].

Rewards for deceased organ donation

In 2007 Van Dijk and Hilhorst submitted an advisory report on incentives for donation to the Dutch Health Minister. The report presents two ways of encouraging deceased organ donation by allowing rewards.

The first is rewarding someone for registering as a donor [10]. The report suggests rewards including small gifts (e.g. a discount card or a free first-aid kit), a small sum of money, a free passport, discount on health insurance premiums and priority on the wait list, if the registree were to need an organ [10].

The second way of encouraging deceased organ donation is by rewarding surviving relatives. This can occur by giving them a sum of money or by paying the funeral expenses [10].

The authors conclude that although these measures may have some impact, financial incentives to stimulate deceased donation are unlikely to produce a really significant effect because the number of organs available is limited and continues to fall [10].

Rewards for living kidney donation

Already in 1997, about ten years after the prohibition of organ sales was first proclaimed, the Bellagio Taskforce wrote that international declarations against commercialism are 'put forward in one or two terse sentences with no supporting arguments' [65]. The authors wrote that 'the grounds for condemnation are not as obvious as declarations imply'. For that reason it could not find an unarguable ethical principle that justified the ban on organs sales under all circumstances [65].

The debate over rewarded gifting for live kidney donors has been ongoing since the 1980s and has not achieved consensus [66,67]. It is conducted from various perspectives, which are outlined below.

Ownership

The concept of ownership addresses the question who is the owner of the organs. These answers vary from God, the government to the individual, depending on legal, historic, religious and medical contexts [5].

In most (Western) states, the principle of autonomy is dominant, meaning that (living) individuals are considered to be the owner of their organs [5]. This is why we have full autonomy for dangerous activities such as hang gliding, smoking, bungee jumping and eating to excess [68]. Governments restrict autonomy if it harms others (e.g. speeding, drunk driving, fire arms possession). That is why organ donation is permitted but sale is prohibited [10,69]. Payment is presumed to harm the poor and vulnerable [18]. According to Radcliffe Richards, this prohibition means that people are unable 'to enter freely into contract from which both sides expect to benefit, and with no obvious harm to anyone else' [70].

Indeed, the degree of harm perceived to be inflicted upon organ sellers is not without controversy. Some authors point out that it is a matter of social perception and acceptance of norms. Societal norms differ over time. Issues that used to be considered shocking, such as women's equality, interracial marriage, children born out of wedlock, necropsies, and cadaver organ transplants, are now accepted aspects of Western society. Societal norms also vary across countries. Whereas euthanasia, prostitution, abortion and drug sales are prohibited in many countries, they are accepted phenomena in some others [68].

According to authors such as Radcliffe Richards, the prohibition of organ sale violates our right to ownership over our bodies [71]. She argues that individuals should be free to trade organs between themselves and that the burden of proof lies with the government to put forward arguments that justify this prohibition. Friedlaender argues that a future in which people have autonomy in selling their own body parts is not unimaginable [68].

Payment is repugnant

Some people believe that the idea of paying for an organ is 'repugnant' [72]. Yet, others do not agree with this argument. They point out that people who buy and sell organs clearly do not feel this repugnance. They argue that something may cause feelings of repugnance without being immoral or being banned. Prostitution, pornography and the drugs trade can also be repugnant, but that is not a good enough reason to ban them [10].

Payment undermines human dignity and human integrity

Another reason why payment for organs is prohibited is because it is presumed to 'convey the idea that organ sellers lack dignity' [18,66]. An organ is not something for which you should be able to pay. Against this, people claim that it has never been empirically verified whether those selling organs, eggs or sperm indeed felt diminished self-dignity [73,74].

It is also claimed that this argument would be a reason to prohibit all living donation, even unpaid ones. The fact that transplants are possible already turns an organ into a commodity, something that has value also outside the body, and that can even be bartered through exchange programs. The organ thus becomes a (potentially) tradable good [10]. Why are we permitted (in some countries) to barter organs in exchange programs, but not to trade or exchange them to financially benefit the individuals involved?

Payment undermines altruism

One of the most widely-used arguments against payment is that payment for organs 'undermines altruistic donation' [18]. Against this, authors claim that 'altruism as a value is overestimated' and that we 'set ethical standards far too high as a result' [10]. In practice, people donate for many different reasons. Why is it considered an act of altruism if a father in The Philippines donates his kidney to his daughter who is suffering from a serious kidney disease, but morally reprehensible for the same father to sell his kidney to raise money to pay for a life-saving treatment for his daughter? [10,70]

Organ sale can occur for many different reasons, some of which are altruistic. Several motivations can co-exist. As Radcliffe-Richards points out, 'Selling in itself is not in itself at odds with altruism, it all depends on what the money is wanted for' [70].

Altruism also plays another part in the debate on rewarding organ donations. Why would you, as a relative, still donate if your intended recipient can obtain a kidney from an anonymous, paid donor instead? Against this it has been argued that this should not necessarily be regarded as a problem. Those who think that transplants between people who know each other are more desirable than those between strangers would see a decline in related donations as a shortcoming. But for those who prefer anonymous donations, for example because they have less impact on family relationships would see this as a benefit. In short, the view that living donation is or should always be an act of altruism is incorrect both empirically and morally. People can have numerous different reasons for donating an organ without payment [10].

Payment jeopardizes free will

Prohibition of organ sales exists to protect those (the vulnerable poor) most prone to sell [66]. The argument is that payment jeopardizes their free will, because the poor will feel pressured to sell.

Against this, authors have put forward several counter arguments. First, the question must be raised how money affects the behaviour of potential sellers. If a large sum of money is offered, this might be attractive, even irresistible, to some persons. But there is an important distinction between irresistible and forced: 'putting a gun against one's head to make them donate is force; offering someone a load of money in return for an organ is an attractive offer' [75]. The statement that the donor's free will might be jeopardized is not an argument against payment, but against involuntary donation. Absence of free will is a risk that is associated not only with paid donations, but also with unpaid ones. If donors can be forced to sell a kidney, then arguably they can also be forced by circumstances such as family pressure or the intolerable sight of seeing a loved one suffer.

In addition, it is said that money is only one factor among many others that influences decisions. Not all people will sell their organs for the sole purpose of payment. Indeed, in a study by Rouchi et al, performed among 600 kidney sellers in Iran, 60% reported their motivations to be partly emotional/altruistic and partly financial [76]. This shows that payment and free will are not mutually exclusive.

Payment exploits the poor

Prohibition of organ sales also exists because payment is expected to exploit or traffic the poor. Against this argument various counter arguments have also been given. The first is that prohibition of payment utterly fails to protect the poor and vulnerable. Prohibition does not prevent victimization. On the contrary, prohibition of organ trade has the paradox of increasing the likelihood of commercialism and trafficking. Prohibition of organ payment keeps organ supply low, thus increasing their scarcity. If organs are scarce, they become valuable, and ultimately, profitable to buy, trade and sell [57]. This has the unintended consequence of driving illegal trade underground where victimization (as illustrated above) of the vulnerable is far more likely to occur that in regulated markets. Furthermore, criminalization of sellers makes it more difficult to identify and help potential victims of trafficking [77]. Concern over exploitation of the poor should lead to regulation of a market, not its continued prohibition [78]. Indeed, this argument (prevention of abuses in the black market) was one of the main reasons why prostitution, pornography, abortion and soft drugs were legalized in The Netherlands. Evidence-based studies have illustrated that legalisation has significantly reduced the abuses of the black market [79].

The second counter argument is related to free will. To justify the prohibition of kidney sales by poor donors, it is necessary to illustrate that organ selling must always be against their interests. According to Radcliffe Richards, 'Removing their option to sell leaves them poor, and makes their range of options smaller still' [69]. The poorer the potential seller, the more plausible it is that the sale of the organ will be worth whatever risk

there is. 'If a living donor can do without an organ, why shouldn't the donor profit and medical science benefit?' [69].

To die or let buy?

Some people argue that perhaps it is a good thing that money persuades people to donate. Not only may it more effectively deal with the abuses in current illegal markets, it may also relieve the shortage of organs [10]. Matas states 'organ sale simply does not feel right; but letting candidates die on the waiting list (when this could be prevented) also does not feel right' [80]. Are doctors 'failing their patients' [68] as long as the ban on payments is maintained?

This may not be applicable in all countries. In some jurisdictions such as The Netherlands, the number of LKD is now so high, that the waiting list has decreased substantially. Models of rewarded gifting may not be necessary in countries with high LKD rates.

The live kidney donor contributes financially to society

Proponents of financial rewards or incentives for live kidney donors say that the ban on payment is 'hypocritical' [81]. In contemporary transplant medicine, everyone profits, except the donor: society benefits, the hospital benefits, the surgeon and the medical team are paid, the transplant coordinator gets paid and the recipient receives an enormous benefit.

Donors, if they are lucky, will be compensated for costs made as a (direct) result of the donation. Compensating live organ donors for certain costs is legitimate, but is not common practice in transplant centres [40]. WHO Guiding Principle 5 states:

> 'The prohibition on sale or purchase of cells, tissues and organs does not preclude reimbursing reasonable and verifiable expenses incurred by the donor, including loss of income, or paying the costs of recovering, processing, preserving and supplying human cells, tissues or organs for transplantation' [18].

The WHO thus permits compensation for the costs of making donations, lest they operate as a disincentive to donation. The need to cover legitimate costs of procurement and of ensuring the safety is acceptable as long as the human body and its parts are not a source of financial gain [18].

Yet, opponents of the ban on payment say that donors deserve much more than mere compensation or reimbursement of costs. Organ transplants are expensive procedures, yet, the long-term care needed while waiting for the transplant (kidney dialysis for instance), is more expensive than the transplant procedure itself. Transplantation of kidney patients saves the costs patients would otherwise have had on dialysis.

Thus, one live kidney donor makes a significant contribution to society. How much does this contribution entail? De Charro et al [82] and Matas and Schnitzler [83] illustrate the enormous economic benefit gained with one (live) kidney transplantation. Combining information about quality adjusted life years, De Charro et al. estimated that the total benefit to society of one live kidney transplantation equals €80,000 annually (for Western

countries). Matas and Schnitzler, using the same analysis in the US, calculate an amount of $100.000 each year [82,83].

The authors of these studies suggest that giving such large payments to donors in return for their organs is not impossible. Furthermore, they illustrate that if a regulated, vending system would be established for kidney donors, a significant payment could be made to them without increasing the overall costs to the health care system [83].

Van Dijk and Hilhorst on the other hand say that the risk of offering too large a sum of money is that the wrong people, or people with wrong or dubious motives, may register as donors. These may be people who are medically unsuitable or who are not acting freely. It would be better to offer small amounts or 'indirect' rewards such as life-long exemption from health insurance fees [10].

De Charro et al. claim that given the high amounts, trade is inevitable, albeit legal or illegal. Therefore conditions should be implemented, based on regulation, that are favourable from the sellers' and patients' perspectives [82]. Others also state that an effective and appropriate response is regulation or a monopsonistic market [10,81,84]. Erin and Harris, for instance, propose the following standards or conditions for such a market:

1. The market would be limited to a state or the European Union.
2. Only the country's citizens can sell into the system. They and their families would be equally eligible to receive organs. Thus, organ sellers would know they were contributing to a system which would benefit them and their families and friends.
3. There is only one purchaser; a national agency would buy and distribute the organs according to fair allocation and medical priority.
4. There would be no sales or purchases between patients and sellers and no exploitation of low income countries and their populations.
5. The organs would be tested for viruses and there would be strict controls and penalties to prevent harms.
6. Prices would have to be high enough to attract people [81].

Chapter 7 of this thesis further explores strategies to regulate and deter organ trade.

CONCLUSION

The aim of this chapter was to illustrate that with the growth of organ demand, ethical and legal aspects become more important. Transplant doctors and other professionals are increasingly confronted with these considerations. In contemporary transplant medicine, considerations of ethical, legal and psychosocial nature can no longer be ignored.

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II

THE BATTLE FOR HUMAN ORGANS

ORGAN TRAFFICKING AND TRANSPLANT TOURISM IN A GLOBAL CONTEXT

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While the trade in human organs remains largely in the darkness as it is hardly reported, detected or scientifically researched, a range of key institutional stakeholders, professionals, policy makers and scholars involved in this field show remarkable high levels of moral condemnation and share a rather unanimous prohibitionist line. Some have equated this phenomenon to genocide or talk about 'neo-cannibalism', others present it as dominated by mafias and rogue traders. However, organ trafficking takes very different shapes, each one with their own ethical dilemmas. Simplistic formulaic responses purely based in more criminalization should be critically evaluated. Based on a qualitative study conducted on the demand for kidneys (transplant tourism) in and from The Netherlands, we present in this article some of the main empirical results and we discuss their implications. But before doing that, this contribution briefly describes the global patterns of contemporary organ trade and the way the problem has been framed and constructed by international policy bodies, professional (transplant) organisations, and some scholars.

1 INTRODUCTION

In September 2010, a South African hospital pleaded guilty to charges stemming from having allowed its employees to conduct over a hundred illegal kidney transplant operations between June 2001 and November 2003 [1]. In addition to this hospital, the parent company (Netcare), its CEOs, five transplant physicians, two transplant administrative coordinators and a translator were charged for the illegal kidney transplants. Charges against the hospital and its staff included fraud, forgery, uttering, assault and breaches under the Human Tissue Act and the Prevention of Organized Crime Act [2]. A month later in Kosovo, indictments were filed against six physicians and a former senior level representative of the Ministry of Health. They are among others accused of trafficking in human beings for the purpose of organ removal. The trial of this case (also known as the *Medicus Clinic* Case), is now before the District Court of Priština [3]. Both cases can be considered landmark cases: never before were organ trafficking networks of this scale discovered involving so many legal players.

These cases illustrate the multifaceted, complex nature of the trade in human organs including the wide range of criminal activities, its integration in legal institutions, its cross-border nature, the different actors involved and the dedicated investment that is needed to eventually bring perpetrators to justice [4]. Inherent to organ trade is also the distress of those 'forced' to sell [5] and the despair of patients confronted with the dilemma to die or to buy [6]. Organ trade involves different varieties, ranging from human trafficking for organ removal, selling the body parts of deceased persons [7], the sale of kidneys by the poor [8], the purchase of organs by patients on the black market [6] to advertising the sale of organs online [9]. Other forms involve financial or material benefit between willing donors and recipients [10]. The cross-border variety involves recipients travelling to 'supply' countries to receive a new organ, a phenomenon known as 'transplant tourism' [11].

This article starts by describing the global patterns of contemporary organ trade. We subsequently focus on the way in which the trade in human organs is portrayed by international public organisations, professional transplant societies and in literature. In section 3, we present arguments that refute the universal condemnation of organ trade and transplant tourism. In section 4, the empirical findings of a study conducted in The Netherlands on 'transplant tourism' are presented, showing that the phenomenon is ethically and legally more complex than portrayed by instruments such as the Declaration of Istanbul and the World Health Assembly Resolution. The last section addresses the ways in which organ trade can best be approached.

2 THE GLOBAL TRADE IN HUMAN ORGANS

Organ transplantation is one of the most remarkable medical inventions. Ever since the first transplant in 1954, organ transplantation has saved and prolonged the lives of thousands of patients. Until the 1980s it was regarded a risky and experimental procedure. After the introduction of immunosuppressive drugs (which moderate the body's response while not suppressing the immune system's reactions to infectious diseases) it became a standardized procedure, now conducted in hospitals in more than 90 countries [12]. Survival rates of transplant patients have risen dramatically over the past decades. According to the Global Observatory and Database on Donation and Transplantation more than 100,000 solid organ transplantations including kidneys, livers, hearts, lungs and pancreases are performed annually [13]. Human organs for transplants have two sources, the most common being deceased donors. The second source is living donors who can donate a whole kidney, half of a liver or the lobe of one lung.

Transplantation is becoming a victim of its own success, with demand for organs far outpacing supply. In the United States, in 2007, 21,489 deceased donors were reported to the Global Database on Donation and Transplantation. As of the end of February 2010, 105,966 patients were on waiting lists for transplantation [14]. At the end of 2010, in the European Union (EU), 47,773 patients were waiting for a kidney. The average waiting time for a deceased donor kidney, for example, is now 3-5 years. An estimated 10 people in the EU die every day waiting for an organ. Annual mortality rates range from 15% to 30% [15].

Despite strategies to enlarge the donor organ pool, the worldwide organ shortage persists. Under these circumstances, desperate patients seek strategies to obtain organs from outside their home countries. With organs' increased value comes their increased potential profitability, fuelling desire with some people to trade and sell. Hence, next to altruistic procurement systems of organ supply, a black market coexists to meet the demand that altruistic systems fail to fulfil.

The first accounts of organ trade date from the late 1980s by transplant doctors in the Gulf States who were confronted with patients for follow-up who had received transplants of purchased kidneys in India [16]. Around the same time, Scheper-Hughes wrote about 'body snatching rumours' that she picked up during her ethnographic research in Brazilian shantytowns [17]. Most accounts of organ trade in the 1990s were not regarded very

seriously. They were regarded as modern folklore or 'global mass hysteria' [18]. Actual cases were never verified [19].

In 1997, the Bellagio Task Force was established to address the international trade in human organs. The group could not find reliable evidence to substantiate allegations of kidnappings and murder for organs. It mentioned organ selling and organ buying reports in Asian and Gulf countries, pointing out that physicians were pursuing ethically dubious strategies for obtaining organs in a number of countries [20].

From the beginning of the twenty-first century, cases of more verifiable nature came to light. Researchers began to report on negative outcomes of people selling their kidneys in countries such as India [5], Pakistan [21], Egypt [22] and The Philippines [23]. An increasing number of physicians publish articles on the medical outcomes of 'transplant tourism' [24-26]. Organ trade patterns generally evolve around a group of 'donor-exporting' countries (Egypt, China, India, Pakistan and The Philippines), 'demand' countries (the United States, Canada, Israel, the United Kingdom and some other European countries) and countries where the transplants take place including the United States, Israel and South Africa [2,12].

In November 2012, a man from New York was convicted to 2.5 years in prison for brokering kidney sales between Israeli recipients and 'donors' recruited from mainly Eastern European countries. The patients paid up to $160,000 for the transplants, conducted in New York City hospitals and were consequently reimbursed by their health insurance companies [27]. This case and the before-mentioned *Netcare* and *Medicus Clinic* cases have similarities. They illustrate how organ trafficking networks operate in various countries, bringing patients in need of transplants together with organ 'donors', with the help of legal players such as insurance companies.

Whereas the aforementioned examples involve organised, cross-border trafficking networks, there are indications that milder, more voluntary forms of organ trade exist. In a survey performed by Van Buren amongst 250 living kidney donors in The Netherlands, some donors reported that they had received 'rewards' or 'gifts' from their recipients. Examples were weekly meals, exotic vacations, a race car, jewellery, a racehorse and a painting [10].

By 2007, the World Health Organization (WHO) estimated that out of all transplants worldwide, 5-10% is conducted illegally [8,11]. In 2011 a Washington Institute, Global Financial Integrity estimated that the illicit organ trade generates illegal profits between $600 million and $1.2 billion per year [28]. It ranks the trade in human organs on number ten of the twelve illegal activities studied in terms of illegal profits made. The most common reported form of organ trade is the live kidney trade [12].

3 THE CONDEMNATION OF ORGAN TRAFFICKING, TRANSPLANT COMMERCIALISM AND TOURISM

Organ trade is prohibited worldwide. The WHO first prohibited organ trade in 1987, claiming that such trade is inconsistent with the most basic human values and contravenes the Universal Declaration of Human Rights [29]. Its 'Guiding Principles on Human Cell, Tissue

and Organ Transplantation' (hereafter Guiding Principles) declare that organs should be '*donated freely, without any monetary payment or other reward of monetary value*' [30].

The United Nations Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children (otherwise known as the Palermo Protocol) supplementing the UN Convention against Transnational Organized Crime (UNTOC) was the first international legal instrument to define and prohibit *trafficking in human beings for the purpose of organ removal* (often referred to as organ trafficking). In this definition, organ trafficking is regarded as a form of organised crime and defined in the context of trafficking in human beings (THBS). This provision does not prohibit organ sales for financial gain or other rewards. Key is the *trafficking* element, which involves force, exploitation or coercion of any kind [31].

Whereas the UNTOC prohibits organ trafficking as a form of organised crime, the WHO Guiding Principles highlight the prohibition of financial gain (often referred to as transplant *commercialism*). The distinction between commercialism and trafficking is followed by other organisations, such as the Council of Europe [32].

Professional transplantation societies also condemn organ commercialism and trafficking. In 2008 the Transplantation Society and International Society of Nephrology convened in Istanbul to establish the 'Declaration of Istanbul on Organ Trafficking and Transplant Tourism' (hereafter referred to as DoI). This is the first universal document, drawn up by transplant professionals, which condemns transplant tourism globally (next to commercialism and trafficking). It defines transplant tourism as travel for transplantation that involves '*organ trafficking and/or transplant commercialism or if the resources (organs, professionals and transplant centres) devoted to providing transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population*' [33] Despite its non-binding character, the influence of the DoI is significant. More than 100 transplant organisations endorse it [34].

In addition to international organizations and transplantation societies, the crime is also condemned by some academic researchers and doctors in their writings. Scheper-Hughes argues how the body—as part of the contemporary global capitalist economy—is treated as an object and as a 'commodity' that is bartered, sold or stolen in divisible and alienable parts [35]. Prof. Delmonico, president of the Transplantation Society and one of the founders of the DoI, writes: '*organ trafficking, transplant tourism and transplant commercialism threaten to undermine the nobility and legacy of transplantation worldwide because* [...] *the vulnerable in resource-poor countries are exploited for their organs as a major source of organs for the rich patient-tourists*' [36].

These and other authors have played a prominent role in the last decades to establish universal principles in organ donation and transplantation. Organ donation should occur *altruistically* [30], with respect for human dignity, without financial gain or comparable advantage and with voluntary and informed consent of donors [32]. The belief is that altruism rules out any financial motivation for donation. Whereas '*reasonable and verifiable expenses*' [30] incurred by the transplant are allowed, the practice of selling, buying or otherwise facilitating trade in human organs is prohibited [32]. Also, advertising the need for,

or availability of, organs with a view to offering or seeking financial gain or comparable advantage, shall be prohibited [32].

As a result of the condemnation against organ commercialism and trafficking, almost all countries have implemented the prohibition into their domestic laws. Iran is the only exception. It permits transplant commercialism through a governmental, regulated, organ procurement system. Confronted with very low deceased donation rates, the government in 1988 introduced a model of 'rewarded gifting' to promote live kidney transplantation. People who wish to donate can refer to a government institution who matches them to a prospective recipient. Middlemen and brokers, it is claimed, remain uninvolved [37]. All donors receive a payment (the equivalent of $1200) and a health insurance from the government. A large number of donors also receive an award or gift from the recipient. This reward is considered a private matter that is not interfered with [38]. The 'Iranian model' is critically scrutinized by some authors [39], yet others claim the model could—and should—be explored in other countries to increase the number of donations [40].

Indeed, the condemnation against organ trade may not be as universal as it may seem. Evans argues that the organ trade prohibition is a Western belief that is wrongly inflicted universally. He accuses contemporary position statements against transplant tourism of being '*ethnocentric*', regarding the world primarily from the perspective of Western culture [41].

The condemnation of organ trade as a serious (organised) crime problem is questionable for various reasons. The Bellagio Taskforce stated that '*the grounds for condemnation are not as obvious as declarations imply*'. For that reason it could not find an unarguable ethical principle that justified the ban on organs sales under all circumstances [20]. A group of doctors and philosophers published a paper in the Lancet in 1997, explaining why arguments commonly offered for prohibiting organ sales do not work and arguing that 'the debate should be reopened' [42]. The debate continues until this day [43,44]. Below we present arguments that have been put forward in an attempt to refute the universal prohibition of organ purchases and sales.

4 A CRITICAL PERSPECTIVE: FROM TRAFFICKING, TO COMMERCIALISM, TO TOURISM

Perhaps the strongest claim of all is that transplant commercialism is prohibited for the wrong reasons. Transplant commercialism and trafficking are prohibited to protect those most prone to sell. Scholars have raised the question whether there is anything intrinsically wrong with the buying and selling of organs (commercialism), or whether what is wrong in practice is the circumstances under which it occurs and their undesirable consequences [45]. They claim that harm (*trafficking*) already caused to donors and recipients in prohibited black markets is sufficient proof that the protection argument is no longer valid. As Radcliffe-Richards et al. wrote, '*there is much more scope for exploitation and abuse when a supply of desperately wanted goods is made illegal*' [42]. The point here is that prohibition does not prevent victimization. On the contrary, prohibition and criminalization of sellers

renders it more difficult to identify and help potential victims of trafficking. The argument made in favour of prohibition (namely that putting as price on organs will automatically lead to trafficking) is devoid of any empirical substance and is thus unconvincing [46].

Radcliffe-Richards et al. further argue that to justify the prohibition of kidney sales by poor vendors, it is necessary to illustrate that organ selling must always be against the interests of potential vendors. Removing their option to sell leaves them poor, and makes their range of options smaller still. The only way to improve their situation is to tackle the root cause of the problem (poverty) and develop effective strategies to help vulnerable donors [42].

Another critique is made against the belief that selling body parts violates human integrity and dignity. It is claimed that it has never been empirically verified whether those selling organs, eggs or sperm indeed felt diminished self-dignity or are considered to be or feel less altruistic [46,47].

It is said that the alarming organ shortage and resulting deaths on the wait list justifies the exploration *of* a legal, regulated market in organs (especially kidneys) [48]. The ban on organ sales keeps organ supply low, increasing their value, their potential profitability and thus reinforcing the problem. Furthermore, the ban is 'hypocritical' [48,49]. In contemporary transplant medicine, everyone profits, except the donor: the hospital benefits, the surgeon and the medical team are paid, the transplant coordinator gets paid and the recipient receives an enormous benefit. In an ethical, regulated organ market, organ vendors should equally benefit and be rewarded for their gift to the recipient and society.

The foregoing arguments shed a different light on the negative image of transplant commercialism. But they are more theoretical than empirical, thus raising the need for an evidence-based approach. Yet, this is impossible to achieve with a maintained ban on organ sales. Opponents of regulation often point to harms committed against organ vendors, yet these harms are the result of transactions in *unregulated* markets. The large number of organ vendors included in studies on outcomes of kidney vending stand in stark contrast to the number of organ recipients included in studies on outcomes of organ purchase. Studies on transplant tourism exist, yet the number of reported organ buyers is much lower than reported organ sellers [24,25].

There are strong indications that transplant tourism takes place in the same hospitals and clinics where transplants to locals and other medical procedures are carried out. Search engines lead to websites of centres worldwide that offer organ transplantations amongst many other common medical procedures. Health insurance companies see the benefit of outsourcing transplants to contracted centres in places including Bangkok, New Delhi and Bombay. Patients are encouraged to bring their own '*legitimate donor with a desire to donate*' [50].

Transplant tourism is increasingly referred to as a perilous procedure involving evils and dangers for recipients and suppliers [8]. The DoI declares that 'transplant tourism violates the principles of equity, justice and respect for human dignity and should be prohibited' [33].

It is questionable whether transplant tourism, derived from the universally and legally accepted phenomenon of medical tourism, deserves the reputation of a crime [51].

Closer scrutiny of studies that present data about transplant tourism reveals that the majority in fact do not present any real evidence that the organs were illegally obtained [24,25]. An information gap exists about micro-level interactions between physicians and their patients who opt for presumed commercial transplants abroad.

The next section addresses this gap by presenting the results from a fieldwork study conducted in The Netherlands on transplant tourism. First of all, the methodology of the study is presented. Second, we briefly describe the scale and dark number of transplant tourism from The Netherlands. Third, we address the reasons why patients go abroad. The fourth and final part focuses on the way physicians deal with transplant tourism.

5 CROSS-BORDER QUEST: AN EXPLORATIVE STUDY ON TRANSPLANT TOURISM FROM THE NETHERLANDS

5.1 Methods

In 2005, the Dutch National Rapporteur on Trafficking in Human Beings (NRM) initiated an explorative, empirical field study on organ trafficking that we performed by interviewing transplant professionals in Dutch transplant hospitals [52,53]. The main research question was whether the professionals knew kidney patients who wanted to, had tried to or had succeeded in buying a kidney for transplant in The Netherlands or abroad.

Nineteen half-structured interviews were conducted with transplant professionals (considered as gatekeepers), and policy-makers. The respondents are listed in table 1. A topic list with open questions was used. All respondents were contacted by a letter (by e-mail) of introduction stating the nature and aim of the study and stating a request for an interview. Thirteen transplant professionals were interviewed: eight kidney specialists (nephrologists), four transplant coordinators and one transplant surgeon. Because the seven transplant centres are specialized in giving post-transplant medical aftercare, it was expected that these centres would have the most knowledge and information about transplant tourism. The focus was predominantly on kidneys because kidneys are the most commonly traded organ. We interviewed physicians in all transplant centres to ensure a good geographic coverage. In addition, two patients were interviewed, one of whom bought a kidney in China. This interview was conducted in the patient's home. The other received a kidney through the Dutch wait list. Finally, we interviewed four policy makers for background information on organ donation policy.

The interviews lasted between 1-2 hours. All interviews, except for three (one with the transplant surgeon, one with a nephrologist, and one with the patient who went to China) were audio-recorded and transcribed verbatim. The interviews with physicians and patients were handled anonymously.

5.2 The scale of transplant tourism and its dark number

All transplant physicians and three transplant coordinators were confronted with patients who had expressed a desire to obtain organs for transplantation abroad. They also knew

or had heard of patients who had succeeded in travelling abroad for kidney transplantation. The policy-makers did not have any information or knowledge about patients going abroad.

Almost all respondents referred to the number of patients going abroad for kidney transplants as '*incidental*'. The number of cases mentioned by the doctors per centre ranges from two patients a year to less than five over three decades. Nationally, the estimated total number is four per year. The incidental scale of transplant tourism corresponds with studies from other countries that report small numbers of patients engaging in transplant tourism [24-26].

Most cases became known to doctors and coordinators after the transplant abroad had taken place and the patient returned to the transplant centre with complications. On some occasions, cases became known in the pre-transplant stage because patients told their physicians that they had found information on the Internet and were exploring the possibility of undergoing a transplant abroad.

Patients who go abroad for kidney transplants are not reported or registered. Various implications arise when attempting to assess the true number of transplant tourism cases. Below we present five reasons why a dark number of transplant tourism likely exists.

First of all, this study was performed in transplant centres, but not in regional hospitals or local dialysis centres. It is possible that transplant tourism cases are known with local dialysis doctors and in regional hospitals, but not reported to the larger transplant centres. One doctor said:

> *The problem is that we don't see it. We never know for sure. We also do not have a clear view of what patients do. When patients engage in transplant tourism, their dialysis doctors will come to us for advice and refer the patients to us.* —Nephrologist IV

Second, some patients who have travelled abroad may not be known to the medical system because they may not require medical help due to lack of complications. Some may not even be registered on the wait list when they go abroad for a transplant [54]. Transplant tourism commonly becomes known when patients seek medical care after undergoing a transplant abroad. A transplant coordinator claimed that:

> *We know because they come back. They live here. They come back because of complications or because of their regular checkups* [...] *we give them medical care, but we don't ask them anything.* —Transplant coordinator I

It is possible that some patients are successfully transplanted and that they do not require (immediate) post-transplant care. These patients may stay out of sight of the medical system. The latter seems unlikely however, as almost every patient will require regular checkups and immunosuppressant drugs to prevent the body from rejecting the implanted graft.

However, as long as this has not been properly investigated, the possibility of this dark number must be taken into account.

The third explanation for a possible dark number in this study is that our respondents often needed to recollect from memory to answer our questions such as the number of 'transplant tourists' they knew, the destination countries, the date or year of the transplant and the nature of the complications that patients experienced. Due to the lack of registered cases, the respondents were not able to provide exact numbers of transplant tourism cases. Instead, they gave estimations based on how many times it occurred each year, or every five, or 10 years.

Legal aspects, in particular the doctor's professional secrecy oath, the patient's right to privacy and the privilege of non-disclosure, are a fourth explanation why a dark number likely exists. Doctors have a professional secrecy oath and are therefore exempted from the duty to report their patients' crimes to the police[55]. Most doctors in the study emphasized their secrecy oath. This secrecy oath strongly affected our findings, first, because respondents were not always *willing* to provide detailed information to us, including the information in patient's medical records. They were reluctant to give us specific information and thus spoke about their patients in a generalized manner. Second, respondents were not always *able* to give us detailed information. They told us that they commonly did not talk with their patients about their alleged wrongdoing and thus were not aware of what had happened exactly. One nephrologist noted:

> *I did not want to interrogate the patient, for I am his doctor and I will remain his doctor.* —Nephrologist VIII

Another doctor said that it was not his responsibility to discover more about his patients' wrongdoings.

> *I don't know how the procedure works and what happens to them [the patients]. I don't ask them, because they won't tell me. They will act as if they don't understand me. Anyway, it's not my responsibility.* —Nephrologist VI

Many nephrologists emphasized that they believed patients would not come to them to talk about '*these kind of things*' (nephrologst VI). '*They know better than to tell their doctors about it*' (nephrologist V), was an explanation given for physicians' lack of knowledge and information about transplant tourism.

Under law, the professional secrecy and privilege of non-disclosure prevail over crime enforcement. Thus, if the physician reports information confidentially entrusted upon him by the patient without patient consent, the doctor can be held (criminally) liable. For these reasons, doctors interviewed in this study may have chosen to withhold certain information to us about transplant tourism, despite the anonymity of the study. The privilege of non-disclosure is also the reason why 'transplant tourists' are not reported or registered in The Netherlands. Given the firm entrenchment of this right in national

legislation, it is also very unlikely that doctors can be legally bound to report or register this information.

Our fifth and final explanation for a dark number lies with the definition of transplant tourism. As explained in section 3, the DoI is the only (international) document that defines transplant tourism. Whereas it considers 'travel for transplantation' as the legitimate 'movement for transplantation purposes, 'travel for transplantation becomes 'transplant tourism' if it involves '*organ trafficking* and/or *transplant commercialism*' [33].

Legal complexities arise in attempting to *identify, prove and enforce* transplant tourism by relying on this definition. Commercialism and trafficking are prohibited acts in almost every single country. However, a closer look at how these laws are framed reveals that these laws are not always equipped to tackle transplant tourism. Most laws apply to acts committed *within* the territory of the state, not outside it [56–58].

For example, if a patient purchases an organ on the territory of another state (*the destination state*), he or she is criminally liable and can be persecuted under the law of the destination state and not of the (*resident*) state. The main legal implication of transplant tourism therefore is that when the patient leaves a country after buying an organ that goes unnoticed or is ignored by local enforcement institutions, the legal consequences for the patient cease to exist. Consequently, whereas the purchase of organs is illegal, the purchase of organs will not (always) be *punishable*.

Even if conditions of extraterritorial jurisdiction are fulfilled, this does not automatically legitimize the state to prosecute its patients. It is practically impossible to prove whether transplants performed abroad involved commercialism and/or trafficking, i.e. whether they were in fact *illegal*. For instance, when a nephrologist was asked whether he knew patients who had purchased organs abroad, he replied:

> *I do not know patients who bought organs abroad, but I know patients who went abroad and came back with an [implanted] organ. They don't tell me whether they bought the organ.* —Nephrologist VI

The returning patient's possession of an implanted organ, *by nature a legal good*, does not constitute proof of commercialism or trafficking. All transplant physicians in this study said that the patients bring back no or very limited information about the transplant and the donor. If they bring back information, it is commonly a letter, written by a doctor of the transplant hospital or clinic. These letters sometimes mention when and where the transplant took place, the medicine the recipient received and additional (medical) details about the functioning of the implanted graft. In these letters nothing is written about the potential illegality of the act, such as costs of the transplant procedure, the costs or financial profit or the origin of the donor kidney. *If* something is mentioned about the donor at all, this information is limited to blood group, gender and age, or simply stating that the organ donor was '*related*', a '*cousin*' and/or that '*the donor was very healthy*'.

The limited documentation available is a recurrent theme in studies on transplant tourism [54,59,60]. The reporting of donors as being 'related' has also been mentioned by

Cronin et al. who found that of 245 patients from the United Kingdom who underwent transplants abroad, 68 received their organ from a related donor, the majority of which were reported as '*cousins*' [54]. Lundin and Berglund also mention that a patient travelled abroad and received a kidney from a '*distant relative*' [6].

The DoI defines and condemns transplant tourism when it involves 'commercialism'. Many studies on transplant tourism mention the costs of the transplant, and conclude on this basis that the transplant was 'commercial', illegal and/or constituted transplant tourism [60]. Yet, the costs of the transplant procedure also do not constitute proof of an illegal act. There are numerous commercial, legitimate medical procedures that are paid for, at home or abroad [58]. Transplant procedures are one of them. What makes a transplant at home or abroad *illegal* (under criminal legislation) is the financial profit made with the purchase or sale of the *organ* (the payment overriding the costs) and/or the exploitation of the *trafficked donor* [51,56].

The meaning thus given to transplant tourism is 'confusing' [41]. It is 'emotionally charged' [41] without practical or legal significance. Its attributed meaning lacks the ability to distinguish between legitimate 'travel for transplantation' and illegitimate 'tourism'.

To conclude, a dark number of transplant tourism cases likely exists for many reasons. The current definition given to transplant tourism in the DoI fails to identify true transplant tourism cases. The taxonomy given between 'travel for transplantation' and 'transplant tourism' has more theoretical than practical purpose. Governments that prohibit transplant commercialism jurisdiction and agreements needed to effectively *enforce* tourism. Even if such legal structures were in place, in the absence of *clear* proof that the organ was bought or that a donor was trafficked for the organ, neither the presence of the implanted organ (the graft), the presence of medical complications, nor the (lack of) information given in the patient's medical file constitutes sufficient proof that his endeavour was an 'illegal' act of transplant tourism.

In section 5.4, we present recommendations to tackle and prevent tourism more effectively. The next section focuses on the reasons why patients travel abroad for transplants.

5.3 'I was insecure and longing': why patients opt for transplants abroad and the role of culture

All physicians highlighted that the desperation of patients waiting for a transplant is the predominant reason why they go abroad or explore the possibility of undergoing a transplant abroad. The average wait time for a kidney transplant in The Netherlands is four years. Currently, over 45% of the patients do not survive the wait. The waiting time starts with the first dialysis treatment. Dialysis is a process of cleaning and achieving chemical balance in the blood of patients whose kidneys have failed. Although dialysis is regarded as a life-saving treatment, it has a large impact upon quality of life, since it decreases patient's health. In some cases health deteriorates in such a manner that a transplant is no longer an option. Second, dialysis treatments are time-consuming. Patients receive dialysis treatments at home or in clinics or hospitals about three times a week.

Not only the physicians but also the patients interviewed emphasized the insecurity that is accompanied by the long wait on the wait list. One patient (he received a deceased donor kidney in The Netherlands through the wait list) expressed:

> *I was insecure and longing. I was continuously thinking about the average waiting time and how long I still had to wait. And what I could do to somehow accelerate my transplant.* —Recipient I

A patient who bought a kidney in China said:

> *The dialysis treatments were terrible. Once you begin you can no longer do without. You are stuck to it. Going on holiday becomes almost impossible, unless there is a dialysis centre nearby. It also became impossible for me to keep my job.* —Recipient II

The impact of dialysis treatments on the quality of life of patients was emphasized by a doctor, who asked:

> *Have you ever seen patients on dialysis? If you do, you won't ask me again why they engage in transplant tourism.* —Nephrologist IV

Not all doctors shared this view however. One physician explained:

> *Dialysis is a very humane treatment. You are still capable of many things because of it. It is a treatment that is bearable. If the treatment is no longer possible for a patient [...] he or she can easily get a donor kidney. We [physicians] have that power. It is possible to live with dialysis. It's a different story if you need a heart. That's when it is about your life. Without a heart there is no life. A living donor cannot donate his heart. Everything has its price.* —Nephrologist II

Yet, desperation alone is not a causal or driving factor of tourism. It does not explain why some patients on the wait list opt for a transplant abroad, but most do not. This suggests that more dominant factors, aside from the desperation caused by the illness and the (expected) long wait for an organ, play a role. As put by a patient from The Netherlands who received a kidney from the wait list:

> *There are groups of people that do not have ethical objections [to organ trade]. They have an 'everything can be bought' attitude [...] this has to do with culture* [...]. *I do not believe these people fit into my social group.* —Recipient I

Indeed, almost all respondents in the study emphasized the 'ties' between '*transplant tourists*' and their countries of destination. They mentioned that patients often have an affinity

with the country of destination, either because this is their country of origin, because they have family or friends living there, and/or because they have worked or lived there. For these patients, they assumed, it was perhaps easier to make the decision to go abroad. For example, one physician explained:

> *Often they are Dutch, but with a different ethnic background. For the average Dutchman it is too big of a step to go to China. They are too compliant. The average patient will calmly wait in line for a transplant. There are a few people that explore the ethical boundaries of organ tourism, or who will trespass them. This kind of people do not come and tell me what they've been up to.*
> —Nephrologist V

One nephrologist (I) knew four to five patients who travelled to China, Iran, India and Pakistan. The patients who travelled to Iran and Pakistan also had the nationality of those countries. Another nephrologist (II) knew three patients who went to China, US and India. The patient who travelled to China was Chinese, the other two were Dutch. A third nephrologist (III) knew two patients of Chinese origin who travelled to China and two who travelled to Iraq. Of the latter, one was a young Iraqi woman. The other was a man of Turkish, Kurdish or Iraqi origin. Nephrologist VI knew six to seven patients who travelled to China, Pakistan and India. Not all respondents remembered the nationality of patients who travelled abroad. One transplant coordinator (II) knew a patient who went to Pakistan, but she did not know the nationality. A nephrologist also knew two patients who went to China and India, of which he did not know or mention the nationality.

Not all patients had the nationality of the destination country. One nephrologist (VI) mentioned two patients ('*refugees*') of Moroccan and Lebanese origin who travelled to China and Pakistan. The fourth patient that he mentioned was a Dutch man who had worked for a large multinational company in Singapore and had managed to obtain a transplant in India from there. The nephrologist assumed that he obtained his transplant in India because his physicians in Singapore had informed him about the transplant opportunities there.

Respondents generally referred to the patients as '*immigrants*' or '*refugees*'. One nephrologist (V) spoke of an exchange student who went to his home country (India) for the transplant and came back after that. Only one nephrologist (VI) emphasized that his patients had varied backgrounds. He explained: '*they live in luxurious villas but also reside illegally in the basements of houses in the big city*'.

These findings illustrate that cultural factors play an important role. Ethnic ties between patients and their destination countries are a recurrent topic in almost all studies on transplant tourism. Cronin et al. found that of 245 UK residents that travelled to Pakistan and India, 62% were of South Asian ethnic background [54]. A study performed in the United States amongst 10 patients found that all were foreign-born. Within each ethnic group, patients travelled to the same country, being Somalia (8), China (1) and Japan (1) [24]. Gill et

al. identified 93 Canadian 'tourists', the majority of which were 'ethnic minorities' travelling to their country of origin [61].

Yet very few authors deal with the role of culture or ethnicity as part of the broader global context. Cronin et al. are one of the few who raise the issue that minority ethnic groups in the United Kingdom are least likely to receive a transplant and that it is therefore not surprising that these groups are more likely to travel to their country of origin where they may have a greater familiarity and trust with the country's health care system [54]. Studies from The Netherlands [62], the United States [63] and Canada [64] also found that minority ethnic communities are far less likely to receive organ transplantations. The reasons for this are the greater propensity of certain ethnicities (mainly South Asians and African-Caribbean persons) to develop chronic kidney failure [54] and lack of awareness and information about treatment options [62]. Given this, it is plausible that a link exists between the likelihood to receive a transplant in the home country and the propensity of some patients to opt for (paid) transplants abroad.

Only very few researchers have interviewed patients directly about their perspectives and experiences of going abroad for a transplant [6,65].

Recipient II indicated that his familiarity with the Chinese health system was an important reason for him to undergo his transplant there. He explained that his dialysis treatments in The Netherlands and the expected waiting time were not the primary reason why he started looking into transplant opportunities in his birth country. An important reason was the language barrier. He had poor knowledge of the Dutch language. Communication with his physicians about his disease was difficult. He complained that his physicians '*spoke too fast*' for him. He felt relieved when he arrived in a hospital in China because he could finally communicate in his mother tongue with his physicians about his illness and understand the nature of his disease. A third reason why he went abroad was because the medical procedure in China was less complicated and bureaucratic than in The Netherlands. He explained that it was easier and quicker for him to receive treatment in China.

Recipient II's narrative corresponds with Berglund's and Lundin's results of three interviews conducted with patients, living in Sweden, who underwent transplants abroad. All three patients (men) were foreign born (Iraqi, Iranian and Lebanese) and travelled to Pakistan, Iran and Pakistan respectively for their transplants. In their research, Berglund and Lundin focused on how people assign meaning and give a personal voice to their decision to go abroad. One of the main explanations that these patients gave about going abroad, were their feelings of alienation and being discriminated against in the Swedish health care system. The authors refer to insufficient understanding between the patients and medical staff when it comes to each other's language and culture [6].

Indeed, several nephrologists in our study emphasized the language barrier between them and their patients. One doctor pointed out that, '[the patients] *won't tell me. They will act as if they don't understand me anyway*' (nephrologist VI).

In addition to waiting time and feeling of alienation and desperation, we also found an important *pull* factor that explains why some people travel abroad for transplant. An

important finding in our study was the importance of ties with family and friends in the country of destination. Recipient 11 pointed out that he would not have been able to undergo his transplant if it wasn't for the help of his family and friends in China. Although he had looked for information about Chinese hospitals on the internet, his Chinese family and friends facilitated his transplant by finding a Chinese physician who was willing to treat him. They also paid a large part of the costs of the transplant and found a man who was willing to sell his kidney. He could not say exactly how much the transplant eventually cost him in total (somewhere between €10,000 and €50,000) because his family had taken care of most of the costs.

Berglund and Lundin also mention that the patient's transplant in Pakistan was arranged with help from one of his brother's employees in the United States, whose brother in turn owned a hospital in Pakistan. The other patient who also went to Pakistan explained that his mother helped him pay for the transplant, by selling a piece of land.

A final reason why patients are found to travel abroad has to do with ethical or cultural norms. Whereas in many Western countries the sale or purchase of body parts is perceived to be repugnant, this belief is not universally felt [41]. Perceptions of body concepts, ownership, sale, gifting, liberty and personal dignity differ across cultures and religions. Berglund and Lundin warn that because those who pay for organs are highly stigmatized, they will rarely want to tell their story truthfully [6].

This study revealed that doctors are often the first to encounter, or find out about the aspirations of patients to go abroad, or about those who have gone abroad. Recommendations against transplant tourism should therefore be primarily aimed at doctor-patient interactions. Below, in the final section, we address our findings on how doctors perceive transplant tourism and how they act towards patients who travel abroad for presumed commercial transplants. In the last section we focus on the way recommendations or guidelines for transplant professionals should best take form.

5.4 'I am the donor's advocate': how physicians deal with transplant tourism

The common belief is that transplant commercialism and moral transplant practice do not go together. Danovitch, for instance writes that '*commercialization of transplantation has the potential to subvert and distort the traditional advocacy and caring role of doctors when they evaluate potential living kidney donors*' [66]. Giving financial rewards for donation pressures transplant doctors to act 'against their best medical judgment and transplant donors to act against their best medical interests' [66]. Indeed, the DoI proclaims that the prohibition of transplant tourism should include '*penalties for acts—such as medically screening donors or organs, or transplanting organs—that aid, encourage, or use the products of, organ trafficking or transplant tourism*' [33].

Consequently, physicians presumed to be involved in trafficking or transplant tourism are considered to be outlaws, 'renegade' and detached from the 'mainstream' transplantation community [65]. The 'moral' physicians by contrast are those who take no part in organ trade but find themselves burdened with a responsibility for medical care of the recipient who returns home after a paid transplant abroad [8].

Physicians are often the first to find out about the patient's endeavour to travel abroad for presumed commercial transplants. Considering the growing anti-transplant tourism sentiment and the influence doctors can exert on their patients, physicians are expected to prevent 'transplant tourists' from going abroad [61]. But what if physician's individual considerations and opinions conflict with the prohibition of transplant tourism and its rationale? Below we present some of the opinions and attitudes of doctors in this study. Why did they condemn transplant tourism? Did their opinions or attitudes influence their behavior towards their patients?

All physicians and transplant coordinators expressed ethical, legal and medical concerns about patients travelling abroad for transplants and therefore dissuade their patients from going abroad.

Ethical concerns involved the likelihood that the organs were procured from impoverished, exploited donors. Nephrologists highlighted that although proof of this was non-existent, they assumed that patients had bought organs through unregulated, black market transactions. '*I am the donor's advocate*' one nephrologist (II) exclaimed. '*I sometimes tell my patients that I am willing to butcher a cow in order to give them a piece of meat. But I won't slaughter a person to give them a kidney*'. Yet, some acknowledged that organ sales might not always have adverse negative effects for the donor, required that they get proper access to post-transplant medical care.

One nephrologist (VII) said:

> *I would sell my own kidney if I could therefore feed my children or give them good education. I cannot be judgmental about that.*

The respondents did not only express an understanding of those who sell, but also of those who buy. '*It's a matter of life and death*', one nephrologist (I) said. '*It is to be expected from a rational minded person that he will look for other ways to find organs*'.

Apart from the ethical risks involved, doctors also dissuade their patients from embarking on paid transplants abroad because it is illegal. The respondents emphasized that not only patients are forbidden from buying organs but doctors are also prohibited by law to (help) facilitate the purchase. Thus, they do not help their patients because the law prohibits them from engaging in illegal activities. '*However, if a patient returns with complications, I will help him*,' all respondents said. In one instance legal considerations prompted a nephrologist to help a patient of Iranian nationality to undergo a transplant in his home country, '*because it is legal for Iranian nationals to undergo paid transplants there*,' the physician explained. He considered this case an exception and therefore decided to help. He supported the patient with undergoing medical tests and put the results on paper for him prior to his departure.

The limited knowledge and control over the quality of care that patients will receive abroad is a third reason why physicians dissuade their patients to engage in it. Respondents often emphasized the medical risks involved in getting a transplant in countries where

safety and protection measures are likely to be poor. Dutch nephrologists' experiences with the well-being of patients that underwent commercial transplants abroad vary. One nephrologist stated that he gets back '*rubbish*', another exclaimed that '*in the end, all those tourist kidneys did not do well. Eventually justice is done!*' Yet the same physician stressed that the transplantations in China of two patients were performed '*...very neatly. It was state of the art. Not just a third-world transplant, but the same as they do here*'.

These varying outcomes are also reflected in the literature. A systematic review performed by Sajjad et al. of 30 studies on the medical outcomes found in recipients who were transplanted abroad reported detrimental outcomes including lower graft survival, incomplete peri-operative information, wound infections, thrombosis, urinary leaks, malaria and fungal infections [60]. Yet other studies report comparable outcomes to control group patients who received a transplant through a 'regular' transplant procedure in the home country [24].

Physicians' concerns affect the way they cope with transplant tourism. One nephrologist (VIII), when asked why he did not try to gather information about one of his patient's organ purchases in China, said:

> *I refrained myself from knowing* [...] *I believe it was my way of ostracizing. I wanted to keep my hands clean and not be accessory to things that are ethically unacceptable. I did not want to feel guilty.*

The prohibition to engage in activities that are potentially illegal versus the duty of medical care causes a dilemma for physicians. Some doctors emphasized that by providing medical care to patients that potentially aids them with a paid transplant abroad (such as giving them their medical file upon departure) they may potentially breach regulations under criminal law that prohibit doctors to help facilitate commercial transplants. Reversely, if doctors would refuse to provide medical care, such as withholding patients' medical files, they would breach vital health care regulations including patients' rights to care.

Despite this conflict of duties, all physicians emphasized that they would provide medical care to 'transplant tourists', not only out of professional duty, but also out of a sense of moral obligation. Thus, the perceived dilemma between prohibition of commercialism and duty of care did not affect the way they treated their patients.

However, many physicians remained secretive and defensive about transplant tourism. They emphasized their secrecy oath. Their guarded, cautious attitude became clear when they trivialized transplant tourism by emphasizing that it occurs '*only incidentally*', and that when it occurs, it happens without them knowing. Most doctors and transplant coordinators regard it as a phenomenon that occurs outside the Dutch medical sphere and that is beyond their control.

6 THE WAY FORWARD: REFLECTIONS ON HOW THE TRADE IN HUMAN ORGANS SHOULD BEST BE TACKLED

An effective approach to organ trade acknowledges that it takes on a wide variety of forms. Only after we agree on the definition of commercialism and trafficking, and on what we find condemnable, can we agree on their prohibition. Putting a price on organs (commercialism) is different from coercing someone into selling one (trafficking) [67].

International instruments, such as the DoI, correctly define and differentiate trafficking from commercialism and tourism, yet they do not mention how both acts should be approached by policy. They wrongly conflate organ trafficking and transplant commercialism to constitute one and the same problem that both warrant equally repressive, punitive responses. Policies aimed to suppress or reshape an illegal market work differently from policies addressing coercion and other harms associated with trafficking. Evaluative studies in other illegal markets have shown that criminalization of commercialism is likely to *reinforce* trafficking [68].

In section 3, we explained that organ trade can be broadly distinguished into three categories: transplant tourism, transplant commercialism and trafficking in human beings for the purpose of organ removal (organ trafficking). Below we introduce an approach for each form of trade.

6.1 A bottom-up approach to transplant tourism

The cross-border and complex nature of transplant tourism possibly makes it one of the most difficult crimes to prove and prosecute. This complexity raises challenges for doctors and other health carers. Transplant tourism shifts the traditional role of doctors as medical carers to 'agents', encouraged to deter and prevent transplant tourism [61]. What would be the appropriate way of action if a health carer is confronted with a patient who considers going abroad for a—presumably—paid organ transplant? The *type of* response warranted depends on ethical, legal and medical factors. These factors differ for each individual situation. Any guidelines or recommendations developed for doctors on dealing with tourism should thus distinguish between different scenarios [51].

First and foremost, when a patient enquires about the possibility to *undergo* a transplant abroad, the doctor should not immediately speculate that this will be an illegal transplant constituting transplant tourism. Without evidence pointing to the contrary, the patient's intention to go abroad should be regarded as a legitimate endeavour. Nevertheless, considering the medical complications that accompany transplants abroad [60], health carers should dissuade the patient from going abroad by warning him/her against the medical risks. Contrary to what Gill et al claim [69], doctors should refrain from informing or 'educating' *all* patients about going abroad: this may bring the unintended consequence of putting ideas into the heads of patients who otherwise might not have considered the possibility at all. Such warnings should only be directed towards the individual patient who has expressed an interest or desire to undergo a transplant abroad.

If the patient is adamant on leaving and asks for his medical records and additional medical support, this falls within the duty to provide care. *Refusal* to give the medical record to a departing patient, or any other medical support, even if the physician *is certain* that the patient is going to buy the organ, constitutes medical negligence and thus breaches the physician's duty to give care and the patient's right to receive it. Not providing care to those in need, be they uninsured, imprisoned for atrocious crimes, or planning to buy an organ is likely to be considered a flagrant violation of human rights as laid down in the European Convention of Human Rights and Biomedicine [70]. The European Court of Human Rights has stated that medical care prevails over other interests [71].

Whereas the patient's right to receive medical care remains untouched, it could be claimed that the doctor *may* consider disclosing patient information to the police. This consideration may arise in the situation where the patient outright declares to his doctor that he is going to *buy* an organ for transplant abroad from a trafficked or paid donor.

Generally, the declaration of the patient that he is going to commit a crime falls within the scope of the patient's right to privacy. The professional secrecy oath, derived from the patient's right to privacy, is a right of the patient, of which the doctor merely is keeper [71]. What flows from the right to privacy is the privilege of doctors not to disclose patient information to police authorities. The professional secrecy and privilege of non-disclosure prevail over crime enforcement. Thus, if the physician reports information confidentially entrusted upon him by the patient without patient consent, the doctor can be held criminally liable. However, from established case law, it is clear that the doctor's privilege of non-disclosure is not absolute. In very exceptional cases, when overriding interests or conflicts of duties are at stake, a duty *may* arise to *breach* the professional secrecy oath when the doctor is confronted with information that, if not reported, will lead to '*direct and severe*' harm to another individual [71].

The question thus arises whether a patient's declaration that he is going to *buy* an organ for transplant abroad from a paid donor, constitutes sufficient justification to report the patient to the police. Considering contemporary case law it is very unlikely that a paid donor provides sufficient justification to breach professional secrecy and report the patient to police authorities. 'Direct and severe harm' is generally defined in the context of intended homicide or child abuse. The purchase of an organ from a paid donor will likely not be equated as a similarly severe crime. However, if the organ would be taken by force from a severely exploited (trafficked) donor, or a murdered donor, this is likely to be accepted as sufficient justification to report the patient to police. Yet, considering that the doctor must clearly motivate breach of professional secrecy, the physician would need to require clear evidence, such as a patient declaration or confession that the donor is going to be directly and severely harmed. In the absence of such information, a breach of the professional secrecy oath is likely to be considered illegitimate.

The foregoing focuses on pre-transplant scenarios, yet these considerations are equally relevant for post-transplant situations. All patients returning from (presumed illegal) transplants abroad are entitled to medical care. Only in the case of clear evidence of direct and severe harm to the *trafficked* donor, may a doctor *consider* reporting the patient

to the police. Legal implications for patients and doctors will differ in each individual case. Doctors will need to weigh the information known to them before deciding to treat presumed 'transplant tourists' differently from other patients. Providing suboptimal care to patients should not be based on speculations or presumptions that the transplant abroad was illegal.

In conclusion, rather than relying on strict measures aimed to prevent and punish transplant tourism, we believe it is more effective to focus on a bottom-up strategy that tackles the root cause of the problem, namely the demand for organ transplantation. Doctors should make patients aware of safe alternatives such as a live kidney donation. Living kidney donation is acquiring an outstanding record worldwide. Although live donation involves risks including morbidity and mortality for the live donor, these risks are very low [72]. Bottom-up initiatives to prevent patients from going abroad, should also take account of more sensitive, cultural issues that play a role in everyday patient-doctor interactions.

6.2 Transplant commercialism: a plea for regulation

An increasing number of transplant professionals claim that the ban on transplant commercialism is not justified. Some people argue that perhaps it is a good thing that money persuades people to donate. Not only may it more effectively deal with the widespread, documented abuses in current illegal organ markets, it may also relieve the shortage of organs [40]. Matas states: '*organ sale simply does not feel right; but letting candidates die on the waiting list (when this could be prevented) also does not feel right*' [46]. Are doctors '*failing their patients*' [73] as long as the ban on payments is maintained?

Various authors have proposed standards or conditions that a regulated or 'monopsonistic market' should fulfil [48]. Erin and Harris mention, amongst others, that the market should be confined to a self-governing geopolitical area such as a nation state or the EU, with only one purchaser. Only citizens resident within the union or state could sell into the system. There would be no direct sales or purchases and no exploitation of low-income countries and their populations. Sellers of organs would know they had saved a life and would be reasonably compensated for their risk, time and altruism [48].

Matas et al. add that such a system would need to comply with 'protection' (risk to the donor should be in accordance with currently accepted standards as defined for current donors), 'regulation and oversight' (each country will need to enact guidelines for evaluation and selection of donors, institution of the program of incentives and oversight), and 'transparency' [40].

6.3 Organ Trafficking: improving the non-legislative response

As a result of the ratification of the Palermo Protocol [31], organ trafficking (the trafficking of persons for their organs) is prohibited practically worldwide. There is little doubt that organ trafficking should remain universally prohibited. However, this prohibition largely remains a paper exercise. Organ trafficking prosecutions are practically non-existent.

Legislative prohibitionist efforts, no matter how sophisticated, are fruitless if they are not accompanied by *enforcement* by local, national and international policing agencies.

In 2010 in Vienna, the United Nations Office on Drugs and Crime (UNODC) organized an expert meeting about the incidence of trafficking in persons for the removal of organs[74]. At this meeting three issues became evident: first, organ trafficking researchers may have information about organ trafficking, but this information is hardly shared amongst them. Doctors also do not share information about organ trafficking. Second, there are no partnerships between researchers, transplant doctors and judicial/law enforcers. Third, there is no awareness of the crime with judicial/law enforcement authorities. Organ trafficking is not on the 'enforcement agenda' of these authorities. The lack of multinational partnerships hampers effective, non-legislative response to organ trafficking.

Awareness about the crime should be raised with local, national and international law enforcement institutions. Partnerships should be established between various groups. Target groups are for instance Judicial and law enforcement authorities, transplant professionals, international organizations and human rights NGOs involved in protection of THB victims.

Enhanced collaboration between these partnerships can be encouraged by EU-funding mechanisms for research projects and cooperation actions, such as by the European Commission *Home Affairs* Program. In 2012 this program will start funding a project that aims to improve the non-legislative response to human trafficking for organ removal (the HOTT project), coordinated by the Erasmus MC University Hospital in Rotterdam.

Other platforms with opportunities for enhanced collaboration lie with the Council of Europe, the WHO and the OSCE. These organizations are known to have written organ trafficking reports, yet little collaboration exists between these organizations and law enforcement institutions. Toolkits for Member States and Competent Authorities should be developed that provide *indicators for police personnel to identify organ trafficking activities*.

Training of police investigators should be encouraged regarding evidence gathering of organ trafficking cases and know-how about the *modus operandi* of the actors involved, training of prosecutors and judges. Bilateral and/or multilateral cooperation in cross-border criminal procedures should be encouraged and established.

Respondents	Number of years in practice	Number of 'transplant tourists'	Countries of destination	Nationality	Year
Nephrologist I	30 years	4-5 patients	China, Iran, India, Pakistan	Iranian, Pakistani	Not known
Nephrologist II	30 years	3 patients	China, US, India	Chinese, Dutch, Dutch	2004, 1990
Nephrologist III	20 years	4 patients	China, Iraq	Chinese, Iraqi	2002, 2003
Nephrologist IV	25 years	3 patients	Iran, unknown, US	Iranian, unknown, Dutch	unknown
Nephrologist V	25 years	1 patient	India	Indian	unknown
Nephrologist VI	27 years	6-7 patients	Pakistan, India, China	Moroccan, Libanese, Chinese, Dutch	unknown
Nephrologist VII	12 years	1-2 patients each year	Pakistan, India	Pakistani, Indian	Each year since 1994
Nephrologist VIII	10 years	2 patients	US, China	Dutch, Chinese	2004 (China)
Transplant Surgeon	30 years	None			
Transplant Coordinator (TC) I	25 years	Would not say	China, Pakistan, Colombia	Not known	
TC II	8 years	1 patient	Pakistan	Not known	2003
TC III	11 years	None			
TC IV	4 years	1 patient	Not known	Not known	
Policy maker I	Not anonymous	None	Not known	Not known	
Policy maker II	Not anonymous	None	Not known	Not known	
Policy maker III	Not anonymous NIGZ	None	Not known	Not known	
Policy maker IV	Not anonymous	None	Not known	Not known	
	Year of transplant	**Country of destintion**	**Origin of organ**	**How procured**	**Nationality**
Recipient I	2005	The Netherlands	Deceased donor kidney	Through the national organ transplant wait list	Dutch
Recipient II	2004	China	Living donor kidney	Bought from a living donor	Chinese

table 1 Summary of Respondents

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3

THE SCALE, MOTIVATIONS AND EXPERIENCES OF PATIENTS WHO BUY ORGANS ABROAD

III

ON PATIENTS WHO PURCHASE ORGAN TRANSPLANTS ABROAD

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The international transplant community portrays organ trade as a growing and serious crime involving large numbers of traveling patients who purchase organs. We present a systematic review about the published number of patients who purchased organs. With this information, we discuss whether the scientific literature reflects a substantial practice of organ purchase. Between 2000 and 2015, 86 studies were published. Seventy-six of these presented patients who traveled and 42 stated that the transplants were commercial. Only 11 studies reported that patients paid, and eight described to what or whom patients paid. In total, during a period of 42 years, 6002 patients have been reported to travel for transplantation. Of these, only 1238 were reported to have paid for their transplants. An additional unknown number of patients paid for their transplants in their native countries. We conclude that the scientific literature does not reflect a large number of patients buying organs. Organ purchases were more often assumed than determined. A reporting code for transplant professionals to report organ trafficking networks is a potential strategy to collect and quantify cases.

INTRODUCTION

Over the years, the trade in human organs has become an object of international concern. While first regarded as an organ theft rumor, organizations including the World Health Organization (WHO), the Council of Europe, and Global Financial Integrity now present it as a lucrative and serious form of organized crime that exploits vulnerable donors worldwide. The WHO estimated in 2007 that 5-10% of the approximately 60 000 kidney transplants performed annually around the globe occur via organ trade [1,2]. According to the Council of Europe, the trade is growing worldwide [3]. Global Financial Integrity ranks the trade among the top 10 of the world's most profitable crimes, with an estimated annual illegal profit of $614 million to $1.2 billion [4].

A closer look at these reports reveals that they lack empirical foundations for their claims that the organ trade is widespread and growing [5]. Nonetheless, these estimates are relied on to emphasize the trade's seriousness and to underscore the need to make it an object of punitive crime control [6-8]. The prevailing response to the trade is illustrative thereof: countries are implementing strict(er) laws against all commercial dealings in organs. However, it remains unclear whether this type of response is proportionate to its nature and scale [5,9,10]. What is needed is a better understanding of the trade, in particular of its prevalence. This knowledge can help the transplant community, together with policymakers, to develop effective measures to prevent and curb it.

Here, we systematically review the literature on the number of patients who buy organs. With this information, we discuss whether the scientific literature reflects a substantial practice of organ purchase. We begin by describing the number of patients who traveled for transplantation, including their departure and destination countries. Next, we

examine whether they paid for their transplants and, if yes, to whom or what they paid. We also describe payment for organs within countries (travel abroad not involved).

METHODS

Data sources

In conformance with the PRISMA guidelines [11], we retrieved articles from online databases and cross-checked reference lists. The following databases were searched in cooperation with a medical information specialist (W.B.): Embase, MEDLINE (Ovid), Web of Science, Scopus, and Cochrane Central. Additional references were retrieved from PubMed (limited to the subset as supplied by publisher, to identify the most recent articles) and Google Scholar (limited to the 200 most relevant articles). The databases were last searched on 17 June 2015.

Selection criteria

The searches consisted of two elements: 'organ transplantation' and 'commercial phenomena.' All databases were searched for synonyms for 'commercialism' in close proximity with synonyms for 'organs.' When controlled terms were available (MEDLINE and Embase), appropriate thesaurus terms were combined using 'AND.' To reduce off-topic references, exclusions such as 'blood,' 'gametes,' and 'bone marrow donation' were added with 'NOT.' The searches can be found in the (online) supplementary material.

We then selected peer-reviewed, empirical (quantitative and qualitative) English-language publications about patients who received organ transplants abroad and/or who purchased organs domestically (no travel involved). We also included studies among donors and/or physicians who provided information about patients who purchased organ transplants. Publications published before 2000, opinion articles, and presentations were excluded. Two researchers (F.A. and J.J.) screened the titles and abstracts against the inclusion and exclusion criteria. Finally, we obtained the full texts of potentially relevant abstracts and examined them for eligibility.

Data analysis

The following data were extracted from each article: first author and year of publication, number of patients who obtained organ transplants, year of transplant, home country, nationality or ethnicity, destination country and number of patients per country, type of donation/transplantation, transplant tourism or commercialism (yes, no, not written), domestic commercialism (yes/no), and amount/beneficiary. In case of multiple publications referring to the same patients, data were extracted from the most recent record only. One author extracted data, which was reviewed by a second author for accuracy and completeness.

RESULTS

Literature search and definitions

The search yielded 12 472 results. Of these, 2808 were published before 2000 and 3758 were duplicates. We thus screened 5906 records on title and abstract: 5636 articles did not meet the inclusion criteria and 270 articles were selected for full-text review. Eighty-six articles were considered eligible and included in the final analysis.

We used the definitions given for 'travel for transplantation,' 'transplant commercialism,' and 'transplant tourism' that are presented in the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (DOI) [12]. The DOI defines travel for transplantation as the (legitimate) 'movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes.' Transplant commercialism is defined as 'a policy or practice in which an organ is treated as a commodity, including by being bought or sold or used for material gain,' and transplant tourism is defined as 'travel for transplantation that involves organ trafficking and/or transplant commercialism or if the resources (organs, professionals and transplant centers) devoted to providing transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population' [12]. Notably, although more than 40 articles were published on travel or tourism after the DOI, only five present or apply the DOI's definitions.

The majority of the included studies (76 of 86) present patients who traveled. Of these, 42 state that the transplants were commercial and/or obtained through transplant tourism. Eleven studies report the amount that patients paid for their transplants. Eight report the beneficiary of the payment. Fifteen studies present domestic organ trade (five of which present overseas as well as domestic purchases). These and other characteristics of the included studies are presented in table 1. A flow chart of the inclusion process is presented in figure 1.

Travel for transplantation

Scale and geographic scope: The literature that was published between 2000 and 2015 reports that 6002 patients traveled to another country for transplantation between 1971 and 2013. This number includes traveling patients who were not reported to have paid and excludes transplantations within countries. Most patients traveled from Taiwan and South Korea to China. China is the most popular destination country, followed by India and Pakistan (table 2).

Common trends: Most patients traveled for kidney transplants, the majority of which were living unrelated [13-52]. Patients also traveled for liver transplants [53-60]. Eleven patients traveled for heart transplants [61-64]. One person traveled for a lung transplant [63]. For many kidney and liver transplants, the donor relationship is not reported (table 1). Many patients are ethnically affiliated with the countries or regions to which they traveled. Desperation as result of the long waiting time and a lower quality of life experienced on dialysis were

the main reasons why patients traveled [65,66]. Other reported reasons were patients' cultural and ethnic affinities with the destination country or region [18,67]. Inequality in access to transplantation is a third explanation of why patients traveled abroad [32,67].

Transplant tourism

Terminology and transplant documentation: Of the 76 articles that present patients who traveled, 42 articles describe them as 'transplant tourists' [43,68] who 'bought' organs [69] by undergoing 'commercial' [42], 'self-sponsored' [70], or 'paid' [41] transplantations abroad (table 1). Together, these articles report 2921 'tourists' (table 3). Most authors, however, do not explain what they mean by each of these terms [51,71]. Those that do, however, define them differently. Gill et al and Alghamdi et al, for example, define transplant tourists as patients 'who travel abroad for transplantation' [23,72]. Adamu et al. define commercial transplants as transplantations involving organs from 'non-emotionally related donors' [15]. Others adopt the definitions of the DOI [12].

Information that patients brought back about their transplantations abroad was commonly unavailable or inadequate, in particular the details and circumstances surrounding donor selection [73-75]. The variations in terminology and inadequate documentation make it difficult, if not impossible, to assess whether a commercial transaction was involved. We therefore examined whether the literature reports the amounts that patients paid and to what or whom they paid.

The amounts that patients pay and to what or whom they pay: Eleven articles present the amounts that patients pay. In total, these articles report 1238 patients who paid between $10 000 and $200 000 for kidney transplants. Liver transplants were more expensive (range $40 000-$300 000). Eight articles describe to what or whom patients paid. These articles report 158 patients in total (one article does not report the number of patients [76]). Of these, 129 paid their donors, 22 paid brokers, five paid to hospitals, two paid to private companies, and an unknown number paid physicians for a transplant (tables 1 and 3).

Domestic transplant commercialism

Not all patients who paid for organ transplants traveled. We identified 15 articles that report domestic commercialism (table 1). Most of these articles (10 of 15) do not report the number of patients, which prevents us from determining the scale of patients who purchased organs domestically. Nevertheless, domestic trade is said to 'perhaps comprise the majority of organs beings trafficked worldwide' [77].

DISCUSSION

The underlying review illustrates that (based on the literature published between 2000 and 2015) 6002 patients were reported to have traveled to another country for transplantation between 1971 and 2013. Of these, only 1238 (21%; 1238 of 6000) were reported to

have paid for their organ transplants. Taiwan and South Korea are the most commonly reported departure countries. China, India, and Pakistan are the most popular destination countries. An additional unknown number of patients were reported to have paid for their transplants in their domestic countries.

Because the literature presents inconsistent terminology about what constitutes tourism or commercialism, it is not possible to distinguish those who traveled for transplantation from those who traveled to participate in transplant commercialism. While the majority of studies present patients as 'transplant tourists' who 'purchased organs' by undergoing 'commercial transplants' abroad, many do not define these terms. Those that do, define them differently. For example, some authors define 'transplant tourists' as patients who travel abroad for transplantation. Others describe transplant tourists as patients involved in organ trafficking and/or commercialism. However, many of the studies preceded the DOI and its definitions. The issue therefore is not the inconsistency of definitions but the inadequate information about the transplants. For instance, although many authors write that patients obtained transplants commercially, only 11 (of the 76) articles report that patients (1238 in total) paid for their organ transplants. Even fewer articles (8 of 76 (158 patients in total)) describe what or whom the patient paid. Those that report the amounts and beneficiaries provide little detail on how these transplants were facilitated and present relatively small samples of patients.

Under many jurisdictions, payments by recipients for organs and the subsequent profit made by donors, brokers, or other middlepersons are prohibited [78]. Paying a hospital for a transplant procedure, however, is not forbidden. When examining the reported payments, our review reveals that only in a small number of cases were proof of payment and illegality presented. We therefore conclude that the literature is speculative about patients buying organs: their purchases are more often assumed than determined.

Our documentation of 6002 patients (and 1238 of these involving commercial transactions) stands in contrast to the WHO's estimate that 3000-6000 organs are traded each year. Various explanations may exist for this discrepancy. First, the trade's clandestine nature by definition makes it difficult to gather reliable data and to confirm trends in global patterns, even through rigorous scientific research [78]. This limitation is an inherent part of crime research: when a particular act is forbidden, the numbers drop. This is not because the crime incidence decreases; it simply moves to an underground market [79]. For instance, it is possible that the remaining 4764 patients paid for their organs but that this information was not sought or disclosed. Our reported numbers thus probably represent the tip of the iceberg. Second, transplant centers do not routinely publish the number of cases of either travel for transplant or transplant tourism [80]. In fact, it is likely that there are good reasons why they do not publish these figures. A third possible reason is that most studies are written by physicians who, because of their duty of confidentiality, may be prohibited from or unwilling to write about their patients' (alleged) illegal organ purchases. Finally, our search strategy excluded materials that are neither published in scientific databases nor peer-reviewed, such as media reports, police reports [81], and reports written

by international organizations [82,83]. The WHO's estimate, by contrast, is not only based on journal articles but also on media reports. Nonetheless, as pointed out, it remains unclear how exactly the WHO established or corroborated its estimate [5]. It indeed recognizes that the state of the trade is obscure and acknowledges that its figures should be regarded as 'provisional and tentative' [2].

The anecdotal and speculative nature of the literature is caused, according to the WHO, by a lack of efforts to synthesize available data [2]. Many others add that the scholarly research of the trade, in particular of organ purchase, is poorly developed [5,84,85]. Thus, what is needed is not only more rigorous quantitative and qualitative studies but also efforts to integrate available information. First, national surveys could be circulated among transplant professionals to document domestic cases of organ purchase [69]. Second, transplant professionals could contribute to gaps in knowledge by conducting anonymous interviews with patients about their motivations and experiences with undergoing commercial transplants abroad [86]. Third, targeted searches in registration systems of national police forces and other law enforcement agencies have illustrated that such sources can reveal possible cases of organ trading that were not recognized as such during the initial stage of police investigations [81]. An international registry that integrates these data [80] or a reporting code that documents trafficking networks [69] is a final strategy to collect and quantify cases.

To summarize, we conclude that the literature is speculative and anecdotal about patients buying organs: their purchases are more often assumed than determined. This hampers the drawing of firm conclusions about the scale of patients' involvement in the trade. The empirical data published in the literature do not reflect a large number of patients buying organs. More rigorous quantitative and qualitative research is needed to enable a more reliable picture of the trade's scale.

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table 1 Characteristics of the included studies

First author and year of publication	No. of patients	Year of transplantation	Home country	Nationality or ethnicity	Destination country and no. of patients per country *	Type of donation/ transplantation (Tx)	Transplant tourism/ commercialism (yes, no, NW)	Domestic commercialism (yes, no)	Amount/ beneficiary
Abdeldayem, 2008 [51]	15	Not written (NW)	Egypt	NW	China	Deceased liver donation	Yes	No	Range $40 000-75 000/NW
Ackoundou-N'Guessan, 2010 [95]	16	1995-2009	Ivory Coast	NW	India (5), Tunisia (5), NW (6)	Living related (6), unrelated (6) and deceased (4) kidney donation	NW	No	NW/NW
Adamu, 2012 [35]	45	2006-2009	Saudi Arabia	NW	Pakistan (28), Egypt (10), Philippines (6), China (1)	Living unrelated renal transplantation (Tx)	Yes	No	NW/NW
Alghamdi, 2010 [72]	93	2003-2008	Saudi Arabia	Saudi Arabian	Pakistan (46), Philippines (26), Egypt (11), USA (3), China (2), Iran (2), Syria (1), Lebanon (1), Jordan (1)	Living kidney (90) and deceased donation (3)	NW	No	NW/NW
Al-Khalidi, 2012 [53]	16	1995-2004	Kuwait	NW	USA (10), UK (6)	Deceased (9) and living related liver Tx (7)	NW	No	NW/NW
Alkhunaizi, 2005 [71]	80	1998-2003	Saudi Arabia	Saudi Arabia	Pakistan (1), Iran (1), Philippines (1), NW (77)	Living unrelated renal Tx	Yes	No	NW/NW
Allam, 2010 [66]	74	2003-2007	Saudi Arabia / Egypt	NW	China	Deceased donor liver Tx	NW	No	NW/NW
Al-Wakeel, 2000 [16]	57	1990-1996	Saudi Arabia	NW	India (37), Egypt (14), USA (5) Pakistan (1)	Living unrelated renal transplant	NW	No	NW/NW
Ambagtsheer, 2013 [78]	45 (est.)	1994-2005	The Netherlands	Iranian, Pakistani, Chinese, Dutch, Iraqi, Moroccan, Lebanese, Indian	China, India, Iran, Iraq, Pakistan, USA, Colombia	Kidney Tx	Yes	No	€10 000-50 000/NW
Ambagtsheer, 2015 [69]	NW	2008-2013	The Netherlands	NW	NW	Kidney Tx	Yes	No	NW/NW
Ben Hamida, 2001 [17]	20	1995-1999	Tunisia	NW	Iraq (14), Egypt (3), Pakistan (3)	Living unrelated renal Tx	Yes	No	$10 000/NW

Berglund, 2012 [18]	3	2005-2006	Sweden	Iraq, Iran, Lebanon	Pakistan (2), Iran (1)	Living unrelated (1), related (1) and deceased kidney Tx (1)	Yes	No	NW/donor
Budiani-Saberi, 2011 [100]	n/a	NW	Egypt	Egyptian	Egypt	Living unrelated renal donation	Yes	Yes	NW/NW
Budiani-Saberi, 2014 [105]	n/a	India	Indian, also foreign patients	India	Living unrelated renal donation	Yes	Yes	NW/NW	
Cader, 2013 [52]	39	NW	Malaysia	Malaysian	China	Commercial living renal unrelated Tx (23), living related/ unrelated (16)	Yes	No	NW/NW
Canales, 2006 [73]	10	2002-2006	USA	Somali, Chinese, Iranian	Pakistan (8), China (1), Iran (1)	Living unrelated renal Tx	NW	No	NW/NW
Cha, 2011 [19]	87	2000-2009	South Korea	South Korean	China	Living unrelated (29) and deceased kidney donation (58)	NW	No	NW/NW
Chen, 2010 [59]	19	NW	Taiwan	Taiwanese	China	Liver transplant	Yes	No	NW/NW
Chien, 2000 [20]	100	1991-1998	Taiwan	Taiwanese	China	Renal Tx	NW	No	NW/NW
Chung, 2010 [21]	69	2002-2008	South Korea	South Korean	Philippines (3), China (66)	Kidney Tx	NW	No	NW/NW
Cronin, 2011 [67]	245	2000-2009	UK	Asian, black, Chinese, Oriental, white	Pakistan (121), India (48), China (12), Philippines (8), Iran (8), Egypt (7), USA (4), NW (37)	Heartbeating (21) and non-heartbeating (1) Tx, living related (68) and unrelated Tx (142), not reported (1)	NW	No	NW/NW
Dodo, 2000 [61]	8	NW	Japan	Japanese	USA (7), Germany (1)	Heart Tx	NW	No	NW/NW
Dulal, 2008 [22]	452	2003-2008	Nepal	Nepalese	India (449), Germany (2), USA (1)	Related (134) and unrelated kidney Tx (315), not reported (4)	NW	No	NW/NW
Erikoglu, 2004 [45]	6	NW	Turkey	Turkish	Iraq (5) and India (1)	Nonrelated renal donors	Yes	No	$20 000/NW
Fan, 2009 [54]	177	1998-2007	Hong Kong	Chinese	China (mainland)	Liver Tx	NW	No	NW/NW
Fukushima, 2013 [62]	1	1992	Japan	Japanese	USA	Heart	NW	No	NW/NW

table 1 (continued) Characteristics of the included studies

First author and year of publication	No. of patients	Year of transplantation	Home country	Nationality or ethnicity	Destination country and no. of patients per country *	Type of donation/ transplantation (Tx)	Transplant tourism/ commercialism (yes, no, NW)	Domestic commercialism (yes, no)	Amount/ beneficiary
Geddes, 2008 [92]	18	2000-2007	UK	Indo-Asian race	Pakistan	Living donor kidney Tx	NW	No	NW/NW
Gill, 2011 [68]	93	2000-2007	Canada	Caucasian, East Asian, South Asian, Filipino, Black	China (39), India (14), Iran (5), Philippines (16), Pakistan (11)	Deceased (27) and nonrelated living kidney Tx (40), not reported (33)	NW	No	NW/NW
Gill, 2008 [23]	33	1995-2007	USA	Vietnamese, Chinese, Taiwanese, Japanese, Cambodian, American, Iranian, Armenian, Filipino, Ecuadorian, Russian, Chilean, Mexican, Syrian, Thai	China (14), Iran (6), Philippines (4), India (3), Pakistan (1), Peru (1), Egypt (1), Turkey (1), Mexico (1), Thailand (1)	Living related (9), unrelated (15) and deceased kidney Tx (9)	NW	No	NW/NW
Go, 2004 [24]	53	1993-2003	Malaysia	NW	NW	Living (36) and cadaveric kidney Tx (17)	NW	No	NW/NW
Greenberg, 2013 [103]	10	NW	Israel	Israeli	Egypt	Illegal kidney transplants	Yes	No	$200 000/NW
Guy, 2013 [25]	1	NW	USA	Guyanese	Guyana	Living kidney related donation	NW	No	NW/NW
Hsu, 2011 [26]	643	NW	Taiwan	Taiwanese	China	Kidney Tx	NW	No	NW/NW
Huang, 2011 [55]	15	NW	Taiwan	Not specified	China (14), USA (1)	Liver Tx	NW	No	NW/NW
Inston, 2005 [27]	6	NW	UK	Indo-Asian	India	Living unrelated donor	Yes	No	NW/NW
Ivanovski, 2011 [28]	36	2006-2007	Macedonia	Kosovo, Macedonia and Albania	Pakistan	Living kidney donor	Yes	No	NW/NW
Ivanovski, 2005 [29]	16	NW	Macedonia	NW	India (15), Nepal (1)	Living unrelated kidney donor	Yes	No	NW/NW
Jung, 2015 [46]	33	2009-2013	Mongolia	Mongolian	South Korea	Living kidney donation	No	No	NW/NW

Kapoor, 2011 [75]	10	2001-2007	Canada	Chinese, East Indian, Caucasian	China (4), Pakistan (3), India (1), Philippines (1), Mexico (1)	Living unrelated (6) and deceased donor kidneys (4)	Yes	No	NW/NW
Kennedy, 2005 [31]	16	1990-2004	Australia	NW	China (7), India (4), Iraq (1), Philippines (1), East Europe (1), Lebanon (2)	Kidney transplantation	Yes	No	NW/NW
Khalaf, 2004 [56]	67	1993-2004	Egypt	Egyptian	Europe (49), USA (12), Japan (6)	Cadaveric liver Tx (61) and living donor liver Tx (6)	Yes	No	$130 000 (range $70 000-300 000) /NW
Krishnan, 2010 [32]	40	1996-2006	UK	Indo-Asian, Chinese, white	Pakistan	Unrelated living (37) and deceased kidney donors (2)	NW	No	NW/NW
Kucuk, 2005 [88]	220	1978-2001	Turkey	Turkish	India, Iraq, Iran	Kidney Tx, cadaveric (66) and living (154)	Yes (supplied by brokers)	No	NW/NW
Kwon, 2011 [57]	966	1999-2005	South Korea	South Korean	China	Deceased and living kidney Tx (462), living and deceased liver Tx (504)	Yes	No	$42 000 for K $63 000 for L /NW
Leung, 2007 [33]	12	2001-2002	Hong Kong	Chinese	China (mainland)	Kidney Tx	No	No	No
Lu, 2014 [47]	19	NW	Taiwan	Taiwanese	NW	Kidney Tx	NW	No	NW/NW
Majid, 2010 [96]	45	1993-2009	Dubai	UAE nationals/ others non UAE nationals	Philippines (15), Pakistan (7), India (7), Iran (2), Syria (1), Jordan (1), Egypt (1), Germany (2), UK (2), France (1), Singapore (1), USA (1), Israel (1), NW (4)	Living unrelated (33), related (10) and deceased kidney Tx (2)	NW	No	NW/NW
Malakoutian, 2007 [91]	n/a	2005-2006	Iran	Iran	Iran	Living unrelated kidney donation	Yes	Yes	NW/Recipients gave 'rewards' to donors
Mendoza, 2010 [98]	n/a	NW	Local, Japanese, Americans, and Middle Easterners (recipients)	Not specified	Colombia	Eye, heart valve, kidney, liver (part), lung (lobes), pancreas (segment)	Yes	Yes	< $1712 median to donors for kidney/ $1881 median for livers/donors were paid by brokers

table 1 (continued) Characteristics of the included studies

First author and year of publication	No. of patients	Year of transplantation	Home country	Nationality or ethnicity	Destination country and no. of patients per country *	Type of donation/ transplantation (Tx)	Transplant tourism/ commercialism (yes, no, NW)	Domestic commercialism (yes, no)	Amount/ beneficiary
Mendoza, 2010 [97]	n/a	NW	Filipino and foreign	NW	The Philippines	Commercial kidney Tx	Yes	Yes	$2133 median/donors were paid by brokers
Merion, 2008 [63]	173	1986-2006	USA	NW	35 countries, most in China, India, Philippines	Kidney (158), liver (13), lung (1) and heart Tx (1)	NW	No	NW/NW
Moazam, 2009 [34]	n/a	NW	Recipients referred to as Arabic	Pakistani	Pakistan	Commercial kidney Tx	Yes	No	70 000 Rs./NW
Moniruzzaman, 2012 [77]	n/a	NW	Recipients are local or overseas residents (Bangladeshi born foreign nationals)	Bangladeshi	Bangladesh	Live Kidney donation	Yes	Yes	$1400/donors were paid by brokers
Morad, 2000 [35]	515	1990-1996	Malaysia	NW	India and China	Live unrelated (389) and cadaveric kidney Tx (126)	Yes	No	NW/NW
Muraleedharan, 2006 [89]	20	NW	India	Indian	India	Kidney Tx	Yes	Yes	$2298/paid to middleman/broker
Ng, 2009 [30]	4	1989-2007	Singapore	Chinese, Malay, Indian	China	Deceased donor kidneys	NW	No	NW/NW
Polcari, 2011 [101]	9	2001-2007	USA	Middle East, Asia	China (3), Pakistan (3), Philippines (1), India (2)	Deceased (3), living related (1) and unrelated kidney donors (5)	Yes	No	NW/NW
Prabhakar, 2000 [36]	115	1986-1991	Singapore	NW	India	Live nonrelated renal Tx	Yes	No	NW/NW
Prasad, 2006 [37]	22	1998-2005	Canada	White, African, Canadian, East Asian, South Asian	South Asia (12), East Asia (5), Middle East (4), Southeast Asia (1)	Nonbiologically nonemotionally related donors	Yes	No	NW/NW
Rizvi, 2009 [94]	126	1993-2007	Pakistan	Pakistani	Pakistan	Living unrelated kidney donors	Yes	Yes	$7271, payment to vendor was $1801

Rodríguez-Reimundes, 2014 [38]	40	1971-2008	Argentina	Argentinian	USA (19), Bolivia (17), Brazil (10), Iran (3), France (3), Chile (2), Australia (1) Cuba (1), Pakistan (1), Spain (1)	Deceased kidneys (18), related living (6) and unrelated kidney Tx (16)	Yes	No	NW/NW
Sanal, 2004 [65]	2	1995, 1992	Turkey	Turkish	Russia, India	Cadaveric kidney, living kidney donor	Yes	No	$25 000, $15 000/ private company
Scheper-Hughes, 2000 [76]	NW	1997	Brazil	Brazil	Brazil	Cornea, kidney	Yes	Yes	$3000 (cornea) $1000-lump sums (kidney)/to doctor
Scheper-Hughes, 2006 [90]	1	2003	USA	West Indies	South Africa	Kidney Tx	Yes	No	$65 000/broker
Scheper-Hughes, 2011 [102]	1	NW	Israel	Israeli	South Africa	Kidney Tx	Yes	No	$145 000-$180 000/ broker
Sever, 2001 [39]	115	1992-1999	Turkey	Turkish	India (106), Iraq (7), Iran (2)	Unrelated renal Tx	Yes	No	NW/NW
Shimizu, 2007 [74]	1	2006	Japan	Japanese	NW	Deceased kidney Tx	NW	No	NW/NW
Shoham, 2010 [40]	19	2006	USA	NW	Asia or Middle East (11), India (3), Pakistan (2), Philippines (1), Lebanon (1), Iran (1)	Living unrelated kidney Tx	Yes	No	NW/NW
Solak, 2010 [41]	1	NW	Turkey	NW	Egypt	Living-unrelated kidney Tx	Yes	No	NW/NW
Solak, 2012 [14]	14	2003-2010	Turkey	Turkish	Egypt (5), Iraq (4), Pakistan (2), Russia (2), India (1)	Living unrelated renal Tx	Yes	No	NW/NW
Spasovski, 2008 [48]	1	NW	Macedonia	NW	Pakistan	Living kidney Tx	Yes	No	NW/NW
Sugiyama, 2009 [64]	1	Japan	NW	NW	NW	Heart Tx	NW	No	NW/NW
Sugo, 2002 [58]	14	1985-2001	Japan	Japanese	NW	Liver Tx	NW	No	NW/NW
Sun, 2006 [42]	31	1984-2004	Taiwan	Taiwanese	China	Cadaveric renal Tx	Yes	No	NW/NW
Tan, 2014 [70]	47	1993-2012	Brunei Darussalam	NW	Singapore	Unrelated renal Tx	Yes	No	NW/NW
Tsai, 2014 [43]	185	NW	Taiwan	Taiwanese	China	Kidney Tx	NW	No	NW/NW

table 1 (continued) Characteristics of the included studies

First author and year of publication	No. of patients	Year of transplantation	Home country	Nationality or ethnicity	Destination country and no. of patients per country *	Type of donation/ transplantation (Tx)	Transplant tourism/ commercialism (yes, no, NW)	Domestic commercialism (yes, no)	Amount/ beneficiary
Tsai, 2011 [44]	215	1987-2006	Taiwan	Taiwanese	China	Cadaveric renal Tx	Yes	No	NW/NW
Van Buren, 2010 [99]	n/a	NW	The Netherlands	European, Asian, Turkish, Arabic, African	The Netherlands	Genetically related, unrelated live kidney Tx, altruistic, exchange program	No	Yes	Recipients gave 'rewards' to donors
Vathsala, 2009 [49]	209	2001-2006	Singapore	Singaporeans, Chinese, Malay, Indian, other	NW	Deceased (189) and living unrelated Tx (20)	NW	Yes	NW/NW
Wahab, 2014 [60]	12	2004-2012	Egypt	Egyptian	China	Living donor liver Tx	NW	No	NW/NW
Wright, 2012 [33]	3	NW	Canada	Asian, Canadian	Asia	Living unrelated donor kidney Tx	Yes	No	NW/NW
Yakupoglu, 2010 [50]	5	NW	Turkey	Turkish	Egypt	Living kidney donors	Yes	No	$35 000-$40 000/ hospital
Yea, 2010 [85]	n/a	2001-2009	The Philippines	Filipino	The Philippines	Live kidney Tx	Yes	Yes	Yes (PP45 000-PP200 00)/ paid by brokers to donors
Yea, 2013 [104]	n/a	NW	The Philippines	Filipino	The Philippines	Commercial live kidney Tx	Yes	Yes	$2000/paid to donors by brokers
Zargooshi, 2001 [87]	n/a	1989-1995	Iran	Iranian	Iran	Living unrelated kidney donors	Yes	Yes	NW/NW
Zargooshi, 2008 [93]	100	2006-2007	Iran	Iranian	Iran	Living unrelated kidney donors	Yes	Yes	NW/NW

The terminology corresponds with the terminology in the articles.
** When more than one destination country is mentioned, and when reported, the number of patients per country is written.*

table 2 Travel for transplantation: reported number of patients and their departure and destination countries*

Departure countries	No. of patients	Destination countries	No. of patients
Taiwan	1227	China	2700
South Korea	1122	India	817
Malaysia	607	Pakistan	367
Nepal	452	The Philippines	83
Turkey	363	Egypt	68
Singapore	328	USA	64
Saudi Arabia	324	South Korea	33
United Kingdom	309	Iran	31
USA	246	Iraq	31
Hong Kong	128	United Kingdom	8
Canada	128	Japan	6
Egypt	122	Germany	5
Macedonia	51	Tunisia	5
Dubai	51	Lebanon	4
Brunei	47	France	4
The Netherlands	45	Russia	3
Argentina	40	Syria	2
Mongolia	33	Lebanon	2
Japan	24	Mexico	2
Tunisia	20	Guyana	2
Kuwait	16	Peru	1
Australia	16	Israel	1
Ivory Coast	16	Thailand	1
Israel	11	Nepal	1
Sweden	3	Turkey	1
		Australia	1
		Singapore	
Total	6002	Total	4244

** Six articles do not report the number of patients that travel (table 1). In addition, the country to which they travel is not reported for all patients. This explains the discrepancy in the total number of patients between both categories.*

table 3 Transplant tourism: reported number of patients who undergo commercial transplantation abroad

	No. of patients
Travel for transplantation	6002
'Transplant tourists'	2921
Paid for transplantation	1238
Paid a donor	158
Paid a broker	22
Paid a hospital	5
Paid a private company	2

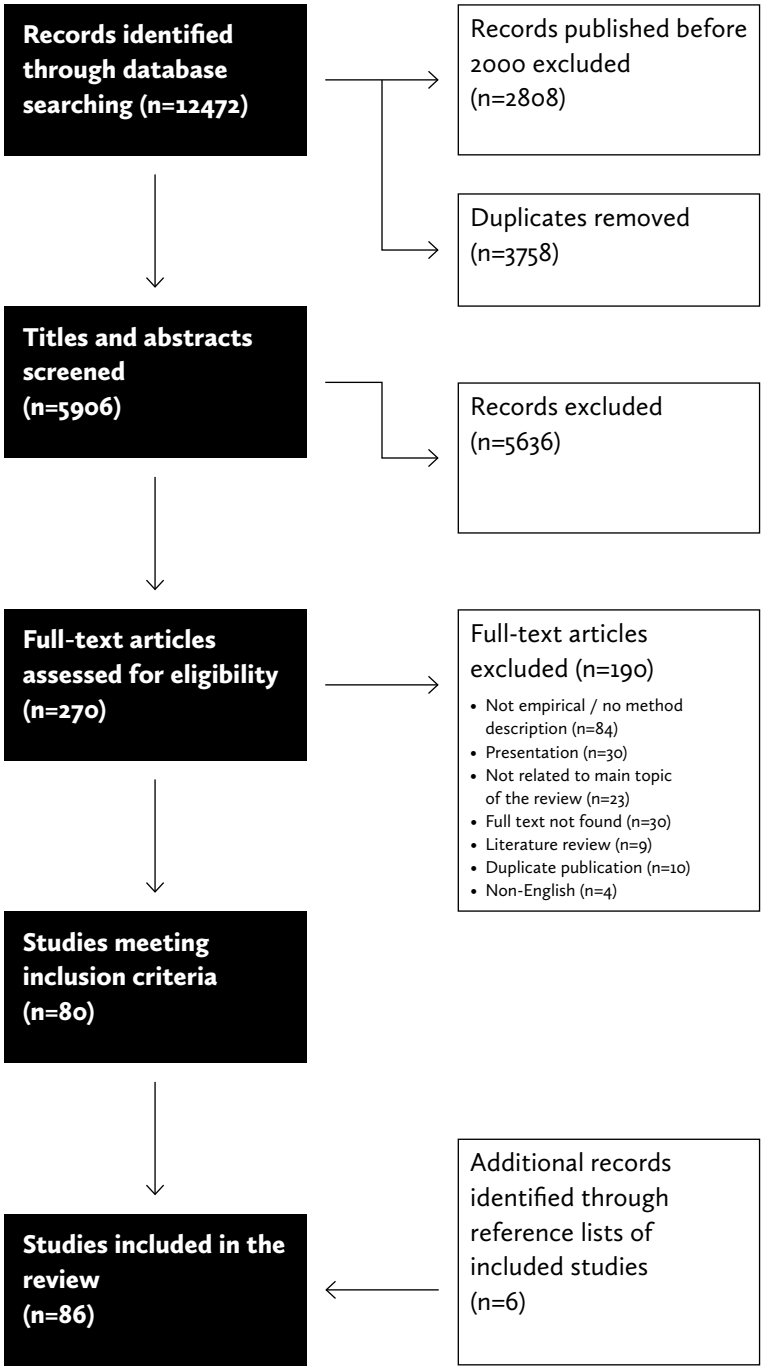

figure 1 Flow chart of the study selection process.

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Total	**12472**	**9664**	**5938**

Embase

(('organ transplantation'/de OR 'liver transplantation'/de OR 'kidney transplantation'/de OR donor/de OR 'kidney donor'/de OR 'living donor'/de OR 'organ donor'/de OR 'unrelated donors'/de OR 'donor selection'/de) AND ('commercial phenomena'/de OR market/de OR marketing/de OR purchasing/de)) OR (((purchas* OR buy* OR bought OR commerc* OR tourism* OR traffic* OR overseas OR abroad OR sale OR sales OR sold OR selling OR crime OR criminal* OR vending OR vendor* OR pay* OR paid OR retail* OR trade OR trading OR business* OR market* OR solicit* OR entrepreneur* OR financ* OR broker* OR profit*) NEAR/3 (organ OR organs OR kidney* OR liver* OR transplant* OR graft* OR donor* OR donation*)) OR ((donor* OR donat*) NEAR/3 recruit*)):ab,ti) NOT ([animals]/lim NOT [humans]/lim) NOT (blood/exp OR 'blood donor'/de OR tissues/exp OR 'tissue transplantation '/exp OR sperm/exp OR 'sperm donor'/de OR 'bone marrow'/exp OR 'bone marrow transplantation '/exp OR oocyte/exp OR 'oocyte donation'/de OR (blood OR cell OR tissue OR sperm OR semen OR egg* OR marrow* OR oocyte* OR skin OR ovocyte* OR ovum):ab,ti)

Medline OvidSP

((("organ transplantation"/ OR "liver transplantation"/ OR "kidney transplantation"/ OR "living donors"/ OR "unrelated donors"/ OR "Donor Selection"/) AND ("Commerce"/ OR marketing/)) OR (((purchas* OR buy* OR bought OR commerc* OR tourism* OR traffic* OR overseas OR abroad OR sale OR sales OR sold OR selling OR crime OR criminal* OR vending OR vendor* OR pay* OR paid OR retail* OR trade OR trading OR business* OR market* OR solicit* OR entrepreneur* OR financ* OR broker* OR profit*) ADJ3 (organ OR organs OR kidney* OR liver* OR transplant* OR graft* OR donor* OR donation*)) OR ((donor* OR donat*) ADJ3 recruit*)).ab,ti.) NOT (exp animals/ NOT humans/) NOT (exp blood/ OR blood.xs. OR "Blood Donors"/ OR "Tissue Donors"/ OR "tissue transplantation "/ OR "Skin Transplantation"/ OR semen/ OR "sperm banks"/ OR "bone marrow"/ OR "bone marrow transplantation "/ OR oocytes/ OR "oocyte donation"/ OR (blood OR cell OR tissue OR sperm OR semen OR egg* OR marrow* OR oocyte* OR skin OR ovocyte* OR ovum).ab,ti.)

Cochrane

((((purchas* OR buy* OR bought OR commerc* OR tourism* OR traffic* OR overseas OR abroad OR sale OR sales OR sold OR selling OR crime OR criminal* OR vending OR vendor* OR pay* OR paid OR retail* OR trade OR trading OR business* OR market* OR solicit* OR entrepreneur* OR financ* OR broker* OR profit*) NEAR/3 (organ OR organs OR kidney* OR liver* OR transplant* OR graft* OR donor* OR donation*)) OR ((donor* OR donat*) NEAR/3 recruit*)):ab,ti) NOT ((blood OR cell OR tissue OR sperm OR semen OR egg* OR marrow* OR oocyte* OR skin OR ovocyte* OR ovum):ab,ti)

Web-of-science

TS=(((((purchas* OR buy* OR bought OR commerc* OR tourism* OR traffic* OR overseas OR abroad OR sale OR sales OR sold OR selling OR crime OR criminal* OR vending OR vendor* OR pay* OR paid OR retail* OR trade OR trading OR business* OR market* OR solicit* OR entrepreneur* OR financ* OR broker* OR profit*) NEAR/3 (organ OR organs OR kidney* OR liver* OR transplant* OR graft* OR donor* OR donation*)) OR ((donor* OR donat*) NEAR/3 recruit*))) NOT ((blood OR cell OR tissue OR sperm OR semen OR egg* OR marrow* OR oocyte* OR skin OR ovocyte* OR ovum)) NOT ((animal* OR swine* OR chick* OR rat OR rats OR sheep OR mouse* OR mice OR fish*) NOT (human* OR patient*)))

Scopus

TITLE-ABS-KEY(((((purchas* OR buy* OR bought OR commerc* OR tourism* OR traffic* OR overseas OR abroad OR sale OR sales OR sold OR selling OR crime OR criminal* OR vending OR vendor* OR pay* OR paid OR retail* OR trade OR trading OR business* OR market* OR solicit* OR entrepreneur* OR financ* OR broker* OR profit*) W/3 (organ OR organs OR kidney* OR liver* OR transplant* OR graft* OR donor* OR donation*)) OR ((donor* OR donat*) W/3 recruit*))) AND NOT ((blood OR cell OR tissue OR sperm OR semen OR egg* OR marrow* OR oocyte* OR skin OR ovocyte* OR ovum)) AND NOT ((animal* OR swine* OR chick* OR rat OR rats OR sheep OR mouse* OR mice OR fish*) AND NOT (human* OR patient*)))

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((((purchas*[tiab] OR buy*[tiab] OR bought[tiab] OR commerc*[tiab] OR tourism*[tiab] OR traffic*[tiab] OR overseas[tiab] OR abroad[tiab] OR sale[tiab] OR sales[tiab] OR sold[tiab] OR selling[tiab] OR crime[tiab] OR criminal*[tiab] OR vending[tiab] OR vendor*[tiab] OR pay*[tiab] OR paid[tiab] OR retail*[tiab] OR trade[tiab] OR trading[tiab] OR business*[tiab] OR market*[tiab] OR solicit*[tiab] OR entrepreneur*[tiab] OR financ*[tiab] OR broker*[tiab] OR profit*[tiab]) AND (organ[tiab] OR organs[tiab] OR kidney*[tiab] OR liver*[tiab] OR transplant*[tiab] OR graft*[tiab] OR donor*[tiab] OR donation*[tiab])) OR ((donor*[tiab] OR donat*[tiab]) AND recruit*[tiab]))) NOT ((blood[tiab] OR cell[tiab] OR tissue[tiab] OR sperm[tiab] OR semen[tiab] OR egg*[tiab] OR marrow*[tiab] OR oocyte*[tiab] OR skin[tiab] OR ovocyte*[tiab] OR ovum[tiab])) AND publisher[sb]

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IV

INTERVIEWS WITH PATIENTS

WHO TRAVELED FROM MACEDONIA/KOSOVO, THE NETHERLANDS, AND SWEDEN FOR PAID KIDNEY TRANSPLANTATIONS

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Background: **Patients travel worldwide for paid kidney transplants. Although transplantations abroad are not always illegal, they are commonly perceived to be illegal and unethical involving risks.** Aim: **We aimed to describe the motivations and experiences of patients who traveled abroad for paid kidney transplantations and to examine how these transplantations were facilitated.** Methods: **We interviewed 22 patients who traveled from Macedonia/Kosovo, The Netherlands, and Sweden for paid kidney transplantations between years 2000 and 2009.** Results: **Patients traveled because of inadequate transplant activity in their domestic countries and dialysis-related complaints. However, 6 patients underwent preemptive transplantations. Cultural factors such as patients' affinity with destination countries, feelings of being discriminated against by the health-care system, and family ties also help explain why patients travel abroad. Seven of the 22 patients went to their country of origin. They were able to organize their transplantations by arranging help from family and friends abroad who provided contacts of caregivers there and who helped cover the costs of their transplants. The costs varied from €5000 to €45 000 (US$6800-US$61 200). Seven patients paid the hospital, 5 paid their doctor, 4 paid a broker, and 6 paid their donors.** Conclusion: **Research should include interviews with brokers, transplant professionals, and other facilitators to achieve a full picture of illegally performed transplantations.**

INTRODUCTION

Worldwide, patients travel abroad for transplantation, mainly for living kidney transplants. [1-3] Although transplantations abroad are not always illegally performed, they are commonly perceived to be illegal and/or unethical, involving risks for donors and recipients. [4] Travel for transplantation becomes 'transplant tourism' when transplant commercialism or organ trafficking is involved, according to the Declaration of Istanbul. [5] The trade in human organs is prohibited worldwide (except in Iran). [6] The most commonly reported explanation for travel for transplantation is the mismatch between the demand and supply of organs. [7,8] However, only 3 qualitative studies have been performed that describe patients' motivations and experiences of undergoing transplantations abroad. [9-11]

Scheper-Hughes, for instance, described how an Israeli patient obtained a kidney in South Africa through an organ trafficking network. [9] Huang et al conducted an interview study among 15 patients who traveled from Taiwan to China and the United States for liver transplantations. One patient organized the transplantation overseas with the help of a broker, 1 was referred by his local doctor, and the other 13 organized the transplants themselves or with the help of their families. [11]

Although these studies offer insight into why and how patients travel for transplants, they report only small populations and provide limited information about the potential illegality of the transplants. The present study aims to fulfill these gaps of knowledge. It presents the results of interviews with 22 patients who traveled abroad from Macedonia/Kosovo, The Netherlands, and Sweden for paid kidney transplantations. The aim of the

study is twofold—first, to describe patients' motivations and experiences, and second, to describe how, where, and by whom their transplantations were facilitated. To date, this is the largest group of patients that has been interviewed on this issue.

METHODS

Design

This is a report of one-to-one interviews of patients who traveled outside their country of residence to obtain a kidney transplant. We interviewed patients who traveled for a kidney transplant after 2000 from Macedonia/Kosovo, The Netherlands, or Sweden. Ethical approval was obtained by the board for ethical approval of research involving humans in Sweden (registered under No 2013/769, December 11, 2013) and by the medical ethical committee in The Netherlands (MEC-2013-577, December 10, 2013). Ethical approval was not required in Macedonia/Kosovo.

Geographical Setting

Participants were outpatients from the University Clinic of Nephrology in Macedonia (UCM); from the Section of Nephrology and Transplantation at the Erasmus Medical Center (EMC), Rotterdam, The Netherlands; and from transplant clinics in Sweden. Thirty-five patients are known at UCM who traveled abroad to buy kidneys. The total number of patients who traveled abroad from The Netherlands to purchase kidney transplants is unknown. A list compiled by transplant professionals in Sweden contains approximately 40 patients who traveled abroad for paid transplants. At the time the patients went abroad, the wait time in Sweden and The Netherlands was approximately 3 to 4 years. In Macedonia, there was no wait list.

Sample

At UCM, 10 patients were approached for interviews. All agreed to participate. At EMC, we asked transplant professionals whether they knew patients who went abroad for kidney transplantation. In total, the professionals identified 13 patients whom we approached for interviews. Six of the 13 patients (2 females, age 42-57 years/median: 48.5 years; ethnicity: Somalia, Morocco, Georgia, Pakistan [2x], and China) did not participate: 1 patient died, 2 moved to another country, 1 patient was no longer being treated at EMC, and 2 refused to participate. In Sweden, 12 patients who traveled abroad for transplantation were approached. Information about the 7 nonparticipating patients in Sweden was unavailable.

Data Collection and Analysis

We developed an interview protocol with predetermined topics and questions. These can be found in the online Supplementary Material. The topics were patients' characteristics, pretransplant stage, transplant stage, and posttransplant stage (table 1). The protocol included questions such as 'What motivated you to look into transplant options abroad? Did you make payments for the transplant? How? How much? To what/whom? How was the

trip arranged? Did you meet your donor?' In The Netherlands and Sweden, the interviews were conducted semistructurally—questions were openly formulated, following the list of topics. The interviews were audio recorded, transcribed, and encoded, which led to summaries based on recurring themes. In Macedonia/Kosovo, the study was performed more structurally—questions were formulated as stated in the protocol and the answers were written down. In addition to the information obtained from the interviews, EMC and UCM also used information found in the medical records.

table 1 Interview Topics

Topic	Description
Patients' characteristics	Gender, age, place of birth, family situation, education, employment status
Pretransplant stage	Domestic transplant attempts, motivations, practical arrangements, payments, and financial support
Transplant stage	Destinations, transplant experiences
Posttransplant stage	Hospital stay and complications, donors, moral perspectives

Procedure

Interviews were performed between December 2013 and April 2014. During 4 interviews, an interpreter was present. The respondents were informed about the aim and methods of the study by letter, phone, or during their regular follow-up in the hospital. All were informed that the study was anonymous and that names would be kept strictly confidential. The patients who agreed to participate signed an informed consent form.

RESULTS

Patients' Characteristics

We interviewed 22 patients—10 from Macedonia/Kosovo, 7 from The Netherlands, and 5 patients from Sweden (table 2). Three of the patients from Sweden have been described before.[12] Ten of the 12 patients from The Netherlands and Sweden were born in Asia; patients from Macedonia had a Kosovar or Macedonian background. Four of the 5 patients in Sweden had a university degree. Patients' employment status differed per country; the majority was unemployed. The unemployment status was highest in The Netherlands (5 of the 7).

Summary of Interviews

Pretransplant stage

Domestic transplant attempts. Sixteen patients underwent dialysis before traveling abroad. The dialysis duration ranged from 12 to 140 months (median: 46.5 months). Six patients underwent preemptive transplants; 8 patients from Sweden and The Netherlands were wait-listed in their domestic country when they went abroad. At the time of the interviews, Macedonia/Kosovo did not have a wait list.

Seven patients (4 from Macedonia/Kosovo and 3 from Sweden) explored the possibility of receiving an organ from a living-related donor prior to going abroad for transplantation. Yet their donors were rejected because they were considered unfit for donation

			N=22 (%)
Gender			
Male			19 (86.4)
Female			3 (13.6)
Age (median: 49; range: 29-65)			
25-35 years			4 (18.2)
36-45 years			4 (18.2)
46-55 years			8 (36.4)
56-65 years			6 (27.3)
Family situation			
Married, with children			20 (90.9)
Unmarried, no children			2 (9.1)
Education			
No education			1 (4.5)
Primary school			6 (27.3)
High school			4 (18.2)
College/university degree			10 (45.5)
Unknown			1 (4.5)
Employment status			
Employed			9 (40.9)
Unemployed			13 (59.1)
Destination for transplant	**Country of birth**	**Country of residence**	
Pakistan	Macedonia/Kosovo	Macedonia/Kosovo	7 (31.8)
Pakistan	Pakistan	The Netherlands	3 (13.6)
Pakistan	Lebanon	Sweden	1 (4.5)
Pakistan	Iraq	Sweden	1 (4.5)
Pakistan	Somalia	The Netherlands	1 (4.5)
India	Macedonia/Kosovo	Macedonia/Kosovo	2 (9.1)
India	Sri Lanka	The Netherlands	1 (4.5)
Iran	Macedonia/Kosovo	Sweden	2 (9.1)
Russia	Macedonia/Kosovo	Macedonia/Kosovo	1 (4.5)
Colombia	Curacao	The Netherlands	1 (4.5)
China	China	The Netherlands	1 (4.5)
Iraq	Iraq	Sweden	1 (4.5)
Total transplant costs paid per country (€ and US$)			
Pakistan			€6000-€26 000 (US$8200-US$35 400)
India			€5000-€22 000 (US$6800-US$29 900)
Iran			€13 000 (US$17 700)
Russia			€45 000 (US$61 200)
Colombia			€11 500 (US$15 600)
China			€25 000 (US$34 000)
Iraq			€9000 (US$12 200)
Posttransplant complications			
Infections (sepsis, hepatitis C, tuberculosis, and infected kidney stone)			4 (18.2)
Perineal hematoma necessitating reexploration			2 (9.1)
Severe rejections			2 (9.1)
Viral syndrome (origin unknown)			1 (4.5)
Rupture of bladder			1 (4.5)
No complications			12 (54.5)
Donors			
Living unrelated donor			14 (63.6)
Related donor			5 (22.7)
Deceased donor			3 (13.6)

table 2 Patients' Characteristics and Transplant Details

and/or because their visas for Sweden were refused. Other patients did not want to burden their family members by asking them for donation of their kidney. Therefore, they did not explore this possibility.

Motivations. Four patients said that they initially went abroad to visit family or to celebrate holidays, without having intentions to undergo transplantation. Two of them were persuaded by their family to be transplanted there. The others had complications during dialysis treatment abroad and grasped the opportunity to become transplanted.

Seventeen patients emphasized that they felt there was no other option available to them than going abroad for transplantation. The majority mentioned reasons for travelling abroad related to dialysis; they described life on dialysis as depressing, complicated, and difficult because of nausea, fatigue, and pain. Another motivation to go abroad, especially mentioned in The Netherlands but also expressed in Sweden, was the long wait time for a deceased donor kidney. Other reasons given by patients in Sweden were feelings of being discriminated against by the Swedish health-care system. Patients in Macedonia/ Kosovo traveled abroad because of the absence of transplant activity in the country. In The Netherlands and Macedonia/ Kosovo, the decision about a transplant abroad was made even though the patients expressed confidence in the local health system. The patients from Macedonia/Kosovo held the government responsible for going abroad as the only chance to become transplanted.

Practical arrangements. Patients from Sweden and The Netherlands were assisted by family and friends abroad with obtaining a transplant. Their help consisted of establishing contacts with transplant professionals. Family members of 3 patients from Sweden helped them by finding donors; the transplant centers abroad recruited donors for the patients who traveled from The Netherlands. Relatives of 4 patients from The Netherlands and 1 from Sweden also accompanied them during their travel. According to the patients, the help of their friends and family resulted in reducing transplant costs and shorter wait times. Patients in Macedonia/Kosovo, by contrast, organized the trip themselves by contacting the hospital or doctor. They knew about the possibility of buying organs abroad from other patients who traveled. These patients were all accompanied by family members or friends. Three of the patients from Macedonia/Kosovo mentioned that a broker helped them facilitate their transplants. Visas, if required, were issued without problems.

Seventeen patients did not tell their domestic caregivers about their intention to travel for transplantation. Of the 22 patients interviewed, 5 reported asking for medical information to take with them as they traveled abroad seeking transplantation. In all cases, the medical evaluation and matching procedures were performed in the country where the transplant was performed.

Payments and financial support. All patients paid for their transplant procedures. The amounts varied per destination country (converted at the 2014 exchange rate)—Iran (€13 000/US$17 700), Iraq (€9000/US$12 200), India (€5000-€22 000/US$6800-US$29 900), Russia (€45 000/US$61 200), Pakistan (€6000-€26 000/US$8200-US$35 400), China (€25 000/US$34 000), and Colombia (€11 500/US$15 600). The patients stated that these payments included services such as the surgery, the kidney, hospital stay, medications, and food. Seven patients paid the hospital directly, 5 paid the doctor, 3 paid a broker, 1 paid a 'middle man,' and in 6 patients it is unknown whom they paid. Six patients said that they also paid their donor (range: €600-€2700/US$816-US$3670): 2 stated they paid for the organ and 4 pointed out that they paid their donor out of gratitude. Eight patients received financial support from family, and 1 patient was supported financially by the church in his domestic country. Five patients in The Netherlands mentioned that they received (partial) reimbursements from their health insurance companies.

Transplant stage

Destinations. The patients were transplanted between 2000 and 2009. Most of them went to Pakistan (n=13). The others went to India (n=3), Iran (n=2), Russia, Colombia, China, and Iraq (n=1). All patients from Sweden and The Netherlands who traveled abroad were foreign born; 7 of the 12 traveled to their countries of birth for transplantation. The transplants were performed at 3 days until 7 months after arrival in the country.

Three patients mentioned that the transplant procedure required proof of a relationship between them and their donors; they had to be family or they had to prove that there was a strong emotional relationship. Therefore, their family names, birth certificates, and identity documents were verified. However, the patients said that not all donors were questioned about their motivations to donate. Based on the Pakistani law, for instance, the medical staff at the hospital was required to write a letter that described the patient's health situation, explained why transplantation was needed, and provided information about the donor and the donor-patient relationship. This letter was then given to a judge for approval of transplantation. Some patients hinted that the procedure could be circumvented if you had money or connections.

Transplant experiences. All patients met their surgeons prior to the transplant. Most of them emphasized that they had good skills. Patients who went to Pakistan pointed out that that their doctors had studied in the United Kingdom or in the United States. The majority described the medical care as 'good' or 'sufficient.' Four patients said that the more they paid, the better care they received. However, almost all patients mentioned a lack of hygiene in the hospital. Two patients highlighted that there was a trade in and a shortage of certain medicines and that these were very expensive. Most patients had a private room, sometimes with their family. Nobody shared the room with their donor. All patients in The Netherlands saw other foreign, hospitalized transplant patients from all over the world (Europe, South America, Asia, and Africa). The patients in Macedonia/Kosovo saw other patients from the Balkans and Kosovo.

Posttransplant stage

Hospital stay and complications. The patients were discharged from the hospital 14 days after the operation, if there were no complications. The duration of the hospital stay varied from 1 to 6 weeks. Twelve patients had no complications. Ten patients had severe complications ranging from a rupture of the bladder (1 patient) and perineal hematoma necessitating reexploration (2 patients), 2 severe rejections, and 4 infections (sepsis, Hepatitis C, tuberculosis, and an infected kidney stone). One patient had a viral syndrome of unknown origin. If the transplanting hospitals' discharge sheets that were provided to patients contained any information, it ranged from a list of medications to scarce information about the patients' medical background and hospital stay or the name of the hospital.

Donors. Fourteen patients received a kidney from a living-unrelated donor. Five reported to have received a kidney from a related donor and 3 from a deceased donor. Nine patients who received an unrelated donor kidney and all 5 patients who received a related donor kidney met their donors before or after the operation. Most patients are no longer in contact with them, including those who said that they received a kidney from a relative. In most cases, the information about the donor provided by the hospital abroad was limited ('a good matching donor') or even nonexistent.

Moral perspectives. Eleven patients reflected on the ethical considerations of going abroad for paid transplantation or, without relating this to their own travel, gave their opinion about organ trade in general. A summary of moral perspectives is displayed in table 3.

table 3 Patients' Moral Perspectives

Topic	n=11 (%)
Knew organ trade was forbidden	10 (90.9)
Had a guilty conscience about their organ purchase	2 (18.2)
Experienced a dilemma between their individual circumstances and the moral aspects concerning their donor	5 (45.5)
Is against a regulated organ market	1 (9.1)
Is against organ trade	5 (45.5)
Organ trade goes against religious beliefs	3 (27.3)
Would go abroad for transplantation again	2 (18.2)
Organ purchase is part of the culture	1 (9.1)

All patients from Macedonia/Kosovo knew that it was forbidden to buy a kidney abroad. Nonetheless, the majority stated that buying a kidney is not a question of ethics but a question of life and death. Two patients said that they had a 'guilty conscience' about paying for organs and about the possibility of 'using the poverty of the donors.' Others pointed out that 'many other things in life are forbidden.'

The patients who traveled from Sweden experienced a dilemma between their individual circumstances and the moral aspects concerning their donor. One patient who went to Iran said that although paying for kidneys is not forbidden in Iran, she did not think a regulated market of organs was acceptable. Another patient blamed his purchase abroad

on the situation he was in but also stated that he was not 'the kind of person who wants to buy from others.'

Five patients who traveled from The Netherlands said that they were against the organ trade. Three of them stated that selling and buying (parts of) a body went against their religious beliefs. Two patients said that they would go abroad for transplantation again, if necessary. One patient who underwent a transplant from a 12-year-old deceased donor in Colombia said—'If I have the means, I will go there again. I can highly recommend it. It suited me well.' A patient who went to China mentioned that people in China are 'used to paying for everything. You just pay to receive something that is normal in China. That is just the culture. The trade is still going on, as long as you can pay.'

DISCUSSION

The present summary of interviews shows patients traveled for paid kidney transplantations because of inadequate transplant activity in their domestic country—patients from Sweden and The Netherlands complained about a long wait time, whereas patients from Macedonia/Kosovo had no transplant options in their region at all. Almost one-third of the patients were transplanted preemptively, and some patients refused to receive a kidney from a relative in their home country. This illustrates that other motivations exist why patients travel abroad for transplantation.

One reason is patients' affinity with the destination countries. As mentioned before, all patients from Sweden and The Netherlands who traveled abroad were foreign born and most returned to their country of birth for transplantation. In addition, they received help from their family and friends abroad who provided contacts for caregivers and helped cover the costs of their transplants. Previous studies also emphasize the importance of friends and family ties with countries where patients undergo transplantation. [4,13] Furthermore, some patients felt that they were being discriminated against by the domestic health-care system, which perhaps enhanced their motivations to go abroad.

Another factor that arose in the present report of interviews is differences between countries in perspectives toward the purchase and sale of organs. Patients emphasized that mind-sets toward organ trade in the destination countries differ from those in their domestic countries, for example, 'everything is for sale, including organ transplants.' However, none of the respondents mentioned poverty or inequality as the driving force behind organ sales. Only few authors have pointed out that cultural aspects and differences in ethical perceptions may influence patients' decisions to go abroad for transplantation. [14,15] Current position statements against transplant tourism have been described as 'unapologetically ethnocentric,' reflecting only Western views of organ trade. [15] This may explain why most patients in the interviews did not tell their domestic caregivers that they were going abroad for transplantation.

Apart from a lack of suitable donor organs, cultural factors help explain why patients travel abroad for paid transplants. In addition, the study revealed that health insurance companies (partially) helped to cover the costs of some patients' transplants. In The

Netherlands until 2010, health insurance companies could refuse covering the costs of transplants abroad. A regulation established in 2010 allowed health insurers to reimburse the costs of transplants performed outside the European Union only if the recipient can prove that the donor was a blood relative, a spouse, or a registered partner. [16]

Under Macedonian, Dutch, and Swedish law, paying for organs is prohibited. The interviews provided no data on whether the patients' donors were exploited and limited data on whether they were paid. As a result, it is not possible to establish with certainty whether all transplants were legally performed. The findings raise suspicions of illegality. Not only did 17 patients travel abroad without informing their domestic caregivers beforehand, but also they brought back limited or no information about their donors. Third, most patients who claimed that they received a related donor kidney are no longer in contact with their donors. Fourth, more than half of the patients went to Pakistan for transplantation, which is known as one of the world's most common destination countries for illegal transplantation [17] and the exploitation of donors. [18,19] Finally, the majority of patients paid their doctors or brokers directly for their transplant. Consequently, it is highly likely that many of the transplantations were illegally performed, even though patients were given the impression that the transplantations were legally conducted.

These findings should be interpreted in light of several limitations. First of all, considering the delicate nature of the interview questions, it is likely that patients did not share information about possible organ purchase with the researchers, which affects the reliability of the results. The discrepancy between what the medical records revealed and what the patients said points out that not all patients knew or were truthful about the manner in which their transplants were obtained. For example, upon return, a patient reported that a cousin had donated a kidney, whereas the letter provided by the surgical team stated that he had received a 'suitable donor kidney.' A second limitation is that there are no reporting mechanisms for professionals or transplant centers to report possible organ purchases. Countries do not have registries of (possible) organ purchases. [20] As a result, we relied on information that transplant professionals provided based on their experiences, which in Sweden and in The Netherlands consisted only of patients with a foreign background. Although other studies also report that patients who travel abroad commonly have an affinity with the destination country, it is possible that Swedish and Dutch natives traveled specifically for transplantation. However, these were either not known or identified by the transplant professionals.

With these limitations, the present findings suggest that certain factors should be taken into account when addressing paid transplants abroad. The severity of the complications experienced by almost half of the patients in the underlying study illustrates the importance that transplant professionals (continue to) warn patients against the medical risks of undergoing transplants abroad. In addition, transplant professionals should emphasize the legal risks that may occur when patients buy organs. [21-23] The results reveal that caregivers often find out that patients go abroad *after the fact*. This demonstrates that aside from pretransplant measures, equal consideration should be given to posttransplant strategies.

One such strategy could involve the reporting of suspicious transplants by transplant professionals.[24] Research shows that the (possible) purchase of a kidney by a patient can raise difficulties for their caregivers. In a survey study among 241 Dutch transplant professionals, 100 (42%) of them reported that they had treated patients who had traveled between 2008 and 2013 from The Netherlands to a country outside the European Union for a kidney transplant. Thirty-one (31%) of them were certain that patients had bought the kidney; 65 (65%) had suspicions that the kidney had been bought. Most (85%) reported that they understood why their patients bought a kidney, and they (72%) believed that the purchase was covered by the secrecy oath. However, they (72%) also felt that they have a duty to prevent kidney purchase. The majority (53%) believed that kidney purchase harmed the relationship with their patients. The professionals (65%) reported a conflict of duties and a need for guidelines (more than 80%) in treating patients who purchase organs.[24]

Although transplants abroad commonly involve medical risks, legitimate travel for transplantation should not be discouraged if the patient has exhausted domestic transplant opportunities and/or lives in a country that has no transplant activity. Indicators that support transplant professionals in differentiating legal from illegal transplantations may be a helpful instrument to identify illicit organ purchases.[25] Finally, research should include interviews with brokers, transplant professionals, and other facilitators to achieve a full picture of the purchase of organs for transplantation.

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SUPPLEMENTARY MATERIAL: INTERVIEW PROTOCOL

Patients characteristics

1. Gender
2. Date of birth
3. Place of birth
4. Years of schooling
5. Occupation, employment
6. What did you work with prior to your current occupation?
7. Please describe your family situation. Do you have children? Partner? Do you live together with them?
8. Where do you live? Under what circumstances?

Pre-transplant stage

Tell me about your experiences of illness and treatments prior to going abroad for transplantation.

1. How did you react when you found out that you had kidney failure?
2. How would you describe life on dialysis?
3. Why do/did you want to be transplanted?
4. Experience, feelings about waiting time and organ shortage
5. Did you ask your family/friends to donate a kidney to you? Were they willing?
6. Suspended from wait list?
7. Experience with domestic health care system
8. Relationships with doctors, nurses and others
9. Trust in health care system/doctors
10. Knowledge about transplant possibilities in your native country
11. Friends, relatives transplanted abroad?
12. What motivated you to look into transplant options abroad and how did you start? How was the trip arranged?
13. How did you find out about the possibility of going abroad to buy a kidney?
14. Who did you discuss this possibility with? Family? Friends? Fellow patients? Medical practitioners? What did they say?
15. What made you finally choose to go abroad and buy a kidney?
16. Who helped you *prepare* the transplant? How?
17. Did you ask for your medical record from your domestic doctors? What did doctors say?
18. Did you explore the transplant costs and whether they could be reimbursed by your health insurance?
19. Did you make payments for the transplant? How? How much? To what/whom?
20. Did you negotiate a price or was it fixed? How did you raise the money?
21. Package deal? What was included?
22. Why did you choose to go to ... ?
23. Who helped *facilitate* the transplant? Who were the persons? (doctors, nurses, brokers, ... ?)
24. Were you accompanied by anyone?
25. Did you trust the facilitators?
26. Were copies of medical records asked? Screening? HLA matching?
27. Did you get a visa/go to an embassy? What did you say was your purpose of the trip?
28. What did you know about the origin of your donor kidney?
29. Did you get to meet the donor/seller? Who was he/she? (gender)
30. Were you given the opportunity to view medical evaluations of and choose between potential donors/sellers?
31. What happened when you got there? Tell me about the events that led up to the operation.
32. How would you describe the doctors and nurses that you met?

Transplant stage

1. Where did you travel to?
2. How was the operation organized? Did you and the donor/seller share a ward?
3. Were there other patients in the room with you? If so, from where were they?

Post-transplant stage

1. What happened after the operation? How did you feel? Did you meet the donor/seller afterwards?
2. (Where) did you receive after care?
3. Do you still have contact with the donor/seller? The broker? The surgeons/nephrologists/nurses?
4. Did you experience complications?
5. How would you describe the quality of care? Hygiene, duration of stay, infection, rejection (...)
6. Do you believe commercialization/regulated organ sales would be a good solution to the organ shortage?
7. In retrospect, what do you feel about your choice to go abroad and buy a kidney? Do you have any moral quandaries?
8. What are your feelings towards the seller/donor? Do you think about him/her?
9. Were you aware that it is forbidden by law?

4

EXPERIENCES, ATTITUDES, BEHAVIORS AND NEEDS OF TRANSPLANT PROFESSIONALS WHO TREAT PATIENTS WHO BUY ORGANS ABROAD

V

REPORTING ORGAN TRAFFICKING NETWORKS

A SURVEY-BASED PLEA TO BREACH THE SECRECY OATH

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Patients travel worldwide to purchase kidneys. Transplant professionals can play a role in identifying kidney purchase. However, due to the tension between their rights and obligations, a lack of understanding and knowledge exists on how to prevent and report purchase. We present the results of a national survey that describes transplant professionals' experiences, attitudes, behaviors, conflicts of duties, legal knowledge and needs for guidelines toward patients who purchase kidneys abroad. Second, we clarify professionals' rights and obligations regarding organ purchase and propose actions that they can take to report purchase. Of the 100/241 (42%) professionals who treated patients who traveled to a country outside the European Union for a kidney transplant, 31 (31%) were certain that patients purchased kidneys. Sixty-five (65%) had suspicions that patients had bought kidneys. The majority reported a conflict of duties. Eighty percent reported a need for guidelines. Professionals can help prevent organ purchase by disclosing information about organ trafficking networks to law enforcement. Such disclosure can support the investigation and prosecution of networks. We offer key components for guidelines on disclosure of these networks.

INTRODUCTION

The purchase of organs is prohibited in almost all countries [1]. Nevertheless, patients buy organs (mostly kidneys) for transplantation and commonly do so by travelling overseas [2]. Commonly reported destination countries are China, Pakistan and India [2]. Transplant professionals (TPs) who treat these patients pre- and post-operatively can play a role in identifying and reporting kidney purchase [3,4]. TPs however report a tension between their obligations to provide medical care and maintain secrecy on the one hand and their duty to prevent harm on the other [5-7]. This conflict of rights and duties may underlie 'the blind eye' [4] that TPs turn toward patients who (plan to) purchase an organ [5].

TPs who keep their 'eyes wide shut' to kidney purchase juxtapose initiatives fuelled by, for instance, the World Health Organisation [8] and the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (DOI) [9]. The DOI calls upon TPs to help eradicate the harm and sufferings inflicted upon victims of organ trade [3,9,10]. Building upon the DOI, the Policy Statement on Organ Trafficking and Transplant Tourism by the Canadian Society of Transplantation and Canadian Society of Nephrology (CPS) clarifies TPs' rights and obligations in relation to organ purchase. It also presents guidance and recommendations on how doctors can interact with patients [11]. The DOI Custodian Group (DICG) in its 2013 'Doha Communiqué' resolves to 'develop [...] systematic ways for physicians to identify and report to appropriate registries [...] patients returning with a donor organ from an "unverifiable source"' [3]. It further proposes 'a "white paper" discussing professional responsibilities in responding to patients who travel or plan to travel abroad for a transplant that would be illegal in their country of residence.'

Notwithstanding the importance of these initiatives, there is a lack of knowledge and understanding concerning TPs' experiences, conflicts of duties and needs for guidelines toward patients who purchase organs. A better understanding of TPs' regard for patients

who buy organs, as well as a clarification of their rights and obligations is needed. In this paper we first present the results of a national survey that describe TPs' experiences, attitudes, behaviors, conflicts of duties, their legal knowledge and their needs for guidelines toward patients who purchase kidneys abroad. We then clarify TPs' rights and obligations in relation to organ purchase and propose actions that TPs can take to report the purchase of organs.

METHODS

Design

This study involved a cross-sectional survey that was distributed to TPs in transplant centers and dialysis units in The Netherlands (NL).

Participants

With the help of the Dutch Transplant Nurses Society and the Dutch Transplant Foundation, contact details of transplant surgeons, nephrologists, transplant coordinators, nurses, nurse practitioners and social workers were collected. Then, all units were contacted by telephone to verify accuracy of contact information and accuracy of names. During this process missing data/new names were added to the list and inaccurate or outdated information was removed. This led to a total of 546 transplant professionals (286 nephrologists, 60 transplant surgeons, 50 nurses/transplant coordinators/nurse practitioners, and 150 social workers).

Procedure

The survey was built and distributed using Survey Monkey and sent via e-mail to TPs between March and August 2013. Each nonresponding participant received up to two reminders. The online survey setting was such that only one response by each participant (computer) was possible. The e-mail explained the nature and purpose of the study and stated that names of persons and institutions would be kept strictly confidential. Because the study participants were TPs and not patients, an application for ethical approval to the medical ethical committee was not required.

Measures

The survey was created after discussions among TPs, lawyers, and criminologists. The survey was tested by several persons before circulation. It included 50 questions that enquired the participants about their socio-demographic characteristics, experiences, attitudes, behavior, conflicts of duties, legal knowledge, and need for guidelines.

Socio-demographic data included gender, age, nationality, profession, and career duration. TPs were asked about their experiences with patients who traveled between 2008 and 2013 from NL for kidney transplantation, and whether in these cases they were certain or had suspicions that the patients had purchased the kidneys. Participants could respond to a set of predetermined explanations for their reasons for certainty.

table 1 Attitudes of transplant professionals

statements	agree		disagree	
	n	%	n	%
Kidney purchase harms the relationship with my patient	128	53.1	67	27.8
Regulated organ trade is acceptable	51	21.2	163	67.6
As a transplant professional I do not judge my patient for buying a kidney	85	35.3	127	52.7
I understand why patients buy kidneys	204	84.6	15	6.2
Patients should be prosecuted for buying kidneys	64	26.6	101	41.9
The purchase of a kidney is covered by my secrecy oath	173	71.8	34	14.1
Transplant professionals have a duty to prevent kidney purchase	173	71.8	36	14.9
It is impossible to prevent kidney purchase	139	57.7	70	29.0
I approve of the patient's purchase of a kidney abroad when:				
The patient's chances of survival will otherwise be small	50	20.7	151	62.7
The patient cannot find a donor in NL	29	12.0	176	73.0
The patient does not want to burden his/her family with a living donation	13	5.4	204	84.6
The country of destination does not prohibit the purchase of kidneys	27	11.2	175	72.6
It appears that the donor sold his/her kidney voluntarily	52	21.6	153	63.6
It appears that the donor is family	86	35.7	114	47.3
The patient has the nationality of the country of kidney purchase	18	7.6	171	71.0
The country of destination is a member of the European Union	15	6.2	180	74.7
The country of destination is a Western country	13	5.4	181	75.1

table 2 Behavior of transplant professionals

If I have a *suspicion* that the patient is going to buy a kidney outside the country	**yes**		**If the patient *tells me* that he/she is going to buy a kidney outside the country**	**yes**	
	n	%		n	%
I prepare my patient in the same way as if it were for a regular transplant in NL	82	63.1	I prepare my patient in the same way as if it were for a regular transplant in NL	69	53.1
I share my opinion with the patient	117	90.0	I share my opinion with the patient	121	93.1
I give the patient his/her medical record	48	36.9	I give the patient his/her medical record	48	36.9
I ask my colleagues for advice	103	79.2	I ask my colleagues for advice	103	79.2
I defer/refer the patient to a colleague in my unit for medical care	19	14.6	I defer/refer the patient to a colleague in my unit for medical care	20	15.4
I refer the patient to a colleague abroad	7	5.4	I refer the patient to a colleague abroad	7	5.4
I consult a lawyer in my hospital	60	46.2	I consult a lawyer in my hospital	75	57.7
I report the patient to the police	0	0	I report the patient to the police	6	4.6

table 3 Conflict of duties and confidentiality

	n	%
Because of my secrecy oath, I cannot protect the possible victim-donor	117	74.5
Because of my secrecy oath, nothing is done to deter the crime	100	63.7
If I give the patient his/her medical record, I possibly participate in an illegal act	78	49.7
If I prepare the patient for the transplant, I possibly participate in an illegal act	75	47.8
Because of my secrecy oath the patient can commit the crime without getting punished	69	44.0
Other reasons	6	3.8

table 4 Legal knowledge

	true	%	false	%	don't know	%
The purchase of kidneys in NL is forbidden	237	98.3	3	1.6	1	0.4
I MAY report a patient who is considering purchasing a kidney abroad to the police	35	14.6	141	58.6	65	27.0
I MUST report a patient who is considering purchasing a kidney abroad to the police	10	4.2	173	71.7	58	24.1
I MUST report a patient who returns from abroad with a purchased kidney to the police	20	8.3	163	67.6	58	24.1
I MAY report a patient who returns from abroad with a purchased kidney to the police	35	14.6	145	60.2	61	25.3
Purchase of kidneys falls under my secrecy oath. I am therefore never allowed to report a patient	128	53.1	54	22.4	59	24.6
A patient who has bought a kidney abroad has a right to medical care	229	95.0	5	2.1	7	2.9

Attitude (table 1) was measured using a 5-point scale ranging from 1 'totally agree' to 5 'totally disagree' to rate 17 statements such as: 'Kidney purchase harms the relationship with my patient,' 'Regulated organ trade is acceptable,' and 'I approve the purchase of a kidney abroad when the patient's chances of survival would otherwise be small.'

Behavior (table 2) was measured by asking what the participant would do in two different situations:

1 the professional has a suspicion that the patient is going to buy a kidney outside NL;

2 the patient told the professional that he/she is going to buy a kidney outside NL.

Participants were required to respond 'yes' or 'no' to 8 propositions portraying possible behavioral responses to these two situations. Because of a technical issue in the online survey tool, 111 respondents were not able to view and respond to the statements related to 'behavior.'

Participants were also asked whether they experienced ('yes' or 'no') a conflict of duties if they believe that their patient will buy an organ abroad (table 3). If 'yes,' respondents could select 5 different reasons for this conflict.

Participants' knowledge about legal (reporting) requirements was measured with 7 statements such as: 'The purchase of kidneys in NL is prohibited' and 'I may report a patient to the police if he/she considers buying a kidney abroad' (table 4). Participants could respond 'true' or 'false.'

Finally, participants were asked 4 questions about their need for guidelines ('yes' or 'no'). For example, TPs were asked: 'Do you have a need for guidelines that could guide you in treating/dealing with patients whom you suspect are going to buy an organ?' and 'Do you have a need for guidelines that could guide you in treating/dealing with donors whom you suspect have sold an organ?'

Statistical analyses

The data were entered into and analyzed with SPSS Version 21. Descriptive statistics were performed to describe the demographics, experiences, attitudes, behaviors and knowledge of the participants. Univariate analyses (chi-squared statistics, Spearman's rho, and Mann-Whitney) were performed to describe the relationships between the aforementioned variables. Nonparametric tests were performed due to the skewed distribution of the data. For the univariate analyses of 'attitudes' we used a 5 point-scale. To summarize the findings of 'attitudes' more cogently, we dichotomized the answers into 'totally disagree/disagree' and 'totally agree/agree.' The responses to the 'neutral' response category are not shown (see table 1). Taking into account the large number of tests of 'attitudes,' we applied a Bonferroni correction, whereby a value of $p<0.001$ was considered to be statistically significant. Relationships were analyzed between the socio-demographic characteristics on the one hand and attitudes, behaviors and knowledge on the other hand. Due to space restrictions, only some significant relationships are presented.

RESULTS

Study participants

Of the 546 transplant professionals, 241 (44%) completed the survey. One hundred thirty were male (53.9%). The median age was 48 (range 26-68).

Experiences of transplant professionals with patients who purchased kidneys abroad

One hundred eleven out of 241 TPs (46%) responded that they treated patients between 2008 and 2013 who had traveled from NL for a kidney transplant. One hundred TPs (42%) responded that they treated patients who had traveled outside the European Union (EU). Thirty-one of these (31%) wrote that they were certain that patients bought the kidneys. TPs' reasons for certainty were: 'The patient said that he/she had bought the kidney' (29 TPs), 'The patient said that the donor had received money for the kidney' (8 TPs), 'The patient said that he/she had paid a large amount for the transplantation' (7 TPs), 'The kidney purchase was mentioned in the patient's medical record' (4 TPs). Sixty-five of the 100 TPs had suspicions that the patients had bought the kidney. Because patients are treated by more than one TP, these numbers do not represent the number of patients that travelled. However, the survey was completed by TPs from all transplant centers, and all centers reported clusters of patients that travelled.

Attitudes of transplant professionals toward patients who purchased kidneys

Table 1 reveals that most TPs report that they understand why patients buy kidneys (85%), believe that the purchase of a kidney is covered by the secrecy oath (72%) but also feel that they have a duty to prevent kidney purchase (72%). The majority believes that kidney purchase harms the relationship with their patients (53%), deems a regulated organ market unacceptable (68%) and judges their patients for buying kidneys abroad (53%). A minority (27%) believes that patients should be prosecuted for buying kidneys. On the other hand, 58% argue that prevention is impossible. Most TPs answer that they disagree with a kidney purchase abroad, even if the patient's chances of survival will otherwise be small (63%), even if the patient cannot find a domestic donor (73%) and even when the destination country does not prohibit kidney purchase (73%). The longer the career of a TP, the more likely he/she is to agree with the statement that 'the purchase of a kidney is covered by my secrecy oath' (r_s=0.257, $p<0.001$). No other significant relationships were found.

Behavior of transplant professionals toward patients who purchased kidneys

The results in table 2 reveal that there are few differences in reported behavior when TPs have suspicions of intended kidney purchase versus when the patient tells them that he/she is going to buy a kidney. In both situations the majority would share their opinion with the patient (90%), they would not give the medical record (63%), they would ask colleagues for advice (80%) and they would not refer the patient to a colleague in their hospital (85%) or to a colleague abroad (95%). If a patient tells the TP he/she is going to buy

a kidney, the TP is more likely to consult a lawyer and less likely to prepare the patient for transplant a usual. Although none of the professionals would report their patients in case of a suspicion, 6 (out of 130) TPs answered that they would report their patient to the police if the patient tells them he/she is going to purchase a kidney. These 6 TPs however had not actually seen or treated patients who traveled abroad for a transplant.

Conflict of duties and confidentiality

The majority of the TPs, 157/241 (65%), indicated that they experience a conflict of duties when suspicions arise about a patient's kidney purchase. TPs' most commonly reported explanation for a conflict of duties is that because of their secrecy oath, they are unable to protect the possible victimdonor (75%). Sixty-four percent emphasized that because of their secrecy oath, nothing is done to prevent the crime. Others reasons were that by giving the patient his/her medical record, TPs possibly participate in an illegal act (50%), and because of their secrecy oath, the patient can commit the crime unpunished (44%).

Knowledge about the law against organ purchase

In NL, TPs are released from their duty of confidentiality 'if the patient grants consent, in the event of a legal duty to provide information, during consultations with care providers who form part of the treatment unit and in the case of conflicting obligations' [12]. Although the purchase and sale of organs is forbidden in NL, doctors do not have an obligation to report patients who *will* buy organs to the police. Yet, they *may* do so if the disclosure prevents severe harm to the patient or another individual [13]. Doctors are prohibited from reporting patients who *have committed* a crime [13]. The Royal Dutch Medical Association has installed a reporting mechanism to which TPs may report child abuse and domestic violence [12]. However, no guidelines or bodies exist for the reporting of organ purchases and sales.

Almost all TPs (98.3%) correctly stated that purchase of kidneys in NL is forbidden. A minority correctly believed that they *may* (15%) and wrongly assumed that they *must* (4%) report a patient to the police who considers to purchase a kidney abroad. Only a minority wrongly assumed they may or must report patients that return from abroad with a purchased kidney (15% and 8%, respectively). While 53% of the TPs believed that they are never allowed to report a patient because of the secrecy oath (and 25% did not know), still 22% disagreed and saw possibilities to report the patient.

Finally, TPs' needs for guidelines were asked. Most participants expressed a need for guidelines in treating patients and/or donors who purchase and/or sell organs. The indicated need was highest (86%) when TPs treat patients whom they suspect are going to buy an organ. The need was lowest (71%) when treating donors whom they suspect have sold an organ.

DISCUSSION

This study reveals the large number of TPs who have suspicions or are certain that their patients purchased kidneys. In particular, it highlights TPs' belief that they carry a duty to prevent kidney purchase. This supports the international transplant community's recognition that TPs are no longer 'just' care givers but that 'as members of the medical community they also have a duty to prevent harm to other individuals' [11]. Despite this recognition, little understanding exists on how TPs' actions towards kidney purchase can take form. This lack of understanding is illustrated by the TPs' experienced conflict, their reported need for guidelines but also by their ambivalent responses: Most (72%), feel a duty to prevent purchase, but express understanding toward their patients (85%), believe the purchase is covered by their secrecy oath (72%), and feel that it is impossible to prevent purchase (58%). Below we explain how kidney purchase affects TPs' rights and duties, and we propose actions that TPs can take to prevent their patients from purchasing kidneys.

The rights and duties of transplant professionals

TPs' duties include the duty to 'first, do no harm' [14], the duty to uphold confidentiality of information shared by the patient (secrecy oath) and the duty to give medical care. The secrecy oath, which originates from the Hippocratic Oath and is required of doctors in many countries, exists to maintain confidentiality between patients and their physicians [15]. Confidentiality is central to trust between doctors and patients. It grants doctors the privilege of nondisclosure [16]. These rights and duties are universally accepted principles endorsed by international organizations such as the World Medical Association (WMA) [17] and the American Medical Association (AMA) [18], and they are codified into legislation worldwide [19-21]. TPs' rights and duties are interlinked and exist in conjunction with the rights and duties of patients. They serve to protect the interests of patients in two ways: to protect patients' rights to privacy and autonomy, and to guarantee accessibility of care [13]. Accessibility of care entails that patients have the right to receive care under all circumstances, even after they have committed a crime. When patients experience acute medical problems, TPs have an obligation to provide care [13]. The duty of care however is not absolute. In situations that are not life-threatening, doctors may choose to defer care to another physician [11,15]. The right to privacy is also not absolute [16,22]. The AMA declares that 'when a patient threatens to inflict serious physical harm to another person or to him or herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, which may include notification of law enforcement authorities' [18].

Jurisdictions accept that doctors may disclose confidential information when required by law, when patients agree to the disclosure, when conflicts of duties arise and/or in the case of overriding interests [9,13,16,18,23]. A conflict of duties arises when a doctor is confronted with a situation needing a solution and in which harm can be prevented by a breach of his confidentiality [13]. Accepted reasons for disclosure are 'violent crimes' such as

gun and knife wounds, child abuse, and crimes that may lead to death of the victim, as well as infectious diseases that threaten the public health [13,19].

How are TPs' rights and duties affected by the prohibition of kidney purchase? The CPS clarifies TPs' rights and duties in relation to kidney purchase and offers pretransplant and posttransplant guidance for their interactions with their patients [11]. Gill et al also offer strategies to prevent kidney purchase [10]. Although these statements are useful, they overlook a number of issues that TPs should take into consideration before taking action to prevent patients from purchasing organs.

First of all, the (intended) purchase and sale of organs is one of the most difficult crimes to prove [24]. Indeed, the present study illustrates that most TPs (70%) were uncertain that the kidney was bought. Patients generally do not tell their doctors that they are going to purchase an organ [5,25]. Patients who return from a commercial transplant overseas also commonly do not tell their TPs how the organ was obtained [5,10]. Most bring back little information about the transplant [26], which makes it difficult if not impossible to determine that the purchase occurred. Under law, a kidney purchase, commonly defined as 'transplant commercialism' [9] or the 'prohibition of financial gain' [21] means paying the donor and/or a broker in return for an organ. Thus, if a patient travels abroad and pays a hospital for a kidney transplant, this payment does not qualify as a kidney purchase. In order to establish that a kidney purchase will take or has taken place, it needs to be proven that the donor and/or broker received or will receive remunerations for the kidney. However, TPs do not carry an obligation to investigate and prove whether their patients will commit or have committed crimes [13].

Second, even if the TP can determine that the patient is going to purchase a kidney, this will not instantly mean that the purchase is illegal or punishable [24]. Iran for example (with the exception of the province of Shiraz) does not forbid recipients to purchase kidneys from donors [27,28]. Israel prohibits its citizens from buying kidneys in and outside the country, but does not prosecute patients who buy organs [29]. Although jurisdictions generally forbid organ purchase by law, they do not always lay a sentence upon those who buy (or sell) kidneys. Furthermore, not all countries have extra-territorial jurisdiction to prosecute patients who purchased organs abroad [24,30]. With the exception of South Africa, no other country, with the appropriate legislation in place, is known to have prosecuted patients for buying organs, even when purchase by patients was proven [31]. This suggests that the global moral condemnation against organ purchase may not be as widely accepted as assumed [32].

Third, there may not always be a 'reasonable probability' [18] that kidney purchase leads to serious physical harm to patients and/or donors [33,34]. The CPS declares that 'healthcare providers cannot speculate regarding the relative safety of commercial transplants abroad in different countries' and subsequently proposes a restriction of patients' rights [11]. While the most commonly used argument against payment is that buying organs compromises donors' free will and leads to coercion and exploitation [9,35-37], empirical evidence shows that kidney purchases in themselves are not always exploitative and in some cases can even benefit patients and donors [27,38].

Any restrictive action toward patients should be based on the probability of severe harm inflicted on the patient and/or donor. The current state of knowledge reveals that harm is difficult if not impossible to predict and prove, in particular when a patient leaves independently to receive a kidney from a 'relative' or 'friend' abroad. Rather, research shows that the probability of harm is largest when brokers and other middlemen who operate in organized organ trafficking networks are involved [31,39-41]. Severe harm is also inflicted amongst executed prisoners in China [42,43]. Brokers and other middlemen (which can include doctors) exploit donors and patients and inflict harm on them. Only one study reveals that severe harm to donors can be committed by patients directly [39].

The foregoing considerations illustrate the complexity of predicting a reasonable probability and magnitude of harm, and show that severe harm cannot reasonably be foreseen on the sole basis of a patient's intended kidney purchase. We argue that restricting patients' rights is unjustified when such restrictions are based on the suspicion of an intended kidney purchase. Rather, measures to prevent the crime should be directed toward those persons that inflict the harm. This has consequences for possible actions that TPs can take.

Pretransplant actions

We argue, in line with most respondents of this survey, that disclosing the identity of a patient (without the patient's consent) who has an intention to purchase a kidney to any authority or registry is not justified. For the same reasons, we argue that withholding care to patients who intend to purchase an organ is also unjustified. The CPS encourages physicians 'not to provide medical records to patients if they believe the information will be used in support of an illegal transplant performed in an unregulated system and that there is a significant risk of harm to the patient or organ vendor' [11]. Sixty-three percent of the present study's participants supports the CPS. Yet, half of the TPs would prepare the patient in the same way as if it were for a legitimate transplant. Withholding medical care from patients who leave nonetheless may result in ill-prepared patients who will undergo the transplant without the proper documentation and work-up. On the other hand, nonpreparation and nonrelease of the chart may be in the patient's best interest from a safety perspective. Practice however illustrates that patients often leave without taking their records and that tests are performed at the center where the transplant takes place [25]. In most jurisdictions patients have a right of access to their medical records. Withholding patients' records may thus constitute a breach of their right of ownership, right of autonomy and right to medical care [19]. We thus encourage TPs to provide patients with their medical charts when they request them.

The most straightforward method to prevent purchase, encouraged by the CPS and DICG, is to inform patients about the ethical, medical, psychosocial and legal risks of buying kidneys abroad [11,44]. Discouragement and a lack of facilitation is the most commonly reported method of deterrence amongst TPs [5-7,10]. The findings of the survey support this method as TPs indicated to be more inclined to prevent purchase (72%), than reporting patients (5%).

Posttransplant actions

May TPs disclose information about patients to the police after the kidney has been purchased, even when it is too late to prevent harm to the patient and/or donor in question? The survey reveals TPs' reluctance to do so. Indeed, most jurisdictions will not accept disclosure if it will not prevent harm. In particular, the disclosure will be illegitimate if based on an assumption that the kidney was purchased and that harm was done. We therefore argue that disclosing the identity of a patient (without the patient's consent) who has purchased a kidney to police authorities is not justified.

This however does not constrain all possible forms of disclosure. The DICG in its Doha Communiqué encourages TPs to report patients to registries [3]. However, a more effective method is to encourage TPs to report organ trafficking networks to reporting centers. Appropriate authorities could be the same national institutions that receive information from TPs on human trafficking, domestic violence and child abuse. A reporting code can be established that may correspond with reporting codes and protocols developed by various professional groups, but it should be tailored to meet the needs of TPs who report organ trafficking. Examples of national reporting institutions could be CoMensha [45], the Royal Dutch Medical Association [12], and the American Council on Ethical and Judicial Affairs [18].

After analyzing the reported information, the reporting center can submit the information to the national police, who in turn contacts the police forces or liaison officers of the transplant destination country. This national-international reporting method would allow for the information to reach the appropriate authorities and would strengthen the cross-border collaboration and enforcement of this crime. Networks include brokers, transplant professionals, hospitals, service providers, translators and law enforcement officials [46]. Reporting information such as the names of hospitals, clinics, cities, hospital staff and other individuals who are involved in potentially illegal transplant activities, is a more effective way to disrupt and deter organ trafficking than reporting patients.

Disclosure of such information may have disadvantages. It may erode the patient-doctor relationship. Patients may provide names of fictitious centers or may even avoid seeking care from their treating physicians upon return. On the other hand, disclosure may have a strong preventative effect, causing illegally operating transplant centers to think twice before performing an illegitimate transplant.

We encourage governments, together with national police forces, lawyers and TPs to establish reporting codes that allow for the identification and disclosure of networks by TPs without them having to reveal patients' identities. This information can support and stimulate the police and judiciary to investigate, disrupt, and prosecute organ trafficking networks. To prevent drawbacks such as distrust and erosion of the patient-doctor relationship, these protocols should build in whistleblower protection mechanisms for patients, TPs and other persons who disclose the information. Below we offer key elements that such a reporting code could contain.

This study reveals TPs' experiences, attitudes and behaviors toward patients who purchase organs and illustrates the complex factors involved in taking measures to prevent the crime. Enforcement of organ trafficking should be harm-based and directed toward

brokers, doctors or other persons who exploit donors and patients. TPs and law enforcement reporting authorities should collaborate to disclose organized organ trafficking networks. We propose a reporting code for such collaboration.

KEY ELEMENTS FOR A REPORTING CODE ON DISCLOSURE OF INFORMATION OF ORGAN TRAFFICKING NETWORKS

The code should at a minimum:

1. Be written *for* TPs *by* TPs, lawyers, police and judiciary;
2. Correspond with domestic legislation;
3. Designate a *reporting center* and include a *roadmap* that guides the TP through the following steps:
   - A Identification of signals with the help of *indicators* (see no.10);
   - B Consultation of colleagues and hospital lawyers;
   - C Consultation with the reporting center to interpret the signals;
   - D Talking to the patient;
   - E Deciding between organizing assistance amongst other TPs or filing a report.
4. Explain to TPs that disclosure is *voluntary* and that no consequences will follow from (non)reporting;
5. Allow TPs to disclose *anonymously*. The code should build in disclosure protection mechanisms similar to whistleblower laws. The identity of patients, TPs and/or their institutions should be protected and they should be waived from any legal liability and/or duty to testify;
6. Allow for consistent monitoring by the *reporting center* that will follow up on the information that TPs provide;
7. Enable TPs to disclose pretransplant and posttransplant. TPs must be satisfied that their rights and duties will not be affected by the timing of their disclosure;
8. Explain to TPs the *purpose* of the disclosure. The purpose is to:
   - A Disclose information that supports police and judiciary in investigating, disrupting and prosecuting organ trafficking networks (brokers, transplant professionals, hospitals, service providers, translators, and corrupt law enforcement officials)[33]. Disclosure may occur without the patient's consent.
   - B Clarify the rights and duties of the TPs when they treat patients and/or donors who wish to purchase/sell an organ abroad and/or who return with a possibly purchased organ. The CPS can serve as an example[12].
9. Describe *what* the TP may report:
   - A The tp should disclose anonymized or coded information that serves the purpose of the disclosure. This includes data that supports the identification, investigation and prosecution of the network (as stated in 8a). If known, disclosure should contain names and locations of the transplant clinic and/or the name of the transplant staff and any other information that serves the disclosure's purpose.

10 Guide TPs through a list of indicators to identify suspicious transplant activity. Indicators that may cause suspicion and warrant probing of the patient can occur when the patient:

A is preparing to leave to a country or clinic that is known to the TP because other patients have gone there and returned maltreated or carried information that indicated their donors were harmed;

B returns with lack of information about where and how the transplant took place, including a lack of donor information;

C returns with clear signs of maltreatment such as wound infections and/or transmitted diseases such as HIV or TBC;

D tells the TP and/or has information in his record that states that a donor, broker, and/or a doctor received payments in return for the organ (transplant).

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VI

‘I AM NOT SHERLOCK HOLMES’

SUSPICIONS, SECRECY AND SILENCE OF TRANSPLANT PROFESSIONALS IN THE HUMAN ORGAN TRADE

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INTRODUCTION

The human organ trade receives increasing attention from international (transplant) organizations, the media, researchers and non-profit organizations. According to the Council of Europe it constitutes a 'major threat to the public health' [1]. The World Health Organization (WHO) has estimated that 5-10% of all organ transplantations take place illegally each year [2]. With an estimated annual profit of $1.2 billion, the trade features in scale and profit alongside the illicit trade in drugs, wildlife and weapons [3]. Defined as a form of human trafficking [4], the prevailing discourse on organ trade is that of an organized crime, driven by mafia-like networks that exploit the poor for their organs [5,6]. As such, the trade is externalised as 'the dark side of transplantation' that contaminates the nobility and legacy of the legal transplant industry [7,8].

This portrayal of the trade has led to a worldwide adoption of punitive legislation against it [9,10]. Nevertheless, only a few cases have appeared at the judicial level [11]. Furthermore, with most studies addressing the contexts and consequences of kidney sales on the black market [12-14], limited empirical data exists on the role of other actors, such as transplant professionals. In incidental cases, transplant doctors have been convicted for taking part in organized networks that trafficked persons for their kidneys [11,15]. Nevertheless, it is unlikely that these cases represent the trade as a whole [14].

Over the last few decades, a growing number of transplant professionals from countries worldwide have published reports in which they state to be 'unwillingly confronted' with patients whom they suspect underwent illegal organ transplantations abroad [16,17]. The most commonly obtained organs are kidneys [18]. Often, these patients return with serious complications in need of post-operative care with implanted grafts of which the origins are unknown [19]. These reports however, do not provide information on the presumed illegal nature of the transplants, such as how patients obtained the kidneys, how much they paid and to what or whom. Information about patients' kidney donors is commonly also absent [20,21].

Doctors are commonly prohibited from reporting their patients' alleged wrongdoings. Their rights and duties towards patients are firmly entrenched in national health care regulations. These include the duty to provide medical care, the professional secrecy oath, and the privilege of nondisclosure [22,23]. Nevertheless, in recent years, professional transplantation societies have become increasingly active in the fight against organ trade [24], and demand a more proactive role of transplant professionals in preventing patients from purchasing organs abroad. The underlying rationale is that donors (organ sellers) should be protected from harm. Gill et al., have stated, for example, that doctors have a duty to advocate for their patients, but 'as members of the medical community, they also have a duty to prevent harm to other individuals' [25].

As part of this development, it has been pointed out that legislative frameworks should accommodate the reporting of suspicious transplant activities by transplant professionals to law enforcement [26-28]. Caulfield et. al., for example, have stated that 'given their interactions with patients, professionals seem well placed to play a role in the monitoring

and perhaps, the reduction of organ trafficking practices' [29]. Yet, in the absence of knowledge and information about these doctor-patient exchanges, it remains unknown how much (if anything) professionals know about their patients' organ purchases, how they respond to these patients, and if they are willing (or allowed) to disclose information about their patients' alleged organ purchases.

Recently, we found, through an explorative survey, that almost half of the Dutch transplant professionals involved in the care of kidney patients, treated patients who travelled to a country outside The Netherlands for a transplant between 2008 and 2013. [A] Whilst a majority suspected that the patients had purchased the kidneys, one third reported to be certain that patients had bought the kidneys. Their reported reasons were because the patient said that he/she had bought the kidney, because the patient said that the donor had received money for the kidney and/or because the purchase was mentioned in the patient's medical record. A majority reported a conflict of duties because they felt unable to protect the victim-donor and because they felt unable to prevent the crime. Almost all expressed a need for guidelines in treating patients who buy organs [30].

Building further on these results, we conducted a qualitative interview study amongst these professionals with the overarching aim to examine their experiences with and attitudes towards patients who purchased kidneys more closely. This article poses the following questions: what are transplant professionals' experiences with patients who purchase kidneys and how do they deal with these patients? How can professionals' attitudes and behaviours towards the patients be understood and explained? And finally, how do they consider their roles and responsibilities in preventing organ purchases? At the time of writing (2016), this is the first qualitative study to shed light on this topic.

METHODOLOGY

We interviewed 41 of the transplant professionals, based in hospitals throughout The Netherlands, who completed our previous survey and who reported to have treated patients whom they suspected or knew had purchased kidneys abroad. The respondents ranged in age from 31 to 67 years (mean age 49.2 years). Their career duration was 0-37 years (mean 13,7 years). We interviewed 29 nephrologists (N), 5 nurse practitioners (NP), 5 social workers (SW), one research nurse and one transplant surgeon. Nephrologists [B] constituted the largest group of respondents who received and completed the survey which is why most interview respondents were nephrologists. All respondents were informed beforehand that their names and the names of their institutions would be kept confidential.

The interviews were semi-structured, lasting between 45 minutes and 1,5 hours and took place in the respondents' offices. The interviews were recorded, transcribed and analysed through a mixture of thematic and open coding, using QSR*NVIVO software. The participants' names were coded to ensure anonymity. For the coding process, we used a list of predetermined criteria that we defined based on our research questions. Thereafter, we assessed and compared codes, discussed overlaps and differences and integrated them into one coding structure.

The interviews covered the following themes: professionals' experiences with patients who purchased kidneys abroad, their opinions and attitudes towards these patients and their ideas and views on their roles and responsibilities in deterring organ purchase. With the transplant professional being the main focus of this article, the results below reflect and represent their experiences, values and perceptions.

Transplant professionals' experiences with patients and their kidney purchases

From the interviews it emerged, first and foremost, that the respondents' experiences with patients who purchased kidneys abroad are shrouded in suspicion, secrecy and silence. A social worker explained:

> *We never know whether the kidney was paid for. We always have a suspicion. We ask them but of course we don't get an honest answer because people aren't stupid. They won't tell us: 'Yes, I paid thousands of Euros for it'. We all have a gut feeling but we can't prove it.* (SW28)

Transplant professionals experience the issue incidentally. Over the course of their careers, the majority treated one to two patients who travelled abroad to obtain a kidney transplant that was assumed to have been bought. [c] Respondents spoke of patients who travelled between 2006 and 2013 but they also treated patients who travelled before that time period. The majority of patients travelled to Asian and Middle Eastern countries for kidney transplantation; a minority went to Western countries (Europe, Canada and United States). Many of these patients were still under the care of professionals when the interviews took place.

The professionals' experiences with these patients varied: whereas the majority found out that their patients obtained a kidney transplant abroad after it had taken place, a minority reported that they knew beforehand that their patients were going abroad. Unaware of their patients' plans, the former group of professionals stated that their patients left unannounced and unexpectedly returned with a strange implanted kidney in need of aftercare. The following statement captures the limited control and knowledge of the respondents regarding their patients' transplant ventures:

> *A woman suddenly appeared in our ward and said, 'Hello, I was in Afghanistan and I got very sick and needed a kidney and then my nephew in Pakistan donated his kidney'. I never discovered how she had arranged it. I had many questions that she didn't answer. It was a bizarre story.* (NP24)

Respondents described their experiences with recipients of suspected kidney purchases as an unwelcome issue that they were unwillingly confronted with and had no control over. This finding coincides with reports in the literature [19,31]. Nonetheless, their information and knowledge about the suspected purchases was limited. One reason is that patients and their (suspected) kidney purchases are not reported or registered. Furthermore, the

documentation that patients bring back from abroad is often incomplete or absent. If available, only a few details about the medications and post-operative outcome are provided. Consequently, professionals couldn't rely on a registry or comprehensive documentation. Rather, they based their accounts on their recollections. Sharing an experience about a patient who returned from a transplant in China, a nephrologist recalled:

> *He merely said, 'it had been arranged'. We asked whether the donor had been someone from the death list and if he had bought the kidney but he didn't want to tell us. He didn't answer. There was an awful silence. I remember that. Yes, that was quite extraordinary.* (N29)

The participants generally associated their patients' transplants abroad with organ trade, especially those obtained in countries such as India and Pakistan which are renowned for their 'kidney bazaars' [13,24], and China, for its harvesting of organs from executed prisoners [32]. In the absence of verifiable information about their patients' donors, respondents often imagined them to be the impoverished kidney sellers or executed prisoners whom they had seen, heard or read about in the media.

What exacerbated their suspicions, was patients' silence about how they had organized their transplants. They explained that when they asked their patients how and where they obtained the grafts, patients acted '*vaguely and suspiciously*', avoided answering questions or '*mumbled*' that it '*had been taken care of*' for them. Others told their caregivers that they had received the kidney from a relative. However, because participants could not verify this based on the available documentation, these statements were met with suspicion and doubt. Only on rare occasions patients told their caregivers that they had purchased the kidney.

The respondents' limited knowledge about their patients' transplantations was also reported by those who knew beforehand that their patients were going abroad. In most of these cases, patients did not say they were getting a transplant but told their doctors that they were going 'on holiday' and returned with an implanted kidney of which the origin was unknown.

In describing their experiences, the participants predominantly spoke about the complex treatment that these patients required due to their post-operative complications. Many patients, in particular those who went to Asia or the Middle East, returned with complications such as infections (Hepatitis, Tuberculosis, Typhus), acute graft rejection and/or graft loss. One patient died when transplanted in Pakistan. A few others passed away upon return. These findings correspond with other doctors' accounts in the literature [20,33]. The complications often constituted a source of frustration and worry amongst professionals. They pointed out that these patients demanded a more time-consuming treatment than 'regular' kidney transplant recipients. Notably, these reports require some nuance, as not all patients who went abroad experienced post-transplant complaints. Some professionals treated patients who returned without infections and with properly functioning grafts. Others remarked that post-transplant complications are common in The Netherlands as

well. Overall, however, most professionals didn't have a high regard for the quality of care that patients received in these regions. They assumed that the complications resulted from old-fashioned treatment or overdoses of immunosuppressant drugs, and presumed that the transplantations had been performed in '*shady*' or illegal circumstances.

'Cultural' explanations for cross-border kidney purchases

Similar to accounts published in the literature [34-36], almost all participants pointed out that patients who went abroad for transplantation had an ethnic affinity with their destination country. Only a few respondents indicated that they treated native Dutch patients who purchased organ transplants abroad. The participants explained that patients usually had the nationality of the destination country, had lived or worked there in the past and/or had family and friends living there.

In highlighting patients' ethnic ties, professionals speculated that it was probably easier and cheaper for them to buy kidneys abroad than for native Dutch patients. Frequently, they brought up these patients' '*cultural otherness*' and stated that the patients came from '*cultures where everything is for sale, including people and their kidneys*'. Furthermore, they referred to differences in ethical perspectives towards organ purchase between the native Dutch and non-native Dutch, to explain why some patients travel overseas to buy kidneys, and most others (i.e. the native Dutch) do not. As one doctor pointed out:

> *The native Dutch have a different ethical perspective than those who come from those countries. I think those people more easily accept that the poor are exploited for the rich. In their perspective that is probably everyday business. The native Dutch, I believe, have a different kind of realisation. They probably find it [kidney purchase] more unacceptable.* (N14)

The foregoing reveals the respondents' rather 'static' interpretation of culture [37], given that, strictly speaking, a culture that accepts organ purchases does not exist. Their interpretation served to differentiate the 'suspected' transplants (in Asia and the Middle East) from those obtained in Western countries. The professionals generally assumed the latter to be legally obtained and indicated that they felt more 'reassured' about these transplants.

The professionals were generally more understanding towards patients who obtained or purchased kidneys in their countries of origin than towards patients of native Dutch origin. As a nephrologist pointed out:

> *My Turkish patients believe that the health care in Turkey is better and they feel more at home there too. I can understand that. It doesn't mean that I support them, but I find it less condemnable.* (N22)

This statement illustrates that patients' perceived 'otherness' or ethnic ties alleviated respondents' condemnation of organ purchase. Consequently, and also because of its

incidental nature, most didn't regard the phenomenon as a serious crime that warranted a repressive response.

Yet, these statements must be understood in light of the fact that patients with a migration background are known to have a higher prevalence of kidney disease and decreased chances of receiving a kidney transplantation [38-40]. Indeed, a few respondents stated that they treated patients who had complained about the Dutch organ procurement system. These patients believed that the wait list only existed for patients of a different ethnic origin and told their caregivers that the only solution for them be transplanted within a short time frame, was to undergo one overseas. Explanations for patients' underrepresentation in transplantation programmes include language barriers and poor communication with caregivers. This, in turn, is reported to lead to shortcomings in knowledge about their disease and treatment options. Other reported reasons are unwillingness of family and friends to donate and reluctance to ask family and friends for a kidney [41,42]. In the underlying study, professionals also frequently brought up language barriers in their exchanges with patients, referred to their families' unwillingness to donate and referred to patients' reluctance to bring up the subject of a kidney donation with family:

> *When they raise the issue, we tell them that it's custom in The Netherlands for family members or others in their environment to donate a kidney. But they consider that a strange solution. Instead they say, 'If I need a kidney, I'd rather buy one than receive one from a family member'.* (N4)

Occasionally, during these exchanges, professionals were told that family members had supported patients by finding donors overseas, by paying or raising funds for the transplantations and by accompanying patients on their journeys abroad.

Nonetheless, the importance that participants attributed to ethnic ties and family bonds as an explanation for cross-border kidney purchases, may be somewhat overstated. First of all, ethnic affiliations didn't guarantee successful transplant endeavours in all cases. A few professionals treated patients who travelled to their countries of origin for transplantation but returned '*empty handed*'. Furthermore, a number of patients were not ethnically affiliated to their destination countries. Respondents spoke, amongst others, of a patient from Morocco who travelled to China, a man from Surinam who was transplanted in Colombia, a Belarusian who travelled to Azerbaijan and a native Dutch patient who presumably bought a kidney in Pakistan. How these patients organized their transplantations, however, is unknown, as most professionals didn't enquire after the transplants. In the following paragraph we address how professionals dealt with their patients' suspected kidney purchases.

Moral ambivalence in professionals' attitudes and their appeals to legal duties

The participants largely disagreed with their patients buying kidneys. They pointed out that the act was prohibited by law and that it was unethical because of the possible exploitation of donors. Most added that it could also involve grave medical risks for patients.

It is worth noting however, that a number of professionals stated to have less objections to kidney purchases if it was strictly government-controlled without middlepersons pocketing the profits and wherein donors received adequate protection and compensation. Professionals' concerns about their patients' suspected kidney purchases thus mainly lay in the likelihood that they had bought the kidneys on the black market from exploited donors.

Although they largely condemned kidney purchases, they also understood why patients bought kidneys. Respondents felt sympathy for their patients, often describing them as '*victims of their illnesses*'. As a nephrologist stated:

> *We aren't robots. There's always an emotional component in which you ask yourself, 'Do I want my patient to benefit from the transplant or not?' or, 'What would I do if I stood in his shoes?'* (N11)

Professionals referred to patients' desperation due to the long wait time and their dialysis-related complaints to explain why they travelled overseas. Some criticised the government for its failure to procure sufficient organs and felt that patients were not to blame.

This ambivalence in respondents' opinions and attitudes towards their patients was a recurrent theme in all interviews. Many described their patients' suspected purchases as ethically complex and '*difficult*'. Sharing his mixed feelings about his patient's transplant venture, a respondent elaborated:

> *If the patient benefited from the transplant, then I'm happy for him. But if you would ask me to share my opinion before he leaves, I would say that I condemn it and that I don't offer my support. Morally we try to find a way out of this, you see? Because we just don't know how to deal with the issue.* (N23)

A minority felt less sympathy towards their patients. These participants explained that having a kidney disease in The Netherlands wasn't simply a matter of life or death. Referring to the country's successful living kidney donation programme (The Netherlands has the highest rate in living kidney donations p.m.p. in Europe), they explained that patients could receive a live donor kidney from friends or family. According to these professionals, going abroad for a kidney transplant wasn't necessary.

Nevertheless, most refrained from sharing their opinions with patients because they didn't want their '*moralistic attitude*' to affect their professionalism:

> *I really condemned what they did. But when I realized I felt that way, I thought to myself, 'I shouldn't communicate that to my patients'. I shouldn't say that I condemn what they did or hold a grudge against them. I don't believe that is professional.* (N1)

Emphasizing the primacy of their Hippocratic Oath (which requires doctors to uphold their obligation 'to first do no harm', their secrecy oath and their duty of medical care) [43], most explained that it was an inherent part of their jobs to set aside their personal, moral convictions:

> *Even if you find your patient intolerable. Even if he is a pedophile who cannot keep his hands off little children. All those persons deserve care. And I will give that to them. I switch off those ethical and moral aspects. I will even care for that horrible pedophile. In my opinion he is not different from those who purchase kidneys abroad.* (N14)

Universally, codes of medical ethics dictate that doctors have a duty to care for any patient in emergent need [22], 'including patients who may have obtained an organ through transplant tourism' [25]. Yet, these codes also contain 'conscience clauses' that allow doctors to defer care in non-emergent situations, such as in the case of abortion or euthanasia [44,45]. In the underlying study however, respondents appealed to their duty of medical care, explaining that it prevailed over other (ethical or personal) considerations, such as deferring care of the patient to a colleague, or protecting the donor from possible harm.

Gill et al., have stated that doctors have a duty to advocate for their patients, but 'as members of the medical community, they also have a duty to prevent harm to other individuals', including the possible exploited donor [25]. According to the professionals in this study however, the primacy of the secrecy oath and duty of care overrode the protection of the donor. Many pointed out that they didn't feel a connection with the donors and were not in the situation to protect them because they were '*unknown and far away*'.

What consistently arose in this study, is that their appeal to their duty of medical care, justified their '*not wanting to know*' or '*not needing to know*' about their patients' suspected kidney purchases:

> *My patient came back with a need for care that I provided. Whether it was an ethically condemnable transplantation or not, has nothing to do with my duty of care. For that reason, I didn't pay attention to whether the donor was paid or not. We don't need to know everything.* (N14)

These findings differ from the results of our previously reported survey, where the majority of professionals reported a conflict of duties, because they felt unable to protect the possible victim donor and because they were unable to prevent the crime [30]. The underlying study, by contrast, revealed that whereas some respondents stated that they experienced tensions, others avoided dilemmas by preferring not to know (too much) about their patients' alleged wrongdoings.

Cohen has described avoidance to, or 'turning away' from crime as a 'state of denial': a form of ignorance that lies in between knowing and not knowing [46]. Indeed, the professionals used a number of justifications or 'excuses' [47] for why they didn't want or

need to know about the alleged purchases. Some explained that it happened a long time ago and thus considered it a 'fait accompli' ('*there's no use in crying over spilled milk*'). Others explained that asking their patients would take up too much of their valuable time, or stated that they simply weren't interested in knowing about the purchase, or pointed out that they wanted to avoid having 'guilty knowledge' about the donor:

> *Our policy is that the kidney was purchased outside our institution. We deliberately don't ask, because we don't want to know. We don't want to hear that he bought the kidney from a poor person who sold his kidney in order to provide shelter for his family. We want to protect ourselves from such sad stories.* (N31)

Nonetheless, Cohen's work and other commonly used criminological theories that are used to explain the denial behaviour of perpetrators and bystanders (see for instance Van de Bunt's work on walls of secrecy and silence in the construction industry [48]), are not fully apt to explain the participants' attitudes and behaviours towards their organ buying patients. Rather, their reasons for looking away should be understood in light of their appeal to 'higher loyalties' [49]. In this study, this constituted the fulfilment of their *legal duties* towards patients. Emphasizing the importance of maintaining trust in the relationships vis-à-vis their patients, professionals explained that they avoided the subject of kidney purchase because they didn't want to give their patients the impression that they were being '*accused*' and feared that '*interrogating*' them would negatively affect their relationship. Indeed, parallels to other studies can be drawn here, for instance regarding those between lawyers and their clients. Mann (1985) found, for example, that lawyers also had no interest in knowing about their clients' wrongdoings because this knowledge could affect the quality of their work [50].

Similar to lawyers, professionals also have a duty to maintain secrecy vis-à-vis their clients (patients). This duty similarly trumped their need to know about the kidney purchase, in particular because, as they pointed out, '*we aren't allowed to report our patients anyway*'. Doctors do not have an obligation to investigate and prove whether their patients will commit or have committed crimes. In addition, they are exempted from the duty to report crimes [51]. Jurisdictions generally only permit (and some obligate) doctors to disclose confidential information about patients to authorities under exceptional circumstances, such as when the disclosure will prevent (severe) physical harm to the patient or another individual. Justified reasons for disclosure are child abuse and crimes that may lead to death of the victim (i.e. gun and knife wounds) [22,52].

The participants however, largely doubted whether kidney purchases passed this harm-threshold and thus didn't believe that a kidney purchase would justify a breach of secrecy. Many therefore feared legal repercussions if they would report their patients. They added that it was practically impossible for them to determine whether patients had, in fact, purchased the kidney, and whether harm was going to, or had been inflicted upon the donor as a result. Furthermore, many were uncertain whether it was, in fact, illegal for patients to purchase organs abroad. It is worth noting that under the Dutch Law on Organ

Donation and the Dutch Criminal Code, a cross-border organ purchase is only punishable if the double criminality principle is fulfilled. [D] Nevertheless, in the absence of legal guidance on this issue, professionals' knowledge of these legal aspects was poor. Indeed, the participants expressed a need for legal clarity on this topic.

Highlighting the demarcation of duties between doctors on the one hand and those of police, detectives and judges on the other, participants added that it wasn't their job or business to prove or know about kidney purchase.

> *I'm not Sherlock Holmes. I'm not going to try to find out whether they purchased the kidney. I'm just not going to do that. I don't care. Why should I care?* (N30)

From their accounts, it was clear that professionals regarded cross-border kidney purchases as links in the illegal transplant chain that they could not wholly prevent and which occurred beyond their control. Hence, they did not consider kidney purchases as part of their job or duty:

> *I don't feel that I take part in the crime. I'm not the treating physician over there. I don't perform the operation. The patient is with me until a certain moment. Then he leaves and comes back. In my opinion, I don't carry responsibility for what happened in the meantime.* (N14)

Elaborating on their responsibilities vis-à-vis their patients' purchases, participants highlighted patients' own autonomy in the matter:

> *My patient has his own responsibility for what he does to another. I don't necessarily carry all of that responsibility.* (N12)

They pointed out that all they could do, was discourage patients from going abroad by emphasizing the medical and ethical risks and informing them about domestic transplant solutions. Many pointed out that their medical duty ended there:

> *At a certain point, my medical duty ends. I can't lie in front of the plane's wheels to stop the patient from going. Besides, we already have enough other problems to worry about.* (N6)

Cohen has stated that intervention to crimes becomes unlikely when responsibility is diffused [46]. However, the attitudes and behaviours of the professionals in the underlying study must be understood in light of their experiences. These reveal that their patients' kidney purchases cannot be rigorously determined. Rather, they are *suspected* and *assumed*. Indeed, some of the presented cross-border transplants may not have constituted illegal purchases at all. They may have been legally performed, for instance with related donors.

And, even if they were illegal, the question remains whether harm or suffering took place, and whether the possible harm would justify a breach of secrecy.

There was some acknowledgment that professionals' duties functioned as a convenient 'veil' behind which the respondents could hide. As a nephrologist articulated:

> *It's easy for a doctor to say, 'I am his doctor. I'll do everything for my patient. I shall keep my mouth shut. I shall not notify the police. I will treat him and that's that'. In a way, we can hide behind that.* (N3)

Another doctor stated the following:

> *It's impossible to tackle transplant tourism if the transplant profession takes on this position.* (N11)

When we asked whether professionals would consider reporting their suspicions—without revealing the identity of patients—to law enforcement to support them with investigating and prosecuting trafficking networks, most replied that they hadn't thought about that possibility. In addition, they were uncertain whether they were (legally) permitted to do so, and if yes, where they could report such information. When asked if they would consider reporting information such as the name of the transplant center where the patient obtained the transplant or the names of hospital staff who carried out the transplantation (if such information was available), many responded that a mandatory, anonymous reporting code could be a good solution to acquire more information and increase detection. Most added that legal guidelines on the issue would be helpful.

Nevertheless, they pointed out that such a code should not harm their relationship with patients. They reiterated that whilst it is the responsibility of governments to combat organ trade, it remains theirs to care for, and protect their patients.

CONCLUSION

Encouraging disclosure of suspicious transplantations

In this study, we have illustrated that Dutch transplant professionals incidentally treat patients who are suspected of kidney purchases abroad and that they turn a blind eye to their patients' presumed purchases. Their attitudes and behaviors are explained by the (national) legal framework in which they fulfil their obligations towards patients. In this framework, a hierarchy of rights and duties exists in which secrecy, care and trust in the relationship with their patients prevail. These duties override other principles or concerns such as preventing kidney purchases and protecting (foreign) donors from harm. Furthermore, professionals are exempted from the duty to report patients who buy organs and may, in fact, face legal repercussions if they would report their patients to authorities. Professionals' rights and duties thus keep in place a wall of secrecy and silence between them and their patients. Secrecy and silence function as a tacit agreement between patients and their

caregivers which keeps the subject of kidney purchase at a safe, unspoken distance and allows professionals to turn away from its suspected occurrence.

It can be argued however, that these walls of secrecy and silence do little to curb the organ trade, and to prevent kidney purchases in particular. Moreover, professionals' perceived 'responsibility gap' towards cross-border kidney purchases contrasts with the aforementioned developments in the transplant community, which increasingly demand a more pro-active approach from transplant doctors in preventing organ purchase [26,27]. There is thus a discrepancy between what is encouraged from transplant professionals at the international level and their actual attitudes and behaviours towards patients in their day-to-day local practices.

Nonetheless, the results of this study indicate room for advancement in encouraging professionals to become more proactive in the international fight against the organ trade. First of all, this study shows that organ purchases remain hidden, not because professionals have an interest in concealing them, but because the law dictates that they must remain silent about their patients' alleged purchases. Thus, to generate a more proactive stance from transplant professionals, changes must be made to the legal framework that governs their rights and duties. More specifically, governments need to loosen the conditions under which professionals can legitimately report suspicious transplant activities [29,53].

Elsewhere, we have proposed the implementation of an anonymous reporting code that enables the reporting of suspicious transplant activities (such as the names of transplant centers and hospital staff that facilitate the cross-border transplants) *without revealing patients' identities* [30]. The participants accepted the idea of a (mandatory) anonymous reporting tool if patients' identities remained protected, and if the legal procedure was clear.

Such a tool can have various aims and benefits: first, it can support law enforcement in investigating those who facilitate illegal organ transplantations abroad. Professionals could disclose this information to the same national institutions that receive information on human trafficking, domestic violence and child abuse. After analyzing the reported information, the reporting center can submit the information to the national police, who in turn contacts the police forces or liaison officers of the transplant destination country. This national-international reporting method would allow for the information to reach the appropriate authorities and would strengthen the cross-border collaboration and enforcement of the crime [30].

Second, a reporting tool can help increase empirical information and knowledge about the mechanics of organ trading. This, in turn, may help address the question whether organ trade largely occurs in an organized manner involving trafficking of donors (as is portrayed in the literature) or whether it can also be viewed in a different context. Although it is not impossible that in this study patients may have organized their transplants with the support of criminal networks, we did not find indications that confirm this claim. Rather, the participants' accounts suggest that patients obtained transplants with the help of family. Despite that one does not necessarily rule out the other, it may be that cross-border organ purchases are better positioned within the discourse on (illegal)

migration and mobility than within a framework of human trafficking and transnational organized crime. Indeed, studies on (illegal) migration have shown that the majority of migrants organize their arrival into destination countries with the help of relatives, and not through organized criminal networks [5,54]. More in-depth research will be needed to enhance understanding of this topic.

Finally, increased empirical information on transplants abroad can help distinguish illegal transplants from legal ones. It has been suggested that so-called 'referral schemes' can be a solution in fostering legitimate transplants abroad for patients who are unable to receive transplants in their resident countries [28].

It is likely that cross-border kidney purchases will persist in the absence of disclosure by transplant professionals who suspect they took place. Transplant professionals who treat patients who are suspected of kidney purchase are important figures in the fight against organ trade and should be considered as such, even if they don't take active or knowing part in the crime. Reporting tools can help break the walls of secrecy and silence in the organ trade. At the time of writing (2016) no such tools exists in The Netherlands, or in other countries.

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NOTES

A Because patients are treated by more than one transplant professional, this number does not represent the number of patients that travelled. However, the survey was completed by TPs from all transplant centers, and all centers reported clusters of patients that travelled.

B Whereas surgeons perform the transplant operations, nephrologists specialize in kidney care and treat people with (chronic) kidney disease.

C Seven professionals knew three or more patients who presumably purchased kidneys. The maximum number of patients one respondent said he treated was ten, although this respondent was only able to recollect details about four patients. Many professionals, in particular those working at the same hospital or in the same transplant region, presumably spoke about the same patients, although we could not establish this with certainty in all cases. Consequently, we were unable to determine the total number of patients who travelled abroad for (suspicious) kidney transplants.

D This principle requires that the patient needs to be of Dutch nationality and the destination country also needs to prohibit organ purchases. At the time of writing, the legal provisions governing (cross-border) organ purchases have not been applied in court or clarified in case law. We discuss the legal implications for patients who buy kidneys abroad in: Ambagtsheer F, Zaitch D, Van Swaaningen R, Duijst W, Zuidema WC, Weimar W. (2012), Cross-Border Quest: The Reality and Legality of Transplant Tourism. Journal of Transplantation:1-7 (http://dx.doi.org/10.1155/2012/391936)

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5

THE MODUS OPERANDI, INVESTIGATION AND PROSECUTION OF NETWORKS

VII

TRAFFICKING IN HUMAN BEINGS FOR THE PURPOSE OF ORGAN REMOVAL

A CASE STUDY REPORT

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INTRODUCTION

Background and objectives

The present report builds upon the conclusions presented in the HOTT project's literature review, 'Trafficking in human beings for the purpose of organ removal: a comprehensive literature review' [1]. This review concluded that a study of the current literature provides limited information and knowledge about the nature and incidence of the crime, and needs to be strengthened by other sources of information.

The HOTT project's objectives are to:

— increase knowledge about trafficking in human beings for the purpose of organ removal
— raise awareness among target groups
— improve the non-legislative response

Purpose of study

This case study report addresses the gaps that were already highlighted in the HOTT project's literature review. This study's purpose is to contribute to existing gaps in knowledge concerning (a) the actors and their modus operandi of contemporary organ trafficking networks and (b) the experiences of police and prosecution in disrupting and prosecuting the persons involved in these networks.

Selection of countries and cases

To acquire in-depth knowledge about the criminal networks involved in trafficking in human beings for the purpose of organ removal (THBOR), the research team collected information in the field by interviewing people worldwide who were directly involved in and affected by the events that led to prosecutions and convictions. With the financial support of the European Commission Directorate General Home Affairs, the Central Division of the National Police of The Netherlands, the Magnus Bergvalls Foundation (Sweden) and the Royal Physiographic Society (Sweden), the research team travelled to 4 countries to study 3 trafficking cases:

1 South Africa, Durban (November 2012)—Netcare case
2 Republic of Kosovo, Priština (September 2013)—Medicus Clinic case
3 State of Israel, Tel Aviv and Jerusalem (October 2013)—Netcare and Medicus Clinic case
4 United States of America (USA), New York (March 2013)—Rosenbaum case

Visiting these countries made it possible to talk to key persons and to access data that would not have been acquired through literature—or desk research. The countries and cases were selected because of common features: police and prosecution investigated international networks involving (elements of) THBOR and succeeded in gathering sufficient evidence to bring these cases to court that led to convictions of the accused, they

relied on assistance from other countries and were able to demonstrate how to achieve successes and overcome obstacles in international criminal collaboration.

Aims of study

The research questions were:

1. What were the signals of the illegal activities that led to the police investigation?
2. How was the criminal investigation performed?
3. What were the modus operandi of the actors?
4. Under what laws and charges did the prosecution(s) take place?
5. What were the obstacles to prosecution and how were they addressed?
6. What was the judgment in the case?

Other cases and countries

The cases presented in this report show that recipients and sellers from European and non-European countries have undergone transplantations which were facilitated by criminal organizations. It's important to mention that these cases do not fully reflect the current global status quo of the human organ trade. Investigations and convictions of (suspected) networks took/take place in other countries as well.

Consultation of Europol, human trafficking police experts in European countries and the Organization for Security and Co-operation in Europe report on trafficking in human beings for the purpose of organ removal in the OSCE Region [2] have shown that since 2000 criminal investigations into human trafficking for the purpose of organ removal have taken place in at least five European countries: Bulgaria, Greece, Moldova, Ukraine and the United Kingdom. These cases are presented in the Dutch police report 'The trade in human organs and human trafficking for the purpose of organ removal. An exploratory study into the involvement of The Netherlands and Europe' [6]. In addition, investigations and convictions took/take place in China, India, Singapore, Jordan, Turkey, Belarus, Costa Rica, Spain and Brazil. These cases are presented by the Organization for Security and Co-operation in Europe in its report mentioned above [2], in the United Nations Office on Drugs and Crime (UNODC) Case Law Database [3] and in the media [4]. According to Organs Watch, networks also exist in Argentina, Cyprus, Honduras, Panama, The Philippines, Ecuador, Bolivia, Colombia, Syria, Iran (where brokers infiltrate a regulated system of organs trafficking), Vietnam, Cambodia, Nepal, Thailand, Pakistan, Egypt and Albania.

Furthermore, recent research reveals that indications and suspicions of organ trafficking occur in many European countries, that are/have not been investigated. For instance, the HOTT project's second report [5] illustrates that patients travel abroad from Sweden, The Netherlands and the former Yugoslav Republic of Macedonia to purchase kidney transplants in China, Pakistan, India, Iran and other countries. A 2013 survey held amongst transplant professionals in The Netherlands found that almost half of the professionals have treated patients in the last 5 years who travelled abroad for kidney transplants, with suspicions or certainty of organ purchase in 70% of cases. These patients are not reported due to doctors' duty of confidentiality and their privilege of non-disclosure. The

Dutch police report mentioned above [6] presents signals of trafficking in human beings for the purpose of organ removal in The Netherlands that could not be further investigated, because the signals did not contain sufficient information in order for a police investigation to be performed. The impact of the demand for organs originating in Europe and other regions on the global organ trade should not be underestimated and should be more rigorously addressed. The organ trade is an international crime that is not confined to the regions and countries presented herein.

METHODS AND SOURCES

This study is based on the following research methods:

— in-depth interviews
— study of case materials

The interviews were the predominant research method. In addition, the research team collected a large number of documents. The team also conducted one field observation. This took place during a court hearing in South Africa and was recorded in field diaries. The methods are described in more detail below. The research materials were supplemented by published research in scholarly, medical and human rights journals and media reports.

Interviews

The number of interviews and respondents are listed below. Most interviews were held with more than one person and some respondents were interviewed more than once. The respondents came from a variety of backgrounds. Three interviews were conducted with the help of an interpreter: with a police officer, with a representative of the Ministry of Health and with an organ recipient. The interviews aimed to get insight into the respondents' experiences and perspectives.

table 1 Interviews and respondents

respondents	number of respondents	number of interviews
Police officer	8	6
Prosecutor	8	5
Dpt. of International Affairs representatives	2	
Defense lawyer	7	5
Ministry of Health representative	3	3
Ministry of Internal Affairs representative / National Coordinator Human Trafficking	2	1
International organization representative	7	4
Insurance company representative	1	1
Nephrologist / surgeon	4	3
National transplant coordinator	1	1
Social worker	1	1
Organ recipient	3	6
Founders of non-profit organization on organ donation	2	1
total	**49**	**37**

Selection of the respondents

Respondents assisted the team members to get in touch with new involved persons after their arrival in the country. Interviewees were e-mailed and/or phoned with the request for an interview. All were given an information sheet prior to each interview. This sheet described the purpose of the HOTT project, the aims of this study and presented the names, affiliations and contact details of the members of the research team. It also emphasized that data would be used anonymously and be kept strictly confidential.

Data processing and analysis

The interviews were tape-recorded if so permitted by the respondent and transcribed verbatim by the project team. Due to the sensitive nature of the topics, a number of respondents did not allow being tape-recorded. In these cases, the research team took notes during the interview and had written reports based on the notes immediately after the interview.

Questions

The interviews took place using a 15-page, uniform, semi-structured list of prepared questions that addressed different themes, derived from the research questions. Small modifications were made in order to adapt questions to the country in question.

Case materials

Case materials formed the second source of this study. The following documents were provided by respondents and given to the research team:

— Kosovo: indictment, closing statement, judgment (containing witness- and victim statements), various legislation, defence letters, security council resolutions;
— South Africa: charge sheets, legislation, judgment, a large number of (court) documents including notices of motion, respondents' answering affidavits, applicant's practice notes, admissions of guilt, plea sentence agreement;
— USA: transcript of the sentencing hearing, criminal complaint, pre-sentence memorandum of the defence, charge sheets;
— Israel: Organ Transplant Act, Penal Act, Prohibition of Trafficking in Persons Act (Legislative Amendments), Organ Transplantation Regulations, Memorandum of the Ministry of Health's Director General, indictments, protocols of court sessions, court's rulings and judicial decisions, presentation of the deputy general manager of a health insurance company, presentation of the director of Overseas Surgeries Department in a public healthcare provider and presentations by the Israel Transplant Center.

SCOPE AND USE OF TERMS

The HOTT project is a response to the call by the European Commission Directorate General Home Affairs for project proposals focusing on *trafficking in human beings* [7]. The

primary scope of this project is therefore *trafficking in human beings for the purpose of organ removal* (THBOR). Consequently, THBOR is the main focus of this report. However, laws directed against human trafficking were not applied in all of the studied cases. Because these cases contained elements of THBOR, they are addressed in this report.

THBOR is defined and prohibited in Article 4 of the Council of Europe Convention on Action against Trafficking in Human Beings [8] and the Directive 2011/36/EU of the European Parliament and of the Council [9]. THBOR is also criminalized in Article 3 of the United Nations (UN) Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children (hereafter Palermo Protocol) which supplements the UN Convention against Transnational Organized Crime [10]. THBOR is further prohibited by the Optional Protocol to the Convention on the Rights of the Child on the Sale of Children, Child Prostitution and Child Pornography [11]. In this report the definition is used as laid down in Article 3 of the Palermo Protocol. This protocol defines THBOR as:

table 2 Article 3 Palermo Protocol

Article 3 Palermo Protocol	
'For the purposes of this Protocol:	
a	'Trafficking in persons' shall mean the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs;
b	The consent of a victim of trafficking in persons to the intended exploitation set forth in subparagraph (a) of this article shall be irrelevant where any of the means set forth in subparagraph (a) have been used [...].'

The full article can be found in Article 3 of the Palermo Protocol [10].

This definition includes 3 key elements: an action (e.g. recruitment and transfer), a means (e.g. coercion and deception) and a purpose (exploitation). These elements have to be present in order for an act to constitute THBOR. If the victim is a child however, the presence of these means does not have to be proven [12]. The definition does not prohibit the trade in organs per se. In order to be classified as a criminal act it is not so much the intended sale and purchase of organs, but the exploitative actions and means used to remove a person's organs that count [13]. The HOTT project's literature review addresses this definition in more detail as well as other terms [A] and definitions that are used throughout this report [1].

CASE STUDIES

SOUTH AFRICA — THE NETCARE CASE

Start of investigation	2003
Charges	Fraud; forgery; uttering; unlawful acquisition; use or supply of tissue, blood or gamete (minors); use or possession of proceeds unlawful activities; illegal receipt of payments (minors)
Convicted	Netcare represented by Ian Goble, 1 nephrologist, 1 recipient, 1 translator, 1 local coordinator and 1 broker
Remaining accused	4 transplant surgeons, 2 transplant coordinators
Respondents of the study [R]	Police investigators, prosecutors, defense attorney, social worker, representative of the Ministry of Health
Case material	Charge sheets [D1], legislation [D2], various court papers from the proceedings [D3]

Case study by Frederike Ambagtsheer, Susanne Lundin, Martin Gunnarson and Jessica de Jong
23 November—3 December 2012; Durban, South Africa

'*After seven years of obfuscation and denial, South Africa's largest private healthcare group, Netcare, finally confessed to its role in a cash-for-kidneys scheme and to benefiting from associated international trafficking of living donors.* [...] *Netcare's conviction in the Durban commercial crimes court is said to be a world first—no other hospital group has been found guilty of supporting an organised trafficking scheme dealing in organs.*' [14]

Signals of illegal activities

In 2003, 'out of an act of conscience' a whistle-blower told the police about the illegal transplantations that took place at Netcare's hospital, St Augustine's, located in Durban [B]. It was suspected that illegal transplants also took place in Cape Town and Johannesburg. This was the first signal that reached the police, and it was decisive in the sense that it motivated them to initiate an investigation. However, once involved in the investigation, the police realized that there had been other signals of illegal transplants taking place prior to the moment when the whistle-blower contacted the police. One of the first came from the American anthropologist Nancy Scheper-Hughes and her organisation Organs Watch, who had picked up on the illegalities and had reported this to various authorities and organisations. In conjunction, a South African transplant surgeon working at a public hospital in Cape Town, wrote an 'open' letter warning his fellow surgeons about 'Israeli transplantations'. Furthermore, employees from Netcare's hospital and a blood bank, where the cross-matching of suppliers and recipients took place, asked their superiors what was going on or shared their suspicions with their superiors. At an international transplantation conference in the USA, surgeons from other countries also accused Netcare and its transplant surgeons [R] [15].

Criminal investigation

When the police found out about the illegal transplantations going on at Netcare's hospital, St Augustine, they first researched transplantation in general and the law regulating it, The Human Tissue Act. According to one of the respondents, knowing the particularities of legal transplantations was crucial in identifying the ways in which the transplantations at St Augustine's deviated from this. Following this, the gathering of evidence started. Quite early on however, they decided to limit the investigation to St Augustine's. This was where the evidence was the strongest. Still, it became a major investigation [R].

At the outset, the dilemma arose that an immediate search of the transplant clinic and blood bank would reveal to the perpetrators that the police was on their tail. Therefore, the investigating team chose to take 'the undercover route' [R]. But this route failed, due to technical problems. However, unexpectedly, one of the organ brokers involved in the illegal activities opened a charge of theft in which he openly stated that an organ supplier had run off with money that he had received in advance, which was subsequently established to be true. Now the police had to act since they were worried that Netcare and their accomplices would start destroying evidence. They stopped the supplier and his wife at the airport and took their statements. Four days later they obtained a search warrant and searched the transplant clinic for the first time. During this search they successfully gathered all the 'transplant files', which contained the records of the patients, and the transplant register, in which all the transplantations that had been performed were recorded and where the surgeons were mentioned by name [R]. A couple of weeks later they performed a second search at St Augustine's hospital as they became aware of the need to gather the records of the patients' entire hospital stay and the documentation pertaining to the operating theatres where the surgeries had taken place. To get access to these files, they brought with them a representative from the Ministry of Health who was authorized under the Human Tissue Act to function as an 'inspector of anatomy' with access to all of the hospital's documentation. They also performed a search of the blood bank, where they collected documents that proved that potential recipients were cross-matched against several suppliers which, in turn, indicated that they were not related [R]. The office of a nephrologist was also searched and medical files were confiscated. These were mostly files related to the recipients of kidneys. Computers were also seized. It was established that data entries in these letters provided to recipients were changed from 'non-related' to 'related'. The typist who changed these letters was identified and she provided a statement under oath that she had been instructed to do this.

An organ broker, a local coordinator, a nephrologist, a transplant coordinator and a translator were consequently arrested. These arrests and the hearings that followed also became essential evidence. Furthermore crucial was the investigating team's collaboration with the other involved countries. In Brazil and Romania the team interviewed suppliers and/or local organ brokers. Establishing collaboration with Israel proved more difficult. A request for mutual legal assistance and police assistance was forwarded to Israel in order to obtain statements from suppliers and recipients of kidneys. This was done at an early stage of the investigations. Statements arrived in '*drips and drapes*' over a long period of

time. Only later, after the withdrawal of the case against the surgeons and coordinators, the investigating team finally received permission to visit Israel. After this, they collaborated successfully with the customs officials and received written statements from suppliers and recipients [R]. Despite this vast body of evidence, the South African state decided to provisionally withdraw the charges against Netcare in 2007. According to the respondents, the withdrawal had several causes. Two major causes were the delay in evidence coming from Israel and the failed attempt to have the main organ broker extradited to South Africa. In 2010, however, the charges were reinstated [R].

Modus operandi

The illegal transplants at St Augustine's started when an Israeli organ broker approached Netcare in 2001. His proposition was that he would provide well-paying Israeli patients in need of a kidney and paid suppliers willing to sell one of their kidneys. What Netcare would bring to the equation was the provision of transplant services [D1].

The vast majority of organ recipients were recruited from Israel. Four recipients came from the USA and South Africa. The price of around $120.000 included the kidney, the services as well as the travel and accommodation. The suppliers were initially also recruited from Israel and got paid around US$20.000, but later on the organ brokers became aware that they could acquire cheaper kidneys in Romania and Brazil. Here, the suppliers were willing to take part with a kidney for between US$3.000 and US$6.000. In Brazil, from where the vast majority of suppliers came and 2 local recruiters (one an expatriate retired Israeli military officer, the other a retired Brazilian military police captain) also took care of practical tasks such as assisting the suppliers with passports, visas, travel bookings and preparatory blood tests. On arrival in South Africa, the suppliers were chaperoned by local actors. Some of them also acted as interpreters. Initially suppliers were housed in hotels and later, when the number of suppliers increased, in an apartment at the Durban seafront [R,D1].

In South Africa at this time there was a ministerial policy in place that required all transplants between non-related donors and recipients to obtain prior approval from a ministerial advisory committee. In order to circumvent this requirement, Netcare and its accomplices made all suppliers and recipients sign papers that said that they were related when in fact they were not. Taking care of this, 2 transplant coordinators were employed by Netcare. Another crucial actor was a South African nephrologist who was responsible for referring all patients to the transplant clinic. The transplant surgeons were also central players. Four of them were charged. Prior to the operations a blood bank performed the cross-matching of recipients and suppliers [R,D1].

The payments relating to the transplantations were transferred in different ways and at different points in time. The recipients paid the Israeli organ broker in advance, who then paid Netcare, who in turn distributed the money to the various involved actors in South Africa. The nephrologist who was later convicted also received payments directly from the main broker into a bank account in Canada. The suppliers were paid in cash, usually after the operation [R,D1].

Laws and charges

At the time of the illegal transplantations at St Augustine's, South Africa did not have legislation specifically prohibiting trafficking in persons for the purpose of organ removal. Two laws were applied, The Human Tissue Act (dating from 1983), and the Prevention of Organised Crime Act (dating from 1998). None of them were well suited to the situation. The Human Tissue Act 'was old and badly written', as one of the respondents expressed it [R]. One of the main loopholes in this law was that it only targeted persons or organizations that received financial remuneration for an organ. The buying of organs was thus not illegal. It was also not illegal for so-called authorized institutions to accept money for an organ [D2]. The charges that were brought, varied to some extent between the defendants. But in the charge sheet issued in 2010—which contained charges against Netcare, the 2 transplant coordinators, the 4 surgeons, the nephrologist and one of the interpreters—the majority of charges that were used were specified. These were: fraud, forgery, uttering, unlawful acquisition, use or supply of tissue, blood or gamete (minors), use or possession of proceeds from unlawful activities, and illegal receipt of payments (minors) [D1, D2].

Judgment

Since 2003, 12 people have appeared in court records, 12 have been indicted and 6 have been convicted. In 2010 the Netcare health group was convicted. Netcare was fined Rand 4-million (approximately US$380.000) for its role in 109 illegal operations at St Augustine's involving non-related donors and recipients. Five of these operations involved minors, which is also illegal, even with parental consent. Netcare also forfeited R3,8-million (approximately US$345.000) to the Assets Forfeiture Unit. In terms of the plea agreement finalised in court, criminal charges were withdrawn against Friedland as Netcare's chief executive [R, D1].

The 4 surgeons and 2 transplant coordinators who were accused of involvement in the illegal transplants were arrested in 2004 and 2005 but released on bail. In 2011 they requested a permanent stay of prosecution [c] to the Kwazulu-Natal High Court in Durban which was granted to them on 14 December 2012 [R, D3]. The court granted them the permanent stay because of 'an inordinate delay in doing what had to be done to facilitate the beginning of the trial and driving it to its conclusion' [D3] and because the evidence was deemed insufficient [R]. At the time of writing it is not known whether prosecution will appeal the court's decision.

Start of investigation	2008
Charges	trafficking in persons, organized crime, unlawful exercise of medical activity, abusing official position or authority, grievous bodily harm, fraud, falsifying documents, falsifying official documents
Judgment	29th April 2013 (published 12th November 2013): prison sentence for 5 defendants; acquittal of 2 defendants
Defendants (7)	urologist/owner of Medicus Clinic, director of Medicus Clinic (son of the owner/director), 3 medical doctors, specialist anesthesiologist, anesthesiologist, medical doctor/anesthesiologist
Fugitives (2)	organ broker and transplant surgeon
Respondents of the study [R]	police investigator, lead prosecutor, defense attorney, senior protection officer UNHCR, officer in charge of inspection at Health Ministry, task manager/rule of law EU Office in Kosovo, head rule of law liaison office UNMIK, senior policy adviser, Interpol officer, Chief of Mission of IOM, national coordinator trafficking in human beings/ deputy minister Ministry of Internal Affairs.
Case material	amended indictment [D1], closing statement [D2], judgment [D3], legislation [D4], security council resolution [D5]

Case study by Frederike Ambagtsheer, Jessica de Jong and Martin Gunnarson
16-20 September 2013; Priština, Republic of Kosovo

> *'An EU-led court in Kosovo has found five people guilty in connection with a human organ-trafficking ring. The five are accused of carrying out dozens of illegal transplants at the Medicus Clinic in the capital, Priština. Meanwhile two former government officials also charged in the case have been cleared of involvement.'*[16]

Signals of illegal activities

Suspicions first arose among the Kosovo Police (KP) and Immigration Services at Priština Airport (exact date unknown) [R, D1-3]. A KP investigator was assigned to lead the investigation in October 2008. He discovered that foreigners upon arrival in Kosovo brought with them invitation letters from the Medicus clinic. The letters stated that they were coming to Medicus for treatment of heart conditions. This caused suspicion amongst the airport authorities because in the foreigners' countries of origin, heart treatments are considered to be superior to those in Kosovo [R].

Criminal investigation

The principal investigator compared these letters and discovered that 2 individuals, A and S were actually in Kosovo at that time (A would later turn out to be the organ supplier for S). On inspection of A's flight ticket, the investigator knew when A would return to Istanbul. The KP stopped and questioned A at the airport on 4 November 2008. He was accompanied by an Israeli broker and the brother of S. During questioning KP noticed that A had been coached to provide a particular story, and say that he had undergone heart treatment. 'A' made a very 'concerned' impression [R]. Eventually he admitted that he had undergone surgery, but he did not (immediately) explain that he had sold his kidney. The investigator asked A to show his scar. He then stated that his kidney had been removed and that he had been promised $15.000 for his kidney [R]. After medical examination, A was confirmed to be in poor medical condition and incapable of traveling. He was then taken into hospital. Following this, KP investigators, medical experts, Ministry of Health officials, the Department of Organized Crime and UNMIK International police searched the Medicus clinic. During this search, the recipient of A's kidney, S (an Israeli national) was identified. The director (X) and the owner (U) of the Medicus clinic were arrested on 4 November 2008. Seizure of medical and business records, medical supplies, medications and computers occurred at Medicus until 11 November [D1-3]. At some point (date unknown), UNMIK Police took over the lead of the investigation from the KP due to the 'very sensitive nature'. [D]

After the European Union Rule of Law Mission in Kosovo (EULEX) was deployed in Kosovo the case was handed over to EULEX. [E] The alleged nexus between the owners of the clinic and certain persons within the political elite, made it difficult for local authorities to initiate a robust and independent investigation [R]. A second complication was that a search warrant had not been issued by a pre-trial judge, during police operations at the clinic, due to exigent circumstances concerning patients and medical care. In addition, the actual assistance provided by the local court administration in Kosovo to organize expert and forensic testimony, video link witnesses, key translations and court hearings was 'extremely difficult in a very challenging environment' [R]. Receiving international legal assistance was also an issue because Kosovo was not recognized as a sovereign state by a number of countries. For that reason receiving cooperation from countries such as Russia was 'dismal and appalling' [R]. Eventually, once personal relationships were established with specialists abroad, international cooperation became 'very good' [R]. Evidence included the evidence seized at the clinic, forensic evidence, pharmaceuticals, medical records, e-mail correspondence, customs records, witness- and victim testimonies and most importantly, anesthesiology logs that documented when the transplants took place, which doctors were present and on whom (recipients and suppliers) the surgeries were performed [R].

Modus operandi

In March 2005 the urologist/owner of Medicus Clinic (U) attended the twentieth Annual Congress of the European Association of Urology in Istanbul, Turkey. There he discussed the need to make kidney transplants available for the Kosovar people. These transplants at

the time did not take place, due to a lack of medical expertise in transplant surgery.[F] After expressing his desire to receive assistance in locating a medical expert, he was provided the contact details of a Turkish transplant surgeon (V) [D1].

In 2006 U and V contacted each other. Together with X (the director of Medicus) and an Israeli organ broker (M) they planned to perform kidney transplants in Kosovo. In December 2007 U applied for V to be licensed as a non-Kosovar health professional, which was granted by the Ministry of Health (MOH) in January 2008. That same month an employment contract was established between the Medicus clinic and V for him to perform (as a general surgeon) living donor kidney transplants. In March 2008 U inquired about the possibility of conducting kidney transplants at Medicus. The licensing process involved multiple meetings with senior local officials including the then Minister of Health and the Health Advisor to the Prime Minister. In May 2008 the Office of the Permanent Secretary at the MOH issued a confirmation of license approval for performing living donor transplants. This license contravened the prohibition of transplants laid down in the Kosovo Health Law and it did not contain all the required constituents to be a proper license [D1].

From March-November 2008 at least 24 individuals were recruited in foreign countries and transported to Kosovo in order to have one of their kidneys removed. These 24 individuals were matched to 24 recipients, leading to 48 surgeries, all of which took place at the Medicus clinic. Although proof was found of only 24 transplants, prosecution believes that more transplants actually took place [D1-3]. M played an important role as 'fixer' of the transplants, by maintaining contacts between suppliers and recipients and accompanying them and the families of recipients.

The organ suppliers came from Israel (4), Turkey (3), Moldova (1), Russia (3), Ukraine (2), Kazakhstan (1) and Belarus (1). Of 9 individuals' their nationality is unknown [D3]. Most were 20-30 years old. Suppliers identified and contacted the brokers ('fixers') via internet searches or newspaper advertisements [R]. After undergoing blood tests, suppliers flew to Priština, via Istanbul. At the immigration office most would present a letter of invitation stating that they came for medical check-ups at a 'certain clinic' [R]. They would then be picked up and brought to the Medicus clinic. The planned surgery was presented to suppliers as being a routine medical procedure without risk after which they could resume a healthy life without restrictions. They were not given sufficient time to make a 'final and conscious voluntary decision' to donate their kidney. They would go into the operation room almost immediately after their arrival, after signing false declarations in the local language that were not explained to them and were often in languages they did not speak or understand. They also signed so-called 'Deeds of Donation' stating that they were donating their kidney for altruistic reasons or to a relative, which in all cases was false [R,D1-3]. After 4-5 days the suppliers were discharged and returned to their home country. They were not given any documents or medicines. All were promised amounts up to $30.000. However some of them were only partially compensated or even received nothing at all. Many were later contacted by the 'fixers' and urged to find other 'donors' and given assurances that they would receive the money owed to them, and even more, should they cooperate with this proposal. Six of the 24 suppliers testified in trial. By the

court they were considered victims of abuse of their position of vulnerability and in certain cases victims of coercion, fraud and/or deception and were found to be exploited by the removal of their kidneys [D3].

Recipients came from Ukraine (1), Israel (14), Turkey (1), Poland (1), Canada (1) and Germany (1). Of 5 recipients the nationality is as yet unknown. Recipients were generally over 50 years of age. They were ill and desperate for a solution to save them from years of dialysis. Most located M and other brokers through word of mouth, and prices up to $108.000 would be agreed. Payments were often made in instalments, electronically and/or in cash at Medicus. Patients would fly to Priština via Istanbul and were often escorted. Frequently their prospective suppliers would be on the same flight. Recipients were given invitation letters for getting medical treatment at Medicus to use if needed on entry into Kosovo or instructed to say they were visiting as tourists. They would met at the airport and taken to the Medicus clinic. The operation would take place not long after their arrival at the clinic and they would have to sign documents, which were not explained to them. After a limited number of days they were discharged and given medicines and instructions relating to their condition and the procedures they had undergone to present to the doctors in their home country [R,D1-3].

Judgment

On 29 April 2013 U and X were found guilty of trafficking in persons and organized crime. The other accused (including U) were found guilty of unlawful exercise of medical activity. The charges abusing official position, grievous bodily harm, fraud and falsifying documents were rejected. U received 8 years imprisonment and €10.000 fine. X received 7 years and 3 months, and a €10.000 fine. The other accused received 3 years and 1 year imprisonment. Two defendants were acquitted [D3]. [G] M and V are presently the subject of an Interpol International Wanted Notice [D1,D3].

STATE OF ISRAEL — THE NETCARE AND MEDICUS CLINIC CASES

Introduction

The Netcare and Medicus Clinic cases clearly demonstrate the global nature of THBOR. In these cases, the trafficking networks functioned in several nations and involved Israeli brokers. Law enforcement also covered several countries, including Israel. In order to shed additional light on the complexity of these 2 cases, the research team travelled to Israel and analyzed these cases in the Israeli context, examining the modus operandi, as well as the law enforcement measures, which took place in relation to these cases. Hence, this chapter complements the preceding chapters on the Netcare case in South Africa and the Medicus clinic case in Kosovo and should be read together with them. It will not discuss other legal cases in Israel that are not directly related to the cases in South Africa and Kosovo [17,18]. [H]

Respondents of the study [R]	Israeli police officers, office of the state attorney (prosecutors and department of international affairs representatives), deputy general manager of a health insurance company, kidney recipients (including director of an organization for dialysis patients and kidney recipients), nephrologists. *Note: The Netcare Case was not discussed with Israeli police and state attorneys. As a result, they were not able to respond to the questions regarding the international collaboration in this case.*
Case material	Israeli Organ Transplant Act [D1], Penal Act [D2], Prohibition of Trafficking in Persons Act (Legislative Amendments) [D3], indictments [D4], court's rulings and judicial decisions [D5], presentation of health insurance company [D6], presentation of public health-care provider [D7], Memorandum of the Ministry of Health's Director General No. 7/06 on Funding of Organ Transplants in Foreign Countries [D8], Organ Transplantation Regulations (Payment of Compensation and Reimbursement for Expenses to the Donor) [D9].

Case study by Frederike Ambagtsheer, Jessica de Jong, Martin Gunnarson, Zvika Orr and Linde van Balen
6-14th October 2013; Tel Aviv and Jerusalem, State of Israel

The involvement of Israeli nationals and entities in the Netcare case was multi-dimensional and included several global organ trafficking networks managed by Israelis, Israeli kidney recipients and initially also kidney suppliers, as well as funding of transplants by public healthcare providers and private insurance carriers.

The organ trafficking networks

Significant activity of an Israeli organ trafficking network in South Africa began in 2001. Beforehand most Israelis who purchased organs underwent transplantation in Turkey.[1] In order to compete with the flourishing human organ market in Turkey, where prices were continually skyrocketing—reaching $200.000 for a kidney transplant—the head of the aforementioned organ trafficking network offered transplants in South Africa for a fixed price of $108.000 [R]. After the trafficking in Turkey was exposed and Israeli transplants there were stopped (temporarily), more and more Israelis began traveling to South Africa. Over time, additional Israeli organ trafficking networks began operations in South Africa, including the veteran network that had formerly operated in Turkey. For most of this time, 3 major and one minor Israeli network cooperated with Netcare. In contrast to Turkey, the sums charged to transplant recipients remained fairly constant, reaching a high of $120.000 [R].

Official support for kidney purchase

During the years 2001-2003 South Africa was the main destination for Israelis undergoing organ transplants overseas; mostly in Netcare hospitals in Durban, Johannesburg, and Cape Town [R,D6]. These years were characterized by rapid growth in the number of Israeli patients who purchased kidneys from living suppliers overseas [D6]. Based on information from the public healthcare providers, some 300 Israeli kidney recipients received monetary refunds from their public healthcare providers after returning from South Africa; the sums ranged from $37.000 to $70.000 [R].[J] Kidney recipients who also had private insurance policies received additional remuneration from their insurance company. So in many cases the entire cost of the transplant, or almost all of it, was covered. The Ministry of Defense paid the expenses for those entitled to its services [R,D4]. When necessary, non-profit organizations or employers assisted in raising the missing funds for patients, fundraising campaigns in the media were conducted, and the public responded generously [R].[K] Information about the organ commerce, the costs, the different brokers, the potential destinations and their reputation were all well-known to patients. In the words of a woman who underwent a transplant in South Africa: 'Everyone knew about it. It went ear to mouth, between the sick people. [...] Everyone knew someone who had done that and they got the telephone numbers and I spoke to patients, I got recommendations, and I have met 2 persons [who] organized this (brokers) and I chose the cheaper one' [R]. There were Israeli nephrologists who provided letters and documents for the South African medical centers where the transplants were done. Some even referred their patients to specific organ traffickers, although most refrained from this on ethical grounds [R].

The law before 2006

Official funding for these transplants, as well as the unimpeded and transparent actions by organ trafficking networks in Israel, were possible because of the Israeli law during these years. At this time there were not yet any laws in Israel prohibiting the purchase or sale of human organs, brokering in organs, or THBOR [22]. Consequently, organ brokers were not subject to criminal punishment in Israel for the brokerage itself. This legal situation expressed and also impacted the dominant moral attitudes in Israel towards the topic of buying and selling human organs, which were (and to an extent still are) relatively tolerant of these practices [17,23].[L]

Law enforcement and its challenges

This situation placed challenges and difficulties in the path of those charged with enforcement. For example, in the framework of the investigation by the South African police in the Netcare case, Israeli citizens were called upon to testify in Tel Aviv. One kidney recipient, who underwent her transplant in Durban and was asked to testify, said in her interview that she did not want to incriminate the brokers, towards whom she felt very grateful: 'They took me and [asked]: "How did you pay? How much did you pay?" I didn't give many details because I didn't want to incriminate anyone. I told them that I didn't deal with this, it was my children, my friends, who handled this. [...] I tried to wrangle out of this. [...] They [the

brokers], after all, did me a favor. Why would I go and incriminate them? So I evaded this [issue]' [R]. The police officers who investigated other cases of organ trafficking, including the case in Kosovo, also reported that it was difficult to convince the recipients to make statements against the brokers, but they nevertheless managed to convince some of the patients to cooperate and give a testimony [R]. Prosecutors added that patients who were not doing well after the transplant tended to be more cooperative when asked to testify against the brokers. Other patients who perceived the brokers as 'life savers' were more reluctant to cooperate [R]. As far as South Africa was concerned, a kidney recipient, who is also the director of an organization for dialysis patients and kidney recipients in Israel, claimed that transplants that were performed in South Africa were the most professional and of the highest quality among all the places to which Israelis travelled for kidneys. He expressed regret and indignation that this was terminated [R]. Israeli nephrologists who had opposed organ trafficking noted that the South African hospitals were on the highest professional standard. In the words of the director of nephrology of an Israeli hospital: 'They really did a good job. I mean, the best patients we ever had were from South Africa [...]. But they really had a business there.' [R]

The organ trafficker—who headed the first Israeli network for commerce in human organs to work in South Africa—was arrested in Israel in July 2002. He was suspected of tax evasion to the amount of 25.000.000 NIS in Israel (approximately $5.245.000, at the exchange rate at that time), on income from the transplants done in South Africa. [M] He was also suspected of document forging in relation to these activities (among which was documentation from South African hospitals including official receipts and invoices) and the use of forged documents for fraudulent acquisition of funds; all in aggravated circumstances [D5]. On July 2002 he was released on bail and was not permitted to leave the country. On February 2003 he was permitted to leave the country for short periods, conditional on posting an additional bond payment [D5]. In 2006 he was arrested in a German airport as a result of an international arrest warrant issued in South Africa, but ultimately he was released [R].

Law enforcement in Brazil

A retired Israeli military officer ('G'), was a primary organ trafficker who set up the Brazil-To-South Africa scheme that recruited suppliers in Recife, Brazil. G received $10.000 for each successful transplant [24]. As Nancy Scheper-Hughes notes, he was indicted in Brazil, together with some 24 Brazilians, most of whom were kidney sellers who were wanted for information, not for prosecution [25,26]. The two co-conspirators—one from Israel, one from Brazil—were sentenced to 11 years in prison, a term they began to serve in 2005 [24]. Later on, this sentence was reduced to 8 years and in 2007 G was granted 'conditional liberty'. In 2009 he was granted compassionate leave for one month to visit his elderly mother in Israel, but did not return to Brazil. He was a fugitive for 4 years, until he was arrested in Rome in 2013 by airport police. He was extradited to Brazil in August 2014 [27].

Changes in Israeli law and policies since 2006

In 2006, the Israeli Ministry of Health published a memorandum which instructed public healthcare providers not to provide financial coverage for transplants that involve organ trafficking [D8]. In the same year, lawmakers amended the Penal Act to include imprisonment of up to 16 years as punishment for those who 'traffic in persons for the purpose of removing an organ' [D2-3]. In 2008, the Organ Transplant Act was passed, a law which prohibits giving or receiving compensation for an organ and prohibits 'brokering organ transactions' [D1]. The punishment for 'brokering organ transactions' is imprisonment of up to 3 years or a fine of 226.000 NIS ($61.870). The law does not set a punishment for recipients who buy organs as well as for suppliers. In 2010, regulations based on the Organ Transplant Act were formulated that put forth a payment by the state as limited compensation and reimbursement for expenses for living donors [D9].

Since 2008 there has been a sharp drop in overseas transplants funded by Israeli public healthcare providers and private insurance carriers [R,D6-7]. They have only funded cases where they were convinced that the organ transplant was legal, for example kidney transplants from deceased donors in Riga (Latvia) and Omsk (Russia). These changes in Israeli law and policies, as well as the impact of the Declaration of Istanbul on Organ Trafficking and Transplant Tourism [28] and of the work of the Declaration of Istanbul Custodian Group in combating organ trafficking in various destination countries [N], has led to a significant drop in the number of Israeli patients undergoing transplants abroad. Thus, the annual number of kidney transplants performed abroad decreased from 155 in 2006 to 35 in 2011 and 43 in 2013 [22] [R]. [O] Concurrently, since 2011 there has been a marked increase [P] in live kidney donations [29]. 22% of these are unspecified donors, [Q] most of whom (17%) are matched to recipients on the wait list by the charity organization, 'Matnat Chaim' [30,31] [R]. [R]

STATE OF ISRAEL — THE MEDICUS CLINIC CASE

Start of investigation	2011-present
Indictment	indictment is forthcoming and concerns 5 Israeli nationals
Fugitive	organ broker (Israeli)
Respondents of the study [R]	Israeli police officers, office of the state attorney (prosecutors and department of international affairs representatives), deputy general manager of a health insurance company, kidney recipients (including director of an organization for dialysis patients and kidney recipients), nephrologists
Case material	translated court file [D1], amended indictment Kosovo [D2], judgment Kosovo [D3], closing statement Kosovo [D4], Israeli Organ Transplant Act [D5]

Case study by Frederike Ambagtsheer, Jessica de Jong, Martin Gunnarson, Zvika Orr, Linde van Balen
6-14th October 2013; Tel Aviv and Jerusalem, State of Israel

Signals of illegal activities

The Department of International Affairs at the Office of State Attorney, Israel Ministry of Justice, received a request for international legal assistance (ILA) from EULEX-Kosovo concerning the involvement of Israeli nationals in illegal organ transplants there. The request also identified Israeli nationals who had travelled to Kosovo for the removal and receipt of kidneys [R].

Criminal investigation

As a result of the information which was received from EULEX in the context of the ILA, the investigation in Israel started in 2011 and involved subpoenas of documents from hospitals, clinics, insurance companies, travel agencies and brokers. Based on information received from EULEX-Kosovo, the Israeli police discovered that Israeli brokers who had been organizing illegal transplants in Kosovo, were now buying tickets to a 'new' country where illegal organ activities are now taking place [R]. The activities in this country are currently the focus of the police's investigation. In May 2012 6 brokers were arrested; 3 of these are suspected for recruiting recipients and suppliers for the transplantations in Kosovo [R,D1].

Modus operandi

M (Israeli nationality, born in Turkey) started his activities in 2008 in Israel and was in contact with the Turkish transplant surgeon V by email, SMS and mobile phone [D1]. M performed the financial and logistic arrangements for suppliers and recipients and accompanied them from Istanbul to Pristina [D3]. M received the recipients' money on a bank account in Turkey which he wired to V's bank account [R]. After the search of the Medicus Clinic in November 2008, M gave statements to the police and the pre-trial judge. He was released from custody on humanitarian grounds [R] on the condition that he return to Kosovo if ordered to do so, but then he fled [D1]. M is now the subject of an Interpol International Wanted Notice and an indicted co-conspirator on an indictment filed by the Prosecutor in the District Court in Pristina [D1-2,R]. S and Z were 2 other Israeli brokers who accompanied kidney patients in Israel and handled the financial and logistic arrangements for their travel to Kosovo. Z accompanied the recipients to Kosovo and assisted them during their stay [D3]. S worked inside Israel and started working as a broker because of financial problems [R,D1].

Two Israeli doctors were suspected of collaborating with the brokers and facilitating the transplants in Kosovo by performing medical tests on the recipients in Israel [R]. Accusations against one doctor were dropped after the police concluded that he didn't know that his letters were used for the illegal transplants. The other doctor (surgeon) is alleged to have performed administrative tasks as part of the network [R]. According to the police there is an evidentiary basis to indict him and prosecutors intend to file an indictment pursuant to a hearing that will be held by the District Attorney's office.

Fourteen of the 24 recipients who underwent transplants in Kosovo were of Israeli nationality. Four Israeli suppliers were identified whose kidneys were removed for transplantation purposes in Kosovo [D2-3]. [5] Most recipients met their suppliers in the Medicus

clinic or in the plane from Istanbul and were instructed to sign a document that they were relatives [R]. Suppliers and recipients recovered in the same room. Suppliers were usually discharged before the recipients, without being given medicines or dismissal forms [D2]. Recipients that returned to Israel in a bad condition were picked up by ambulances that brought them to a hospital where they received immediate care [R].

Some recipients used documents provided to them by the Medicus Clinic [D4] to make reimbursement claims for their transplant costs at their public healthcare providers and private health insurance companies. Some of them received reimbursements for their transplant costs but often not for the amounts agreed [R]. Because since May 2008 Israeli public healthcare providers and private health insurance companies have ceased funding out-of-country transplants which are suspected to be illegal, reimbursement claims were denied. This resulted in civil litigation claims where patients attempted to fight the refusal in court. Most claims have been denied by the Israeli courts because these transplant activities were viewed in light of the new 2008 law [R].

Judgment

The brokers are currently the subject of a police investigation. The Israeli police confiscated their assets, froze their bank accounts, seized their bank cards and one apartment; however, the seized property has since been released due to the prolonged proceedings [R]. Prosecutors from the State Attorneys are now writing the indictment [R]. On 23 May 2012 there was a court session, but the judge extended the arrest until the end of May 2012. In June 2012 all suspects were released on bail. At the time of this writing, an indictment against the suspects has not yet been filed [D1].

The suspects will be charged for trafficking in organs and acting as intermediaries with respect to payments between suppliers and recipients [R] under Section 36 of the Organ Transplant Act [D5]. The ongoing investigation of the arrested brokers has focused on trafficking in persons for the purpose of organ removal, organ brokerage, fraud, exploitation, aggravated assault, conspiracy, money laundering and tax transgressions [D1]. One of the Israeli transplant doctors may be charged in the upcoming indictment; the other doctor will not be charged. Neither recipients nor suppliers will be charged. The Organ Transplant Act prohibits organ purchase and sale, and contains criminal sanctions against all third parties involved in these activities. However, the law does not contain a criminal sanction against the organ recipient or supplier for these activities (the explanatory report of the 2008 law details that this is due to consideration of the distress and vulnerability of the supplier and recipient which led them to the purchase or sale of human organs) [R] [17].

Start of investigation	2008
Charges	brokering in human organs and conspiracy
Judgment (11th July 2012)	Rosenbaum is sentenced to 2,5 years in federal prison
Defendant	Levy Izhak Rosenbaum
Respondents of the study [R]	assistant US attorney, FBI-agent, defence lawyer
Case material	transcript of the sentencing hearing [D1], criminal complaint [D2], pre-sentence memorandum of the defence [D3] and charges [D4]

Case study by Jessica de Jong
18-22 March 2013; New York, the United States of America

> '*A man portrayed by his lawyers as a good Samaritan pleaded guilty on Thursday to organ trafficking in the United States in what the prosecutor said was the first conviction under a federal statute banning sales of kidneys by paid donors. The man, Levy Izhak Rosenbaum, admitted in federal court that he had brokered three illegal kidney transplants for people in New Jersey in exchange for payments of $120.000 or more. He also pleaded guilty to one count of conspiracy to broker an illegal kidney sale.*' [32]

Signals of illegal activities

In 1999 the FBI initiated 'Operation Bid Rig': an extensive investigation into corruption of several public officials in New Jersey and money laundering in tax evasion within the orthodox Jewish community. One of the involved ('D') was running a fraudulent investment operation in real estate. When his scheme collapsed in 2006, he was arrested and 'turned into' a FBI informant. D fully committed himself to the operation. In February 2008, he suddenly informed the FBI that his wife's grandfather was purchasing a kidney through an organ broker named Levy Izhak Rosenbaum [21] [R]. [T]

Criminal investigation

In order to collect evidence, D accompanied an undercover FBI-agent to Rosenbaum. She was posing as D's secretary and claimed that her uncle was in need of a kidney transplant [D2,R]. Rosenbaum stated his willingness to find a matching supplier for $160.000. During several recorded meetings Rosenbaum mentioned that he had been a 'matchmaker' for 10 years and explained that it would be necessary to create a fictitious relationship between the recipient and supplier, because of the hospitals' screening processes. He named 2 recipients who had received a kidney through his services and provided the agent with a telephone number at which she could contact one of them as a reference. Rosenbaum wanted 50 percent of the money upfront and 50 percent before the transplant. The first FBI payment of bank checks totalling $10.000 was credited to the bank account of a charitable religious organization in Brooklyn [D2]. In July 2009, Operation Bid Rig resulted in the

arrests of 44 people, including Rosenbaum—whom D and the agent had arranged to meet on the day of the take down [R].

Modus operandi

It was established in court that Rosenbaum had been brokering in kidneys since at least 2001, as a defendant's witness stated that he had received a kidney from a paid supplier in that year [D1]. The undercover operation revealed Rosenbaum's modus operandi. First, he would ask the recipient who approached him for help for a blood sample to find a matching 'donor' willing to sell a kidney, who typically would be located by his associates in Israel. Rosenbaum would arrange for the supplier to travel to and be housed in the United States, where he or she was looked after by one of his associates throughout the pre-transplant procedures. Rosenbaum would help the patient and the supplier to coordinate a cover story to mislead hospital staff into believing that the donation was a purely voluntary act. Finally, he would demand full payment by the date of the transplant [D2-4,R].

In Rosenbaum's early activities, the recipients and suppliers all came from Israel and were presented to one and the same hospital in the name of Rosenbaum's charity. Their story was that they wanted to be treated in the United States, because of better facilities and the financial support of the Israeli government, who reimbursed medical treatments abroad. The suppliers were actually immigrants from Eastern Europe living in Israel. Five years later, Rosenbaum's charity had gone out of business and his method of operation seemed to have changed. At this point, the recipients were overwhelmingly Americans from the Orthodox Jewish communities of New Jersey and New York. The suppliers that were identified were mainly Israelis being brought over from Israel for the surgery. The transplants, reimbursed by American insurance companies, were carried out in different United States hospitals, **U** *chosen by the recipient*. Hence, the police investigation did not uncover anything to suggest that the hospitals and specialists were knowingly complicit in the commercial transplants [R].

Even though there is no evidence to suggest that the suppliers were threatened, subtle psychological ploys were used, such as 'you are doing a mitzvah', to make sure they went through with the transplant [R]. The only supplier traced by the United States authorities testified that he had had second thoughts on the morning of the surgery. However, he was told that he was the only match and that the recipient who would receive his kidney had only about 3 weeks to live. He was not informed about the risks and impact of the surgery and was misinformed about the duration—Rosenbaum's associate told him the surgery would take 10-15 minutes instead of the actual 4-5 hours [D1]. While he received the $25.000 he had been promised for his kidney, it was paid in instalments and he had to chase Rosenbaum down for the last $5.000 [D1, R].

Law and charges

On 27 October 2011, Rosenbaum pleaded guilty to 3 counts of violating 42 US Code §274e, which provides that it is unlawful 'to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce', and to one count of violating 18 US Code §371, which refers to the conspiracy involving his incriminating activities during the undercover operation. As a result, Rosenbaum needed to forfeit $420.000—the sum of the amounts that he received from the 3 recipients ($120.000, $140.000 and $150.000) and the partial down payment of the FBI ($10.000). The authorities were not seeking to charge the recipients or the suppliers: 'Obviously the recipients were under the distress of being in bad health and needing a kidney transplant. The donors, our view was that by and large, if they were desperate enough to sell their kidney for $25.000, there was a certain level of economic distress that they were under to do this, especially if they were willing to [...] come to a country that they were unfamiliar with.' [R] To make it look as if Rosenbaum had actually spent the minimal amount of $120.000 on the suppliers, the defence made very specific claims about the expenses that he had incurred in finding the suppliers, bringing them to the United States and housing them.[v] But through one supplier's testimony the prosecutor demonstrated that most of the expenses claimed by the defence had not really been incurred on the supplier's behalf [D1].

The authorities were not able to identify any of Rosenbaum's recruiters or pin down the number of transplants that Rosenbaum had orchestrated and how much he benefited. The criminal charges were limited to the undercover scheme and the 3 transplantations involving New Jersey recipients between 2006 and 2009. This was due in large part to the statute of limitations, which reaches back only 5 years under the United States law, and the fact that the local prosecutor could only charge violations of federal law that have some connection to New Jersey [R]. However, the profit margin that Rosenbaum received suggested that his profit must have been millions of dollars over the years [D1,R]. Rosenbaum had purchased millions of dollars in real estate in the 2000-2006 period and although he disputed that he had bought the properties with 'kidney money', the authorities did not see any other substantial source of income. Because the prosecution had not located any supplier at the time Rosenbaum pleaded guilty, he could not be charged for human trafficking. Eventually one supplier was located about 2 weeks before the sentencing, which was initially scheduled in May 2011 but then got pushed back to July 2011. According to the prosecutor, coercion was not evident from this supplier's statement, so it would still have been very hard to prove human trafficking [R].

Judgment

As the sentencing guidelines contain no provision applicable for the violation of 42 USC §274e, the judge determined under the factors of 18 USC §3553[w] an imprisonment of 30 months. Rosenbaum did not appeal the sentence of the District Court.

CONCLUSION

With this study, the researchers collected data that would have been difficult if not impossible to collect through desk research. Because of this, the authors were able to fill gaps that were highlighted in this project's literature review [1]. The underlying study's purpose was to contribute to gaps concerning:

a the actors and their modus operandi of contemporary organ trafficking networks
b the experiences of police and prosecution in disrupting and prosecuting the persons involved in these networks.

The modus operandi of contemporary organ trafficking networks

Although respondents used different legal terms to describe the degree of organization of the organ trafficking networks—for example, the scheme in South Africa was described as a 'syndicate' and the network in Kosovo as a 'criminal enterprise'—this study illustrates that these networks are fluid, with a high degree of organization. This corresponds to the literature, in which trafficking in human beings for the purpose of organ removal (THBOR) is often said to require globally active, extensive and highly organized networks [1].

Initially, the networks operated with limited risk of investigation and prosecution. They could continue with their activities despite the presence of (clear) signals for authorities. In South Africa for instance, the network could go on because local hospital staff was complicit or was told that donations were altruistic, voluntary and related. In Kosovo the illegal transplants could be carried out under a false license issued by the Ministry of Health. In the USA activities were successful because persons (including recipients and suppliers) misled hospital staff into believing that the donations were voluntary and altruistic.

The actors were sophisticated in their selection of countries. The reasons why they organized their activities in these countries were because of legal loopholes in South Africa and Israel at the time when the activities took place, the post-war legal 'vacuum' and a high level of corruption in Kosovo, and a complicit hospital/clinic and staff in Kosovo and South Africa. An important contributing factor in the Netcare and Rosenbaum case was that until May 2008 Israeli recipients could be legally reimbursed for their overseas transplant costs by their health insurance companies. Because recipients and suppliers travelled from different countries across the world, it was difficult for police and prosecution to identify the activities and to establish that the transplants were illegal.

The actors also used sophisticated means to recruit suppliers and recipients. The suppliers were carefully selected, based on their dismal economic situation (poverty) and vulnerability. Brokers recruited the suppliers from abroad and made sure that suppliers approached them by posting ads in the newspaper for example, rather than actively approaching suppliers themselves. This 'passive recruitment' made it more difficult for police and prosecution to prove THBOR and to declare the suppliers 'trafficked persons'. By transporting recipients and suppliers via Istanbul and conducting the medical tests there, the network in Kosovo was able to cover part of its activities. In South Africa and the USA, recipients and suppliers made efforts to hide the illegality of their transplants and donations

from hospital staff. The transplants in the USA were reported to have been performed in various hospitals. No evidence was found that hospitals and doctors were complicit. This made it more difficult for police and prosecution to trace the recipients and suppliers.

After recruiting the suppliers however, more coercive and deceptive elements came into play. Brokers manipulated the suppliers to ensure that they would not 'drop out'. In Kosovo, kidney donations were presented as a routine medical procedure without risk. Suppliers were given virtually no time to make a 'voluntary decision to donate'. In Kosovo and South Africa suppliers were given consent forms that were fraudulent and/or written in a language that they did not understand and that stated that they donated for altruistic reasons to a relative. The majority of the suppliers who were brought to Kosovo were given less compensation than agreed (if anything at all) and were informed they would receive remaining compensations on the condition that they would find new suppliers. This way, the Kosovo network was able to maintain a consistent, international flow of suppliers. The suppliers' testimonies in Kosovo were 'fully sufficient' for the court to conclude that THBOR, organized crime and grievous bodily harm were committed. In the USA, although 'subtle psychological ploys' were used upon the supplier, these were not proven to be sufficiently coercive or abusive to charge THBOR.

The successes and obstacles of police and prosecution

The experiences of police and prosecution differed greatly across countries. The level of success of each case depended on the availability of evidence, the dedication of police and prosecution and the existing legal frameworks. In South Africa, police and prosecution struggled from the very start with outdated laws against organ trade, which led them to apply charges of a different nature. Because the country lacked an anti-THB law at the time, no charges for THBOR or other serious crimes could be made. Although this country is the first country to have reached a guilty plea from a hospital for its involvement in organ trade activities, its proceedings against the accused surgeons and transplant coordinators lasted relatively long (9 years). Police and prosecution in the end did not succeed in getting the most important figures—namely the transplant surgeons, transplant coordinators and the head of the network, an Israeli organ broker—convicted for their alleged involvement in arranging and performing the illegal transplants. Convictions involved relatively low penalties (fines, and no prison sentences). A major obstacle according to police and prosecutors was the long time it took to establish international legal collaboration with Israel.

The case in Kosovo, by contrast, involved the most severe sentences and the largest group of transplant doctors that has been convicted until now. This country is the first to have prosecuted transplant doctors as a criminal group involved in THBOR. Because the group operated relatively 'openly' under the issuance of a false license, evidence could be collected that included the anesthesiology logs of the transplants. These logs were—together with the recipient and supplier testimonies—the most important piece of evidence. Furthermore, according to the prosecution, the defense of the case was 'extremely poor'. A large obstacle is the fact that 2 accused (V and M), who are the subjects of an Interpol Wanted Notice and who are seen as 'the most important figures in the criminal scheme',

have until now not been locked up. [x] In addition, non-recognition of Kosovo by a number of states obstructed international legal collaboration which hampered the issuance of evidence. Other hurdles included an 'extremely challenging' trial process.

The involvement of its nationals in Kosovo and South Africa led to a number of arrests in Israel. The head of the Israeli network in South Africa was arrested for tax evasion, but has not received a sentence for illegal organ trading. In addition, 6 organ brokers (of which 3 were active in Kosovo) were arrested. However, until now they have not been indicted for their involvement in the transplants in Kosovo [33]. Because of a lack of evidence of THBOR, these brokers will be charged for organ brokering/trading (3 years prison maximum) and not for THBOR. It is not known when the indictment will be issued.

Similarly in the USA, lack of evidence could not substantiate charges which included THBOR. Only one supplier could be found on whom subtle psychological ploys had been used, but explicit coercion could not be proven. Furthermore, police and prosecution did not manage to identify the actual number of transplants that were performed, as well as the total financial benefits that were gained.

Tip of the iceberg

This report illustrates that prosecutions in South Africa, Kosovo, USA and Israel were successful but leave room for improvement. First of all, prosecutions could have been more successful if the appropriate laws would have been in place at the time when the activities took place. Second, investigations and prosecutions could have been initiated earlier if available signals were identified and picked up already at an early stage and if international collaboration would have occurred sooner. Recent media reports from Sri Lanka [y] and Costa Rica [34] suggest that Israeli brokers, known to authorities, have relocated their activities. Meanwhile, a report from the OSCE [2], new research and recent reports from countries including China [4] and Turkey [35] illustrate that the organ trafficking networks presented in this report are only the tip of the iceberg. The global organ trade is not confined to the regions and countries presented here.

Further steps [z]

This study demonstrates the need for:

— prioritizing prosecution of those who facilitate and conduct illegal transplants, even if not all of the THBOR elements are fulfilled;
— enhancing and improving international collaboration in cross-border organ trafficking cases;
— formulating indicators for police and other authorities to identify THBOR;
— raising awareness of THBOR, in particular amongst law enforcement authorities;
— concerted action between law enforcement and professional transplant/health organizations.

NOTES

A Chapter 1.5.3. of the literature review presents the terms used throughout this report.

B According to Nancy Scheper-Hughes, there were simultaneously whistle-blowers reporting the crime in Brazil. These were kidney suppliers who went to the Federal Police in Recife claiming that they had been cheated and exploited [15].

C A permanent stay of prosecution is a ruling by the court in civil and criminal procedure, halting further legal process in a trial.

D According to the project adviser, Sergio D'Orsi, UNMIK had executive functions over a number of Units of the KP at the time of the investigation. The result of subsequent investigations conducted in this phase (including covert measures on the phones used by the suspects), resulted also in the identification, tracing and arrest of the broker M by hand of the UNMIK investigators after having collected evidence on his involvement in the illegal transplant affecting the supplier A and the receiver S. The broker M was traced and located in Pristina while he was ready to leave Kosovo;

E Following the Kosovo War (1998-1999) a mandate of the United Nations Interim Administration Mission in Kosovo (UNMIK) was established by the UN Security Council (1999). This mandate required the UN to take over the administration and political process in Kosovo. Kosovo declared independence on 17 February 2008 and it has been recognized by more than 100 UN Member States since. In 2008 the UN Secretary-General instructed the Head of UNMIK to facilitate European Union preparations to undertake an enhanced operational role in Kosovo in the rule of law area. Following this, the European Union Rule of Law Mission in Kosovo (EULEX) deployed throughout Kosovo on 9 December 2008. Its mandate runs until June 2014. The Medicus case proceedings took place under the auspices of EULEX.

F Section 46(d) of the Kosovo Health Law declares that (private) organ transplantations are forbidden. The reasons for this prohibition are because the medical and legal infrastructure is not in place, the government's health budget is small, there is insufficient expertise, a lack of standards and medical oversight, as well as the absence of a national center to oversee transplants.

G In April 2013 EULEX confirmed that it was launching a new investigation (Medicus 2.0) into people suspected of involvement in the organ-trading ring that operated from the Medicus clinic. The 8 individuals are being investigated for the criminal offences of organized crime, trafficking in persons, grievous bodily harm, abusing official position of authority, fraud and trading in influence. The statement said that the new inquiry was based on revelations arising from investigations and from information that came out at the trial which suggested that the men who were convicted had help from others in order to traffic victims and sell their organs.

H As of 2007 a number of legal actions were taken against organ traffickers in Israel that ended in convictions. Two organ brokers were sentenced to prison for the crime of trafficking in persons for the purpose of organ removal and for causing severe personal injury, exploitation, receipt of goods under false pretenses, and imitating a physician (or being an accomplice in these offenses). Another broker was given a prison sentence for brokering organ transactions and for exploitation, receipt of goods under false pretenses, making threats, extortion using threats, and other offenses. Six additional organ brokers (in 2 cases) were given suspended sentences and/or community service, and were ordered to pay financial compensation to the complainants or a fine [D4-5] (Orr, 2014; Sperling, 2014). In August 2014 five organ brokers were indicted and in September 2014 the court ruled to extend their arrest until proceedings are completed. A judgment has not yet been decreed on this case.

I The original international trafficking network began in the 1990s between Israel and Turkey, and later expanded to Moldova. According to Nancy Scheper-Hughes, the establishment of this network followed Ministry of Health investigations (The Cotev Commission) that interrupted the recruitment of kidney sellers from the Occupied Palestinian Territories in the 1990s. In the same years, Palestinian patients from the Occupied Territories as well as Palestinian citizens of Israel travelled to Iraq for purchased kidneys [15,19,20].

J The amount of public funding varied with healthcare providers, the time and location of the transplant. One healthcare provider refunded a fixed rate of $70.000 to those with its 'complementary insurance' (this applied to most of the insured). Another healthcare provider paid out the equivalent of DRG-rate of a kidney transplant in Israel, that varied from $37.000 in the years 1993-1994 up to $50.000-$55.000 in 2006-2007. As a condition for receiving a refund, some of the healthcare providers demanded that the insured present receipts, while others did not make this demand (since they assumed they would be forged, in any case), and in lieu accepted an Israeli physician's statement that a transplant had indeed been performed [R,D5].

K For example, Nancy Scheper-Hughes found that Israeli patients raised 'the money required through a publicity campaign aided by a "charitable" organization, Kav LaChayim, "United Lifeline", that has been accused of money laundering activities in the US and Israel' [19]. According to Scheper-Hughes, this organization was one of the most essential components of support of international transplants for Israelis [21].

L Preliminary unpublished results of a survey conducted by Ofra Greenberg on the topic 'public opinion in Israel towards commercial organ transplants,' personal communication with Ofra Greenberg, May 30, 2014

M In August 2013 another organ trafficker and his company, were indicted for tax evasion of 118.000.000 NIS ($32.187.000 at the exchange rate then) on income received from organ trafficking between 1999-2007. Of this, some 47.300.000 NIS ($12.900.000 at the exchange rate then) were received from the Israel Ministry of Defense, and the remainder from private clients [D4]. A judgment has not yet been decreed on this case.

n http://www.declarationofistanbul.org/governance/dicg

o These figures, based on the national dialysis registry, do not include transplants of pre-dialysis patients that are performed abroad [R].

p From 56-71 living kidney donors annually in 2007-2010 to 117 living kidney donors in 2011, 108 in 2012, and 134 in 2013 [29].

q Unspecified donation is donation to an anonymous recipient without a genetic or emotional relationship [30].

r According to the National Transplant Center [29], 30 of the 134 living kidney donors in 2013 were altruistic unrelated donors. This phenomenon is spearheaded by the Israeli charity, 'Matnat Chaim' (www.kilya.org.il/en/) which matches altruistic donors with kidney patients on a voluntary, not-for-profit basis [R] [31].

s See also 'Republic of Kosovo—The Medicus Clinic Case'

t During the sentencing hearing, the assistant US attorney refers to a would-be whistle-blower who contacted Organs Watch back in 2002 by e-mail about Rosenbaum's illegal business [D1]. The attempts of the director of Organs Watch, Professor Nancy Scheper-Hughes, to alert the authorities failed: 'I was told that the information lacked credibility.' [21]

u According to the prosecutor, transplants were taking place in hospitals in Minnesota, Maryland, Pennsylvania and possibly Massachusetts and New York [R].

v According to 42 U.S.C. §274e, at that time 'valuable consideration' doesn't include the reasonable payments associated with the removal, transportation, implantation, expenses of travel, housing, and lost wages incurred by the supplier.

w In determining the particular sentence to be imposed, the court shall consider the following factors: 1) nature and circumstances of the offence and history and characteristics of the defendant, 2) the need for the sentence imposed—to reflect the seriousness of the offence, to promote respect for the law, to provide just punishment for the offence, to afford adequate deterrence to criminal conduct, to protect the public from further crimes of the defendant, to provide the defendant with needed [...] correctional treatment in the most effective manner, and 3) the kinds of sentences available.

x Though neither have been extradited to Kosovo, both were investigated in their home countries related to the Medicus Clinic. M is expected to be indicted in Israel for these same charges, pursuant to information provided by authorities in Kosovo [R].

y The brokers related to Sri Lanka were questioned as suspects and are expected to be indicted in Israel.

z Indicators and recommendations will be written and published under the auspices of the HOTT project in 2015.

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6

IMPLICATIONS OF A STRICT PROHIBITION OF ORGAN TRADE

VIII

RE-CONCEPTUALIZING ORGAN TRADE

SEPARATING 'TRAFFICKING' FROM 'TRADE' AND THE IMPLICATIONS FOR LAW AND POLICY

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INTRODUCTION

The trade in human organs is considered a major international concern. In 2007 the World Health Organization (WHO) estimated that approximately 6000 kidney transplants are performed illegally each year [1]. More recently, the Council of Europe declared that organ trade constitutes a '*major threat to public health*' and that it is growing worldwide due to the '*greed of unscrupulous traffickers*' [3].

The organ trade consists of different practices, nominally defined in the literature as 'organ trafficking' [4], 'trafficking in persons for organ removal' [6], 'organ sales' [7], 'transplant commercialism' [8] and 'transplant tourism' [9]. Although there can be some overlap between these practices, the official and popular discourse predominantly applies the term, 'organ trafficking' without distinction as to the variable aspects involved. As a result, the organ trade as a whole is presented as a serious organized crime that can only be tackled by a punitive response [3,4,10,11]. This approach however, as we will explain below, is potentially counterproductive. Before discussing the possible implications and offering suggestions to improve the response, we first describe the origin of the organ trafficking discourse and address the conflation of organ trafficking with trade.

THE ORIGIN OF THE ORGAN TRAFFICKING DISCOURSE

The WHO first condemned organ trade in its 1987 World Health Assembly Resolution [14]. Organ trade became associated with trafficking in the 2000 United Nations Protocol to Prevent, Suppress and Punish Trafficking in Persons (henceforth, the Trafficking Protocol). The Trafficking Protocol presents a definition of what is generally referred to as 'trafficking in persons for the purpose of organ removal':

> *'"Trafficking in persons" shall mean the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the removal of organs'* [15].

When the phrase, 'the removal of organs', was introduced, there was little empirical data or case law demonstrating that criminal networks were involved in trafficking persons for their organs [6]. Thus, the concept was introduced despite it not being well studied, discussed or defined [17]. Nevertheless, the definition has been reaffirmed by other legal instruments and is now prohibited worldwide [18-20].

The definition in the Trafficking Protocol only extends to 'trafficking in persons'. It does not cover the sale or purchase of organs.

Notably, this definition is the only legally accepted definition of 'trafficking', or more specifically, 'trafficking in persons'. Although in the popular discourse trafficking is occasionally associated with other forbidden activities such as 'drug trafficking' and 'arms trafficking', these activities are connected to an illicit *trade*. Trafficking on the other hand, is legally associated with exploiting persons for various purposes through different means. Hence, when one speaks about 'organ trafficking' the distinction between what is considered 'trafficking in persons for the purpose of organ removal' and 'trafficking of organs', independent of the body, is not clear. Below we discuss the implications of conflating organ trafficking with trade.

CONFLATING ORGAN TRAFFICKING WITH TRADE

Attempts after the Trafficking Protocol to establish universal principles in organ transplantation have added confusion to the conceptualization of organ trade. The explanatory report to the 2006 Additional Protocol on Transplantation of Organs and Tissues that supplements the Council of Europe Convention on Human Rights and Biomedicine for example declares that '*Organ trafficking* [...] *are important examples of such illegal trading and of direct financial gain*' [21].

The conflation of trafficking with trade or commercialism is also demonstrated in the 2008 Declaration of Istanbul on Organ Trafficking and Transplant Tourism (henceforth, the Declaration of Istanbul). Adopting the terminology from the Trafficking Protocol and adding new vocabulary, the Declaration of Istanbul presents a rather broad definition of organ trafficking:

> *'Organ trafficking is the recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation'* [22].

The most recent convention, the 2014 Council of Europe Convention against Trafficking in Human Organs (henceforth, the Council of Europe Convention), calls for a similarly broad prohibition of commercial dealings in organs. It defines 'trafficking in organs' as the 'illicit removal of human organs' [12]. Accordingly, even sales that occur with the consent of donors are considered to be 'trafficking', regardless of the circumstances involved.

The conflation of trafficking with trade is premised on the assumption that organ sales only involve organs that are harvested from trafficked persons [23-25]. Therefore, it would be immoral to permit the commercial exchange of organs. The reasoning is that organ donation should occur altruistically as this would rule out financial motivation for organ donation, hence, protecting vulnerable individuals from exploitation.

The issue with this line of reasoning however is that it lacks an empirical and normative foundation [26-28]. Arguments against an all-encompassing prohibition of organ sales have been presented by scholars worldwide [26,27,30-32]. Hence, we will not reiterate these arguments here. Instead, we address the emerging body of empirical research which demonstrates that trade does not always constitute trafficking.

EVIDENCE-BASED RESEARCH ON TRAFFICKING AND COMMERCIALISM

The claim that organ trade is (or leads to) human trafficking is not supported by the majority of empirical studies that position organ sellers as 'victims of trafficking' [33-36]. While a number of studies reveal the financial difficulties that lead vulnerable people into selling their organs and the negative consequences that follow [33,37,38], there is little or no information to suggest that these cases involve (all elements of) human trafficking [39,40]. Rather, these studies show that the experiences and outcomes of organs sellers/selling can vary extensively [39-41]. Yea, who interviewed organ sellers in a slum in The Philippines notes that '*trafficking is generally assumed rather than rigorously established*' [39]. She points out that organ sellers present '*degrees of trafficking*' as many prospective sellers actively seek out brokers [39]. Recruiters or brokers are sometimes reported to be the neighbors, relatives or friends of organ sellers [39,42]. Moreover, some sellers subsequently become brokers themselves [6]. Though some authors present incidents where victims report to have been (physically) harmed by brokers and patients, these findings appear to be the exception rather than the norm [26,46,48].

Research amongst other participants in the trade is scarce and poorly-developed, in particular research amongst patients, brokers and transplant professionals. For instance, only five studies describe why and how patients buy organs [43-47]. Also, relatively few organ trade cases appear at the judicial level. In the absence of a larger number of criminal investigations and case law research, much remains unknown about the organization of the '*mafia-like*' organ trafficking networks that are reported to dominate the organ trade arena [3,6,10,50].

CONSEQUENCES OF CONFLATION AND THE IMPLICATIONS FOR LAW AND POLICY

The Council of Europe Convention encourages states to introduce new punitive measures against all commercial dealings in organs or to strengthen existing ones, regardless of whether or not trafficking in persons has occurred [51]. Because it does not distinguish between organ sales and trafficking in persons, the situation then arises that unless an organ seller is considered a victim of trafficking, he or she can be held criminally liable. As a result, individuals who have sold an organ may be reluctant to come forward and report instances of abuse to authorities when such violations that would amount to 'trafficking in persons' have actually occurred. Furthermore, extending liability to organ sellers may

push the trade further underground and expose them to greater harm [53]. Indeed, we have found that the reluctance of both sellers and buyers to provide information and to testify in criminal cases is one of the reported difficulties of police and prosecutors in attempting to successfully prosecute cases involving trafficking in persons for organ removal [48,49].

Although criminal prosecution is important insofar as it represents society's intolerance for particular crimes and may act as a deterrent for future offences, punishment does little to alleviate the conditions that produce crime. This equally applies to organ trade [54]. Furthermore, taking into account the poor non-legislative response to even the most exploitative form of organ trade, a punitive response against *all* commercial dealings in organs may place an unrealistic burden on the criminal justice system. Law enforcers' decisions over which activities to prioritize are often based on chances of securing successful convictions. Prohibition may not then always be accompanied by rigorous enforcement when the police face both the challenges of international investigations and difficulties in proving that an organ was illegally bought [55]. Already in its 1980 Report on Decriminalization, the Council of Europe acknowledged that the social costs of criminalizing some activities can outweigh the benefits. [56]. Thus, it may be more effective to bring only the trafficking in persons offences into the realm of the criminal justice system. Less harmful cases (for instance organ sales and purchases not involving traffickers or other middlemen) could perhaps better be approached through alternative policies, which we discuss below.

IMPROVING THE RESPONSE TO ORGAN TRADE

To improve the response to organ trade, the international (transplant) community may wish to change its approach. First, organizations such as the Council of Europe, the WHO and the Declaration of Istanbul Custodian Group may wish to clarify the distinction between transplant commercialism and trafficking in persons. Their instruments should explain that purchasing or selling an organ for material or financial gain is not the same as trafficking a person for his or her organs.

Second, the Council of Europe Convention could consider including a provision which explicitly states that organ sellers will not be considered complicit in any criminal offence(s) involving the sale of an organ. From a law enforcement perspective, resources would be better served by targeting the brokers, recruiters and intermediaries, as well as the transplant centers and staff that perform illegal transplants [57].

Relatedly, it should be recognised that the exploitation that organ sellers experience cannot be reduced to a singular criminal act. Organ sellers are invariably exploited, insofar as their economic position is taken advantage of. As a consequence of their poor bargaining position organ sellers stand to gain significantly less from a commercial kidney exchange than the intermediaries who facilitate the trade. Yet under current legislation their exploitation is only recognised in the context of trafficking in persons. As the empirical body of research suggests, the reasons why people are compelled to sell an organ extend beyond the narrow parameters of trafficking legislation. Efforts aimed at reducing the level of exploitation of organ sellers necessitate measures that look beyond the boundaries

of criminal intervention, taking into consideration the wider political, social, cultural and economic factors that leave people vulnerable to exploitation of various kinds.

Third, the international (transplant) community could offer guidance to governments in addressing other aspects of the organ trade (i.e. commercialism). Countries differ in their local, cultural and socio-political circumstances which can inhibit the adoption of a 'one size fits all' punitive response imposed through a Western design [58]. Examples of alternative, harm-reductionist strategies could involve not only the removal of punishments for sellers, but also of buyers and whistle-blowers, and enhancing their protection. This, in turn, may have the added benefit of potentially increasing their willingness to testify in criminal cases against trafficking networks.

Finally, the relatively low number of convictions involving trafficking in persons for organ removal suggests that a stronger non-legislative response to those who exploit vulnerable sellers and buyers is warranted. Organizations such as the Council of Europe and United Nations could encourage national law enforcement agencies to prioritize prosecution of international organ trafficking networks and facilitate more effective cross-border collaborations to detect and prosecute the crime [59].

In conclusion, more and stricter laws against the organ trade are unlikely to eliminate this practice, and may even be potentially counterproductive. Rather, the international (transplant) community needs to reconsider its approach to organ trade by separating trade from trafficking and introducing harm-reductionist policies.

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IX

A CRIMINOLOGICAL PERSPECTIVE

WHY PROHIBITION OF ORGAN TRADE IS NOT EFFECTIVE AND HOW THE DECLARATION OF ISTANBUL CAN MOVE FORWARD

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The Declaration of Istanbul is the first document that has been established by the international transplant community that defines and prohibits transplant commercialism and organ trafficking. Its Custodian Group has successfully led various countries to implement legislation against trafficking and commercialism. The question arises, however, whether efforts to prohibit organ trade are realistic and effective. The Declaration differentiates trafficking from commercialism, yet it does not mention how both acts should be approached by policy. Policies that address transplant commercialism work differently from policies that tackle organ trafficking. There is considerable room for improvement in the current prohibitive approach to commercialism and organ trafficking. The Custodian Group and World Health Organization (WHO) should address commercialism by encouraging the expansion of living donation in the same manner as they encourage deceased donation. Furthermore, the Custodian Group and the WHO can improve their strategy to combat organ trafficking by raising awareness for enforcement. To achieve a consistent and effective prohibition of trafficking, legislation and law enforcement must go hand in hand. Ideally, this can best be achieved by close collaboration between the medical field and (international) criminal justice agencies.

INTRODUCTION

The Declaration of Istanbul on organ trafficking and transplant tourism (hereafter Declaration) is the first document, drawn up by the international transplant community that defines and condemns transplant commercialism, organ trafficking and transplant tourism. Its primary aim is to inform, inspire and promote ethical practices in organ donation and transplantation around the world [1]. Building on the Universal Declaration of Human Rights and World Health Assembly Resolution 57.18, it aspires to achieve this aim by endorsing prohibition of transplant commercialism, tourism and trafficking of organs and penalization of those that aid or encourage it. The Declaration's custodian group and four task forces have been established to implement and monitor its effects.

The Declaration, by nature nonbinding, has proven to have significant influence. Over 100 transplant organizations endorse its principles. Countries including China, Israel, The Philippines and Pakistan have passed new legislation or strengthened existing laws that ban organ trafficking and organ sales.

This acclaimed success is for a large part because of the World Health Organization (WHO) and its Guiding Principles on human cell, tissue and organ transplantation [2]; hereafter Guiding Principles). Whereas the Declaration is intended to influence transplant professionals and societies, the WHO intends to influence governments. Both act in concert to address growing problems of transplant commercialism, transplant tourism and trafficking by strict prohibition and penalization.

The prohibitionist discourse in the Guiding Principles and Declaration, however, has a predominant focus on prohibition (through legislation) of commercialism and trafficking,

but the importance of enforcement of the crime is neglected. Furthermore, there is a discomforting lack of criminological and legal expertise about what exactly we are trying to prevent by prohibition. Commercialism and trafficking are presented as being equally problematic crimes. However, coercion and exploitation of donors (trafficking) differs from the sale and purchase of organs (commercialism). Both acts warrant a different policy approach. The Declaration's Custodian Group and the WHO, in their discourse on prohibition, do not take account of this distinction. They can improve their strategy to prevent and deter commercialism and trafficking in a number of ways. In the following paragraphs we explain why and how.

WHY ORGAN TRADE IS PROHIBITED

The WHO first declared the prohibition of organ trade in 1987, affirming that such trade is inconsistent with the most basic human values and contravenes the Universal Declaration of Human Rights. The WHO Guiding Principles state the reason why organ sales are prohibited. The commentary to principle five states: 'Payment for [...] organs is likely to take unfair advantage of the poorest and most vulnerable groups, undermines altruistic donation and leads to profiteering and human trafficking. Such payment conveys the idea that some persons lack dignity, that they are mere objects to be used by others' [2].

The organ trade prohibition must be seen in context of when it was formed: at a time when there was no shortage of organs and organ trade and trafficking offences barely occurred. Back then, the prohibition was successful in its aim to prevent trade and trafficking, simply because the root cause of the crime (organ shortage) was not as rampant as it is now. The prohibition worked, not only as a preventative mechanism, but also as a universal norm that organs were not to be used commercially. Almost every single country endorses the noncommerciality principle in organ transplantation and has implemented it into their national laws.

Since the 1990s, however, transplantation has become a victim of its own success, with demand for organs far outpacing their supply. Organs have become more valuable and profitable to sell. This leads to black markets that involve various actors who increasingly make use of organs' high profitability.

THE GLOBAL, ILLICIT FLOW IN ORGANS

Together with drugs, humans, arms, diamonds, gold and oil, organs are becoming the subject of an illegal multibillion-dollar industry. A recent report by Global Financial Integrity estimates that the illicit organ trade generates illegal profits between $600 million and $1.2 billion per year. It ranks the trade in human organs on number 10 of the illegal activities studied in terms of illegal profits made [3]. The report further states that profits from these illicit markets are making their way to transnational crime syndicates through vast international trade networks. These networks take advantage of globalization and new

communication and transportation technologies. Key to the growth and success of global criminal networks is their flexibility and versatility, which have expanded their activities to a wide diversity of legal and illegal fields [4]. Many of these networks are successfully integrated in legal structures and institutions [5].

Indeed, an increasing number of organ trafficking rings are globally active that involve actors who operate in different countries from where recipients and donors are recruited. Organ trafficking accounts come from all over the world, including Egypt, India, South Africa, The Philippines, Israel, Colombia, the Balkan Region, Turkey and Eastern Europe [6-12]. A growing number of countries, including the United States, the United Kingdom, Macedonia and Canada [13-16] report on patients leaving to well-known organ exporting countries who allegedly buy organs on the black market.

Only in very few cases have crime control efforts led to accusations by victims and prosecutions of the accused. Indeed, organ trafficking may be one of the most difficult crimes to detect. Moreover, its enforcement is not a priority of local, national and international law enforcement institutions. The universal response to the crime is characterized by punitive condemnation through legislation but awareness and expertise on how to detect and enforce the crime is practically nonexistent.

PROHIBITION OF DEMAND-DRIVEN CRIMES MAY HERALD SIGNIFICANT RISKS

Prohibition of demand-driven crimes is not new to the field of criminology. For centuries, countries have been struggling to control criminalized, demand-driven activities often with limited effect [17]. Disregarding evidence that crime does not readily respond to severe sentencing, legislatures have over the years repeatedly adopted a punitive 'law and order' stance. David Garland describes this ambivalent response as a form of acting out, which is to say that legislatures engage in a form of impulsive and unreflective action, avoiding realistic recognition of underlying problems [18]. The reasons behind these repressive policies are often political: they are motivated by politically urgent needs to 'do something' decisive about crime, restore public confidence, illustrate good intention and demonstrate state control. These policies are seldom evidence-based, are not aimed at removing the root cause of crimes and do not acknowledge the risks that may arise [17-18].

A wealth of studies illustrates the resilience of demand-driven activities such as drug use, gambling, alcohol consumption and prostitution to prohibition [17]. These studies also highlight how harms associated with these demand-driven crimes including violence, disorder and corruption are, in fact, caused by their prohibition [17,19-20]. These studies show how prohibition generates black markets, drives up prices, provides illegal incomes, displaces crime to other regions and drives trade underground leading to higher crime rates and victimization [20]. One illustration is the 'war on drugs'. A recent report by the International Centre for Science in Drug Policy argues that enforced drug control in the United State led to unintended, harmful consequences [21]. Efforts in the United State to suppress the sale

and use of cannabis have substantially increased in the last years. The costs for stronger enforcement rose from $1.5 billion in 1981 to more than $18 billion in 2002.

The report's authors claim that despite increased repression rates of violence, organized crime, the availability of illegal cannabis and the number of users substantially increased [22]. These conclusions on the failures of the system are in line with reviews of evidence from a global perspective. The authors advise alternatives to prohibition, such as decriminalization and regulation. Indeed, evaluation of more liberal drug and prostitutions policies involving a harm-reduction approach in countries such as The Netherlands have shown that the social harms within regulated markets are lower than in prohibited markets [17].

Despite substantial differences in nature between demand-driven crimes including the organ trade, drug trade and prostitution, the ways in which most states attempt to control them are similar. Unintended implications that may arise from prohibition of crimes such as the drug trade may be equally relevant and applicable to organ trade. First, prohibition of organ trade and drug trade has the similar effect of making them more worth and, thus, more profitable [3]. Second, arguments often made in favor of regulating the drug and organ trade share the view that legalization is likely to reduce social harms inflicted upon vulnerable groups [17,25].

We believe that the risks known to arise despite or as a result of prohibition of demand-driven crimes should be taken seriously. The evidence that organ trade occurs despite its prohibition warrants a careful, critical and realistic approach by the WHO, the Custodian Group and others who prohibit or encourage its criminalization.

The WHO and Declaration in our view take little account of the possible implications that prohibition of organ trade may herald. Their response to organ trade and trafficking has little to no recognition for the limits of crime control and limited acceptance of exploring alternative polices that possibly herald less harmful effects. Rather, their belief seems to be that prohibition will take away the problem and decrease illegal activity. The passing of legislation against organ trade and trafficking is proudly announced and expected to be followed by successful tackling of the problem [23]. Such announcements, in our opinion, are potentially misleading. One example of ineffective prohibition occurs in Pakistan that as a result of the Declaration lobby, passed an ordinance in 2008 prohibiting foreign patients from purchasing transplants there. Despite the initial hope that the ordinance would prevail [23], a recent Pakistani newspaper article admits how despite the new law, Pakistan is being 'sucked back into the vortex of kidney trade and transplant tourism' [24].

The WHO and Custodian Group should, thus, take measures to prevent the current prohibitionist strategy of organ trade from becoming ineffective and symbolic. This does not mean that they should let go of prohibition altogether. It is almost impossible to evaluate whether or to what extent these risks are a direct consequence of prohibition.

The question can be equally posed, 'What the effect of decriminalization or regulation would be on the nature and number of demand-driven trade?'. We argue rather that between prohibition and decriminalization, a wide range of alternatives exists that can be

addressed to control organ trade more effectively. The point is not to choose one over the other, but to think critically and be realistic with what we can achieve and with what means. Later, we present a number of ways in which the current prohibitionist strategy of organ trade can be improved.

WHAT WORKS AND THE WAY FORWARD FOR THE DECLARATION OF ISTANBUL

To assess what works, we need to get our definitions straight. Organ trade takes on a wide variety of forms: only after we agree on the definition of commercialism and trafficking and on what we find condemnable, can we agree on their prohibition. Putting a price on organs (commercialism) is different from coercing someone into selling one (trafficking).

The Declaration correctly defines and differentiates trafficking from commercialism, yet it does not mention how both acts should be approached by policy. Its principles in our opinion wrongly conflate organ trafficking and transplant commercialism to constitute one and the same problem that both warrant equally repressive and punitive responses. However, policies aimed to suppress or reshape an illegal trade or market work differently from policies addressing coercion and other harms associated with trafficking. Evaluative studies have shown that criminalization of commercialism is likely to reinforce trafficking [17]. Indeed, it has been argued that 'there is much more scope for exploitation and abuse when a supply of desperately wanted goods is made illegal' [25-26]. We, therefore, claim that the Declaration should clearly differentiate between policies needed to address commercialism and those needed to address trafficking.

First of all, to tackle and prevent organ trade, the root cause of the problem (organ scarcity) should be addressed. This ultimately means boosting organ supply. One such strategy that the Declaration already strongly supports is to help governments implement deceased donation programs to increase deceased donation rates and achieve self-sufficiency. Such initiatives are being conducted in the Balkans [27] and Black Sea region [28] with the support of the Custodian Group, the WHO and European Union. Yet promotion of deceased donation alone is not enough to fill the gap between demand and supply of organs.

The WHO and Custodian Group should therefore, secondly, also encourage expansion of living donation in the same manner as they encourage deceased donation. They should do so by explicitly stating the need to promote living donation in the text of the Declaration and Guiding Principles. The Custodian Group and WHO should, furthermore, encourage governments to remove restrictions regarding living unrelated or anonymous donation to make alternative living donation programs possible [29-30]. Such programs should be implemented in consistence with international standards to ensure quality and safety of donors and recipients. Current restrictions to unrelated donation are based on the belief that living unrelated donation induces trade. However, there is no evidence of illegal trade in countries with well-organized systems allowing for high numbers of living unrelated donation such as in the United States, The Netherlands, Norway and the United Kingdom.

A final example is to support regulated trials of incentives for donation [26]. This asks for a more liberal approach by both the WHO and the Declaration towards commercialism. In our opinion, there is no validation for the Declaration's and WHO's premise that commercialism should be banned because it leads to profiteering and trafficking [2]. Trafficking will occur as long as scarcity exists, with or without prohibition. A more realistic approach would, hence, be the implementation of harm-reduction policies as witnessed in drug and prostitution regimes. Incentives for donation may, perhaps, be promising examples of a harm-reduction approach. The Declaration should provide scope for governments to explore ways to increase donation through incentives. Ultimately, this indeed will entail decriminalization of organ purchase and sales.

The Declaration and the WHO can also improve their strategy to combat organ trafficking. There is no doubt that organ trafficking is and should remain prohibited universally. The text of the Declaration already emphasizes the prohibition and penalization of acts including brokering and other (medical) practices that aid or encourage trafficking. Indeed, organ trafficking cannot occur without the involvement of medical staff. A recent organ trafficking network uncovered in South Africa illustrates the criminal involvement of medical staff, including nephrologists, surgeons and administrative staff who were found guilty of performing over 100 illegal kidney transplants and receiving payments for them [8]. This case also demonstrates the immense investment that is needed to eventually bring perpetrators to justice. It took investigators 7 years to succeed in gathering enough evidence to bring the case to court. However, dedicated investigations and efforts to identify collusion in hospitals and other criminal activities, in short, the enforcement and police intelligence necessary to bring such cases to court, do not exist in other countries. Organ trafficking case law is practically nonexistent. Prohibition of organ trafficking largely remains a paper exercise. Strict, legislative prohibitionist efforts, no matter how sophisticated, are fruitless if they are not accompanied by enforcement by local, national and international policing agencies.

To achieve a consistent and effective prohibition of trafficking, legislation and law enforcement must go hand in hand. Enforcement strategies include: prioritization and awareness raising of the crime at the local level both with police and judicial authorities, training of police investigators regarding evidence gathering, recognition of organ trafficking activity and know-how about the modus operandi of the actors involved, training of prosecutors and judges and establishment of bilateral and/or multilateral cooperation in cross-border criminal procedures. Ideally, such considerations are best followed when close collaboration between the medical field and (international) criminal justice agencies is achieved.

Perhaps, the greatest achievement for the WHO and Declaration of Istanbul will, thus, lie in bridging the gap between the medical field and the criminal justice realm. These efforts could, for instance, be aimed by lobbying with governments and international organizations such as INTERPOL, UNODC and EUROPOL to raise awareness about the crime. Indeed, the Declaration and the WHO are not law enforcers, but both bodies may be the

most influential forces to stimulate governments into addressing enforcement strategies at the local level. Yet, it must be kept in mind that enforcement is no guarantee that trafficking will stop. The root cause of the crime cannot be removed by strict, top down penal measures. Black market transactions will exist as long as organ scarcity exists. At the very least, successful enforcement might help to disrupt some tip-of-the-iceberg organ trafficking networks, but it will not fundamentally affect the crime.

The organ trade problem will persist and worsen unless the Custodian Group, the WHO and policymakers understand the limitations of prohibition and tackle the root cause of the crime by promoting both deceased and living donation.

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7

STRATEGIES TO REGULATE AND DETER ORGAN TRADE

X

INCENTIVES FOR ORGAN DONATION

PROPOSED STANDARDS FOR AN INTERNATIONALLY ACCEPTABLE SYSTEM

Working Group on Incentives for Living Donation
Authors are listed at the end of the article

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Incentives for organ donation, currently prohibited in most countries, may increase donation and save lives. Discussion of incentives has focused on two areas: (1) whether or not there are ethical principles that justify the current prohibition and (2) whether incentives would do more good than harm. We herein address the second concern and propose for discussion standards and guidelines for an acceptable system of incentives for donation. We believe that if systems based on these guidelines were developed, harms would be no greater than those to today's conventional donors. Ultimately, until there are trials of incentives, the question of benefits and harms cannot be satisfactorily answered.

INTRODUCTION

Every country with an active kidney transplant system is working to increase organ donation. The reasons are clear—for patients with end-stage kidney disease (ESRD), a kidney transplant offers significant advantages compared to dialysis: increased longevity [1], a better quality of life [2] and cost-effectiveness (including cost saving for the health care system [3]). Patients can receive a kidney transplant from either a living (biologically related or unrelated) or deceased donor. However, kidneys from living (vs. deceased) donors are associated with better short- and long-term outcomes [4] and facilitate early or preemptive transplantation, thus avoiding the adverse consequences associated with dialysis [5].

Because of the benefits of transplantation, patients with ESRD increasingly opt for a transplant. Because of the increasing demand for a transplant and a relatively static supply of organs, there is a widening gap between the number of patients wanting a kidney and the number of available organs. This growing shortage persists in spite of efforts to prevent ESRD and the recent expansion of both deceased donation (through the use of such strategies as expanded donor criteria and donation after cardiac death) and living donation (through increased unrelated and nondirected donation, paired exchanges, ABO incompatible transplants, desensitization and transplant chains). Because of the ongoing shortage, many suitable transplant candidates suffer and ultimately die while waiting for a transplant.

In most countries donation is limited to 'altruistic' donors (in the case of deceased donation, donor families) and by law, donors are not allowed to receive anything of material value in exchange for giving a kidney. Within some countries, only biologic relatives are permitted to be living donors. Yet, because of: (1) the shortage of kidneys, (2) the morbidity and mortality associated with long-term (or no) dialysis, (3) increasing desperation of many candidates and (4) the potential for profit, illegal and unregulated organ markets have developed throughout the world. Such underground, unregulated markets have been associated with exploitation of the poor and vulnerable.

Living donors who participate in these unregulated markets are often poorly informed about the procedure, deprived of appropriate screening and of quality postoperative and continuing medical care, and not compensated as agreed upon [6-9]. At the same time, because of limited donor screening, some recipients have developed serious

infections transmitted by the donor organ; others have received little postoperative care or immunosuppressive treatment and have returned to their native country with active rejection and no knowledge of which immunosuppressive medications they were given [9-13]. Often, the medical and surgical details have not been sent with them, so that their home transplant center has tremendous difficulty with continuation of care. Thus, these unregulated markets have been associated with adverse consequences for both donors and recipients.

A regulated system of incentives for donation has the potential to increase both living and deceased donation while eliminating the harms of unregulated markets. When the concept of incentives was first proposed, almost 3 decades ago, there was immediate condemnation [14].

Over the ensuing years, the pros and cons of incentive programs have been debated. At first, many opposed incentives as a matter of principle, claiming that an incentive for donation was wrong in itself. Yet, numerous scholars and consensus conferences have concluded that there are no ethical principles by which incentives should be rejected under all circumstances [15-19]. Surveys have shown that the public: (1) support incentives and (2) would be more likely to donate if incentives were offered [20,21]. More recently, critics of donor incentives have argued on utilitarian grounds that incentives should be prohibited because they would do more harm than good [22]. However, the 'evidence' used as the basis of that argument has almost entirely been drawn from observation of unregulated organ markets. We are fully cognizant of the harms that have occurred with unregulated markets and unreservedly condemn the practice of organ trafficking [23]. However, there are no data to suggest that similar harms would occur in a carefully controlled, transparent and regulated system of incentives.

The debate surrounding the principle of incentives *per se* will no doubt continue. Our view, however is that there is no objection of principle and that a system of incentives for donation could potentially provide enormous benefit to both recipients and donors and is worthy of systematic investigation. Instead of treating the hypothetical harms as a reason for forgoing these benefits outright, we believe the international community should try to devise ways of identifying and eliminating the dangers while maximizing the benefits. To further the discussion, we propose principles and guidelines that would, assuming legal frameworks were changed to make this permissible, provide the basis for an acceptable system of incentives. While not intended as definitive, we suggest that any system that conformed to the proposed guidelines would meet the standards, which both supporters and opponents of incentives could agree are necessary (if not sufficient) for any system of donation and are consistent with the standards that we have developed for current conventional donation.

DONOR MOTIVATION

The discipline of transplantation is suffused with assumptions of an idealized vision of current motives for donation: that is, all organs are and must henceforth be, given in the

spirit of pure 'altruism'. There are two problems with this reasoning. The first is that any realistic discussion of donation must acknowledge the many different and overlapping motives that underlie donation within and outside of families [24]. Although we speak of the 'gift-of-life', we also recognize that current donors often have alternative or additional motives or external pressures, e.g. a sense of obligation, a need to be accepted or valued by family and friends or even an easily identifiable secondary gain [24-28]. If we were to limit donation to those motivated only by pure altruism, it is likely that donors would be few and far between. Conversely, it is entirely possible were incentives permitted, incentivized donors might use the reward for altruistic purposes (such as the care of sick family members). Rather than confirming a dichotomy of altruism versus no altruism, experience is most consistent with a continuum of motivation to donate organs, ranging from complete selflessness to blatant self-interest.

The second problem with the mandate for 'altruism' is that there is no other context in which it is stipulated that something urgently needed must be given without payment or not given at all. Creating such a principle of altruism for organ donation is totally arbitrary and ignores the fact that our current donors frequently receive secondary gain or other unspoken tangible reward. We must also recognize that many highly motivated potential donors do not come forward or do not progress through the evaluation and donation process because of the substantial financial and logistical obstacles (table 1). Others, though initially motivated by the opportunity to help another, might be even more likely to come forward if there were incentives.

table 1 Potential disincentives for a living donor

1	Fear of financial hardship because of:
	A Travel, accommodation, childcare and medication cost at the time of assessment and donation procedures;
	B Loss of income at the time of donation and during the recovery phase;
	C Loss of or difficulty obtaining health and life insurance after organ donation;
	D Loss of employment opportunities after organ donation.
2	Fear of death, disability or functional restriction. These fears encompass both short- and long-term sequelae of donation, including perceived effects on fertility and childbearing.
3	Fear of a lost opportunity. Potential donors may prefer to retain a kidney for future potential recipients, especially children.

TODAY'S SITUATION

Current, unregulated markets that do not offer protection for either the donor or recipient are abhorrent. Yet the arbitrary requirement for what is deemed 'altruistic' donation must be viewed against the backdrop of the organ shortage and its tragic consequences for transplant candidates. In countries able to afford dialysis, waiting time from listing until transplant continues to increase, as does mortality on the wait list. In developing countries, where health care costs are assumed largely by the patients themselves, lifetime dialysis is not an option. Some can manage to afford limited and intermittent dialysis by scraping together resources, a response that typically results in inadequate care and places a severe burden on the financial well being of their families. In such countries, because of its significantly lower long-term costs, transplantation is the only realistic path to long-term

survival. Without a significant increase in donor kidneys, in both developed and developing nations, preventable morbidity and mortality in patients with renal failure will continue.

Although we have focused on kidney donation, the same concerns (lack of sufficient organs; candidates dying while waiting) apply to other solid organ transplant candidates. Most liver, lung and pancreas transplants and all heart transplants, come from deceased donors. Incentives for deceased donation may also help provide more extrarenal transplants.

When a product is desired, a market (legal or illegal) will develop; prohibition simply drives markets further underground [29,30]. The tangible harms of organ trafficking can be directly traced to its illicit, underground features: lack of control, regulation and oversight. These elements conspire to disenfranchise and damage vulnerable donors and ensure suboptimal outcome in recipients. Clamping down on unlawful organ sales without expanding the organ pool will not result in less criminal activity. Patients will continue to die as purveyors of this corrupt trade go further underground and other markets develop elsewhere around the globe.

PROPOSED SOLUTION

Regulated systems that remove disincentives to donation and reward donors have the potential to increase donation, save lives and reduce or eliminate the unregulated markets and the harm they cause. We herein propose for discussion principles and guidelines for development of acceptable systems of incentives for deceased and living donation.

1 Removal of Disincentives

Donors (or donor families) should suffer no short- or long-term financial burden as a consequence of organ donation. Disincentives for living donation should be eliminated. At a minimum, this would entail reimbursement of expenses and lost income, along with provision of term disability insurance, term life insurance and care of donation-related complications.

In some countries, there may also be financial disincentives to deceased donation (e.g. cost of family travel to the medical center to give consent). These should be addressed and abrogated. Within each country, policies to maximize the benefit of deceased donor programs should be enacted. This is particularly important for those waiting for extrarenal transplants, where living donation is not an option.

2 A Regulated System of Incentives

An acceptable system of incentives for donation must ensure—for both the donor (and donor family, in the case of deceased donation) and recipient—respect, benefit and protection from harm. More specifically:

- A the donor (or family) is respected as a person who is able to make choices in his or her best interest (autonomy);
- B the potential donor (or family) is provided with appropriate information to support informed decision making (informed consent);
- C donor health is promoted at every step, including evaluation and medical follow-up (respect for person);

D the live donor incentive should be of adequate value (and able to improve the donor's circumstances);

E gratitude is expressed for the act of donation.

Critical elements of such a system would be protection, regulation, oversight and transparency under the auspices of the appropriate government or government-recognized body.

1 Protection: Risk to the donor should be in accord with currently accepted standards as defined for our current donors [31]. The donor benefit (in addition to helping another person) must be an opportunity to improve their own (or their family's) life. Therefore, the donor must be fully informed, understand the risks, understand the nature of the incentive and how it will be distributed and receive the benefit. There must be follow-up and an opportunity to redress any wrongdoing.

2 Regulation and Oversight: Each country will need to enact guidelines for evaluation and selection of donors, institution of the program of incentives and oversight. Regulations and oversight processes must be clearly defined and available for outside review, whether national or international. There must be clearly defined policies for follow-up, outcome determination and for detection and correction of irregularities. There should be defined consequences for entities within the system that do not adhere to policies.

3 Transparency: Although, for political and legislative reasons, regulation and oversight are only possible at a national level, there must be transparency so that international observation is possible.

GUIDELINES FOR DEVELOPMENT

Guidelines for development of acceptable regulated incentive systems for deceased or living donation are specified in table 2. Critical (in addition to protection, regulation, oversight and transparency) are that the donation should be anonymous and nondirected, allocation should be to the first person on the list (using a predefined and transparent algorithm)

table 2 Guidelines for development of a regulated system of incentives for deceased and living donation

1	Each country implementing a system of incentives should have a legal and regulatory framework for the process.
2	The entire process must be transparent and subject to government and international oversight.
3	The incentive should be provided by the state or state-recognized third party. Under well-defined, transparent and regulated circumstances, prospective recipients may help fund a charity that supports the program. There is no direct payment from the recipient to the donor and supporting the charity will not result in advancement on the waiting list.
4	Allocation of the organ(s) should be performed according to the single recognized system of that country (similar to UNOS in the United States) using a predefined and transparent algorithm so that everyone on the list has an opportunity to be transplanted. Kidneys would be allocated to the number 1 person on the list (as determined by defined and transparent criteria).
5	There should be a plan for administration and for rigorous oversight to ensure that criteria for evaluation, acceptance, allocation and provision of the incentive to the donor (or donor family) are being followed.
6	The donation should be anonymous and nondirected.
7	No other solid organ donor incentive plan would be legal.
8	There should be legislation to govern wrongdoing and how centers would be censured, including criminal sanctions and fines, if wrongdoing is identified.

table 3 Additional guidelines for development of a regulated system of incentives for living donation

1	There should be a clear and transparent process for providing information about risks to the donor, ensuring that the donor understands the operation and its risks and obtaining donor consent.
2	There should be a thorough donor screening evaluation using defined (and widely available) protocols. There should be well-defined and transparent criteria for donor acceptance.
3	There should be a fixed 'incentive' to the donor so that all donors (in any one country) receive equal value. The package of incentives may vary from one geographic region to another but should be designed to improve the life of the donor. Even within the same region, it may be possible to have a choice of benefits recognizing that some incentives may be of value to some donors but not others.
4	The program (donors and recipients) should be limited to citizens and legal residents. This will allow long-term donor medical care and follow-up.
5	The donation should remain anonymous and there should be no contact between donor and recipient.
6	The donor should understand the need for long-term follow-up and should consent to follow-up.
7	There should be a well-defined and transparent method to follow incentivized donors and study outcomes. There should be:
	A Studies of the impact of incentivized donation on the number of deceased and living donors, the number of transplants (covering all organs), the wait list and waiting time for a deceased donor transplant;
	B Comparisons of short- and long-term outcomes (including quality-of-life) of incentivized versus nonincentivized donors;
	C Studies of whether the incentive had an impact on the donor's life.

and the incentive be provided by the state or state-recognized 3rd party. Additional guidelines for living donor systems are specified in table 3. Key items include informed consent, screening similar to our conventional donors, a fixed 'incentive' to the donor, limitation to citizens and legal residents and long-term follow-up studies.

DISCUSSION

The test of any regulated system of incentives for organ donation would be its provision of clear benefit to both donors and recipients. Patients who desperately need organs would obviously benefit if more were available and there is no reason to doubt that many donors would benefit from receiving an incentive under properly controlled circumstances. Permitting incentives would allow competent, properly informed adults to make their own judgments about their own best interests—widely regarded as an essential feature of respect for human dignity.

Many types of incentives that would meet these criteria are potentially acceptable and some donors (within the same system) might prefer different incentives than others. The form and substance should be determined by individual governing bodies commensurate with the principles outlined above. For deceased donation, it would need to be decided if the plan should include predeath benefits (which has the disadvantage that many receiving benefits would not be able to donate at the time of death), an incentive for registering as a donor where the benefit only accrues in the event that the signatory actually becomes a donor, or simply to provide benefits (e.g. funeral expenses) at the time of donation. For living donation, in addition to removal of disincentives [23], benefits could include (but would not be limited to): long-term health care, tax credit, tuition or job training; provision of a job; or payment (which could be a small payment and then additional annual small payments when returning for follow-up visits). Implementing a regulated

system of incentives will clearly be simplest within societies that already have an adequate social safety net, registries of health outcomes and provision of long-term health care for all citizens and legal residents.

The absolute value of the incentive might legitimately differ from one country to another but, for living donors, it should be sufficient to significantly improve the donor's well-being. The GNP and cost of living vary from country to country and the level of benefits within any one country (or geographic area) would obviously have to reflect local economic conditions. Given that incentive programs would be limited to citizens and legal residents (for both donors and recipients; table 3), travel to another country to receive a greater incentive would not be possible. In addition, there could be a 'cooling-off period' between initial evaluation and donation (so that some tests (e.g. viral testing) could be repeated and those seeking an instant payment would have sufficient time to carefully consider the risks).

Whether provision of health care is an incentive or removal of a disincentive is controversial. Most developed countries (the United States is an exception) provide government-sponsored long-term health care for everyone; in these countries the issue is moot. Most developing countries cannot afford universal lifelong health care. At a minimum, donors should be provided with health care for all donation-related issues [23]. Yet, in reality, it will be difficult to determine whether or not many health care issues are related to the donor event. Ideally, long-term health care should be provided as a benefit to all donors. Publically financed health care would: (1) be of major benefit to citizens of all societies and (2) allow donor follow-up and therefore permit the transplant community to prospectively identify and correct any unintended consequences of a program of incentives.

Epidemiologic studies have reported that poverty is associated with increased chronic kidney disease, poorer health and shorter life expectancy [32]. This is of concern given the likelihood that the majority of incentivized donors will come from lower income groups. However, the same data suggest that the health risks associated with poverty are related to increased rates of hypertension and diabetes as well as to reduced access to medical care. Currently, low income is not a contraindication to conventional 'altruistic' donation and our current selection processes eliminate potential donors at increased risk. If we use the same cautious selection and approval process for all donors, long-term outcomes are likely to be comparable. In fact, the provision of long-term follow-up and long-term health care—as one of the benefits of incentivized donation—has the potential to improve overall health of the donors. It is difficult to conceptualize an incentive system in which low income is a contraindication to participation. However, if follow-up studies were to show that low income incentivized donors had worse outcome than nonincentivized donors, an income threshold could become a requirement for future participation. All arrangements should be adjustable in the light of experience.

Would it be necessary to provide an incentive to all donors, directed and nondirected? Each country would have to make that decision. Clearly, disincentives should be removed for all donors. However, as discussed above, directed donation has potential benefits to the donor. For example, a husband donating to his wife benefits from having

a healthy spouse. It may be that the optimal system would occur if all donors receive incentives; it may be that the optimal system is a two-tier system with more incentives for nondirected than directed donors. Trials are necessary to answer this question.

As with any proposal for change, there are potential strengths and weaknesses. The major potential advantages of a regulated system of incentives for donation are increased organ availability for candidates on the waiting list combined with provision of benefits for the donors (or donor families). However, until there are trials, we have no means of knowing under precisely what circumstances such a proposal would best succeed. Thus one concern is that the total number of transplants (especially for extrarenal organs) might decrease. This concern would, however, be mitigated if the opportunity to alter variables within the incentive system were used. The reason we do not know which incentives might be suitable and effective is the historical blanket prohibition of all such efforts. If this prohibition were set aside as we propose, an iterative approach could address all aspects of the process so that it is improved over time.

A second concern is that, today, most unregulated markets occur in countries that prohibit incentives for donation, but lack the appropriate control or willingness to enforce the prohibition. Arguably, similar lack of control could limit the success of our proposed system. Our proposal requires clear legislation and national framework, strong government control and safe and transparent procedures and screenings. For each country, before a system of incentives is tested, policy and guidelines must be developed and a system for their strict implementation must be put in place. Donor and recipient protection is paramount. The single greatest threat to a regulated system of incentives for donors would be that dishonest individuals or groups would seek to subvert that regulation for personal gain, a risk that applies to any legal enterprise. Ways of mitigating this threat would include minimizing transaction fees and making all payments transparent and open to regular audit.

Whereas every possible circumstance cannot be anticipated, this document outlines the broad intent of an ethical framework for a regulated system of incentives for donation. For example, the guidelines (table 3) limit participation (both donor and recipient) to citizens and legal residents. In theory, a country could grant rapid citizenship for the purpose of either donating or receiving a kidney. This clearly contravenes the spirit and intent of this document and such a practice would not meet international acceptance, a criterion that the group felt was an essential component of any ethical system. In addition, some countries (e.g. the United States) currently allow transplant centers to allocate a percentage of deceased donor organs to nonresident foreigners [33]. If regulated systems of incentives are developed for such countries, it will need to be determined if kidneys from incentivized donors could be allocated to foreign nationals.

We recognize that this document—like others of its kind— represents the consensus opinion of the coauthors. Even within our group, some would be more restrictive, some more liberal. However, all agreed on the basic principles outlined herein and that any arrangement that fulfilled all of these criteria would be ethically acceptable. We present it as a pragmatic foundation for developing acceptable systems of incentives for donation.

International experience with transparent, government approved, fully regulated systems, is limited. Once such systems have been developed and tested, the guidelines may need modification; however, the overarching principles—protection (donor and recipient), regulation, oversight and transparency—will remain applicable.

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XI

THE HOTT PROJECT

INCREASING KNOWLEDGE, RAISING AWARENESS AND IMPROVING RESPONSES TO TRAFFICKING IN HUMAN BEINGS FOR THE PURPOSE OF ORGAN REMOVAL

This synopsis is based on:

F. Ambagtsheer, W. Weimar. Organ Trade: Knowledge, Awareness, and Nonlegislative Responses, *Transplantation* 2016; 100(1):5-6

F. Ambagtsheer, W. Weimar. The Hague Recommendations: Improving Nonlegislative Responses to Trafficking in Human Beings for the Purpose of Organ Removal, *Transplantation Direct* 2016; 2(2):e61

F. Ambagtsheer, W. Weimar (eds). *Trafficking in Human Beings for the Purpose of Organ Removal: Results and Recommendations.* Lengerich: Pabst Science Publishers; 2016, pp. 1-149

The HOTT project (2012-2015) was a European Union-funded international research project that addressed an exploitative form of organ trade: 'trafficking in human beings for the purpose of organ removal' [1]. Erasmus MC coordinated the project in collaboration with Lund University, the Bulgarian Center for Bioethics and the Academic Society for the Research of Religions and Ideologies. In addition, 10 associated partners participated on a non-funding basis, amongst which the Dutch National Police, the European Society for Organ Transplantation and the University of St. Cyril and Methodius in Skopje, Macedonia. It was the first international, interdisciplinary research project that aimed to increase knowledge, raise awareness and improve the non-legislative response to trafficking in human beings for organ removal.

We initiated the project for various reasons. First of all, we found that although information and knowledge exists about the crime, this information is not synthesized or shared amongst researchers, transplant professionals, law enforcement and other stakeholders. Furthermore, there is no awareness of the crime, especially amongst law enforcement authorities. Trafficking in humans for organ removal is not on the 'enforcement agenda'. The lack of multinational partnerships hampers an effective response to the crime.

We started our research by describing the state of knowledge on trafficking in human beings for the purpose of organ removal based on the scholarly research. The project's literature review, which was performed through a search of 5 databases and a screening of over 10,000 records, presents 243 references on the ethics, causes and the actors involved in the trade (the network): recipients, suppliers (donors), brokers, transplant professionals, hospitals, service providers, translators and corrupt law enforcement officials. Each chapter describes the roles of these participants, for instance, how brokers recruit patients and donors, how much profit is made, where patients travel to and from and if and to what extent organ sales constitute trafficking in humans. Each chapter ends with a description of the gaps in the literature. The authors conclude that 'the scholarly research in this area is not well-developed' [2].

To acquire more knowledge about the 'demand side' of the trade, we conducted interviews with 22 patients from Sweden, The Netherlands and Macedonia/Kosovo who purchased kidney transplants abroad. To date, this is the largest group of patients that has been interviewed on this issue. The patients provided information about the transplant costs, what/whom they paid, why they went and how their transplants were facilitated. The however shared little information about whether their donors were paid and/or exploited. This makes it difficult to determine the potential illegal nature of their transplants. This study revealed that interviewing patients is an insufficient method to find out how their transplantations were facilitated [3]. Thus, we organized case study research to acquire information about the modus operandi of organ trade networks.

The last study involved research of convicted cases in South Africa, Kosovo, Israel and the USA. Conducting 37 interviews with 49 persons (most of which were police officers and prosecutors), we aimed to find out how police and prosecution discovered each

case, how they performed their investigations, what the modus operandi of the actors were, under what laws/charges the prosecutions took place, what successes and obstacles police and prosecution encountered and what the judgment in each case was. This study revealed, among others, the sophisticated and subtle methods that networks use to recruit patients and donors, as well as the difficulties that police and prosecutors experience in uncovering and convicting these networks [4].

Almost all of the results that were generated under the HOTT project are presented in the underlying thesis, and are published in a book [5]. To share our findings with, and raise awareness amongst transplant professionals, law enforcement authorities, NGOs, policy makers, representatives of governments, international organizations and other stakeholders, we organized a 2-day event at the Headquarters of the European Police Office (Europol) in November 2014 in The Hague, The Netherlands.

On the first day, 40 experts convened in the project's 'Writers' Conference' to formulate recommendations to improve non-legislative responses. These recommendations address the ethical and legal obligations of health care providers, the protection of persons trafficked for the purpose of organ removal, strengthening cross-border collaboration in criminal cases and stimulating partnerships between transplant professionals and law enforcement [6-9].

On the second day, we organized a symposium that was attended by 230 participants from 35 countries. The project's researchers presented their results and police and prosecutors shared their experiences with uncovering organ trafficking networks. In addition, the experts that convened in the Writers' Conference, presented their recommendations. Recognizing that prosecuted cases represent only the tip of the iceberg and that the response of law enforcement agencies to organ trading is almost 'entirely reactive', it was emphasized, amongst others, that transplant professionals need to collaborate more closely with law enforcement. In particular, the transplant community can help improve the non-legislative response by reporting organ trafficking networks to law enforcement authorities.

Finally, together with the Central Division of the Dutch National Police, we developed a list of indicators for transplant professionals, law enforcement and victim support workers. The indicators support data collection and identification of trafficking in human for organ removal. They identify the legitimate and illegitimate service providers for each step in the criminal process: recruitment, transport, entrance, documents, housing, transplant, aftercare and finance [10].

Until now, only 11 convictions involving organ trade/trafficking are known to have taken place worldwide. What is needed is a recognition amongst law enforcement, policy makers and the transplant community, to strengthen not only the legislative response, but also the non-legislative responses (disruption, investigation and prosecution) to the crime. The HOTT project's results and recommendations offer strategies for these stakeholders to improve such responses.

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XII

INDICATORS TO IDENTIFY TRAFFICKING IN HUMAN BEINGS FOR THE PURPOSE OF ORGAN REMOVAL

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This article presents indicators to support transplant professionals, judicial and law enforcement authorities and victim support workers with the identification of trafficking in persons for the purpose of organ removal. It outlines the legal and illegal service providers that facilitate trafficking in human beings for the purpose of organ removal and guides the reader through the following criminal process: recruitment, transport, entrance, documents, housing, transplant, aftercare, and finance. Identification of illegal transplant activities by transplant professionals can support police and judiciary with the investigation, disruption, and prosecuting of trafficking networks.

INTRODUCTION

This article presents indicators to help transplant professionals, law enforcement authorities and victim support workers identify trafficking in human beings for the purpose of organ removal (THBOR). THBOR is defined as 'the recruitment, transportation, transfer, harboring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include [...] the removal of organs'.[1]

The indicators are structured along a barrier model. This model identifies the legal and illegal service providers for each step (barrier) in the criminal process: recruitment, transport, entrance, documents, housing, transplant, aftercare, and finance (figure 1).

Although the indicators are indicative of THBOR, they may point to other forms of organ trade as well, such as transplant tourism and transplant commercialism—forms of organ trade which do not necessarily involve THBOR. The indicators are not exhaustive; they should be extended or modified in response to changes in the modus operandi of traffickers and new research findings.

METHODOLOGY

The indicators are based on empirical research data that has been collected under the HOTT project, an EU-funded project against THBOR, titled combating trafficking in human beings for the purpose of organ removal (2012-2015). They are derived from the following sources: in-depth interviews with police, prosecutors, patients and transplant professionals, witness and victim testimonies, and judgments of prosecuted cases.

TARGET GROUPS

The indicators are for persons who may come into contact with (potential) recipients, donors, or facilitators who have retrieved or provided organs (or are planning to do so) by means of THBOR. These persons can be transplant professionals, judicial and law enforcement authorities (including border police and embassy officials), and victim-aid workers.

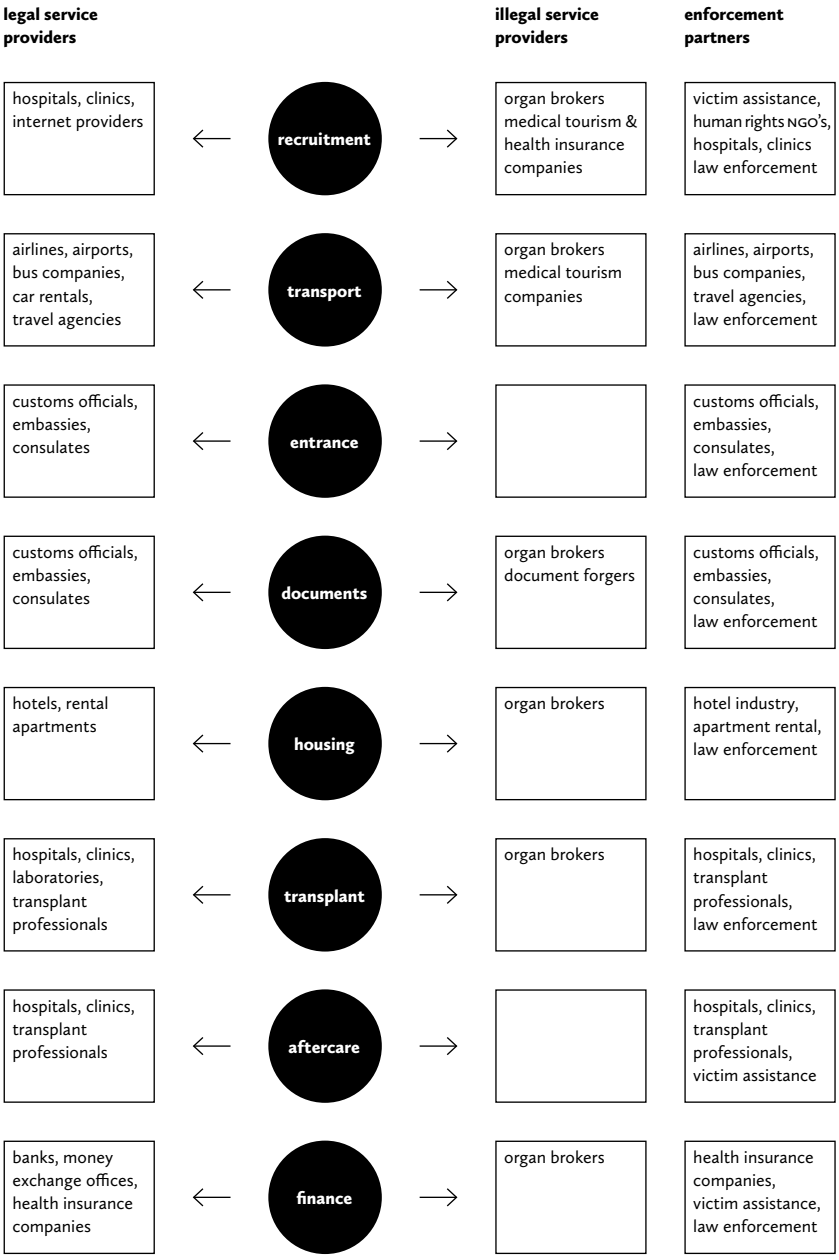

figure 1 Barrier model: human trafficking for the purpose of organ removal

Recruitment

Persons who are going to receive an organ through THBOR may:

— leave for a transplant abroad without notifying their health caregivers;
— refuse to accept local transplant solutions;
— search the internet for transplant possibilities abroad;
— be in (online) contact with a person and/or company that advertises/organizes transplants (abroad) and that does not provide information about the organ donors;
— be in contact with a group of potentially suitable, but unknown donors abroad;
— not know beforehand where the transplant will take place and/or who their prospective donors abroad will be;
— have received a personal invitation from a transplant professional to be transplanted abroad;
— have been asked to send medical test results abroad for review by a person/institution whose medical expertise lacks certification.

Persons who are going to supply an organ through THBOR may:

— be in (online) contact with a person and/or company that advertises/organizes organ donations abroad,
— not have received any or incorrect or misleading information about the pre- and postoperative risks and/or the duration of the operation,
— not know who their prospective recipients abroad will be, not have a (clear) motivation for their donation,
— have a relative/acquaintance who has sold an organ before.

Transport/entrance

Persons who are going to receive/supply or have received/supplied an organ through THBOR may:

— travel together with one or more persons, who do not appear to know each other, to the same destination;
— be accompanied by someone with a medical background;
— show signs of fear of someone who accompanies them, for example sweating, trembling, not speaking;
— suffer from physical complaints, such as pain in the area where the organ was implanted or removed;
— have not organized their own transport and/or do not know their destination;
— be carrying a considerable amount of cash;
— be carrying medical records and/or letters of invitation for medical treatment;
— travel directly to a hospital or clinic upon arrival in a foreign country.

Documents

Persons who are going to receive/supply or have received/supplied an organ through THBOR may:

— have received their travel and/or identity documents from someone else;
— not carry their own travel or identity documents during the travel to or entrance in a foreign country;
— carry identity documents that are very recently issued and/or appear to be forged;
— carry travel documents that do not correspond with the purpose of their travel.

Housing

Persons who are going to receive/supply or have received/supplied an organ through THBOR may:

— be housed in an accommodation owned by a medical professional or a hospital/clinic;
— be housed together in the same accommodation;
— not be allowed or able to leave the accommodation on their own;
— be escorted whenever they go to and return from the hospital/clinic;
— not know the location of their accommodation;
— undergo physical examinations, blood or other tests performed by doctors at their accommodation.

Transplant

Persons who are going to receive/supply or have received/supplied an organ through THBOR may:

— not have received prior medical screening (in their home country);
— undergo the transplant procedure abroad within a very short time frame (2 weeks to 2 months);
— not know the location and/or name of the hospital/clinic and/or transplant professionals involved;
— have not signed consent forms;
— be illiterate and/or signed documents that were not written or explained in their native language;
— have a group of potentially suitable, unknown donors;
— have documents in which the donor-recipient relationship was changed from 'unrelated' to 'related';
— claim to know each other, but do not actually interact or show interest in one another before and/or after the transplant;
— claim to be related to the donor or recipient, but have an inconsistent story about their relationship or give the impression that they were instructed to feign their relationship;
— have not received any or incorrect or misleading information about the pre- and postoperatives risks and/or the duration of the operation;

— have second thoughts and/or not have been given the opportunity to withdraw prior to the operation;
— have seen other foreigners at the hospital/clinic (who arrived in groups);
— have been accompanied by another person when visiting the hospital/clinic, who insisted to answer questions on their behalf and/or to translate all conversations with the medical staff;
— have been operated at a hospital/clinic without the availability of a dialysis machine or other necessary medical equipment;
— not have a (clear) motivation for their donation;
— typically present as a donor/recipient pair consisting of a (foreign) younger donor and a (foreign) older recipient.

Aftercare

Persons who are going to receive/supply or have received/supplied an organ through THBOR may:

— reappear unannounced at their local hospital with an implanted or removed organ;
— have not received appropriate medical aftercare and/or necessary medication;
— have received aftercare in another hospital/clinic than where the transplant took place;
— lack discharge sheets and/or other information about the operation (abroad) in their medical records, for example, the name of the hospital/clinic, transplant professionals and/or source of the organ;
— be reluctant to share information about where and how the operation took place;
— be reluctant to share information about their relationship with the recipient or donor;
— return from an operation abroad with infections, graft failure or other complications, recipients in particular may carry infections such as HBV, HBC, HCV, PCP, HIV, CMV, TB, Pyelonephritis, Aspergillosis, Sepsis, Malaria, liver cirrhosis, UTI, abscesses and meningitis and/or suffer from graft failure or graft loss and/or carry high doses of immunosuppressive regimen, wound drains and/or splints in their bodies;
— show signs of emotional stress/complaints, such as shame, stigma, and regret, about the removal of their organ.

Finance

Persons who are going to receive/supply or have received/supplied an organ through THBOR may:

— state that they will give/receive or have given/received payments in return for the organ;
— have not received the agreed amount of money;
— have paid fees for recruitment, transport and accommodation that were deducted directly from the person's earnings in return for the organ donation;

— have been told that they need to pay or will be paid in instalments (in advance of the operation);
— have paid a donor, doctor and/or other facilitator (in cash) for an organ or an organ transplant;
— not know the name of the person to whom they have paid or who received their payment;
— have made payments through an intermediary person or institution;
— have not received a receipt after payment.

CONCLUSIONS

Indicators are a helpful tool to support transplant professionals, judicial and law enforcement authorities, and victim support workers with the identification of THBOR. Such identification can encourage police and judiciary to investigate, disrupt, and prosecute trafficking networks. The infrastructure that allows transplant professionals to report such activity however may not yet exist in every country. We therefore encourage transplant professionals to follow the HOTT project's recommendations presented in this issue. [2-5] One example could involve liaising with government officials, lawyers, and police to establish national reporting codes that allow for the identification and disclosure of trafficking networks (ie, brokers, hospitals, hospital staff, and other individuals involved in trafficking) without revealing patients' identities. [6]

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SUMMARY AND CONCLUSIONS
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SUMMARY AND CONCLUSIONS

Organ trade constitutes the sale and purchase of organs for financial or material gain. Although in the literature numerous terms are used to denote the trade's various practices such as 'trafficking in human beings for the purpose of organ removal', 'transplant commercialism' and 'transplant tourism', in the underlying thesis, the term 'organ trade' is largely used as an umbrella term to cover these activities.

Although prohibited worldwide, an increasing number of reports indicate the trade's proliferation across the globe. There is, however, a lack of evidence-based research on the topic. The underlying thesis strives to fulfil gaps in knowledge through the following aims (presented in **chapter 1**):

1 Provide insight into the scale of patients who buy organs for transplantation and describe why, where, how and from whom they purchased organs.

2 Acquire knowledge and understanding of the experiences, attitudes, behaviors and needs of transplant professionals who treat patients before and/or after they buy organs.

3 Examine the modus operandi of those who facilitate illegal transplantations and study the investigation and prosecution of organ trade networks.

4 Assess the possible implications of a punitive, legislative approach.

5 Propose alternative strategies that may deter organ trade more effectively.

Through these aims, this thesis strives to acquire a better empirical understanding of organ trade and to use this knowledge to explore strategies that may eliminate—or regulate—the trade more effectively.

Chapter 2 consists of two articles that each present the **background and theoretical framework** of the underlying thesis. The first explores the ethical and legal aspects of live kidney donation, including the commercialization of organs. The second article presents an in-depth account of organ trade by exploring its trends and patterns, its prohibition and the critiques against its prohibition. This article also introduces the first explorative empirical study on transplant tourism from The Netherlands.

In **chapter 3** we studied the scale, motivations and experiences of **patients** who purchased organ transplants. First, we systematically reviewed the literature to assess the number of patients who buy organs, (from) where they buy organs, and how. We found that almost all patients who are reported to buy organs, travel in order to do so. Most patients were reported to travel from Taiwan and South Korea to China. China was the most popular destination country, followed by Pakistan and India. Most patients traveled for kidney transplants, the majority of which were living unrelated. Nevertheless, of the 6002 patients who were reported to travel between 1971 and 2013, only 1238 (21%) were reported to

have paid for their transplants. A small number of patients (187) were reported to have paid donors, brokers, hospitals and private companies in return for a kidney. In the remaining cases, it could not be verified to what or whom they paid. We conclude that the literature does not reflect a substantial practice of organ purchase. It is speculative and anecdotal about patients buying organs: their purchases are more often assumed than determined.

Next, to assess why and how patients go abroad for paid kidney transplantations, we interviewed 22 patients who traveled from Macedonia, Kosovo, The Netherlands and Sweden between 2000 and 2009. The destination countries were Pakistan, India, Iran, Russia, Colombia, China and Iraq. The majority traveled abroad because they felt there was no other option available to them. They referred to the long wait time and dialysis-related complaints as reasons for why they went overseas. The patients who traveled from Sweden and The Netherlands, were foreign-born, had an (ethnic) affinity with their destination countries and arranged their transplants with the help of family and friends at home and abroad. Yet, six patients obtained their transplants pre-emptively, which means that they were not waitlisted and were not undergoing dialysis treatment at the time of transplant. Furthermore, some patients said that they felt discriminated by the health care system in their countries of residence, which enhanced their motivations to go abroad. This illustrates that a long wait time and dialysis-related complaints are not always the primary motivations for patients to travel abroad for transplantation. Rather, other factors such as ethnic ties in destination countries, may play a more important role in securing transplants overseas. By contrast, the patients who traveled from Macedonia/Kosovo obtained their transplants abroad because there was no regular transplant activity in Macedonia at the time. Three of these patients reported that they arranged their transplants with the help of brokers. The amount that patients paid varied from €6000 to €45000. Payments included service costs (surgery, hospital stay, medications, the kidney and food). Seven paid the hospital directly, 4 paid a broker/middleman and of 6 patients it is unknown whom they paid. Six patients said that they also paid their donor. Ten of the 22 patients returned with complications, including graft rejection and infections. We conclude that although our findings raise suspicions of illegality, the interviews provided no data on whether the patients' donors were exploited and limited data on whether they were paid. As a result, we could not establish with certainty whether all transplantations were illegally performed.

In **chapter 4** we addressed the experiences, attitudes, behaviors and needs of Dutch **transplant professionals** (TPs) who treat patients who buy kidneys abroad. First, we explored their experiences, attitudes and needs for guidelines through a survey that we sent to 546 TPs. Of these, 241 (44%) completed the survey. We found that one hundred TPs (42%) treated patients who traveled to a country outside the European Union for a kidney transplant between 2008 and 2013.

— Thirty-one TPs reported to be certain that patients had bought the kidney.
— Sixty-five had suspicions that the patients had purchased the kidney.

We further found that although 85% of TPs understand why patients buy organs, the majority also believes that kidney purchase harms the relationship with their patients (53%) and judges their patients for buying kidneys abroad (53%). A majority (65%) reported a conflict of duties because they felt unable to protect the victim-donor and because they could not prevent the crime as a result of their secrecy oath. Most TPs (>80%) expressed a need for guidelines in treating patients who purchase organs. Discussing the rights and duties of TPs towards patients who purchase organs, we conclude that reporting patients who are going to purchase a kidney, or have purchased a kidney, is unjustified. Rather, measures to prevent kidney purchase should be directed toward those who inflict harm on donors (and/or patients). We propose a reporting code for TPs to anonymously disclose information on organ trafficking networks, without revealing patient' identities. This information can support and stimulate the police and judiciary to investigate, disrupt, and prosecute organ trafficking networks.

In the second part of chapter 4, we present the results of a qualitative interview study that we conducted to examine the experiences and attitudes of TPs more closely. We interviewed 41 TPs who, in the survey, reported that they had treated patients whom they knew or suspected had purchased kidney transplants abroad. This study confirmed that TPs' largely suspect that patients purchased kidneys abroad, instead of being certain of kidney purchase. Whereas the majority found out that their patients obtained a kidney transplant abroad after it had taken place, a minority reported that they knew beforehand that their patients were going abroad. Highlighting patients' ethnic affiliations to 'cultures that are tolerant to organ purchase' and emphasizing the incidental nature of the phenomenon, many participants didn't consider the suspected purchases as a serious issue that warranted a punitive response. Nevertheless, TPs described suspected kidney purchase as an unwelcome issue that they were unwillingly confronted with and which occurred without their knowledge and support. Their knowledge about the suspected purchases was limited because patients were reluctant to tell, and professionals were reluctant to ask and know about the assumed purchases. We conclude that their attitudes and behaviors can be explained by a hierarchy of rights and duties in which their secrecy oath, duty of medical care, and trust vis-à-vis their patients prevail. These duties override other principles such as preventing kidney purchases and protecting (foreign) donors from harm. Professionals are not obligated to report patients who are going to buy, or have bought organs. In fact, they may face legal repercussions if they would report their patients. Professionals' rights and duties thus keep in place a 'wall' of secrecy and silence in professional-patient interactions. Secrecy and silence functioned as a tacit agreement between patients and their caregivers which kept the subject of kidney purchase at a safe, unspoken distance, allowing professionals to turn a blind eye to its suspected occurrence.

Chapter 5 presents a study with a twofold aim: first, to examine the modus operandi of **organ trade networks** and second, to describe the **experiences of police and prosecution in disrupting and prosecuting these networks**. We studied three cases in fout countries: the Netcare Case in South Africa/Israel, the Medicus Case in Kosovo/Israel and the

Rosenbaum Case in the USA. We conducted 37 interviews with 49 persons, most of whom were prosecutors and police officers. We also interviewed government officials, transplant professionals and patients. In addition, we collected and reviewed a vast amount of (case) documentation such as legislation, charge sheets, indictments and witness testimonies.

The networks were well organized with sophisticated modus operandi. This was illustrated, among others, by their careful selection of countries. For instance, South Africa did not have adequate legislation against organ trade at the time when the case took place. In Kosovo there was a 'post-war vacuum' and a high degree of corruption which enabled the false issuance of transplant licenses. Most patients were Israeli, whose overseas transplants costs (legal or illegal) until 2008, were reimbursed by Israeli health insurance companies. Brokers recruited donors from abroad and ensured that donors approached them. This 'passive recruitment' made it difficult for police and prosecution to prove exploitation. After recruiting the donors, more coercive and deceptive elements came into play. In Kosovo, for instance, donors were given less compensation than agreed (if anything at all) and were informed that they would receive remaining compensations on the condition that they would find new donors. In the USA, although 'subtle psychological ploys' were used upon the donor, these were not proven to be sufficiently coercive or abusive to charge human trafficking.

The level of success of police and prosecution in uncovering and convicting each case depended on the availability of evidence, the collaboration with other countries, and existing legislation. South Africa for example, did not have adequate laws against organ trade. This led police and prosecution to apply alternative charges such as fraud and forgery with mild convictions (penalties) as a result. Furthermore, they didn't succeed in convicting the most important defendants—namely the transplant surgeons, transplant coordinators and the head of the network, an Israeli organ broker. The Medicus Case, by contrast, involved the most severe sentences (up to 8 years imprisonment) and the largest group of transplant doctors that has been convicted until now. This country is the first to have prosecuted transplant doctors as a criminal group involved in human trafficking for organ removal. In the USA, lack of evidence of exploitation could not substantiate human trafficking charges. Furthermore, police and prosecution could not identify the actual number of transplants that were performed, as well as the total financial benefits that were gained.

We conclude that prosecutions in these countries were successful but leave room for improvement. First of all, prosecutions could have been more successful if the appropriate laws would have been in place at the time when the activities took place. Second, investigations could have been initiated earlier if available signals were identified and picked up at an early stage and if international collaboration would have occurred sooner.

In **chapter 6** we discuss the **implications of the growing, prohibitionist legislative response** to organ trade. First, we explain that although organ trade consists of diverse practices such as 'trafficking in persons for organ removal', 'organ sales', 'transplant commercialism' and 'transplant tourism', international instruments predominantly apply the term,

'organ trafficking' without distinction as to the variable aspects involved. This conflation is found, amongst others, in the 2015 Council of Europe Convention against Trafficking in Human Organs which does not distinguish between organ sales and trafficking. The possible consequences are that individuals who have sold an organ may be reluctant to come forward and report instances of abuse to authorities. Furthermore, extending liability to organ sellers may push the trade further underground and expose them to greater harm. Punishment of all organ trade forms does little to alleviate the conditions that produce organ trade and may place an unrealistic burden on the criminal justice system. We conclude that more and stricter laws against the organ trade are unlikely to eliminate this practice, and may even be potentially counterproductive. Rather, the international (transplant) community needs to reconsider its approach to organ trade by separating trade from trafficking and introducing harm-reductionist policies.

In the second part of this chapter, we reiterate the risks of prohibition and refer to studies that illustrate the resilience to prohibition of other demand-driven activities such as drug use, gambling, alcohol consumption and prostitution. We explain that prohibition of such activities is known to produce black markets, drives up prices, provides illegal incomes, displaces crime to other regions and drives trade underground which can lead to higher crime rates, harms and victimization. Focusing on the Declaration of Istanbul on Organ Trafficking and Transplant Tourism, we point out that this and other instruments take little account of the possible implications that prohibition of organ trade may herald. Their response to organ trade and trafficking has little to no recognition for the limits of crime control and limited acceptance of exploring alternative policies that possibly herald less harmful effects. We conclude by recommending that the root causes of the trade should be addressed by boosting organ supply, removing restrictions in live donations and by supporting regulated trials of incentives for donation. In addition, we conclude that whilst there is no doubt that trafficking (exploiting) persons for their organs should remain prohibited, the response to this form of trade is almost wholly legislative. To achieve a consistent and effective prohibition of trafficking, legislation and law enforcement must go hand in hand.

Chapter 7 proposes **alternative strategies** that may deter or regulate organ trade more effectively. The first article is a proposal for a regulated system of (financial) incentives for deceased and living organ donation. Such a system can potentially increase donation while eliminating the harms of unregulated markets. It states that such a system should ensure protection of the donor, regulation, oversight and transparency under the auspices of a government or government-controlled agency. Key items include informed consent, screening similar to conventional donors, a fixed 'incentive' to the donor, limitation to citizens and legal residents only and long-term follow-up studies. The type of incentives (or benefits) for live donors could include long-term health care, tax credit, tuition, job training or payment. Implementing a regulated system of incentives will be simplest within societies that already have an adequate social safety net, registries of health outcomes and provision of long-term health care for all citizens and legal residents.

In the second paper we present the HOTT project, a European Union-funded research project that addressed 'trafficking in human beings for the purpose of organ removal' (2012-2015). We initiated the project to increase knowledge, raise awareness and to improve the non-legislative response to the crime. After conducting various empirical studies (which are presented in this thesis), we shared our findings with more than 200 transplant professionals, law enforcement authorities, policy makers, government representatives, international organizations and other stakeholders at an international symposium at the Headquarters of the European Police Office (Europol) in November 2014 in The Hague, The Netherlands. At the expert meeting (writers conference) that preceded this event, 40 experts formulated recommendations to improve non-legislative responses to trafficking in human beings for the purpose of organ removal. More specifically, they developed recommendations to clarify the ethical and legal obligations of health care providers in relation to the crime, to enhance protection of persons trafficked for the purpose of organ removal, to strengthen cross-border collaboration in criminal cases and to stimulate partnerships between transplant professionals and law enforcement. Recognizing that the prosecuted cases probably only represent the tip of the iceberg and that the response of law enforcement agencies to organ trading is almost 'entirely reactive', it was emphasized, amongst others, that transplant professionals need to collaborate more closely with law enforcement.

Finally, in collaboration with the Dutch National Police, we developed a barrier model and a list of indicators for transplant professionals, law enforcement and victim support workers. The indicators support data collection and identification of trafficking in human for organ removal. They identify the legitimate and illegitimate service providers for each step in the criminal process: recruitment, transport, entrance, documents, housing, transplant, aftercare and finance. Indicators are a helpful tool to support transplant professionals, judicial and law enforcement authorities, and victim support workers with the identification of THBOR. Such identification can encourage police and judiciary to investigate, disrupt, and prosecute trafficking networks.

REFLECTION

The discrepancy between the reality and rhetoric of organ trade

This thesis reveals, first of all, the discrepancy between how organ trade takes place in practice and how it is portrayed in the literature. Our results further illustrate that the common conceptualization of organ trade as an organized crime that exists separately from the legal transplant industry, is most probably false. Rather, organ trade depends on the legal transplant industry (i.e. hospital facilities), and its staff. In addition, organ trade is not necessarily exploitative and not all cases take place through organized, human trafficking networks. In fact, the available evidence suggests that exploitation (according to the definition of human trafficking for the purpose of organ removal) is probably the exception rather than the norm. Organ trade involves a variety of practices which can be placed along a spectrum ranging from exploitation to voluntary, mutually agreed benefits. Thus, instead of conflating all forms of trade with 'trafficking', organ trade should be assessed on a case-by-case basis.

Removing organ trade from the crime control realm

The available empirical evidence also reveals that the current prohibitionist response to organ trade fails to eradicate it. Not only does the existing information demonstrate the trade's resilience to prohibition, prohibition has also pushed the trade further underground, placing patients and donors at greater risk of harm. In addition, a strong legislative framework that governs patients' privacy rights and doctors' secrecy oath, hampers the acquiring of potential valuable information to help curb the trade.

Given these facts, it is striking that the international (transplant) community not only continues to rely on prohibition as the 'default position'[1], but also continues to further tighten the existing legislation against organ trade[2]. These measures can be viewed as symptomatic of the broader 'late modern' developments of the penal state wherein policymakers are more concerned with reassuring a worried public than with offering solutions to remove conditions that produce crime[3]. Current anti-organ trade responses are more concerned with expressing negative sentiments about the organ trade than with effectively eradicating the phenomenon. The worldwide lack of enforcement (including even enforcement of the most organized and exploitative forms of organ trade), is illustrative thereof. With the existing crime control apparatus being more concerned with 'priority crime areas' such as terrorism, illegal migration, the weapon trade and the drug trade, it is unlikely that the organ trade will feature high on the crime control agenda.

Hence, the international transplant community's reliance on crime control to eradicate all forms of organ trade is not only naïve, but also precarious and ineffective. In chapters 6 and 7 we recommend that whilst exploitation of donors (i.e. trafficking in human beings for organ removal) should be subjected to a more proactive non-legislative response

(i.e. enforcement of doctors and others who facilitate illegal transplantations), less harmful forms of organ trade should be placed outside of the crime control framework.

Towards a criminology of organ trade

In positioning less harmful forms of organ trade outside of a criminal justice response, medical professionals (and policy makers) could benefit from 'criminological' knowledge regarding the decriminalization and regulation of other demand-driven phenomena. For instance, similar to prostitution policies, organizations that encourage prohibition of organ trade could instead consider decriminalizing those that buy and/or sell organs and explore safe strategies to incentivize and regulate organ sales. This would, however, require an integration of the 'medical' and 'criminological' realms, combining medical and criminological expertise regarding organ trade. In addition, the trade should be given a more prominent place on the criminological research agenda. [4] This thesis strived to fulfil some gaps in the (criminological) literature, but has also illustrated that much remains to be learned about the trade, and about its regulation and deterrence in particular.

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NEDERLANDSE SAMENVATTING

Orgaanhandel is het kopen en/of verkopen van organen met een financieel of materieel winstoogmerk. De handel in organen kent verschillende verschijningsvormen, zoals mensenhandel met het oogmerk van orgaanverwijdering, transplantatie toerisme en commercialisering van organen. In dit proefschrift wordt 'orgaanhandel' grotendeels gehanteerd als overkoepelende term voor deze verschijningsvormen.

Hoewel orgaanhandel wereldwijd verboden is, laat een toenemend aantal (media) berichten zien dat het in steeds meer landen voorkomt. Er wordt echter relatief weinig wetenschappelijk onderzoek naar orgaanhandel verricht, waardoor er een gebrek aan empirische informatie over dit fenomeen is. Dit proefschrift draagt bij aan het vergroten van de kennis en het verbeteren van het begrip van orgaanhandel. Hierdoor kan mogelijk een effectievere aanpak van het fenomeen worden bewerkstelligd.

Hoofdstuk 1 bevat een korte introductie over orgaanhandel en presenteert de doelstellingen:

1 Inzicht verschaffen in het aantal patiënten dat organen koopt en uitleggen waarom, waar, hoe en van wie zij organen koopt.

2 Het beschrijven, begrijpen en verklaren van de ervaringen, houdingen, gedragingen en behoeften van transplantatie professionals die patiënten behandelen vóór en/of nadat zij een orgaan hebben gekocht.

3 De werkwijze van criminele orgaanhandel netwerken in kaart brengen en beschrijven hoe deze netwerken zijn berecht.

4 De mogelijke implicaties van een repressieve, wettelijke aanpak van orgaanhandel beschrijven.

5 Alternatieve strategieën aanbevelen die orgaanhandel mogelijk effectiever kunnen bestrijden of reguleren dan het huidige beleid.

Hoofdstuk 2 is **het theoretisch kader** van dit proefschrift en bestaat uit twee delen. Het eerste artikel verkent de ethische en juridische aspecten van levende nierdonatie en gaat in op het debat dat gevoerd wordt rondom de legalisering van orgaanhandel. Het tweede artikel verkent de literatuur over orgaanhandel en introduceert een verkennende, empirische studie naar transplantatietoerisme van nierpatiënten uit Nederland.

In **hoofdstuk 3** rapporteren wij de omvang, motivaties en ervaringen van **patiënten** die organen kopen. Eerst verrichtten wij een systematisch literatuuronderzoek naar het aantal patiënten dat organen heeft gekocht. Ook onderzochten wij waar zij de organen kochten en hoe ze dat deden. Wij ontdekten dat bijna alle patiënten waarvan bekend is dat zij (vermoedelijk) organen gekocht hebben, naar een ander land reisden om deze te kopen

en de transplantatie daar te ondergaan. De meerderheid van de patiënten onderging niertransplantaties. De meeste reisden vanuit Taiwan en Zuid Korea naar China—het populairste bestemmingsland, gevolgd door Pakistan en India. De meeste patiënten ontvingen een nier van iemand die geen familie was. Desalniettemin, van de ruim 6000 patiënten waarvan vermeld werd dat zij tussen 1971 en 2013 naar het buitenland reisden voor een niertransplantatie, werd van slechts 1238 (21%) patiënten gerapporteerd dat zij voor de transplantaties betaalden. Van een klein aantal patiënten (187) werd vermeld dat zij donoren, tussenpersonen, ziekenhuizen en privébedrijven betaalde in ruil voor een nier. In de overige gevallen kon niet worden geverifieerd aan wie en/of hoeveel ze betaalden. Wij concluderen dat de literatuur speculatief en anekdotisch is wanneer het over patiënten gaat die nieren kopen en geen volledig beeld geeft van het daadwerkelijk aantal gekochte nieren.

In het tweede deel van hoofdstuk 3 rapporteren wij de bevindingen van een studie waarin wij 22 patiënten interviewden die tussen 2000 en 2009 vanuit Zweden, Macedonië/Kosovo en Nederland naar het buitenland reisden voor betaalde niertransplantaties. Zij reisden naar Pakistan, India, Iran, Rusland, Colombia, China en Irak. De meesten vertrokken omdat zij geen niertransplantatie in eigen land konden krijgen (Macedonië/Kosovo) of omdat zij (in de veronderstelling verkeerden dat ze) in eigen land niet tijdig een niertransplantatie konden krijgen (Zweden en Nederland). Zij noemden de lange wachttijd en dialyse-gerelateerde complicaties als redenen waarom zij naar het buitenland gingen. De geïncludeerde patiënten die uit Zweden en Nederland vertrokken, waren in het buitenland geboren, hadden veelal een etnische affiniteit met hun bestemmingsland en regelden hun transplantaties met behulp van vrienden en familie thuis of in het buitenland. Zes patiënten ondergingen zogenoemde pre-emptieve niertransplantaties. Dit betekent dat zij op het moment van hun transplantatie niet op de wachtlijst stonden en geen dialysebehandelingen ondergingen. Daarnaast gaven enkele patiënten aan zich gediscrimineerd te voelen door het gezondheidssysteem in het land waar zij wonen. Dit versterkte hun wens om naar het buitenland te gaan voor een transplantatie. Deze bevindingen illustreren dat een lange wachttijd en dialyse-gerelateerde complicaties niet altijd de primaire redenen zijn waarom patiënten naar een ander land reizen voor een niertransplantatie. Andere factoren, zoals sociale contacten in, en affiniteiten met het bestemmingsland, spelen wellicht een belangrijkere rol. Daartegenover staat dat de patiënten uit Macedonië/Kosovo naar het buitenland gingen omdat Macedonië in die tijd geen transplantaties uitvoerde. Drie van deze patiënten vertelden dat zij hun transplantatie met behulp van handelaren geregeld hadden. Patiënten betaalden tussen de €6000 en €45000 voor hun transplantaties. Deze bedragen waren inclusief de servicekosten (operatie, verblijf, medicatie, het orgaan, eten en drinken). Zeven patiënten betaalden direct aan het ziekenhuis, vier betaalden aan handelaren/tussenpersonen en van zes patiënten is niet bekend aan wie ze betaalden. Zes patiënten vertelden dat ze daarnaast hun donoren hadden betaald. Tien van de 22 patiënten keerden terug met complicaties, waaronder infecties en afstoting van de nier. Hoewel er vermoedens bestaan dat niet alle nieren legaal verkregen zijn, blijft de vraag

onbeantwoord of de donoren zijn uitgebuit of betaald. Wij kunnen dus niet met zekerheid vaststellen of alle transplantaties illegaal zijn verricht.

Hoofdstuk 4 bestaat uit twee delen en beschrijft de ervaringen, houdingen, gedragingen en behoeften van Nederlandse **transplantatie professionals** (TP's) ten aanzien van patiënten die in het buitenland nieren kopen. Het eerste deel bevat de resultaten van een verkennende enquête die wij aan 546 TP's hebben gestuurd. Van deze TP's vulden 241 (44%) de vragenlijst in. Tussen 2008-2013 behandelden 100 TP's (42%) patiënten die naar een land buiten de Europese Unie reisden voor een niertransplantatie:

— In 65% van deze gevallen vermoedden TP's dat patiënten de nieren kochten.
— In 31% van de gevallen rapporteerden de TP's dat ze het zeker wisten.

Een meerderheid van de TP's vond dat het kopen van een nier de relatie met hun patiënten schond (53%) en veroordeelde hen dan ook voor het kopen van nieren (53%). Vrijwel alle TP's begrepen tegelijkertijd waarom patiënten de nieren kochten (85%). Een meerderheid van de TP's (65%) gaf verder aan dat zij een conflict van plichten ervaarden wanneer zij een vermoeden hadden dat hun patiënt een nier ging kopen. De meest genoemde reden voor dit conflict was dat zij vanwege het beroepsgeheim de mogelijke slachtoffer-donor niet konden beschermen en dat zij—vanwege hun beroepsgeheim—de koop niet konden voorkomen. De meesten (>80%) gaven aan behoefte te hebben aan richtlijnen bij het behandelen van patiënten die vermoedelijk organen gaan kopen.

In onze beschouwing over de rechten en plichten van TP's jegens patiënten die nieren kopen, concluderen wij dat het kopen van nieren door patiënten een doorbreking van het beroepsgeheim van TP's niet legitimeert. De aanpak van orgaanhandel zou zich moeten richten op degenen die schade toebrengen aan donoren en/of patiënten. Wij pleiten daarom voor een meldcode die het mogelijk maakt voor TP's om anoniem vermoedens van orgaanhandel te rapporteren bij politie en justitie, waarbij de bescherming van de identiteit van patiënten gewaarborgd blijft. Het doel van deze meldcode is om politie en justitie te ondersteunen bij het opsporen en berechten van orgaanhandel.

In het tweede deel van hoofdstuk 4 presenteren wij de bevindingen van een kwalitatieve interview studie die wij verrichtten om de ervaringen en attitudes van TP's beter te begrijpen en te verklaren. Wij interviewden 41 TP's die in de enquête hebben aangegeven patiënten behandeld te hebben waarvan zij vermoedden of zeker wisten dat zij nieren in het buitenland hadden gekocht. De meerderheid van de TP's ontdekte de vermoede koop nadat patiënten terugkeerden uit het buitenland met een geïmplanteerde nier waarvan de herkomst vaag of onbekend was. TP's benadrukten de etnische affiniteit van patiënten met hun bestemmingslanden die TP's veelal typeerden als 'koopculturen'. Daarnaast benadrukten ze dat ze het fenomeen incidenteel meemaken. De meesten vonden het kopen van nieren in het buitenland daarom geen serieus probleem dat een harde aanpak legitimeerde. Desondanks beschreven TP's de vermoede aanschaf van nieren door hun patiënten als een fenomeen waar ze ongewild mee werden geconfronteerd en dat 'buiten hen om' plaatsvond zonder hun medeweten en medewerking. De kennis en informatie van TP's over de vermoedelijke nier aankopen was gering omdat hun patiënten niet over

de aanschaf wilden vertellen en omdat TP's er liever niet (te veel) over wilden weten. Wij concluderen dat de attituden en gedragingen van de TP's verklaard kunnen worden door een hiërarchie van rechten en plichten, waarin hun beroepsgeheim, hun zorgplicht en het behoud van een goede behandelrelatie met hun patiënten prevaleren. Deze plichten vinden TP's belangrijker dan het voorkomen van het kopen van nieren door hun patiënten en het beschermen van de onbekende, verre donor. TP's zijn niet verplicht om patiënten aan te geven die nieren gaan kopen of hebben gekocht. TP's riskeren juridische implicaties als ze deze patiënten zouden aangeven, zelfs wanneer zij wel voldoende informatie over de aanschaf zouden hebben. De rechten en plichten van TP's houden een muur van stilzwijgen in stand waarin TP's zich afzijdig kunnen houden van de vermoede nier aanschaf door hun patiënten. Dit zwijgen functioneert als een 'stille' overeenkomst tussen TP's en hun patiënten waardoor het onderwerp van de nieraanschaf onbesproken blijft.

Het onderzoek dat in **hoofdstuk 5** gepresenteerd wordt, diende een tweeledig doel: ten eerste om de **werkwijze van orgaanhandelaren** te beschrijven en ten tweede om de **ervaringen van politie en justitie met de berechting** van deze handelaren in kaart te brengen. Wij onderzochten 3 zaken in 4 landen: de 'Netcare' zaak in Zuid-Afrika/Israël, de 'Medicus' zaak in Kosovo/Israël en de 'Rosenbaum' zaak in Noord-Amerika. We verrichtten 37 interviews met 49 personen, waaronder politieofficieren, officieren van justitie, beleidsambtenaren, transplantatie professionals en patiënten. Daarnaast verzamelden we documenten zoals wetgeving, tenlasteleggingen, getuigenverklaringen en rechterlijke uitspraken.

De netwerken waren goed georganiseerd en gingen geraffineerd te werk. Dit bleek onder andere uit hun keuze van de landen waar ze opereerden. Zuid-Afrika werd gekozen vanwege de verouderde en gebrekkige wetgeving tegen orgaanhandel. Kosovo kampte met de nasleep van een oorlog waardoor er een gebrekkige overheidsstructuur en hoge mate van corruptie heerste. Hierdoor kon er van overheidswege een licentie uitgevaardigd worden om de transplantaties te kunnen verrichten, ondanks het landelijk verbod op het verrichten van transplantaties (of ze nu legaal of illegaal waren). De meeste patiënten die in Zuid-Afrika en Kosovo getransplanteerd werden, kwamen uit Israël. Zij kregen tot 2008 hun buitenlandse niertransplantaties vergoed door hun ziektekosten verzekeraars. Deze verzekeraars stelden geen vragen of de transplantaties legaal of illegaal waren verricht, omdat er tot 2008 geen wet was in Israël die transplantaties in het buitenland waarbij de afkomst van het orgaan onduidelijk was verbood. De handelaren in Kosovo rekruteerden donoren uit het buitenland door middel van advertenties in kranten en op het internet. Doordat donoren instemden met de verkoop van hun nieren, hadden politie en justitie moeite om uitbuiting van donoren te bewijzen. Nadat de donoren in Kosovo aankwamen, nam de (kans op) uitbuiting van donoren toe. De donoren kregen (onder andere) minder betaald dan hen beloofd was. Daarnaast werd hen verteld dat ze het resterende bedrag pas zouden ontvangen als ze nieuwe potentiële donoren wierven. In Noord-Amerika werd een donor overgehaald om te doneren, maar uitbuiting (mensenhandel met het oogmerk van orgaanverwijdering) werd in deze zaak niet bewezen.

De mate van succes van politie en justitie in de berechting van deze zaken varieerde en was afhankelijk van de beschikbaarheid van het bewijs, de samenwerking met andere landen en de wetgeving. Zuid-Afrika bijvoorbeeld, had in de tijd dat de 'Netcare' zaak speelde, geen wetgeving die orgaanhandel (en mensenhandel met het oogmerk van orgaanverwijdering) verbood. Hierdoor moesten politie en justitie alternatieve delicten met lage straffen (geldboetes) ten laste leggen. Daarnaast lukte het hen niet om de belangrijkste verdachten te veroordelen, namelijk de transplantatie chirurgen, de transplantatie coördinatoren en het hoofd van het netwerk: een Israëlische handelaar. In Kosovo daarentegen (de 'Medicus' zaak), werden hoge gevangenisstraffen opgelegd en werd de grootste groep artsen tot nu toe veroordeeld. Dit was de eerste strafzaak waarin artsen veroordeeld werden voor hun deelname aan een criminele groepering en voor mensenhandel met het oogmerk van orgaanverwijdering. In Noord-Amerika (de Rosenbaum zaak) kon door een gebrek aan bewijs geen uitbuiting (en dus geen mensenhandel met het oogmerk van orgaanverwijdering) ten laste gelegd worden. Daarnaast lukte het politie en justitie in deze zaak niet om het daadwerkelijk vermoede aantal illegale niertransplantaties en de daarmee behaalde winsten vast te stellen.

Wij concluderen dat de veroordelingen in deze landen wisselend succesvol waren. Allereerst hadden de veroordelingen succesvoller kunnen zijn als landen zoals Zuid-Afrika gedegen wetgeving tegen orgaanhandel gehad hadden. Ten tweede hadden de opsporingsonderzoeken eerder geïnitieerd kunnen worden als signalen eerder waren opgepikt en als internationale samenwerking sneller en efficiënter was verlopen.

In **hoofdstuk 6** gaan we in op de **implicaties van het toenemende, repressieve, wettelijk beleid** tegen orgaanhandel. In het eerste artikel leggen we uit dat orgaanhandel uit diverse activiteiten bestaat, waaronder mensenhandel met het oogmerk van orgaanverwijdering, transplantatie toerisme, orgaankoop en 'transplant commercialism'. Echter, internationale verdragen en verklaringen gebruiken steeds vaker de term 'organ trafficking' zonder onderscheid te maken tussen de verschillende vormen van orgaanhandel. Deze zgn. 'conflatie' is onder meer te vinden in de brede formulering van de strafbaarstelling in het nieuwe verdrag tegen orgaanhandel van de Raad van Europa (2015). Dit verdrag maakt geen onderscheid tussen mensenhandel en orgaanverkoop. Het mogelijke gevolg hiervan is dat donoren die hun organen verkopen, en wellicht slachtoffers van uitbuiting zijn, deze uitbuiting niet snel zullen rapporteren bij instanties uit angst voor vervolging. Daarnaast heeft een ruime strafbaarstelling van orgaanhandel als risico dat de handel dieper ondergronds gaat en dat de kans op slachtofferschap toeneemt. Het bestraffen van *alle* vormen van orgaanhandel lost niet de oorzaken van het misdrijf op, en legt een onrealistische last op de schouders van politie en justitie. Wij concluderen dat het niet waarschijnlijk is dat door strengere wetgeving het misdrijf bestreden zal worden. Wij bevelen aan dat de internationale (transplantatie) gemeenschap in haar verdragen en verklaringen een duidelijker onderscheid moet maken tussen het kopen en verkopen van organen enerzijds en uitbuiting/mensenhandel met het oogmerk van orgaanverwijdering anderzijds. Daarnaast zou de internationale gemeenschap lidstaten moeten toelaten om alternatief beleid te

voeren dat gericht is op het terugdringen van uitbuiting van kwetsbare donoren. Een voorbeeld is de introductie van financiële stimuli van orgaandonaties en het decriminaliseren en reguleren van orgaanverkoop.

In het tweede deel van dit hoofdstuk benadrukken wij de risico's van een brede strafbaarstelling van orgaanhandel door te verwijzen naar aangetoonde schadelijke effecten ten aanzien van andere vormen van vraag gedreven handel, zoals drugs, gokken, alcohol en prostitutie. We leggen uit dat een verbod op handel kan leiden tot zwarte markten, hogere prijzen en illegale inkomens. Bovendien bestaat het risico dat de handel ondergronds gaat met hogere criminaliteitscijfers en een grotere kans op slachtofferschap tot gevolg. In dit artikel gaan wij vooral in op de formulering van het orgaanhandel verbod in de zgn. 'Verklaring van Istanbul' (2008). Deze verklaring besteedt geen aandacht aan de mogelijke implicaties van een brede, strenge strafbaarstelling en biedt geen ruimte voor alternatieve oplossingen zoals decriminalisering en regulering. Wij concluderen dat orgaanhandel bij de wortel aan moet worden gepakt door het aanbod van organen te vergroten, levende orgaandonaties te stimuleren en te experimenteren met financiële stimuli voor orgaandonatie. Tot slot leggen we uit dat het verbod op mensenhandel met het oogmerk van orgaanverwijdering gehandhaafd moet worden. Echter, de opsporing en vervolging van dit misdrijf vinden niet of nauwelijks plaats. Om deze vorm van orgaanhandel effectief aan te pakken, bevelen we een proactieve opsporing en berechting aan.

In **hoofdstuk 7**, dat uit drie artikelen bestaat, gaan wij dieper in op onze **aanbevelingen**. In het eerste artikel presenteren we een voorstel voor een door de overheid gereguleerd systeem van financiële stimulering van orgaandonatie. Het doel van een dergelijk systeem is om het aantal orgaandonaties te vergroten en uitbuiting in huidige ongereguleerde markten tegen te gaan. In het voorstel leggen we uit dat een dergelijk systeem aan strikte voorwaarden moet voldoen. Zo moet de lange termijn nazorg en bescherming van donoren optimaal georganiseerd zijn en moet het overheidsapparaat op transparante wijze functioneren. Verder moet het systeem gelimiteerd zijn tot de inwoners van het land in kwestie. Voorbeelden van stimuli zijn levenslange vrijstelling van ziektekostenpremies, belastingvoordelen of een geldbedrag. Een dergelijk systeem zal het makkelijkst te implementeren zijn in een land met bestaande adequate sociale vangnetten, registraties van data van donor follow-up en ziektekostenverzekeringen voor alle ingezetenen.

In het tweede artikel presenteren wij het zgn. 'HOTT' project ('combating trafficking in persons for the purpose of organ removal'). Dit internationale onderzoeksproject, dat door de Europese Commissie gefinancierd werd, richtte zich op mensenhandel met het oogmerk van orgaanverwijdering (2012-2015). Wij initieerden dit project om kennis en bewustwording over deze vorm van orgaanhandel te vergroten, en om de handhaving (opsporing en berechting) te verbeteren. De resultaten van de uitgevoerde studies (die tevens in dit proefschrift worden gerapporteerd), presenteerden wij aan meer dan 200 transplantatie professionals, politie- en justitieofficieren, beleidsmakers, vertegenwoordigers van internationale organisaties en andere stakeholders op een internationaal symposium dat in november 2014 op het hoofdkwartier van Europol in Den Haag gehouden

werd. Voorafgaand aan dit symposium, organiseerden wij een expert meeting (de zgn. 'Writers Conference') waarin 40 experts bijeenkwamen en aanbevelingen formuleerden om de handhaving van het misdrijf te verbeteren. In het bijzonder deden zij aanbevelingen om de rechten en plichten van transplantatie professionals ten aanzien van het misdrijf te verduidelijken, de bescherming van slachtoffers te verbeteren, internationale samenwerking in strafzaken te bevorderen en om samenwerkingsverbanden te smeden tussen transplantatie professionals enerzijds en politie en justitie anderzijds. Zij benadrukten dat politie en justitie pro-actiever tegen het misdrijf moeten optreden. Hiervoor is het nodig dat transplantatie professionals nauwer samenwerken met politie en justitie.

Tot slot ontwikkelden wij, in samenwerking met de Landelijke Eenheid van de Nationale Politie, een barrièremodel en indicatorenlijst voor transplantatie professionals, politie, justitie en hulpverleners. De indicatoren dienen om signalering van mensenhandel met het oogmerk van orgaanverwijdering te bevorderen. Het barrièremodel maakt inzichtelijk welke stappen handelaren zetten om hun criminele activiteit te kunnen uitoefenen en laten zien welke organisaties een rol kunnen spelen bij het bemoeilijken of sanctioneren daarvan. Bij dit misdrijf zijn rekrutering, transport, entrée, documenten, huisvesting, transplantatie, nazorg en financiën benoemd als barrières. Indicatoren zijn een praktisch instrument om politie en justitie te ondersteunen in hun opsporing en berechting van strafzaken.

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- European Commission Executive Agency for Health and Consumers (DG SANCO) for the 3rd ELPAT Conference on Ethical, Legal and Psychosocial Aspects of Transplantation, Rotterdam, €100,000. 2013

Conferences

- Organized an international symposium and expert meeting on trafficking in human beings for the purpose of organ removal (HOTT project) at Europol Headquarters, The Hague, The Netherlands (230 participants); 2014
- Organized the 3rd ELPAT Congress on Ethical, Legal and Psychosocial Aspects of Transplantation, Rotterdam, The Netherlands (300 participants); 2013
- Organized 3 ELPAT Working Group Meetings on Ethical, Legal and Psychosocial Aspects of Transplantation (Sicily 2012, Juan les Pins 2013, The Hague 2014) (60-70 participants). 2012-2014

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- Round Table Discussion: 'Together against Human Trafficking: Human Trafficking and Exploitation in the Wake of the Refugee Crisis', European Center for Legal Education and Research, Bucharest, Romania (invited) 2016
- 26th International Congress of the Transplantation Society, Hong Kong, China (2 orals, 1 mini oral) 2016
- 4th ELPAT Congress. Ethical, Legal and Psychosocial Aspects of Transplantation, Rome, Italy (2 invited, 2 orals) 2016
- Congress of the Dutch Transplantation Society, Groningen, The Netherlands (oral) 2016
- Abdominal Transplant Conference, Katholieke Universiteit Leuven, Belgium (invited) 2016

- 8th ELPAT Working Group Meeting. Ethical, Legal and Psychosocial Aspects of Transplantation, Lisbon, Portugal (invited) 2015
- Regiodag Noord, Grolschveste, Enschede (invited) 2015
- Competent Authorities Meeting, European Commission. DG Health & Food Safety (Sante), Brussels, Belgium (invited) 2015
- International Round Table. Health and Gender Aspects and Implications of Human Trafficking. Organ Removal. Establishment of National Health Focal Points, Vienna, Austria (invited) 2015
- 17th Congress of the European Society for Organ Transplantation, Brussels, Belgium (1 invited, 1 oral, 1 brief oral) 2015
- Surveille Project Workshop on Human Trafficking, Birmingham, United Kingdom (invited) 2015
- Workshop on Global Bodies in Grey Zones: Health, Hope, Bio-economy, Stellenbosch Institute for Advanced Study, Stellenbosch, South Africa (invited) 2015
- Criminologie in Actie, Erasmus Universiteit Rotterdam, The Netherlands (invited) 2015
- International Federation of Medical Students' Associations (IFMSA), University Medical Center, Groningen, The Netherlands (invited) 2014
- HOTT Project Symposium. Trafficking in Human Beings for the Purpose of Organ Removal, Europol Headquarters, The Hague, The Netherlands 2014
- European Donation and Transplant Coordination Organization Conference, Budapest, Hungary (invited) 2014
- World Transplant Congress, San Francisco, USA (1 invited, 1 oral, 1 poster) 2014
- Congress of the Dutch Transplantation Society, Leiden, The Netherlands, (1 oral, 1 brief oral) 2014
- University College Amsterdam, The Netherlands (invited) 2014
- Nederlandse Nefrologiedagen, Veldhoven (invited) 2014
- Competent Authorities Meeting. European Commission. DG Health & Food Safety (Sante), Brussels, Belgium (invited) 2014
- International research symposium, globalization and commodification of the human body: a cannibal market?, Brocher Foundation, Geneva, Switzerland (invited) 2013
- United Nations Office on Drugs and Crime, Expert Group Meeting on Trafficking in Persons for the Purpose of Organ Removal, Vienna, Austria (invited) 2013
- 16th Congress of the European Society for Organ Transplantation, Vienna, Austria (1 invited, 1 brief oral) 2012
- Studentenvereniging voor Internationale Betrekkingen, Utrecht, The Netherlands (invited) 2012
- 24th Congress of the Transplantation Society, Berlin, Germany (1 invited, 1 oral) 2012
- Astellas Symposium, Zeist, The Netherlands (invited) 2012
- Rotary, Rotterdam, The Netherlands (invited) 2012
- Congress of the Dutch Transplantation Society, Maastricht, The Netherlands, (1 brief oral) 2012

Lecturing and supervision

- Erasmus MC, lectures to students of medicine and philosophy 2012-present
- Erasmus School of Law, guest lectures for students of criminology 2015-present
- Hospitals in The Netherlands, lectures to transplant professionals 2012-present
- University of Oxford, Summer School lecture for transplant professionals 2014
- Supervision of 2nd year medical students on writing a literature review 2012-2014
- Astellas Development Programme in Transplantation (ADEPT Course), lectures for transplant professionals in Cannes, Nice, Rome, Copenhagen, Paris, Prague, Amsterdam, Vienna, Budapest, Madrid and Barcelona 2009-2012

Other activities

- Reviewer for transplant journals and journals on bioethics 2013-present
- Consultant to the United Nations Office on Drugs and Crime (UNODC), Division for Treaty Affairs, Organized Crime and Illicit Trafficking Branch, Vienna, Austria 2013
- Moderator/chair at transplant conferences 2012-present
- Member of ELPAT (Ethical, Legal and Psychosocial Aspects of Transplantation), Working Group on Organ Tourism and Paid Donation 2008-present

Interviews and media

- 'Rechtszaak "Nier te Koop"', *RTL Nieuws*, 8th May 2015
- 'Onderzoek naar Orgaanhandel', *Rotterdams Gezondheidsrecht Dispuut Magazine* #3, p.10 2015
- 'Internationaal Onderzoek. Orgaanhandel op de Kaart', *Transparant* #60 (magazine of the Dutch Transplant Foundation), December 2014
- 'Ook in Nederland orgaanhandel', Dutch news broadcasters (TV, radio, newspapers, including *NOS Journaal*, *De Volkskrant*), 21st October 2014
- 'Profijt voor de hele samenleving. De maatschappelijke waarde van het medisch wetenschappelijk onderzoek', *Profiel*, Erasmus MC 2013
- 'Op zoek naar een nier', *KRO Brandpunt Reporter*, 14th April 2013
- 'De schimmige handel in organen', *Erasmus Magazine* #13, 14th March 2013
- 'Illegale Orgaanhandel in Nederland', *Studio Erasmus Talkshow*, 28th March 2013
- 'Dutch academic hospital to lead organ trafficking enquiry', International and national news broadcasters (TV, radio, newspapers, including *BBC News*, *New York Times*, *Huffington Post*, *Washington Post*), 15th November 2012
- 'Nier te koop', *HP De Tijd*, week 7, p.18, 17th February 2012

Column

- 'Nieuw Europees verdrag tegen de handel in organen is door slaapwandelaars opgesteld', 111 Jaar Gezondheidsraad 2013

CURRICULUM VITAE

Frederike Ambagtsheer was born on June 6th, 1983 in Gouda, The Netherlands and followed her secondary education (VWO) at De Goudse Waarden in Gouda from 1995-2001. Subsequently, she obtained a first-year degree in Dutch Law at the University of Amsterdam (2002) and Master's degrees in Criminology (MSc) at Erasmus University Rotterdam (2007) and in Public International Law (LL.M.) at Leiden University (2008). During her studies, she completed internships at the Dutch Rapporteur on Trafficking in Human Beings (2006) and the United Nations International Criminal Tribunal for the Former Yugoslavia (2008) in The Hague. For the former, she performed an explorative study on transplant tourism from The Netherlands and wrote her MA thesis on the topic. In January 2009 she started working as a researcher at the Kidney Transplant Unit of Erasmus MC in Rotterdam. From 2009-2014 she coordinated the European Platform on Ethical, Legal and Psychosocial Aspects of Transplantation (ELPAT) and from 2010-2012 she coordinated an EU-funded project on Living Organ Donation in Europe. In 2012 she obtained a grant from the European Commission Directorate General Home Affairs to coordinate an international research project on Trafficking in Human Beings for the Purpose of Organ Removal (the HOTT project). The data that she collected during this project (2012-2015) forms the basis of this thesis.

Stellingen behorende bij het proefschrift **Organ Trade**

1 Het tekort aan nieren is niet altijd de reden waarom patiënten naar een ander land reizen voor een niertransplantatie. (*dit proefschrift*)

2 Tussen patiënten en hun behandelaars bestaat een stilzwijgende overeenkomst over het kopen van nieren: wat niet weet, wat niet deert. (*dit proefschrift*)

3 De bestrijding van orgaanhandel is geen prioriteit van politie en justitie. (*dit proefschrift*)

4 Donoren dienen te worden beloond voor hun nierdonatie. (*dit proefschrift*)

5 In de huidige wetgeving wordt orgaanhandel onterecht met uitbuiting geassocieerd. (*dit proefschrift*)

6 Een algeheel verbod op vraag-gerelateerde fenomenen, zoals drugs en prostitutie, werkt averechts.

7 Meer wetgeving maakt de wereld niet veiliger.

8 Risicosporters zijn emotioneel stabieler, creatiever, onafhankelijker en hebben een groter leiderschapspotentieel dan niet-risicosporters. (*Ogilvie, 1974*)

9 Nederland heeft weinig vrouwelijke hoogleraren, maar dat is géén reden om een vrouwenquotum in te voeren.

10 Stellingen bij proefschriften zijn overbodig.

11 Nature does not hurry, yet everything is accomplished. (*Lao Tzu*)

Frederike Ambagtsheer 6 juni 2017

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