

## Trafficking in Persons for the Purpose of Organ Removal:

### A Comparative Case Study of Organ Donation Policies in Denmark and Sweden and Their Impact on Illicit Organ Trade

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#### *Abstract*

In the 1950's the very first successful transplantation operation was performed. Regardless of its success, up until the 80's this type of operation was considered an experimental procedure and involved a high level of risk. Today organ transplantation is a worldwide practice, which has, unfortunately, become a victim of its own success as the demand for organs far exceeds the supply. Organ transplantation is governed by domestic as well as international organ donation policies. However, the rise in the demand for organs increases their possible profitability, thus encouraging the illicit trade in the latter. Organ trade stems from the global scarcity of diseased organ donations. Due to the high demand and severe organ scarcity worldwide, there is a growing number of identified cases of organ trafficking and trafficking in persons for the purpose of organ removal. While commercial trade in human organs is illegal within the EU, different states have different organ donation and transplantation policies that may have an impact on the crime of organ trade within the region. This research project investigates the impact these regulations have on trafficking in persons for the purpose of organ removal. This study aims to identify the relationship between organ donation policies and the demand in illicit organ transplantations given the cases of Denmark and Sweden. It is an empirical comparative case study, which comprises of multi-methods.

#### *Background*

This research project focuses on the issue of illicit organ trade, which is fueled by severe organ scarcity and as a result high demand in organs. According to the World Health Organization public health review on the state of the international organ trade (Shimazono 2007), organ transplantation is used to treat end-stage organ failure. Unfortunately, the number of people suffering from illnesses causing organ failure is very high. So high, in fact, that the number of transplanted solid organs meets just about 10% of the global need (GODT 2016). The latest available report of the Global Observatory on Donation and Transplantation (GODT 2016) states that the most frequently transplanted organ is a kidney. Kidney transplantation is currently recognized as the best treatment of end-stage renal disease (Maggiore et al. 2015). However, the lack of access and shortage of donor kidneys are preventing many from accessing this form of treatment. A high demand increases the potential profitability of the organs, which encourages the inclination to sell and trade. Therefore, when maintaining one's life lawfully becomes impossible, black markets meet the demand. Approximately 40% of the total number of transplantations

performed globally are kidney transplantations from living donors (GODT 2016). Multiple human trafficking studies have identified that the vast majority of detected victims of human trafficking for the purpose of organ removal are recruited for the purpose of their exploitation as living kidney donors (see for example Bos 2015, Council of Europe/United Nations 2009).

### *Project description and research purpose*

The debate around the issue of organ trade and organ donation is not new. The subject of regulating the organ trade to suppress and prevent human trafficking as well as the question of legalizing the trade in human organs are both on the agenda. Apart from the policy dialogue and the development and implementation of international treaties specifically intended to address the issue of illicit organ trade (see for example Declaration of Istanbul 2008; Joint Council of Europe and United Nations report Trafficking in organs, tissues and cells and trafficking in human beings for the purpose of removal of organs 2009; Council of Europe Convention against Trafficking in Human Organs 2014; European Parliament Trafficking in Human Organs Study 2015) there is also a vast number of scholarly readings that dwell on the issue: from a more general overview of trafficking in human organs (see for example Dudiani-Saberi and Delmonico 2008) to regional research projects of the situation in Europe (Meyer 2006), longitudinal cross-country studies of opt-out cadaveric organ donation policies (Abadie and Gay 2006) as well as case studies with very specific accounts of China's sale of organs of executed prisoners (Matas & Kilgour 2006, Huang et al. 2013), black markets in organ trade in the Middle East (Anwar Naqvi 2007) and oocyte donations in the US as a means to pay for college education (Levine 2010). Extensive studies have been conducted on the impact of the Declaration of Istanbul on transplantation tourism and organ trafficking (see for example Delmonico 2009, Danovitch & Al-Mousawi 2012). As can be seen with the example of the different studies shown above, the study of organ trafficking is interdisciplinary and rather broad. Nonetheless, many of these studies have one factor in common – the desire to generate an understanding of the best strategy to reduce the injustice and inequality associated with illicit organ trade.

Organ trade stems from the global scarcity of diseased organ donations and benefits from two groups of vulnerable/desperate populations: the patients who are waiting in line for a transplant and individuals in desperate economic hardship, so desperate in fact, that they resort to selling their own organs.

Due to this exploitation of the poor, the objection to a living donor market is quite strong. However, with the deficiency in deceased organ donations comes the demand for living organs. To address this issue attempts were made to regulate the organ market, but the solution is yet to be found.

Throughout the world, organ transplantations are governed by transplantation policies that are directed at who can receive and donate organs as well as how, when and where transplantations are possible. The organ transplantation process can be divided into two major categories: living and deceased donations. Both forms of donations exist simultaneously in different countries and both are regulated by various policies. The policies that are currently in place throughout the world have their drawbacks and new approaches are needed to expand the donor pool. A number of strategies have been proposed by experts in the field in order to improve the organ shortage without having to resort to living donations. These strategies include (but are not limited to):

- Instructions concerning the eligibility of donors. Including strategies to promote early identification, integrating organ donation schemes with end-to-life care as well as using expanded criteria donors (ECD), which should potentially increase the donor pool as it involves individuals who may not usually be considered (such as individuals with potential health problems and donors of older age) (Matesanz et al. 2017, Querard et al. 2016);
- Eligibility criteria of organ recipients;
- Guidelines that oversee when a potential donor is considered deceased. Currently in most parts of the world individuals are considered deceased after brain death (DBD). However, some countries have started to include patients after circulatory death (DCD) into the donor pool (see for example Morrissey et al. 2014);
- Regulations vis-à-vis the consent of citizens to donate their organs after death (explicit consent or opt-in; and presumed consent or opt-out). In countries with *presumed consent* organ donation regulations, citizens are presumed to have given consent to become deceased organ donors unless they have expressed refusal. In states with *explicit consent* policies, the potential donors need to register their will to become a deceased donor. However, in both cases individuals have to die in very specific circumstances to become eligible deceased organ donors. This means that even with a large number of citizens on the organ donor registry, the number of actual deceased donors will be considerably smaller as a mere sign up does not guarantee donorship.

The regulations governing the suitability of organ donors and the distribution of available organs can either increase the donor pool or hinder this process. Hindering this process triggers the patients on the waiting list and their loved ones to look for alternative ways of obtaining an organ. The legal alternatives include living organ donations by relatives and other altruistic organ donations by unrelated living donors. However, where these options are unavailable, black markets meet the demand. To date the available data on illicit organ trade reveals that most identified donors come from countries where large parts of the population are experiencing severe economic hardship and most identified organ buyers come from countries with better economic opportunities (see image 1). The brokers who facilitate the organ trade abuse the vulnerability of individuals living in poverty. They offer the sale of a kidney as a way to lift oneself out of poverty. However, in the vast majority of identified cases the payment is substantially smaller than initially promised (see for example Bos 2015, Council of Europe/United Nations 2009, Lundin 2010). Moreover, the organ sellers/donors are in many cases unaware of the potential harms to health after the operation, which can incapacitate them to a state where they are no longer able to perform work that used to be their source of income and thus lead to a much more severe state of poverty. The typical means used to lure individuals into selling their organs on the black market are deception, fraud and abuse of vulnerability. Taking into account the deceptive, fraudulent and misleading way of recruitment as well as the exploitative nature of this transaction, such cases are classified as human trafficking for the purpose of organ removal.

As this is a clandestine crime data is very limited and while there is evidence pointing at certain countries where donors are typically recruited and others where buyers are typically found, this picture is far from complete (see image 1).

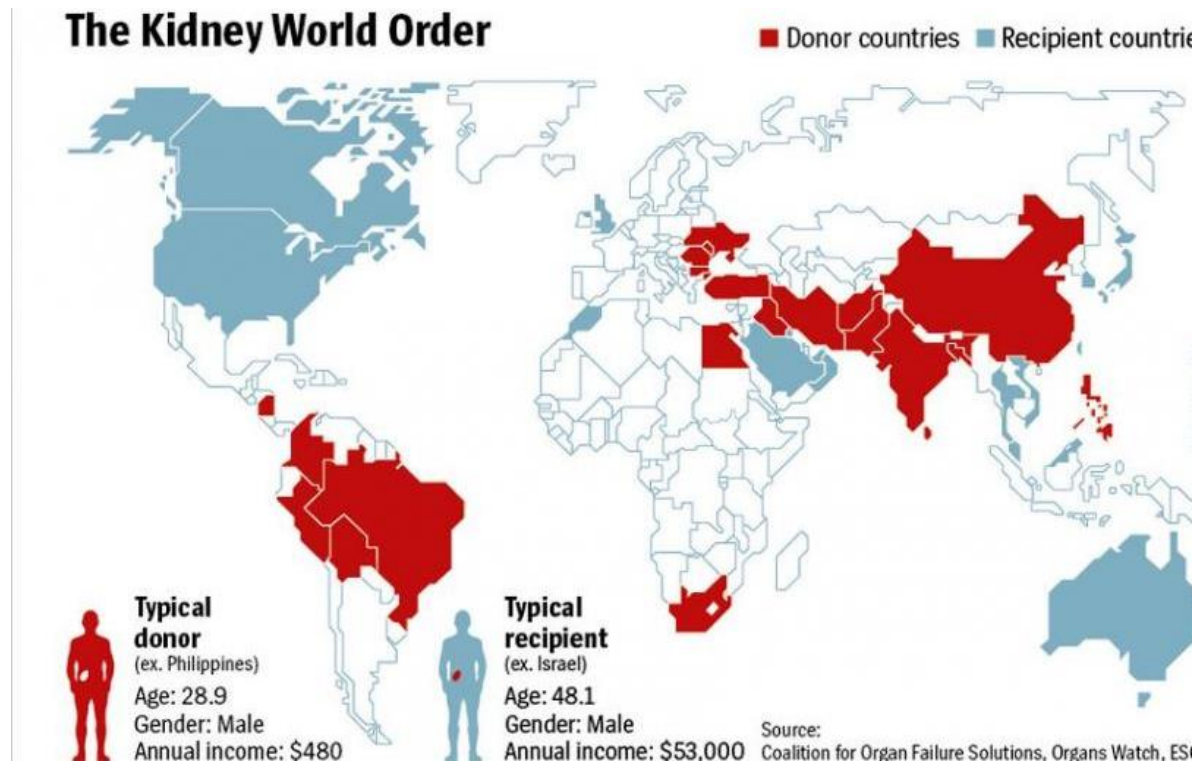


Image 1: Kidney donor and recipient distribution throughout the world  
Source: Bos 2015 from *Coalition for Organ Failure Solutions*.

To date Scandinavian countries have not fallen on the organ trafficking radar. However, there are studies that confirm cases of Swedish patients resorting to transplant tourism (see for example Van Balen et al. 2016, Ambagtsheer et al. 2016). The line between the latter and human trafficking for the purpose of organ removal is very thin.

This research project looks at the organ donation regulations in Denmark and Sweden as two Scandinavian welfare states with similar access to affordable and available medical care, but that (at the time when this paper is written) have two opposing organ donation and transplantation policies as well as, to an extent, different approaches to donor detection.

This study aims to identify the relationship between organ donation policies and the demand in illicit organ transplantations given the cases of Denmark and Sweden. It investigates the impact the Swedish and Danish regulations have on trafficking in persons for the purpose of organ removal.

The main question that is asked in this study is how the different organ donation and transplantation regulations affect the occurrence of human trafficking for the purpose of organ removal.

## *Methods*

This is an empirical case study, which comprises of multi-methods. Bearing in mind the complex nature of this study, the research design of this project employs the combination of qualitative and quantitative approaches.

For the realization of the qualitative part of this research data is being gathered by means of documentary research, collection of observational data and semi-structured interviews with three groups of participants:

1. *Actors concerned with the process of organ trade, such as medical practitioners, activists and policy makers.*
2. *Victims of human trafficking for the purpose of organ removal;*
3. *Patients waiting for a transplant.*

The documents are used alongside observational and interview data. The collected data through documentary research will also be used to develop a quantitative data base.

## *Preliminary findings*

To date two expert interviews have been conducted with members of Swedish activist organizations:

- Mer Organ Donation (an organization promoting organ donation in Sweden)
- Swedish Platform Civil Society Against Human Trafficking (an umbrella organization for anti-trafficking action in Sweden)

More interviews will be conducted and analyzed before the study can produce any conclusive results.

The available transplantation databases have been examined to determine the number of people on the waiting list in Denmark and Sweden; and what criteria may make patients especially prone to traveling abroad for a transplant and thus make them easy targets (buyers) for traffickers. Two databases have been deemed appropriate for this study:

- The Global Observatory on Donation and Transplantation
- Scandiatransplant

According to the Scandiatransplant database as of January 1 2019 and up until the time this paper was written (see table 1), in Denmark 554 people were on the waiting list for a kidney transplant, 30 died on the waiting and 44 have been permanently withdrawn. At the same time in Sweden 666 people were active on the waiting list, 30 died on the waiting list and 54 were permanently withdrawn.

	Denmark	Sweden
Kidney	554	666
Dead on waiting list	30	30
Permanently Withdrawn	44	54

Table 1: Kidney transplant waiting list situation in Denmark and Sweden as of January 2019 and up until May 2019  
Source: Scandiatransplant

According to Scandiatransplant individuals can be permanently withdrawn from the waiting list due to being too sick or not sick enough to receive a transplant. Given the responses of participants of other studies who have traveled abroad for a kidney transplant (see for example Ambagtsheer et al. 2016), this study assumes individuals who are placed lower on the waiting list, in a very critical condition and those permanently removed from the waiting list to be most likely to consider transplant tourism.

Data presented in absolute number and rate per million inhabitants (pmp) (-): data not available or not applicable	Sweden (P.: 9.9 mil.) Opt-out	Denmark (P.: 5.7 mil.) Opt-in	Spain (P.: 46.4 mil.) Opt-out
Actual deceased donors (DD)	192 (19.39)	103 (18.07)	2,183 (47.05)
Actual DD after brain death (DBD)	191 (19.29)	103 (18.07)	1,610 (34.7)
Actual DD after circulatory death (DCD)	1 (0.1)	(-)	573 (12.35)
Total kidney transplants	474 (47.88)	257 (45.09)	3,269 (70.45)
Deceased kidney transplants	349 (35.25)	165 (28.95)	2,937 (63.3)
Living kidney transplants	125 (12.63)	92 (16.14)	332 (7.16)

Table 2: Kidney transplant waiting list situation in Denmark, Sweden and Spain as of January 2019 and up until May 2019  
Source: Global observatory on donation and transplantation & Scandiatransplant

This study has attempted to find a correlation between the actual number of donors in Denmark and Sweden and the donation policies of these countries. Denmark follows an opt-in (explicit consent) organ donation policy, whereas Sweden has adopted an opt-out (presumed consent) approach. Moreover, recently Sweden has begun to test one more avenue of organ donor detection: DCD (see table 2).

The review of studies that have compared countries with opt-in and opt-out donation policies has found that the list of donors in countries with opt-in donation policies are overwhelmingly shorter than those countries that have adopted the opt-out policy (see for example Scandiatransplant). However, when it comes to Denmark and Sweden, although the policies are different, the numbers of actual deceased donors per million inhabitants are not too far from each other (see table 2). As a reference point Spain (one of the opt-out countries with the most deceased donors in the world) was added to table 2 to see in any other factors, except for its opt-out policy, may contribute to the increase of the donor pool. Spain shows higher numbers in all transplantation categories, but the one category that stands out the most is DCD. Denmark doesn't accept donors after DCD, Sweden is testing this avenue and has to date had one such case. However, to date Spain has had 573 cases of donation after circulatory death. One of the expert interviewees in Sweden (Mer Organ Donation) has also confirmed that it is not enough to implement an opt-out system, but other strategies also need to be considered.

Through the review of existing studies on organ trade this study has to date identified six options of increasing the organ donor pool:

- Presumed consent (Opt-out)
- Altruistic organ donations (unrelated living donation)
- DCD (donation after cardiac death)
- Education and Awareness raising
- Improvements to the organ donation system (relevant facilities, training, staff etc)
- Organ markets

Two strategies proposed to provide incentives to sell:

1. Permit sales allowing to broker contracts while alive (mutually agreed upon process)
2. Regulated market (for example Iran has a model of unrelated living donation, involving payment controlled by the government, which according to Iran has resulted in no waiting list for kidney transplants, excellent post-transplant outcomes and no transplant tourism).

### *Next steps*

The following stage of this research project will focus on obtaining data to investigate and compare organ donation strategies to see how they have affected the organ donor pool in Denmark and Sweden. These strategies include:

- Consent (Opt-in and opt-out)
- Altruistic organ donations (unrelated living donation)

- DCD (donation after cardiac death)
- Education and Awareness raising
- Improvements to the organ donation system (relevant facilities, training, staff etc)

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