



# A global bioethical perspective on organ trafficking: Discrimination, stigmatisation and the vulnerable

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Organ trafficking is a growing global phenomenon that not only has abusive consequences, but is also, as far as can be determined, discriminatory and stigmatising. Currently, there is no national or global declaration that rejects organ trafficking because of the discriminatory and stigmatising results of the medical practice involved. The Universal Declaration of Bioethics and Human Rights by the United Nations Educational, Scientific and Cultural Organization (UNESCO) addresses the problem by relating organ trafficking (art. 21.5) to discrimination and stigmatisation (art. 11). Until a global declaration and an accompanying project come into existence, the UNESCO declaration can be used as an influential appeal to the world community to combat these activities together.

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## Global organ trafficking

Global discrimination against and stigmatisation of individuals and groups in the health environment are continually reported.<sup>[1]</sup> In 2014, the International Bioethics Committee (IBC) of the United Nations Educational, Scientific and Cultural Organization (UNESCO), published the *Report of the IBC on the Principle of Non-discrimination and Non-stigmatisation*.<sup>[2]</sup> According to this report, discrimination and stigmatisation continue unabated. On the one hand, these two phenomena are found in globally recurring issues such as neglected tropical diseases, HIV/AIDS, organ donation and trafficking; on the other hand, they surface in new developments such as biobanks, nanotechnology and neuroscience.<sup>[1,3]</sup>

The actuality and necessity of a global bioethics and continuous discourse on discrimination and stigmatisation are evident when referring to global organ trafficking. In most instances, this illicit practice, along with other ethical problems, is inherently discriminatory, and in many instances, the participants are stigmatised, as the IBC's in-depth study clearly shows.<sup>[3]</sup> In his recent dissertation, which studies organ trafficking as a social problem in Israel, Shidlo-Hezroni also shows that the practice is discriminatory and stigmatising in nature.<sup>[4]</sup> Without doubt, discrimination and stigmatisation are also found in legal organ donation programmes,<sup>[2,3]</sup> but the focus in this article is on trafficking. In the early eighties, a new form of human trafficking as a global phenomenon developed in the Middle East, Latin America and Asia, namely, global trafficking in the kidneys of living persons.<sup>[5]</sup> It is accepted that ~5 - 10% of all kidneys that have been transplanted since that time can be traced back to organ trafficking.<sup>[3,6]</sup> Trafficking in kidneys (and other organs) is found in more or less 50 countries over the world today.<sup>[5,6]</sup> It happens that 'medical tourists' from richer countries get hold of organs in poorer countries.<sup>[6-8]</sup> Organ sellers are frequently sent to richer countries to undergo the necessary procedures there.<sup>[6]</sup> In 2004, a syndicate transferring patients and organ sellers from Brazil to South Africa (SA) for kidney transplants was exposed in SA.<sup>[6]</sup>

Although organ trafficking is a global issue and prohibited by most

countries, global efforts have not been successful in stopping the practice,<sup>[2,6]</sup> especially because the involvement of several countries in a single incident complicates prosecution.<sup>[5]</sup> A strong suspicion exists that organ trafficking is increasing every year;<sup>[6]</sup> this idea is strengthened by recent newspaper reports to which this study refers. Any search on Twitter with the keyword 'organ trafficking' affirms the suspicion and actuality of this global problem. The reasons for organ trafficking are: the shortage of organs; the absence of a postmortem donation practice; packages of some medical fund organisations to cover the transplant procedures abroad (for example, the USA), a highly profitable practice;<sup>[5]</sup> complaisant medical personnel;<sup>[8]</sup> the cost of kidney dialysis; the lack of national and international regulation and enforcement of existing laws; and the alleged involvement of governments.<sup>[9]</sup> Mafia-related organisations and intermediaries have come into existence and have used the opportunity to target vulnerable human beings, which has led to an increasingly large black market. Precise and recent information on this matter is scarce, for the very reason that the practice is illicit and underground. The suspicion is that the extent of the problem is underestimated,<sup>[3,6]</sup> therefore, illicit organ trafficking is not expected to be eradicated soon.<sup>[6]</sup>

## Discrimination and stigma

In discussing organ trafficking, the focus is usually only on the exploitative results of this malpractice, but the fact that it is inherently discriminatory and stigmatising receives little attention. Discrimination occurs against non-related living kidney sellers in several ways. The first is that the preference of brokers for potential sellers is not based on the medical benefit and wellbeing of the sellers, but is almost exclusively directed at persons in vulnerable social conditions.<sup>[6,9,10]</sup> This becomes clear when people and populations such as the illiterate, the poor, undocumented immigrants, political and economic refugees, and prisoners are predominantly exploited as sellers.<sup>[3,5,11]</sup> The social conditions render the people and populations very vulnerable when they are under duress (because of poverty,

power relationships, etc.) and 'convinced' by false information (possible harm to health is grossly misrepresented).<sup>[3,11,12]</sup>

Secondly, organ sellers also experience discrimination in their communities. Organ sellers are regularly marginalised in the broader community, and are consciously excluded from activities of the community.<sup>[4]</sup> Research in India by Acharya *et al.*<sup>[10]</sup> has shown, for example, that organ sellers are consciously excluded from positions such as being members of local committees, and that non-governmental organisations give medical preference to people who are not organ sellers. It has also been ascertained that discrimination is found against sellers' children in school, where they are treated differently. The following is a poignant description of the situation:

'Victims gathered in the interaction program conducted in Dhulikhel recounted some bitter experiences in their villages. One victim said neighbours and relatives now treated him as untouchable and discriminated against him by not including him in social gatherings such as marriages and other ceremonies. Another victim encountered such hostility in the village that he left to live in Kathmandu Valley.'<sup>[10]</sup>

Thirdly, discrimination further exists at the workplace against sellers of organs.<sup>[3]</sup> Employers do not take organ sellers back, or society excludes them from practising certain vocations because of their choice to sell their organs and health.<sup>[13,14]</sup>

Fourthly, there is evidence that education, gender, race, ethnicity and religion also play a role in the selection of sellers. Some recipients refuse to buy the kidneys of women sellers for sexist reasons.<sup>[3,5]</sup>

Discrimination also takes place against the recipients of organs. Almost exclusive preference is given to wealthy patients on the waiting list; in this way, there is discrimination against the poorer vulnerable patients, who may need the organ immediately. In other cases, age, single status and certain diseases of recipients are used as exclusion criteria, because some medical teams' desire for success is stronger than their concern for the wellbeing of the patients.<sup>[2]</sup>

One of the dangers associated with selling organs is that the seller runs the risk of stigmatisation in society.<sup>[3,4]</sup> This fact is confirmed by research.<sup>[10]</sup> Organ sellers are frequently stigmatised as 'half people' or 'bodies without organs' and are regarded as 'untouchables' (filthy, immoral) who do not belong in a 'normal' society.<sup>[3,11,14]</sup> There is also evidence that male sellers are stigmatised as 'male prostitutes', who disgrace the community.<sup>[5,15]</sup> Sellers as well as recipients of organs are stigmatised as 'criminals' on returning to their countries, and find it difficult and sometimes impossible to be reintegrated into society, because they are regarded as violators of the law and the existing system.<sup>[2,3]</sup> The result of stigmatisation is that the victims experience rejection, isolation, hatred and avoidance by the community. In some cases, stigmatisation could lead to physical maltreatment and assault.<sup>[14]</sup> The position of the sellers is aggravated by the fact that they do not have the courage to go for medical help after they have undergone the relevant medical procedure.<sup>[2,11]</sup>

## Problem statement

It is clear that addressing the problem requires global action, and that solving it cannot be effected unilaterally. During the past few years, several international projects have come into existence with a view to address the practice of organ trafficking (and other ethical problems associated with legal organ donations) at a moral and human rights level, and to appeal to governments to act according to principles and rights.<sup>[3]</sup> In this regard, one can refer to the recommendations

of the Asian Task Force on Trafficking (2008),<sup>[15]</sup> the *Declaration of Istanbul on Organ Trafficking and Transplant Tourism*,<sup>[16]</sup> the World Health Organization (WHO) Guiding Principles on Human Cell, Tissue and Organ Transplantation<sup>[17]</sup> and the Madrid Resolution on organ donation and transplantation<sup>[18]</sup> (which only reaffirmed the WHO principles), as well as the High-level International Conference on the Fight against Trafficking in Human Organs (2015).<sup>[19]</sup> However, the following comments reflect the crux of the research problem:<sup>[3]</sup>

'Contrary to the ethical principles explicitly stated in the international and national declarations adopted to regulate organ transplants, the principles of non-stigmatisation and non-discrimination have never been clearly highlighted. Indeed, stigmatisation and discrimination were not explicitly addressed in the 2010 *WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation*, the 2008 recommendations of the Asian Task Force on Organ Trafficking, the 2008 *Declaration of Istanbul on Organ Trafficking and Transplant Tourism* as well as the 2010 Madrid resolution on organ donation and transplantation ... The current international initiatives have built their arguments mostly based on exploitation inherent in organ sales and trafficking, but none of those initiatives has considered the perspectives of vulnerable patients as organ recipients and poor people as organ providers, and the discrimination and stigmatisation they experience.'<sup>[2]</sup>

These international initiatives ground the rejection of organ trafficking mainly in the exploitative nature of the practice, which is characterised by violations of the principles of equality, justice and human dignity, but they do not refer to the principles of non-discrimination and non-stigmatisation at all.<sup>[2,3]</sup> The research question of this study is therefore whether an authoritative universal bioethical instrument exists that connects organ trafficking and specifically discrimination and stigmatisation to each other to fill the above-mentioned gap, until a more comprehensive global instrument and project has been developed. The necessity of the study is motivated by the following statement from Bagheri:<sup>[3]</sup> 'It should be noted that all previous efforts have not yet been effective enough to stop the rapid growth of organ markets and trafficking.'

The research question will be answered by pursuing two aims: first, it will be pointed out that the Universal Declaration on Bioethics and Human Rights (hereafter UDBHR) of UNESCO<sup>[20]</sup> can be used as an authoritative instrument to fill the gap. Secondly, the gap will be directly addressed by expounding article 11 of the UDBHR as a grounding principle in judging (condemning) global organ trafficking. The article reads:

'Non-discrimination and non-stigmatisation. No individual or group should be discriminated against or stigmatised on any grounds, in violation of human dignity, human rights and fundamental freedoms.'<sup>[21]</sup>

This discourse could be instrumental and contributory in creating an awareness of the global bioethical problem of organ trafficking and in preventing it; therefore, it could promote the protection of vulnerable people.<sup>[3]</sup>

## Global authority and scope

Attention will now be given to the first aim of the research question by referring to articles 11, 26 and 21.5 of the UDBHR (2006). It is clear that article 11 emphasises condemnation of all discrimination and stigmatisation that violate human dignity, human rights and

fundamental freedoms. Furthermore, all principles, according to article 26, are interconnected and complementary. If one takes into account that the UDBHR was published a long time before the declaration of Istanbul on organ trafficking and transplant, it is remarkable that article 21.5 calls for international commitment:

‘States should take appropriate measures, both at the national and international levels, to combat bioterrorism and illicit traffic in organs, tissues, samples, genetic resources and genetic-related materials.’<sup>[21]</sup>

What authority can be attached to the UDBHR and therefore to articles 11, 26 and 21.5? UNESCO is a specialist organisation within the United Nations (UN), which is a global organisation consisting of 193 member states, i.e. one more than the number of members of the general assembly of the UN in New York. The UN is currently the only platform where all nations can engage in a discourse and eventually agree on normative instruments.<sup>[21]</sup> The UDBHR was accepted unanimously by all member states,<sup>[22,23]</sup> which implies that the declaration with its 15 bioethical principles was the first, and currently is the only bioethical (political) text to which almost all the governments in the world, including SA, have committed themselves.<sup>[23]</sup> It is of utmost significance that all the member states of UNESCO were able to agree on all the principles of the declaration, thus attaining a special achievement for universal bioethics.

Declarations – such as the UDBHR – accepted by UN agencies form part of the ‘soft law’ instruments. They are weaker than conventions because they are not enforceable according to international law;<sup>[24]</sup> for this reason, the word ‘should’ instead of ‘would’ is found in the declaration.<sup>[25]</sup> Nevertheless, the fact that the general assembly of the UN unanimously accepted the instrument with its universal aim, without any notated dissentient vote, reserves or qualifications, means the value of the instrument is not merely symbolic. It is indeed meant and accepted as an instrument that would have moral authority, and put its signatories under obligations, features that have to be regarded very seriously.<sup>[25]</sup> The fact that the bioethical principles and norms are presented in terms of human rights strengthens the moral appeal of the declaration.<sup>[26]</sup>

What is the scope of the UDBHR in which article 11 appears? From the title, aims and ethical principles of the instrument, a global ethical purposefulness can be deduced. The aims of the declaration are discussed in article 2, and the following aim is relevant:

‘The aims of this declaration are: (a) to provide a universal framework of principles and procedures to guide states in the formulation of their legislation, policies or other instruments in the field of bioethics.’<sup>[21]</sup>

From the aims statement, it is clear that states should use the instrument as a universal guideline in formulating legislation and policy, which implies legislation and policy should reflect the contents of the declaration and consider other countries, specifically developing countries.

In the above discussion, it has been shown that the UDBHR of UNESCO is meant as an authoritative instrument, and therefore it can be used to fill the gap in the relation between organ trafficking and the principles of non-discrimination and non-stigmatisation at a global level until a comprehensive declaration and project comes into being.

## Human dignity and equality

Attention will now be given to the second aim of the research question. Because article 21.5 states that organ trafficking should

be combated authoritatively, it will be shown here that the practice ought to be rejected outright, and combated not only because of the consequences of possible harm (according to article 4 of the UDBHR), but also because of the violation of article 11. In this way, the global gap could be addressed. The question of the specific meanings of the concepts of non-discrimination and non-stigmatisation now come to the fore.<sup>[2,27]</sup> UNESCO has no authoritative and final interpretation of article 11 that can be evaluated and applied. To construe a ‘UNESCO understanding’ of article 11, the focus will have to be exclusively on UNESCO sources and authors that specifically interpret the UDBHR. With the help of interpretations, the meanings of the concepts of non-discrimination and non-stigmatisation in the UDBHR are investigated below.

In the first place, the UDBHR relates ‘human dignity’ to the norms of non-discrimination and non-stigmatisation.<sup>[1]</sup> This connection is upheld by article 2, which states that the aim of the declaration is, among others, ‘to provide a universal framework of principles’, with the specific aim ‘to promote respect for human dignity’; article 26, which describes all the principles as ‘complementary and interrelated’, also applies. ‘Nevertheless, in order to use “dignity” in our lives, some practical principles were established’, UNESCO<sup>[28]</sup> declares in a document used for education. The recognition and application of the principles of non-discrimination and non-stigmatisation express human dignity and where these principles are respected, people are treated with human dignity.<sup>[29]</sup> In the second place, the principle of equality, as expressed in article 10, can be regarded as the foundation of article 11. The IBC confirms this viewpoint, and Guessous<sup>[29]</sup> commenting on article 11 explains it as follows:

‘Fighting against discrimination and stigmatisation represents the recognition of equality between human beings, their dignity and the principle of justice in their relations ... It requires the equal treatment of an individual or group irrespective of their particular characteristics.’

The principle of equality states the obligation of equal treatment of all individuals or groups, irrespective of their specific characteristics; therefore, there may be no discrimination against anyone and no person may be stigmatised.<sup>[30]</sup>

## Non-discrimination

From the principle of equality flows the principle of non-discrimination. It is important to draw attention to the fact that UNESCO does indeed distinguish between negative and positive discrimination. The concept of negative discrimination is a juridical and social concept that has a long history in international and national human rights legislation. The word ‘discrimination’ is derived from the Latin ‘discriminare’, which means ‘distinguish between’.<sup>[30]</sup> Garrafa<sup>[1]</sup> contends that the verb ‘to discriminate’ also means ‘to separate’ or ‘to select’; the noun ‘discrimination’ includes these meanings in their noun forms, but it also means ‘segregation’. In searching for a definition of discrimination that can also be used in explaining article 11, Rivard<sup>[27]</sup> finds the definition of the International Convention on the Elimination of All Forms of Racial Discrimination of the UN (1965) the most suitable (see also paragraphs 5 and 6 of the foreword of the UDBHR). Article 1(1) of the Convention defines the concept of discrimination (based on race):

‘The term “racial discrimination” shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or

ethnic origin, which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.'

Important concepts flowing forth from these efforts to define discrimination are separation, distinction, exclusion, restriction, preference, selection and segregation. In the light of the theme of this study, the focus will be on negative discrimination. Two aspects of discrimination will be discussed, namely exclusion and inclusion. Both phenomena minimalise the human dignity of a person or group and put them at a disadvantage.<sup>[30]</sup> On the one hand, people are excluded from political, economic, social or cultural contexts, which will necessarily lead to their disadvantage. On the other hand, discrimination is not only interpreted as an action of exclusion, but also as a behavioural pattern of preference for or inclusion of certain people or populations, precisely because their human dignity is minimalised. It must be reiterated that UNESCO recognises positive discrimination, which gives preference to historically disadvantaged groups with the aim of eradicating inequality.<sup>[1]</sup> However, the organisation also recognises that in some cases, inclusion not grounded on the health and wellbeing of the persons or groups involved can be disadvantageous to those persons, and should therefore also be regarded as 'negative discrimination'. The recommendations of article 11 with regard to the inclusion of participants in research also apply when considering the vulnerability of organ sellers:

'The principle of article 11, however, will also give guidance to the resolution of a wider range of bioethical issues. In the context of research, for example, the selection of research subjects should not be influenced by a belief that members of a given group are less deserving of protection from the risks associated with research than others.'<sup>[28]</sup>

Additionally, Bagheri<sup>[3]</sup> is of the opinion that the preference for and inclusion of vulnerable people with a view to organ sales are discriminatory actions. The practice of inclusive discrimination necessarily accepts some people as 'below the level of the other individuals who make up society' and that they have 'diminished dignity'.<sup>[1]</sup>

It is important to point out that article 11 of the UDBHR does not present an elaborate list of causes of discrimination (and stigmatisation), but rather indicates that discrimination (and stigmatisation) 'on any grounds' is unacceptable.<sup>[28]</sup> The general point of departure of the IBC is the following:

'The lottery of social and biological life should not be grounds for disadvantages or advantages.'<sup>[2]</sup>

It is clear that the declaration recognises and turns down inclusive and exclusive discrimination that take place for economic gain in global organ trafficking. Because organ trafficking is discriminatory, the sellers experience unequal treatment and their human dignity is violated.

## Non-stigmatisation

What is the meaning of stigmatisation? As shown, no other global or international document that addresses organ trafficking morally relates it to stigmatisation. However, the situation is changed when non-stigmatisation is accepted as a universal principle and human right in article 11 of the UDBHR, according to Guessous.<sup>[30]</sup> This use of the concept of stigmatisation is a unique contribution by UNESCO in

general, but a special contribution in the context of organ trafficking:

'In the field of bioethics, UNESCO recognises stigmatisation as a distinguished kind of discrimination that may have a serious impact on the right to health and benefit of scientific research.'<sup>[30]</sup>

Rivard,<sup>[27]</sup> Guessous<sup>[29]</sup> and the *Bioethics Core Curriculum*<sup>[30]</sup> do not use international human rights documents or manuals to formulate a definition of the concept of non-stigmatisation as found in article 11 of the UDBHR, but utilise dictionaries and encyclopaedias, namely the *Oxford English Dictionary Online*, *Encyclopedia Britannica* and *Merriam-Webster Online Dictionary*. 'Stigma' is a complex concept that indicates a disparaging name (verbal label or sticker) for an individual or group because of physical, psychological, moral, medical or social conditions. The name has the purpose of characterising a person or group negatively, and denotes inferiority. The tag further suggests that the bearer of the label is useless, unreliable, dangerous, dirty, full of evil and destructive in many ways.

The disparaging naming connected with stigmatisation has a purpose. Some UNESCO commentators state or suggest that stigmatisation should not be regarded as an independent concept but rather as a sub-norm or part of discrimination to justify discrimination.<sup>[2,30]</sup> As has been shown, Guessous<sup>[29]</sup> refers to 'stigmatisation as a distinguished kind of discrimination'. Garrafa<sup>[1]</sup> comments on article 11: 'it is essential to emphasise that there is a close and interdependent relationship between discrimination and stigma. Discrimination is an inherent part of stigma, because there would not be any stigma if there were no discrimination. Discrimination is the manifestation of stigma. The purpose of stigmatisation is judgement, discrimination, rejection and exclusion of the individual or group.'<sup>[2]</sup>

It is clear that the declaration recognises and turns down stigmatisation that takes place in global organ trafficking. Because organ trafficking is stigmatising, the sellers experience unequal treatment and their human dignity is violated.

It is evident that the UDBHR regards organ trafficking as an illicit medical practice, and that it exhorts states and civil society to fight against it. The practice has to be combated because it violates the norms of non-discrimination and non-stigmatisation, disturbs equality and encroaches upon human dignity.

## Conclusion

Organ trafficking is a growing global phenomenon that not only has exploitative consequences, but is also as far as can be ascertained discriminatory and stigmatising. Currently, there is no national or global declaration that rejects and combats organ trafficking because of the discriminatory and stigmatising results of the medical practice involved. The UDBHR addresses the problem by relating organ trafficking (article 21.5) to discrimination and stigmatisation (article 11). Until a global declaration and an accompanying project come into existence, the UDBHR can be used as an authoritative appeal to the world community to combat these activities co-operatively.

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