

### Organ Allocation Policies on WHO and UNESCO Perspectives

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#### Introduction

I will give a brief introduction into the ethics of organ transplantation. This does not cover all sorts of ethical problems related to organ transplantation but will provide basic information to start with in this section discussion. The ethics of science and technology always has had an international dimension; nowadays many international organizations have programs and activities in this area. This development illustrates that ethics, and bioethics in particular, has evolved from an academic discipline into field of public debate and global policymaking. Following the global dissemination of science and technology, bioethics has also become increasingly international. Also, healthcare practices are becoming increasingly global but guidelines and legal contexts differ and are sometimes absent. Rules for transplantation and procedures for organ donation, for example, vary among countries and these different approaches have contributed to abuses such as organ trafficking and commodification of transplantation practices. Furthermore, the burdens and benefits of scientific and technological advancements are not equally distributed.

Many international organizations have activities and advisory bodies in the area of bioethics. UNESCO and WHO are not an exception. UNESCO and WHO's work on this matter is important. As a member of the UNESCO National Commission for Bioethics Committee, I want to give you some information about UNESCO Universal Declaration on Bioethics and Human Rights. October 19,

2017, will marked the 12th anniversary of the adoption by the General Conference of the United Nations Educational, Scientific and Cultural Organization (UNESCO) of the "Universal Declaration on Bioethics and Human Rights," which was signed by representatives of the 191 member states of the conference. This declaration is of major importance: it was the first legally binding document approved by a global organization to address the whole range of subjects covered by bioethics. The UNESCO declaration and the Universal Declaration of Human Rights are part of an integral whole, which grounds both rights and ethics in the inherent dignity and equality of human beings. Policies concerning the allocation of organs cannot, therefore, disregard the principles affirmed in the Declaration.

On the other hand, other documentation about this issue was from WHO. This document provides an account of the points discussed and the conclusions reached at a consultation on the ethical, access, and safety issues in tissue and organ transplantation held by the World Health Organization (WHO) in Madrid on 6-9 October 2003.

Also we know Istanbul Declaration builds on the principles of the UNESCO Universal Declaration on Bioethics and Human Rights. I will not mention Istanbul Declaration in my speech because I know other speakers will talk about it.

Humankind has always been the focus of the studies that are based on different perspectives of different scientific disciplines.

In this section, the ethical, juridical, religious, sociological and economic problems that people as the subjects and sometimes objects have will be discussed extensively from national and international points of view.

Our aim is to draw attention to the problems encountered in organ and tissue transplantation, produce the ways to solve them and provide information for the relatives and the general public.

It is clear that some Member States of WHO and UNESCO have not assumed or have been unable to assume an appropriate level of responsibility in each of the areas of transplantation.

There are a number of roles for which the World Health Organization and UNESCO are best placed to ensure that minimum levels of human access, safety and ethical practice are adopted universally.

Without intending futurism, scientific evidences suggest that transplantation medicine might be considered a health guarantee for the 21th century. Nevertheless, the paradox of organ shortage, a social, psychological,

ethical, moral and probably legal and political problem, is overriding transplantation, making this foreknowledge uncertain.

This unjustifiable and harmful reality must imperatively be solved to avoid death on the waiting lists. It is also true that thousands of people die every day because of unequal socio economic conditions. The difference concerning donation and transplantation is that the solution is in our hands.

This negative behavior contrasts with the **UNESCO declaration about Responsibility the Present Generations over Future Generations (November 12, 1997)**: *“Recognizing that the task of protecting the needs and interests of future generations, particularly through education, is fundamental to the ethical mission of UNESCO, who’s constitution, enshrines the ideals of justice and liberty and peace founded on ‘the intellectual and moral solidarity of mankind’”*. Article 1 establishes needs and interests of future generations: Present generations have the responsibility to ensure that the needs and interests of present and future generations are fully safeguarded.

Furthermore, **UNESCO Universal Declaration of Bioethics and Human Rights (October 19, 2005)** stated: *“whereas it is desirable to develop new approaches to social responsibility to ensure the progress of science and technology contribute to justice and fairness, and serves the interest of humanity”*. And remarked: *“to promote equitable access to medical, scientific and technological developments as well as the greatest possible flow and the rapid sharing of knowledge concerning those developments and the sharing of benefits, with particular attention to the needs of developing countries”*.

Almost every day, intensive care units are rendered powerless to act because a potential donor cannot be ‘used’ because of family’s refusal. Several explanations for this denial have been suggested. People are not aware that organ transplantation is a common part of medical care. Individuals are not aware that during life, there might be more potential organ recipients than organ donors. Society is not conscious that the use of body parts after death offers a unique source of health. Medical teams are untrained in the subject of organ donation because insufficient education on this topic. It is necessary to educate people about the significance of brain death, including medical doctors and to redefine death as a process in which brain death is synonym of ‘current’ death. Myths, misinformation and prejudices are strong barriers of greater solidarity and altruism, with increased selfishness and doubts.

## The ethics of organ and tissue donation

The ethical problems of organ transplantation result from the fact that it is a highly risky and, at the same time, highly beneficial procedure involving questions of personhood, bodily integrity, attitudes towards the dead, and the social and symbolic value of human body parts. Moreover, words in organ transplantation implicitly and, often, uncritically transport ethical meanings. The word “donation”, for example, implies that there is a person acting voluntarily to benefit someone else. “Donors”, however, can be dead and are no longer able to act. Organs, moreover, are sometimes harvested without the dead “donor’s” former consent. In ethical debates, this problem of an adequate wording has to be kept in mind. However, for the sake of argument, here the donor’s and the recipient’s perspective will be separated. It will be asked: who could and should give an organ? Who could and should receive an organ?

As we said over the past few decades, transplantation has become a unique cure and successful treatment for patients suffering from end-stage organ failure. The shortage of organs for transplantation is a major global health problem. There are different kinds of systems that are adopted by many countries in order to increase the number of the organs donated after death.

**There are two main types of systems** that are adopted by almost every country. One of them is the “opt-in system”, which is adopted by many countries such as USA, United Kingdom, Canada, Australia, Germany, Switzerland and Turkey. In this organ procurement system, the organs of the decedents can be donated only if they expressed their wish by a written consent or by carrying a donor card or by telling their relatives about it when they were alive.

The other system is the “opt- out system”, in which all members of the society are accepted as donors unless they state specifically that they do not want to donate their organs. “Opt-out” is also known as “presumed consent” and is adopted by some European countries such as Austria, Finland, Sweden, Norway, Belgium, Denmark, France, Italy and Spain as well as Singapore. To increase the number of organs donated incentives are also used, such as tax reductions, payments made to the donor’s family or giving priority to patients on waiting lists who have signed a donor card (as is practice in Israel). There are conflicting views on which system is best for avoiding unnecessary death and resulting in an increase in the number of organs donated, including mandated choice.

## Post-mortem donors

In most Western industrialized countries, the major source for transplanted organs are dead or brain-dead

persons, while in countries like Japan or Iran living organ donation prevails. A major ethical question is related to the role of personal autonomy: Is explicit or implicit informed consent required, or does death annul a person's right to determine what will happen with her body?

Different legal and ethical solutions to this problem have been proposed throughout the world. As we said some countries have adopted a so called "opt-in" solution. In this case, explicit informed consent by the deceased person before death is required (by carrying an organ donor card, a written statement, a notice in the driver license etc.). Other countries foster a combination of individual consent and proxy consent, the latter being a substitute for the former. This means that family members can ensure the deceased person's will be observed. In contrast, the "opt-out" solution is based on the idea that everyone counts as potential organ donor and dissenters have to explicitly state their will. In both the opt-in and opt-out systems, individuals have the freedom of choice.

Objection to post-mortem donations can, for example, be based on cultural or religious assumptions on how to appropriately handle the human corpse. Some religious authorities of monotheistic religions like Islam and Christianity have accepted brain death as criterion for the death of a human being and have, thus, endorsed organ transplantation.

Yet, others deny the right to call a still breathing person dead. Cultural conceptions of death, like in Japan, can contravene scientific convictions. Therefore, every case needs an assessment of the donor's and recipient's cultural and religious attitudes towards brain death and organ donation.

### **Living donors**

Procurement of organs is not limited to postmortem organ donation. Living donation is an alternative for patients who are waiting for an organ to be transplanted from a deceased donor. It can be done between family members, relatives or between people who know each other well. The practice of living donation does not solve the problem brought about by the shortage of organs. The scarcity of organs might be caused by many factors including the psychological, religious or other cultural reasons as well as a lack of awareness regarding the importance of donating organs. Due to the insufficient number of donated organs and the high demand for new organs to be translated, new solutions to get over this scarcity come to the fore. As a result of this shortage, patients suffering from end-stage organ failure have started to look for organs abroad, which led to an international trade in organs involving commercial transactions.

The concern over the purchase of organs is expressed by World Health Assembly adopted in May 2010, the WHO's Guiding Principles on Human Cell, Tissue and Organ Transplantation that forbade organ selling and urged its member states to take measures to prevent commercial organ transactions. Maximization of postmortem organ donation is also promoted as an ethically acceptable alternative for compensating the organ shortage. However, on the academic level, it is being discussed that one other possible solution to increase the number of organs is the purchase of transplantable organs from living donor.

The scarcity of organs and the growing ease of Internet communication lead to organ trafficking and transplant tourism. Although there is no reliable data showing organ trafficking, the reported news and some related studies show that there is ongoing market in human organs.

Yet these accomplishments have been tarnished by numerous reports of trafficking in human beings who are used as sources of organs and of patient-tourists from rich countries who travel abroad to purchase organs from poor people. In 2004, the World Health Organization, called on member states **"to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs."**

Due to these problems, in many countries, donating living organs is seen as an important alternative to cadaveric donation. Depending on legal regulations and cultural attitudes, the frequency of living organ donation ranges from 20% to 90% of all organ donations. Close family members, spouses, friends, or sometimes even strangers are considered as possible living organ donors. While living organ donation largely benefits the recipients, the donors' risks include severe health problems or even death. For the donor, organ removal is a non-therapeutic intervention, and the risks are usually not balanced by direct benefits. With regard to the donor, physicians have to infringe on the ethical rule "First do no harm!" (lat. *Primum Nil Nocere*), passed on in the traditional medical ethos and expressed in the Hippocratic Oath. However, in modern bioethics respect for individual autonomy is often given priority over other moral rules, including the principle of non-maleficence.

### **Body concepts and personal identity**

The transfer of organs, extremities, or a face also raises questions of personal identity. A wide-spread fear raised by the transplantation of organs is that the organ recipient might experience psychological change, or more precisely, that personal characteristics might be transferred from one to the other. The idea of the body as

locus and medium of personal identity has cultural as well as medical historical reasons.

Consequently, the transplantation of a body part will change a person's identity – not just in an objective, physiological way, but in the way the recipient perceives and experiences the world. Thus, religious and cultural meanings of particular body parts (such as heart, eyes, gonads, face, etc.) have to be considered in the ethical debate as the patients' beliefs have an impact on their conception of self and personhood.

This includes ethical questions on how living donors and recipients refer to the transferred organ – do they accept the transfer or do they believe it still belongs to the other (like, e.g., my kidney in your body?).

Such a conviction can have a serious impact on the donor-recipient relationship. The body is a challenge for traditional bioethical reasoning usually focusing on autonomous individuals because the concept of autonomy relies on the idea of the body as being the object of one's personal discretion.

This conception of personal individuality ignores the extent to which one's cultural and personal identity is built upon bodily practices, bodily constitutions, and body images. This shows how important it is to think about the normative meaning of bodily-related social interactions and to respect and care for others' bodily integrity.

### **Commodification and organ trade**

The problems of organ trafficking and illegal organ trade have raised increased awareness among ethicists as well as international organizations. Those who criticize a free market of organs fear that this will seriously increase social injustice. Moreover, based on the concept of human dignity, they challenge the right to sell one's body parts. Others, however, argue that a ban on organ trade only leads to illicit and thus badly controlled markets. Instead, national and transnational regulations of the organ market would lead to more transparency, help to stop price dumping, and secure the rights of the vendor. International authorities such as the WHO and UNESCO have expressed concerns about transnational organ trafficking and have set the aim to combat illicit trafficking of organs and tissues. Organ trafficking rests upon complex social networks. Donors often come from poor, developing countries while recipients usually live in rich and highly industrialized countries. Illegal organ trafficking involves so-called brokers dealing in organs as well as surgeons willing to transplant them illegally.

The main types of arguments in favour of commercialization can be grouped around four moral principles:

- a) **Justice:** it is unjust to let people die due to organ scarcity when, in principle, more than enough organs are available,
- b) **Liberty:** personal autonomy implies that one has the right to dispose of one's body as one pleases,
- c) **Beneficence and utility:** commercialization would lead to a win-win situation, both donors and recipients would likewise benefit from it, and
- d) **Efficiency:** a free market will make the system more efficient and solve the problem of demand.

At the same time, these tendencies and arguments can be criticized on the basis of nearly the same principles.

So it is feared that

- The practice of paying money for organs will increase injustice because only the wealthy will then be able to afford an organ transplantation treatment,
- The autonomy of the poor will in fact be limited due to their lower social status and financial constraints,
- Commercial donation will discourage altruistic donors and, consequently, the number of altruistic donations will seriously decrease, and
- A commodification of the human body ignores the existential meaning of the body for personal identity and self-understanding.

### **UNESCO- The Universal Declaration on Bioethics and Human Rights (UDBHR)**

Healthcare practices are becoming increasingly global but guidelines and legal contexts differ and are sometimes absent. Rules for transplantation and procedures for organ donation, for example, vary among countries and these different approaches have contributed to abuses such as organ trafficking and commodification of transplantation practices. Furthermore, the burdens and benefits of scientific and technological advancements are not equally distributed. Poorer countries risk exploitation in biomedical research and exclusion from the benefits of biomedical progress. There also is a risk that double, or at least different, moral standards are applied in different regions of the world.

With this Declaration, UNESCO strives to respond in particular to the needs of developing countries, indigenous communities and vulnerable groups or persons. The Declaration reminds the international community of its duty of solidarity towards all countries. Among the principles laid down in this declaration, those most relevant for the allocation of organs are benefit and harm (Article 4), equality, justice and equity (Article 10), nondiscrimination and nonstigmatization (Article 11), solidarity and cooperation (Article 13), social responsibility and health (including access to quality health care; Article 14), and sharing of benefits (Article

15).

**Article 4 of the Universal Declaration on Bioethics and Human Rights (2005)** on ‘Benefit and Harm’, emphasizes that in applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefit to patients, research participants and other affected individuals should be maximized and any possible harm to such individuals should be minimized. Article 4 follows from Article 3 that refers to ‘Human Dignity and Human Rights’. Both articles treat dignity as an inherent property of being human. Recognition of the central place of dignity in human rights and ethics takes into account the obligations of the human species for other human beings. In health care practice it is important to evaluate benefits and harm. Treatment choices have to be made among patients: an assessment has to be made between risk of harms and potential benefits. This is particularly important for resource allocation, when time and material resources are scarce. Conformity to the obligations of Article 4 requires a combination of prudential judgments and technical competence. Estimates of probability and projections of the expected impact on the individual patient and the society of a proposed treatment must be made.

When we examine the harm and benefits to be gained by carrying out a specific medical procedure on a patient, we must weigh not only the harm and benefits to be gained by the patient while performing the specific procedure, but also the all-inclusive harm and benefits. This means that even by giving up the kidney, the patient can gain more benefits than harm. Policies concerning the allocation of organs cannot disregard the principles affirmed in the Declaration.

I want to remind the participants of the four ethical principles elucidated by Beauchamp and Childress – respect for autonomy, beneficence, non-maleficence and justice and suggest that they might provide one possible framework for phrasing ethical issues in transplantation. Common to all four areas are questions of eligibility and safety of donor and recipient, use of financial and other incentives, equitable access and allocation and issues of cross-border exchanges and commercialization.

There are a number of roles for which the World Health Organization is best placed to ensure that minimum levels of human access, safety and ethical practice are adopted universally.

#### **WHO roles could include**

- Encouraging the development of transplantation therapies in Member States in an ethically appropriate manner.

- Initiating an ongoing programme on transplantation at WHO and establishing a WHO Expert Advisory Panel for transplantation.
- Facilitating the development of a core of technical and ethical standards for the management of the safety, quality and efficacy of human material for transplantation that can serve as a model for Member States.
- Encouraging Member States to develop a legal framework and national policy and plan on transplantation activities, especially ensuring coordination of the procurement of human material from deceased donors.
- Facilitating communication between regulators and providers on the international circulation of human cells and tissues for transplantation, in particular for matched hematopoietic stem cells.
- Collecting data on the extent of paid organ, cell and tissue donation.
- Creating a global map of the known infectious risks and the safety measures that are applied to donors and donations in different countries and regions of the world.
- Helping Member States to develop capacity for national regulatory approaches to quality and safety in particular by encouraging the creation of international support networks.
- Encouraging the measurement of the donor outcomes for living donors in different clinical environments, through collaborative global data collections.

#### **Conclusion**

One thing should be beyond any debate, though: the donor’s long-term medical health and psychological well-being should be assured. Screening criteria should be strict, with the threshold for ruling out unrelated donation for medical or psychosocial problems kept very low compared with the threshold used in the living-related donation setting. Protocols for long-term follow-up of donors should be put into place, and the donors’ rights to medical and psychological assistance related to the donation should be addressed. Finally, in accordance with the Declaration of Istanbul any kind of unrelated donor transplants done for residents of one country in another country should be prohibited. Each country should strive to solve its own organ shortage, with or without an unrelated donation program.

UNESCO strives to create a better understanding of the major ethical issues raised by science and technology and supports analysis and discussion of those issues internationally, regionally, and nationally. An essential part of this work is raising public awareness and stimulating public debate.

Public involvement is important for two reasons. First,

ethics is of interest to policymakers because of public concerns. Because there is public concern and debate on issues such as cloning, research with human beings, transplantation, nuclear energy, or environmental pollution and global warming, ethics has been set on the national and international agendas.

Ethics no longer is the sole concern of scientists, engineers, or health care professionals. It has transcended the exclusive domain of experts, showing that science is first of all a public enterprise, a social activity, and cultural good. Second, scientific developments often affect all people. This is clear in medical research, which is increasingly dependent on the cooperation of large numbers of patients and healthy volunteers, often in international trials. The interests of science and research should be balanced with the interests of participating people, exactly because human rights and freedoms can be at stake. Public debate and awareness raising are therefore important to make clear that science and technology are advancing within an ethical framework of respect for human dignity and human rights. They also show that scientists have responsibilities toward society and do take into account the possible effects of their work on society, for example, with respect to protection of the environment, promotion of justice, and prevention of biohazards and bio-events.

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