Organ Donation and Transplantation Medicine: Ethical Framework and Solutions*

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Abstract

Advances in surgery and the introduction of drugs that suppress the immune system have paved the way for transplantation medicine. Today, the donation and transplantation of tissues and organs (including heart, kidney, liver, lung, pancreas, cornea, bone marrow, and face) are feasible. Transplantation medicine has created new areas of ethical and legal discussion. In these discussions, four principles generally accepted in medical ethics - beneficence, non-maleficence, autonomy, and justice - have featured in their different aspects. In particular, the principles of non-maleficence and autonomy can collide. The dramatic increase in the number of people waiting for an organ shows that any deadlock on this subject means the death of many; hence, it is important to find a solution appropriate to the values held in society. In this study discussing current transplantation methods throughout the world, basic ethical dilemmas are addressed and effective solutions sought in accordance with ethical perspectives.

Keywords: Transplantation, Ethics, Beneficence, Nonmaleficence, Autonomy, Justice

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The History of Transplantation

Transplantation in the World

Until the nineteenth century, the human body was viewed as a functional whole. Diseases were thought to occur as the result of an imbalance in bodily fluids, and treatment methods such as medication, emesis, blood letting, and purging were often employed to rebalance these fluids. In the 1850s, physicians began to see the body as a composite of tissues and organs responsible for specific functions and therefore became more prone to use surgery to remove diseased components from the body. Advances in surgical techniques have increased the success of operations and patient survival rates (Schlich, 2011).

In the last quarter of the nineteenth century, surgeon Emil Theodor Kocher found that in patients from whom he removed the thyroid gland to prevent the recurrence of goiter, signs and symptoms such as weight gain, hair loss, cognitive and speech slowness, and anemia developed. These complaints resulted from the lack of thyroid hormones (Parangi & Phitayakorn, 2011; Schlich, 2011; Ziegler, 2001). He reversed this operation in 1883 by transplanting thyroid tissue into a patient whose thyroid gland previously had been removed. This event can be considered as the first organ transplant. Surgeons then initiated a number of animal experiments in which they removed and transplanted organs in order to understand their functions in the body. Kocher was awarded the Nobel Prize in Physiology or Medicine in 1909 for discovering the function of the thyroid gland (Schlich, 2011; Testi, 1991).

In the early years of the twentieth century, surgeon Emerich Ullmann transferred kidneys from one dog to another. He argued that the functionality of the transplanted organ was more prolonged with closer genetic proximity between donor and recipient. In the late 1920s, skin transplantations were initiated in humans, and it was found that no tissue rejection occurred between monozygotic twins (Flaman, 1994). Biologist Peter Medawar, who was conducting experiments on rabbits in the 1940s, showed that the tissue rejection that made transplantation attempts fail was an immune response and that tolerance to the transplanted tissue could be achieved. Upon these findings,

medications to suppress the immune system and prevent tissue rejection were introduced (Starzl, 1995). The first successful kidney transplantation was conducted between monozygotic twins in 1954 and between dizygotic twins in 1959; the first successful liver and heart transplants were performed in 1967; and the first successful bone marrow transplant was done in 1968. In the same year, at Harvard Medical School brain death was for the first time defined according to neurological criteria. The first successful lung transplantation was performed in 1983; the first successful small intestine transplantation in 1989; the first successful hand transplantation in 1998; and the first successful face transplantation in 2005 (U.S. Department of Health & Human Services, n.d.). Tissue or organ transplantations from animals to humans (xenotransplantation), having been studied intermittently for around a hundred years, gained renewed popularity in the 1990s -this time with the idea of benefitting from genetic engineering. Although there have been some applications, such as providing heart valve tissues from pigs, animal-to-human organ transplantation has not yet been fully achieved (Ekser et al., 2012). In recent years, stem cell technology, rather than xenotransplantation, has become a more attractive option for increasing the number of transplantable organs.

Transplantation in Turkey

Organ transplantation in Turkey was performed for the first time in 1968 at Ankara High Specialty Hospital; however, this heart transplantation attempt failed. This was followed by the first successful kidney transplants at Hacettepe University Hospital, in 1975 from a live donor and in 1978 from a cadaver (Bayezid, Balkanay, Öztek et al., 1990; Erek, Süleymanlar, & Serdengeçti, 2002). In 1979, the first law covering organ transplant surgery, the Law on Organ and Tissue Removal, Retention, and Transport, took effect. Thereafter, the first liver transplantation from a cadaver was conducted in 1988 and the first successful heart transplantation the following year (Ateş, Çanakçı, Alkış, & Saygın, 1994; Bayezid, Balkanay, Carin et al., 1990).

Ethical Analysis of Organ Donation

Organ Donation from Live Donors

Today, the donation and transplantation of many tissues and organs –heart, lung, liver, pancreas, kidney, bone marrow, and cornea– is possible in Turkey. The greatest success of recent years has been face transplants, which began in 2012. Live organ donation in Turkey is usually performed between first-to fourth-degree relatives. Transplants between non-relatives are carried out only after approval by an ethics committee, in compliance with legislation and ethical standards (T.C. Sağlık Bakanlığı [Republic of Turkey, Ministry of Health], 2012).

Most medical treatments in medicine cover only the sick person; however, in live organ transplantation, both a healthy donor and a recipient patient are involved, while the transplantation is conducted solely for the benefit of the sick recipient. The healthy donor is undergoing this medical intervention – ideally– entirely of his/her own accord. In organ donations between relatives, where both the donor and the recipient already know each other, physicians must ensure that the donor is making the donation without being pressured to do so and without any material or non-material expectations (*Problem 1*). The outcome of the transplantation may be unsuccessful for the recipient or result in serious physical complications in the donor. Strong emotions like anger, depression, or a sense of futility may develop when the desired result is not obtained, and anger in the donor can arise if perceiving a lack of gratitude in the recipient.

Organ transplantation is a process in which two ethical principles, beneficence and autonomy, may conflict (*Problem 2*). The physician is in a dilemma regarding the donor: Given that every surgery involves risks, the physician, who has sworn not to do harm, should not operate on a healthy donor. However, the donor is autonomous; he/she has the right to donate tissues or organs from his/her body altruistically, even if this act goes against his/her interests. The physician is responsible for respecting this right of self-determination that the donor has over his/her own body.

Problems 1 and 2 can be resolved only through a healthy process of approval that we call informed consent. Organ donation is an excellent example of the donor's sacrifice and a unique healing chance for recipient. However, the physician is responsible for spending an adequate amount of time explaining the various aspects of the procedure (the risks and complications of the surgery, the possibility of failure, postoperative physical difficulties, and poor outcomes) to both the donor and the recipient in lay language (i.e. free of medical terms), making sure that both parties are sufficiently enlightened. Thus it can be made sure that an organ donation is made with sufficient information, without pressure or unwarranted expectations, and entirely voluntarily. Once this is achieved, the physician is entitled operate on the donor, despite the latter's authority over his or her own body, in the name of healing the recipient, whose consent remains the reference point for the operation. The physician's fulfillment of his/her humanitarian and professional obligations depends on meticulously obtaining the informed consent of both parties.

Removal of organs from children is another issue with important ethical aspects. Article 5 of Law No. 2238 on Removal, Retention, Grafting and Transplantation of Organ and Tissues, dated June 3, 1979, states that, "It is forbidden to take organs or tissues from individuals under the age of 18 or *non-compos mentis*." Article 20 of the European Convention on Human Rights and Biomedicine (Oviedo, April 4, 1997), which was signed by Turkey, reads as follows: "(1) No organ or tissue removal may be carried out on a person who does not have the capacity to consent. (2) Exceptionally and under the protective conditions prescribed by law, the removal of regenerative tissue from a person who does not have the capacity to consent may be authorised provided the following conditions are met:

- i. there is no compatible donor available who has the capacity to consent;
- ii. the recipient is a brother or sister of the donor; ..."

Apparently then, the Oviedo Convention in some cases permits harvesting organs or tissues from non-adults. Turkey, while codifying the Oviedo Convention into Law No. 5013 (published in the *Official Gazette* on December 9,

2003), has put in place the following reservations (Mumcu & Küzeci, 2005): The government of the Republic of Turkey, conforming to art. 36 of the "Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine", has reserved the right not to apply art. 20 clause 2 of the convention, as it is not in conformity with art. 5 of law 2238 on "Removal, Retention, Grafting, and Transplantation of Organs and Tissues" allowing the removal of self-regenerating tissues from a person who does not have the capacity to consent. ("Biyoloji ve Tibbin Uygulanması Bakımından...", 2003).

Although being banned in Turkey, a discussion of the ethical aspects of organ donation and transplantation in children is still warranted. Living children and adolescents are often referred to transplantation specialists as potential donors (usually as tissue donors) when their sibling's life or health is in question. The referring of such donors under the age of 18 can be deemed reasonable when tissues or organs cannot be obtained from an adult donor or cadaver and when no other treatment option is left, thus minimizing the ethical dilemmas. Children cannot make decisions or give legal consent for a medical intervention. A physician trusts the parents' judgment and their decision regarding their dear and indispensable two children. Nevertheless, the little donor should be addressed by physician and family and, just as with adults, should be informed about the procedure.

The challenge of understanding organ donation, the risks involved, and its importance for the recipient would not be the same for two donors at ages 7 and 17. Considering his/her age, informing the donor should be done in sufficiently clear language. Then, his/her opinion regarding the operation should be sought and evaluated, again, considering the age. The process can be compared to a pair of scales in which the decision made by the parents on behalf of the donor weighs on the right pan and the donor's own decision on the left. At birth, all 18 weights are on the right pan, while one weight is transferred from the right pan to the left for every year the donor's age approaches the legal limit. This analogy can be made for any medical intervention that requires the consent of an individual under the age of 18. If it is suspected that a young person does not

want to make an organ donation, then it should be ensured that he/she is not being directed to do so by other family members.

Organ transplantation can be lifesaving for an infant patient. However, there are few organs of suitable size for pediatric organ transplantation available; organ procurement is more difficult than in adult cases. As a solution, the use of non-viable anencephalic babies (those born lacking a skull and brain) as organ donors was first admitted in the 1980s. However, despite the absence of the endbrain, anencephalic babies can maintain a heartbeat and respiration due to the presence of the brainstem; therefore, they can live for a short while after birth. These babies do not fulfil the brain death criteria, so their organs cannot legally be used for transplantation while waiting for the cardiorespiratory death of these babies (Bioethics Committee, Canadian Paediatric Society, 2005). When an anencephalic newborn is dedicated as a prospective donor, there is the danger of harvesting an organ from a living individual who cannot give consent - which constitutes a crime. Anencephalic babies are a limited source for tissue/organ procurement, given that the incidence of anencephaly in the United States, Europe, and Turkey is below 0.5% (Li, 2006). The best ethical option regarding these cases seems to be not giving priority to these individuals as a source for organ donation but maintaining palliative treatment until natural cardiorespiratory death takes place.

Organ Donation from Cadavers

Since the beginning of transplantation surgeries, the "dead donor rule" has been valid and dead donors have been preferred to living donors (Truog & Miller, 2008). The "cadavers" in organ transplantation are patients who have been diagnosed brain-dead and are on ventilator support in a hospital intensive care unit. For brain-dead individuals who had declared to be organ donors when alive it is still recommended to ask for their relatives' opinion (although this is not legally required). For those who had not made a declaration of donation, close relatives are their legal decision-makers.

¹ The organ transplantation approach in which dead donors are preferred rather than living ones not to harm the latter group.

Some patients' relatives, when informed that treatment has failed and brain death has occurred, tend to believe that the patient is still alive (due to the continuing heartbeat thanks to mechanical support) and hope that he/she will survive. They want to avoid the pain of loss. Some confuse coma and vegetative state with brain death.² These relatives should be sensitively informed that brain death is death and signals the inevitable end of the individual's life.³ Subsequently, their approval for organ donation may be sought by explaining its reasons.

Another challenging scenario arises with homeless persons whose relatives cannot be reached and individuals whose bodies have not been identified. Naturally, it is not possible to assess their potential decision in favor of or against donation. If an individual's stance is not known, it can be argued that the procurement of his/her organs is contrary to the person's autonomy. This is a safe but very simplistic approach. The bereaved relative, when acting on behalf of the deceased person, might indeed prefer the dead being beneficial to another patient, rather than burying the body intact in the name of autonomy; hence, the proxy might decide in favor of organ donation.

Also the use of aborted fetuses for cell, tissue, or organ transplants – for medical treatment and research purposes – must be discussed. It is thought that giving the option of using fetal tissues might increase the number of abortions, because some pregnant women might terminate their pregnancies in order to obtain such tissue (Sanders, Giudice, & Raffin, 1993). Some parents might plan another pregnancy just to procure the necessary tissues or organs for their existing child(ren) in need. However, abortion after the expiration of the legally recognized duration of pregnancy is considered legal and ethical only if it is performed for reasons pertaining to the fetus or the mother. In other words, abortion has to be justified by the risk of the pregnancy for the mother's

² In a United States survey, it was found that some of the participants did not regard brain-dead patients as dead, and the majority of survey respondents did not know the neurological criteria of brain death completely; they also considered patients in a coma or a vegetative state as dead (Siminoff, Burant, & Youngner, 2004). Robert Veatch (2004) questioned how taking organs from patients in a coma or vegetative state, who are alive according to the law, can be deemed legitimate: by regarding them as alive and taking their organs nevertheless, or by expanding the definition of brain death to include these patients and thus taking the organs from the dead?

³ The authenticity of death in cases of brain death has also been discussed by some doctors. In these cases, heartbeat and respiration continue because of mechanical ventilation even after the irreversible loss of brain function; "traditional death" as known in the pre-ventilation era cannot be expected. Brain death is a result of -or a price paid for- the development of medical technology; it is a new form of death produced by human intervention.

physical and mental health (except for cases of severe fetal disability), not by a potential transplant recipient's needs; it should not be approved otherwise.

Further discussion on transplantation ethics may arise from this issue. Suppose that a mother whose fetus has been diagnosed with anencephaly, instead of making the decision to terminate her pregnancy at that moment, decides to give birth and thereby provide organs for other sick babies. Would it be ethical for a physician not to object to this decision? Being born with an incurable disease and dying in a short time would be contrary to the wellbeing of the fetus. On the other hand, a mother cannot be forced to terminate her pregnancy, as she is autonomous. Which is more important and primary, the well-being of an anencephalic fetus or the treatment of other babies as a result of its death? What about consolation for the mother who tries to make sense of her ill-fated pregnancy by saving the lives of other babies? It should be discussed with the mother what it means refusing other babies' treatments at the expense of harming one baby's body.

Perspectives on Organ Donation

Many people are *uninformed*, *insensitive*, or *passive* about organ donation. Those who are uninformed do not know that they may play a role in the treatment of patients by donating organs. Those who are insensitive know but do not care about it. Those who are passive know the importance of organ donation and generally wish to help but do not take action to obtain a donor card that declares their intent. The commonality among these three groups is that they do not make a choice about whether or not to become organ donors. If a majority of the population in Turkey does not donate, this is mainly because they have not made a declaration of consent, not because they reject the use of their organs after death. Just like in an unexplored underground mine, there is an unevaluated donor potential in society. The increasing donation rates in countries that presume the dead to be donors unless they have declared otherwise in advance is an indication that a majority of the population is inactive, not opposed to donation.

Additionally, the number of people who refuse organ donation because of false information, particularly based on religious misconceptions, cannot be overstated. Yet, organ donation and benefitting from organ transplantation have been approved and encouraged by religious authorities. Pope John Paul II viewed organ donation positively, "if conducted for providing a chance of health, even life [,] for those who have no other hope left [,] and acceptable in terms of ethics" (Pope John Paul II, 2000). His successor, Pope Benedict XVI, carried a donor card during his years as a cardinal (Squires, 2011). Islam, too, is not opposed to organ donation and transplantation. Even the use of animals which adherents of some religions are forbidden to eat, such as pigs, to provide tissues/organs for transplantation has been deemed appropriate in case of necessity. The Republic of Turkey's High Council of Religious Affairs has approved the transplantation of organs from dead and living donors if "...the patient has no other option for saving his/her life or a vital organ; ...the person whose organ or tissue will be taken is dead at the time of the operation[;]... if alive, the organ or tissue which will be taken is not a vital organ[;]...the person whose organ or tissue will be taken has given his/her consent before his/her death or[,] if he/she has not stated otherwise, his/her relatives have given their consent; no remuneration is taken in return for organ or tissue donation; [and] the recipient patient... [has given] consent for the transplantation..." (T.C. Diyanet İşleri Başkanlığı [Republic of Turkey, Presidency of Religious Affairs], 1980). Conditions such as there being no other treatment options and having obtained the consent of donors, donors' relatives, and recipients are also followed by medical authorities in line with the non-maleficence principle of ethics and informed consent. Conveying these opinions to people who have religious scruples can correct their misconceptions.

Recipient's Choice

If the donor and the recipient have known each other prior to the transplantation, then promises, expectations, and negotiations may take place between the two. In a system where the recipient is determined by an official institution, however, it is easier to ensure that donations are purely voluntary.

Should there be a priority group of recipients that benefits from selection criteria for organ donation? Considering the scarcity of organs to be transplanted and the great number of potential recipients, candidates for whom the benefit of transplantation and the chance of success are greatest should be chosen. Accordingly, blood and tissue compatibility between donor and recipient, the age of the donor, and his/her current state of health and motivation are the main factors.

Even under these guiding criteria, some difficulties may arise in the selection of recipients. For example, the United Kingdom and the United States both prioritize younger people over elderly patients for kidney transplantation (Beauchamp & Childress, 2001). The principle of justice would require that we not ignore the waiting time for the organ. Considering two biologically compatible recipient candidates, should we give a kidney transplant to the 55-year-old patient who has been waiting for an organ for five years or to the 25-year-old who has been waiting for one year only? Or, if all other parameters mentioned are identical, should a mother have priority over a prostitute? Can we object to an approach that postpones a patient who needs a liver transplant due to alcoholism, stating that "It's his/her fault," by simply saying, "To err is human?" Most importantly, is it possible to answer such questions without subjective judgments? Having a formulation that would rank organ recipients using numerical parameters like degree of biological compatibility, chance of medical success, and waiting time would be the most ethical approach.

Organ Donation Models in the World

Lifesaving organ transplants are possible primarily through organ donation. Different approaches have been formulated to increase organ donations from both the dead and the living (Ertin, Harmancı, Mahmutoğlu, & Başağaoğlu, 2010):

Spanish Model

In order to increase the low rate of organ donation in Spain, the National Transplant Organization was founded in 1989.⁴ The organ donation process itself is left to teams of specially trained transplant coordinators. These teams consist of people with good governance of the process who can also inspire confidence, establish satisfactory relationships with families before making organ donation requests, and find the appropriate time to make these requests. The teams request organ donation only after a family has understood that their relative has died.

The Spanish system identifies potential donors primarily in intensive care and ensures the timely reporting of brain deaths. Thus, an option to make a donation is given to the family in each brain death case. According to the coordinators, the main problem in organ donation is the difficulty of locating potential donors and obtaining consent, not the lack of suitable donors. Thanks to these team efforts, families' rejections of organ donation requests in recent years have dropped to 21.5%. Spain is now considered a high-donation-rate country. This success shows that organ donation may increase with people's willingness and determination (Ertin et al., 2010). It can be said that the Spanish model, which depends upon the persuasiveness of health workers towards donors' relatives, resembles modern commercial marketing and inducement methods. However, it is a tactic which, unlike marketing that encourages consumption, has undergone a moral transformation.

Belgian Model

According to the "consent by default" law in force in Belgium, priority is given to organ donation volunteers. Individuals fill out a donor form at one of the designated centers, and this information is sent to the national records center. This information is available only to transplant team members. The organs of the individual who has filled out the donation form can be harvested after his/her death even if the family objects. Individuals who have not completed a form

⁴ In Spanish Organización Nacional de Trasplantes (ONT)

are presumed to be donation volunteers, and no permission is sought for the donation from their families. There is no obligation to notify families about harvesting organs, although organs cannot be removed if the family refuses. This approach eliminates informed consent and assumes consent by default unless indicated otherwise. The argument used is that "tissue/organ donation must be a duty, just as military service is a national duty." Thus, 98% of the Belgian population is organ donors. However, considering that people who did not state their opinion when they were alive may have had no intention to donate, they may be deprived of their right to determine what happens to their own body, which represents a violation of the autonomy principle of medical ethics (Ertin et al., 2010).

Iranian Model

The striking feature of the Iranian model, different from that of many other countries, is that the donor can receive a significant payment for the donation. After the adoption of a regulation on kidney donation from unrelated living persons in 1998, it has been reported that there are no individuals left in Iran who are waiting for a kidney donation.

Some ethicists have expressed that, even if the organ is not sold, it could be permitted to compensate the donor, considering the financial amount received for the organ donation "a rewarding gift." Some also think that paying a donor for the organ is different from purchasing goods in a store; the former is a way of expressing appreciation for the donor's dedication and effort to save someone else's life by compromising his/her own. Some thinkers, such as Robert Veatch, have interpreted the term "rewarding gift" as a language distortion and have objected to its application, stating that the amount of money given is not "a reward" but clearly "a payment." Nevertheless, it has been found reasonable to meet the donor's expenses. Organ selling and purchasing through intermediary institutions is not widely accepted (Nuffield Council on Bioethics, 1995).

Although many people in Iran have found organs and survived thanks to this approach, success does not eliminate its risks. The appropriate or sufficient

price for an organ may vary from society to society and from person to person in the same society. The line between "appropriate or sufficient" and "tempting" amounts is very thin and subjective. Examples where money has become a tool for malicious intent and abuse are countless; offering desperate people amounts of money which they cannot refuse would be unethical.

Because of the drawbacks mentioned regarding the organ donation practices in Iran and Belgium, the Spanish model seems to be the most acceptable, from the perspective of medical ethics, among these three approaches. This model is intended to sensitize and influence the community. Thus, consent can be taken from individuals for the use of their organs after death. As autonomous individuals, people should not be forced into any particular decision; they should be able to accept or reject organ donation as they wish. The persuasion process employed should be inclusive enough to emphasize all the benefits that organ donation will provide to the individual and society; however, it should be restrained enough so as not to abuse the humanitarian and religious values of the individual (Ertin et al., 2010).

Organ Donation in Turkey and its Problems

According to the Law on Organ and Tissue Donation, Retention, Grafting, and Transplantation, individuals who are at least 18 years old and *compos mentis* become donors by declaring their willingness to donate their organs in writing in front of two witnesses. If no donor declaration has been made during life, it is essential that the relatives of a brain-dead individual give written permission for organ donation.

The "National Organ and Tissue Transplant Coordination System Directive," which was promulgated under the abovementioned law of May 28, 2008, introduced a new National Coordination System in Turkey. Similar to the Spanish model, Turkey has been divided into nine geographic regions. Hospital coordinators report brain-dead prospective donors to their Regional Coordination Center and, from there, to the National Coordination Center. Organ distribution is then decided according to the patient queue. In the

distribution of kidneys, for example, a scoring system is used in which the key patient factors are blood/tissue compatibility, dialysis period, and age. Kidneys procured from cadavers are sent to those hospitals where patients on the waiting list have the highest scores.

Coordination of organ transplants in the United States is largely carried out by nurses. The Organ Transplant Coordination System in the United Kingdom is based entirely on nurses. In Spain, coordination teams take part instead of a single coordinator, and intensive care specialists and nurses often work together on these teams. In Turkey, nurses can be employed as part of the solution.

The scarcity of donors is an important problem for Turkey. Thousands of new patients are added to the waiting list every year, while organs cannot be obtained for them. It is essential to go beyond the current approaches to resolve this situation.

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