

Balancing the right to privacy with the needs of organ transplantation: the European context and ECtHR case law

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ABSTRACT

The likelihood of developing diseases that may require transplantation progresses, which further emphasizes the importance of this issue in the modern medical discourse. However, this medical practice also gives rise to numerous legal and ethical dilemmas, especially in the context of protecting the personal data of donors and recipients. Europe, with its diverse legal systems and cultural values, faces unique challenges in this area. The purpose of the article is to analyze the legal aspect of ensuring the right to privacy, as well as the legislative regulation of organ transplantation. This article examines how European legislation and case law affect transplantation activities and assess how the ethical and legal dilemmas that arise in this context can be resolved.

RIASSUNTO

Bilanciare il diritto alla privacy con le esigenze del trapianto di organi: il contesto europeo e la giurisprudenza della Corte EDU.

La probabilità di sviluppare malattie che potrebbero richiedere il trapianto progredisce, il che sottolinea ulteriormente l'importanza di questo problema nel discorso medico moderno. Tuttavia, questa pratica medica dà anche origine a numerosi dilemmi legali ed etici, soprattutto nel contesto della protezione dei dati personali di donatori e riceventi. L'Europa, con i suoi diversi sistemi legali e valori culturali, affronta sfide uniche in questo settore. Lo scopo dell'articolo è analizzare l'aspetto legale della garanzia del diritto alla privacy, nonché la regolamentazione legislativa del trapianto di organi. Questo articolo esamina come la legislazione e la giurisprudenza europea influenzano le attività di trapianto e valuta come i dilemmi etici e legali che sorgono in questo contesto possono essere risolti.

Parole-chiave: diritti umani, generazione dei diritti umani, trapianto, diritto alla privacy, ECtHR.

Keywords: human rights, human rights generation, transplantation, right to privacy, ECtHR.

1. Introduction

Human-centeredness is the basic principle of the modern functioning of world powers. International law is aimed at protecting human rights. The evolution of human rights over the years has proved that the role and importance of the individual in international relations and domestic legislation has changed significantly. The gradual recognition and expansion of individual rights and freedoms have become key features of global legal trends. Modern international law not only recognizes basic human rights, but also constantly adapts to new challenges and needs arising in a complex and rapidly changing world. The evolution of human rights encompasses the expansion of protection from traditional civil and political rights to economic, social and cultural aspects. This includes the right to education, healthcare, as well as environmental rights and the right to protection from discrimination [1]. The development of international law also shows a growing attention to the rights of vulnerable groups, such as children, women, refugees and national minorities.

This development has led to the formation and recognition of different generations of human rights, which can be traced back to certain historical, social and political processes. Generally speaking, the division of human rights into generations is intended to reflect the evolution and expansion of the concept of human rights in response to changing historical, social and political realities. Each generation of human rights reflects a particular stage in the development of human society and responds to the specific challenges and needs of that period.

The first generation was civil and political rights. These rights emerged as a response to absolutism and authoritarianism. They emphasize the protection of individual freedom from state interference and political participation. The rights of this generation include freedom of speech, freedom of assembly, the right to a fair trial, etc.

The second generation includes economic, social and cultural rights. They began to develop in accordance with the needs of industrial society, where the emphasis has shifted to social justice and equality. These rights include the right to work, the right to education, the right to social security, and the right to participate in cultural life [2].

The third generation is solidarity rights. These rights reflect the global challenges and interdependence of states and peoples that have become particularly relevant in the second half of the 20th century. They include the right to peaceful existence, the right to a healthy environment, the right to development, and the right to a common heritage of humanity [3].

This intergenerational division helps to analyze the development of human rights and provides a systematic approach to their study and application. It also demonstrates how the concept of human rights has expanded over time to include not only individual freedoms, but also socio-economic and collective rights that reflect the global challenges of the modern world.

The fourth and fifth generations of human rights are conceptually newer and less well established in legal theory, but they have emerged as a response to ongoing societal changes and global challenges. The fourth generation includes rights related to

digital technologies and bioethics. We cannot but recognize that people without access to the Internet face limitations in their opportunities compared to those who actively use the global network [4]. This generation considers rights that have emerged in response to technological developments, especially in the areas of digital communications and biomedicine. These include the rights to digital privacy, data protection, bioethical rights such as genetic privacy, and the right to be protected from artificial intelligence and automation [5]. The right to organ transplantation can be attributed to the same generation. This was formed as a result of technological progress and the latest medical advances. The problem of life and death of a human being as a biological being is now at the forefront. It is multifaceted, ambiguous, and will remain so as long as people live [6].

Finally, the fifth generation includes rights related to environmental and space challenges, as well as those of the fourth generation. This generation of human rights is evolving in response to the growing awareness of global environmental challenges and space exploration. They may include rights to environmental security, the right to protection from climate change, and rights related to the use and exploration of outer space [7].

These new generations of rights reflect the continuing evolution of human rights and the response to current global trends and technological change. They emphasize the need for legal systems to adapt to a rapidly changing world and to address new issues arising from technological advances and environmental challenges.

The appearance of new generations of

human rights can lead to situations where there is a potential conflict or even violation of older generations of rights. This is because each new generation of human rights evolves in response to changes in society and technology, and sometimes these new developments can create tensions with existing rights and freedoms. With the growth of digital technologies and the greater availability of personal data on the Internet, privacy issues arise that may conflict with the right to the free flow of information. For example, the expanded use of surveillance cameras or the collection of user data may violate the right to privacy.

A similar situation arises in the context of transplantation [8]. At the current stage of development, the issue of organ transplantation is extremely important. This is due to a number of medical factors. In particular, the world is witnessing an increase in the incidence of chronic diseases such as diabetes, hypertension and heart disease, which often lead to organ failure requiring transplantation of the affected organ. The aging of the population, especially in developed countries, is leading to an increase in the number of people in need of organ transplants. With aging, the risk of developing diseases that may require transplantation increases.

Today, thanks to medical advances, organ transplantation has become more successful and accessible. This includes improvements in surgical techniques, organ preservation, and approaches to matching donors and recipients. As a result, more patients are considering transplantation as a suitable treatment option. However, despite the advances in transplantation, the number of organs available for transplantation has

not kept pace with the growing demand [9]. This leads to long waiting lists and increases the need to find new ways to increase the number of donated organs. At the same time, the increase in transplant requests raises another issue: ethical and legal questions, including the fair allocation of resources, ensuring the confidentiality of donors and recipients, and considering alternative methods of organ procurement.

The right to organ transplantation, which is vital for life-saving medical procedures, may potentially conflict with the right to privacy of donors and recipients [10]. This conflict arises due to the need to exchange sensitive medical and personal information in the process of transplantation. The right to privacy of an organ donor includes preserving the anonymity and confidentiality of his or her personal and medical data. However, in the process of selecting a donor for a particular recipient, it may be necessary to disclose certain information about the donor, which may pose a risk to his or her privacy.

Problems also arise for recipients of organs and tissues. They also have the right to confidentiality of their medical information. However, during the transplantation process, it may be necessary to discuss their medical condition with various medical professionals, which may affect their right to privacy. In situations where the donor is a deceased person, it may be necessary to inform their relatives about the transplant. This may violate confidentiality, especially if the donor did not want information about his or her donor status to be disclosed.

In general, the transplantation process requires the collection and processing of a

large amount of medical data, which may include sensitive information. The need to ensure the accuracy and security of this data can create additional privacy risks for both donors and recipients. In such cases, it is important to find a balance between the need for transplantation and the protection of the right to privacy.

At the same time, there are differences in the legal acts of medical law regarding transplantation in European countries. Countries have different approaches to organ transplantation regulation and data protection, which creates a complex multinational legal and ethical picture. All of this requires finding an adequate balance between effective transplantation on the one hand and the absence of rights violations on the other.

2. Materials and methods

The study is based on a comprehensive methodological approach to analyzing the relationship between the right to privacy and the process of organ transplantation in the European legal context. The selection of relevant documents was based on scientifically sound criteria ensuring their relevance and legal significance. The selection of legal acts was based on the following criteria: binding nature; impact on the regulation of organ transplantation and personal data protection; and availability of precedent-setting court practice. Acts without legal binding force (e.g., recommendations), outdated documents and court decisions without a significant impact on law enforcement were excluded.

The application of the formal legal me-

thod allowed the authors to examine international law at the universal and regional levels, as well as case law, to assess how they affect transplantation activities and how the ethical and legal dilemmas that arise can be resolved. They focus on the analysis of legal acts regulating the protection of personal data, as well as legal aspects of organ and tissue transplantation. The study used doctrinal analysis. It involves a comprehensive review of regulatory texts to determine their content, scope and legal effects. This contributes to a deeper understanding of how European legislation and case law define the relationship between the right to privacy and the need for organ transplantation.

The comparative method is used to compare two important inalienable human rights, namely the right to privacy and the right to life and medical care, which is manifested through transplantation. The authors examine the differences in legal acts on organ transplantation and data protection, which creates a complex legal and ethical picture at the multinational level.

The historical method is used to analyze the evolution of human rights and their impact on organ transplantation, in particular in the context of the development of international law and its impact on human rights in different historical periods. The authors also used this method to study the generations of human rights and the factors that influence their formation, and substantiated the idea that the emergence of new generations of human rights is due to the development of science and technology. At the same time, the emergence of a generation of newer rights often leads to the violation of rights belonging to an earlier ge-

neration. All this requires a balance between development and respect for natural rights. This method allows the study to be holistic and comprehensive, and points to the links between the history of human rights, the current state of the right to privacy, and the challenges facing transplantation in the modern European context.

Given that the issue under study involves law, medicine, and ethics, an interdisciplinary approach was taken. Medical sources were analyzed to understand the practical implications of legal regulation of transplantation, especially with regard to the processing and confidentiality of patient data. The study provides a predictive analysis of future changes in legislation, taking into account the latest medical and technological developments. The analysis is based on the study of trends in court practice, changes in EU policy and international discourse on transplantation and personal data protection.

3. Results

3.1 Legal basis of the right to privacy and organ transplantation

The legal framework is the basis of human life and the functioning of society. Therefore, it is advisable to provide a brief overview of international and European legislation in the area of ensuring the right to privacy. Of course, we cannot provide an exhaustive analysis of all legal acts regulating the right to privacy in one article. Therefore, we will consider here a number of those that we consider to be the most important. We will also draw a conclusion

about their impact on the implementation of the relevant right by European countries based on the analysis.

At the universal level, the United Nations has adopted two important documents stating that the right to privacy is an inalienable human right. Thus, the Universal Declaration of Human Rights [11] in the provisions of Article 12 protects against arbitrary interference with privacy, family, home or correspondence, as well as against contempt of honor and reputation. In addition, Article 17 of the International Covenant on Civil and Political Rights [12] prohibits arbitrary or unlawful interference with privacy, family, home, correspondence, or unlawful attacks on the honor or reputation of the person. The Article also provides for the right to legal protection against such interference. In other words, it no longer just declares the right, but also emphasizes the need for a legal framework for its defense. It should be noted that as of the beginning of 2024, 173 countries have ratified this Convention. This means that all countries have implemented the need to respect the right to privacy in their legislation [13].

Relevant norms are also reflected at the regional European level. Thus, the Council of Europe adopted and approved the European Convention on Human Rights [14]. Art. 8 of the Convention guarantees the right to respect for private and family life, home and correspondence, limiting the possibility of state interference. It is worth noting that all European countries, except Russia and Belarus, are members of the Council of Europe, and thus have committed themselves to follow all the norms adopted by this organization.

Among the important treaties adopted within the framework of the Council of Europe is the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data [15]. This document, also known as Convention 108, was the first international legal act regulating the protection of personal data. The Convention establishes the basic rules for the processing of personal data, security requirements, as well as the cross-border transfer of personal data.

Another important actor in international relations is the European Union. Given the importance of the right to privacy, a number of legal acts have also been adopted within its framework. First of all, it is the Charter of Fundamental Rights of the European Union [16]. According to Article 7, respect for private and family life is guaranteed, while Article 8 specifically protects the protection of personal data, including the right to access and rectify data.

Also, the General Data Protection Regulation (GDPR), 2016 plays a key role in protecting the right to privacy in the European Union. The GDPR is one of the strictest data protection laws in the world and aims to give individuals control over their personal data, as well as to harmonize data protection rules across Europe. The main aspects of the GDPR that protect the right to privacy:

- 1) The right to be informed – organizations are obliged to inform people about the collection and use of their personal data in a clear and transparent manner.

- 2) The right to access – individuals have the right to access their data and find out how it is used

- 3) The right to rectification – indivi-

iduals can request correction of inaccurate or incomplete information about them.

4) The right to erasure (“right to be forgotten”) – individuals can request that their data be deleted in certain circumstances.

5) The right to restriction of processing – individuals may request restriction of the use of their data.

6) The right to data portability – individuals can receive their data in a standardized format and transfer it to other organizations.

7) The right to object – individuals have the right to object to the use of their data under certain conditions, especially for marketing purposes.

The GDPR stipulates that consent to the processing of personal data must be explicit, informed and given voluntarily. Individuals have the right to withdraw their consent at any time. Organizations must implement data protection measures at the design stage of their systems and by default. In the event of a data protection breach that poses a risk to the rights and freedoms of individuals, organizations are required to immediately notify the relevant authorities and, in certain circumstances, the affected individuals. Thus, the GDPR establishes a solid foundation for the protection of the right to privacy in the European Union by giving individuals significant control over their personal data and setting strict requirements for organizations that process this data [17].

International and European law covers a wide range of aspects, from the protection of personal data to the protection of privacy and correspondence. These laws define the rights of individuals and the obligations of organizations, providing

comprehensive privacy protection. Legislation, especially the GDPR, reflects efforts to adapt to the modern challenges of digitalization and globalization. It sets high standards for data protection and requires organizations to ensure transparency and security in the processing of personal data. It emphasizes the need to ensure the autonomy and control of individuals over their personal data by granting them the rights to access, rectify, delete and restrict the processing of their data. Together, these documents form the basis of international law on the right to privacy, establishing the basic standards and principles of personal data protection and privacy at the global and regional levels. Based on this, we can note that in all European countries the right to privacy is a recognized and natural human right.

It is also worth emphasizing that the relevant acts of international law clearly reflect the ethics of human centeredness. International law reflects a growing recognition of the importance of ethical approaches and human-centeredness in the protection of privacy, emphasizing the need to respect individual autonomy and human rights. This view is very important for our further research.

Let us now consider the legal basis of the right to organ and tissue transplantation. The international instruments regulating the right to organ transplantation are not as clearly defined as those relating to the right to privacy. However, there are several important documents that address transplantation issues. At the universal level, attention should be paid to the WHO Guiding Principles on Human Cell, Tissue and Organ [18]. This document defines the

ethical and legal principles that countries should follow when implementing national organ transplantation programs. It includes the principles of consent, lack of financial gain, donor and recipient anonymity, and transparency in decision-making.

We would also like to draw attention to the Convention on Human Rights and Biomedicine [19], adopted by the Council of Europe. This document is the first international legal agreement that deals with the protection of human dignity and personal rights in connection with the application of biology and medicine. It includes provisions on consent to medical intervention, patients' rights, and the prohibition of financial gain from the use of human body parts. It is the first and only international treaty to enshrine the rights of a person as a patient in organ and tissue transplantation.

In 2002, the Additional Protocol to the Convention on Human Rights and Biomedicine concerning the Transplantation of Organs and Tissues of Human Origin [20] was adopted to this Convention. This protocol establishes standards and principles to guide organ donation and transplantation, with the aim of ensuring respect for human dignity, identity and integration and ensuring a high level of protection of human health.

The Istanbul Declaration on Organ Trafficking and Transplant Tourism [21] was developed and endorsed jointly by The Transplantation Society (TTS) and the International Society of Nephrology (ISN). This declaration is an important international document that establishes ethical and legal standards for organ donation and transplantation, with a particular focus on

combating illegal organ trade and transplant tourism. The Declaration unequivocally condemns organ trafficking and transplant tourism because they violate human rights and undermine the legitimate practice of transplantation. It emphasizes the need for ethical practices in organ donation and transplantation. It advocates that organs should be donated freely without any form of financial gain or comparable reward.

The Declaration promotes the legitimacy of organ donation, emphasizing voluntary and altruistic donation, ideally within national self-sufficiency frameworks. The Istanbul Declaration has been influential in guiding policies and practices related to organ transplantation worldwide. It represents a collective commitment to ensuring that organ transplantation is carried out ethically, legally, and with respect for human dignity and rights.

Although there is no direct "right to transplantation", it is of great importance for the fulfillment of other natural rights, such as the right to life and health care. The human rights described in the main documents of international law that are relevant to the field of organ and tissue transplantation include: the right to life and the right to physical integrity, the right to necessary medical care for the preservation of health, and the right to equal access to health care [22].

However, the implementation of transplantation must respect other fundamental rights, including the right to privacy and dignity of the individual. On the other hand, the process of organ transplantation is accompanied by a number of ethical, legal and social problems. The issues of illegal

organ trafficking and transplant tourism are particularly troubling, as they pose a serious threat to the rights and safety of vulnerable populations, particularly in lower-income countries. The illegal removal of organs violates basic human rights, including the right to physical integrity and personal dignity, and also violates the right to privacy through the use of personal medical data without the consent of the individual. A constant balance needs to be maintained between the need for organ transplantation and protection against possible abuses and human rights violations. The development of international and national legislation, proper regulation, transparency of processes and active participation of civil society are key to creating an effective and ethical organ transplantation system [23].

3.2 Ethical dilemmas in transplantation: confidentiality of donors and recipients

Based on international law on the right to privacy, we have determined that privacy is a right of every person. On the one hand, the right to privacy is fundamental and its protection is important in all areas, including medicine. On the other hand, the process of organ transplantation requires a certain level of information exchange between donor and recipient to ensure medical safety and compatibility. Typically, the evaluation of an organ's suitability for donation is performed by medical professionals who specialize in transplantation, including transplant surgeons, transplant coordinators, and pathologists. They work as a team to ensure that the organ selected is suitable for transplantation and that it is a

good match for the recipient. Evaluation is key to ensuring the success of the transplant process, as it reduces the risks of organ rejection and possible complications after surgery. This, in turn, helps to improve patient care and increase the overall effectiveness of transplantation procedures [8]. In the context of organ transplantation, the need to disclose certain medical information about the donor and recipient is critical to the success of the procedure. This includes information about blood type, tissue compatibility, and possible infectious diseases or chronic conditions that may affect the organ's survival and the recipient's overall health. In addition, it is important to consider the general physical condition and possible medical complications. Disclosure of the following information is necessary to ensure a high level of safety and reduce risks during and after the transplantation procedure [24].

Therefore, donor and recipient confidentiality in the context of organ transplantation is a significant issue for several reasons:

1. Protection of personal information - medical information of donors and recipients is extremely sensitive and its disclosure without consent may violate the right to privacy;
2. Risk of stigmatization or discrimination - information about health and medical status can lead to social stigmatization or discrimination of persons involved in the transplantation process
3. Psychological impact, because for donors, recipients and their families, the knowledge that their personal data may become known may create additional psychological stress.

Finding a balance between these two needs is a key challenge that requires careful regulation and ethical decisions. Ensuring confidentiality while allowing for the necessary exchange of medical information is an important part of ethical practice in transplantation. For example, information about a donor's health history may be important to ensure the safety and effectiveness of a transplant, but such information must be handled with a high level of confidentiality to avoid violating the right to privacy.

In addition, there is a risk of unauthorized access and use of personal data of donors and recipients. Unauthorized access or dissemination of this information can have serious consequences, including invasion of privacy and possible loss of trust in the medical system. A unified approach to cybersecurity is essential for the entire network at a time when the number of medical records stolen in cyberattacks exceeds the annual number of inpatient hospitalizations [10].

To combat the risk of unauthorized access and use of personal data of donors and recipients in transplantation, a number of safe measures should be taken. First of all, it is important to use reliable cybersecurity technologies and methods to protect medical databases and information systems. This may include the use of strong encryption, firewalls, and intrusion detection systems.

The legal aspect of the issue is also important. For example, the development and application of legal rules that define liability for breaching the confidentiality of medical information. It is also important to establish strict procedures for controlling

access to medical data to ensure that only authorized healthcare professionals have access to confidential information.

It is also important to understand that confidentiality in organ transplantation is not only a matter of personal data protection, but also an ethical principle that promotes respect for the dignity of the individual. On the other hand, as we have defined earlier, the right to organ and tissue transplantation is an integral part of the right to life. When it comes to saving a person's life, all available methods should be used. In view of this, we believe that disclosure of personal information of donors and recipients is possible, but only to the extent necessary for prompt intervention and to an authorized circle of persons. Effectively addressing these challenges requires a comprehensive approach, including a clear legal framework, strict data protection procedures, and training and education of medical personnel on the importance of confidentiality in transplantation.

We cannot ignore the issue of living donor transplantation either. Indeed, most of the legal provisions governing organ transplantation focus on transplants from deceased donors. However, living donor transplants also present significant challenges, especially in terms of confidentiality. According to the WHO Guideline Principle 3 [18], living donation is acceptable if the donor's informed and voluntary consent is obtained. Particular attention should be paid to cases where there are no family or emotional ties between the donor and recipient, such as paired kidney donation and altruistic organ donation.

Recipients of donor organs have the right to participate in decision-making

about their treatment. Persons who meet the requirements of legal capacity should give their consent voluntarily and without any pressure. Patients with end-stage organ disease are in a vulnerable position due to the lack of treatment options other than transplantation. Therefore, the validity of their informed consent may be questioned, as their choice seems obvious. Medical teams working with such patients should be as transparent as possible about the risks and possible dangers associated with transplantation. They should consider and offer alternative treatment options. These options may include refusing to transplant or determining an acceptable degree of risk, as well as choosing a specific type of donor or donation method [25].

It should be noted that crossover transplantation is carried out in cases where biological incompatibility between the donor and recipient makes it impossible to transplant an organ directly. In such situations, donor and recipient pairs are formed [26]. They exchange organs in accordance with medical indicators. This mechanism greatly expands the possibilities of transplantation, but creates additional privacy risks. In most countries, the identity of the donor and recipient remains anonymous. This legislative approach minimizes the risk of psychological pressure or indirect coercion to donate. At the same time, certain jurisdictions allow for the exchange of information between the parties by mutual consent. This raises discussions about how to prevent possible pressure or expectations of gratitude from the recipient.

The situation with Samaritan transplantation is even more complicated [27]. This is when a donor voluntarily gives his or her

organ to an unknown recipient without any financial or emotional benefit. Such an altruistic act can have profound ethical and psychological consequences. This is especially true if the donor or recipient seeks to establish contact. In most European countries, legislation provides for the complete anonymity of the Samaritan donor to prevent pressure or potential risks of exploitation [28]. However, some studies [10] show that donors sometimes want to know who received their organ. This creates a potential conflict between the right to privacy and the desire for communication.

Another threat is the protection of medical data of donors and recipients. As the transplantation system is increasingly digitalized, there is a risk of unauthorized access to personal information through data leaks or imperfect cybersecurity mechanisms. This issue is particularly relevant in cases where transplantation involves the registration and storage of sensitive medical information in electronic systems.

Given these challenges, clear legislative regulation is needed, which should include

- mechanisms of anonymity for donors and recipients, if they wish to do so;
- protection of donors from emotional or social pressure after transplantation;
- Strict standards of medical data storage and liability for their disclosure.

Another pressing issue is the protection of personal data in the case of organ transplantation from extended criteria donors (hereinafter – ECD). These are donors whose organs have certain risk characteristics [29]. Such characteristics may include: age over 60, presence of concomitant diseases, etc. The use of such organs requires the recipient's informed consent. Ac-

cordingly, this brings us back to the issue of confidentiality of ECD data. The main dilemma is to determine the optimal amount of information that should be disclosed to the recipient. On the one hand, the information should support the decision to transplant, and on the other hand, it should ensure the donor's right to confidentiality. Many EU Member States practice an approach where the recipient is provided with general information about the characteristics of the organ, but the donor's personal data is not disclosed. In cases of increased medical risk, the law may provide for the mandatory provision of more detailed information, but only to the extent necessary to make an informed decision.

Some legal systems also allow limited disclosure of additional medical data if it is critical to the safety of the recipient. For example, if an organ has an infectious risk, the recipient has the right to know about this fact, but without disclosing personal information about the donor. In the European Union, the issue of confidentiality of organ donors and recipients is regulated by Directive 2004/23/EC [30]. According to this Directive, Member States must take all necessary measures to prevent the disclosure of information about the identity of the recipient to the donor or his or her family, and vice versa, without prejudice to the provisions of national law on the conditions for disclosure of such information with the consent of both parties. Thus, EU law establishes a general principle of confidentiality between donor and recipient. The Directive allows Member States to determine the conditions under which information may be disclosed by mutual agreement of both parties. In general, the legal

policy on ECD transplantation aims to balance the recipient's right to be fully aware of the risks with the inviolability of the donor's medical confidentiality. Improvements to legislation in this area may include clearer criteria for data anonymization.

Thus, the balance between the right to privacy and the effectiveness of transplantation is possible only if there are clear legal norms and ethical standards that take into account both the medical needs and the rights of transplant participants.

3.3 ECtHR case law on human rights in transplantation

Analyzing the case law on the protection of human rights in transplantation, we can identify several interesting cases that have laid down guidelines for resolving ethical and legal dilemmas related to organ transplantation. It is worth noting that there are not many cases in this area, but a certain practice has been formed.

The first case to be noted is *Petrova v. Latvia*, 2014 centers around the unauthorized organ removal from Ms. Svetlana Petrova's son after his death. Ms. Petrova contended that the organs were removed without her consent, violating her rights under the European Convention on Human Rights, specifically Article 8 which pertains to respect for private and family life. The European Court of Human Rights deliberated on whether the removal of her son's organs, conducted under the presumed consent system in Latvia, constituted an infringement of her rights. The Court's judgment in this case addresses the intersection of national transplantation laws, the rights

of deceased individuals and their families, and the broader implications for organ donation practices.

It is worth emphasizing that Latvian legislation did not contain clear mechanisms for informing relatives about organ harvesting after death. The ECtHR emphasized that the issue of transplantation requires a proper balance between the public interest in preserving life and the rights of the deceased's relatives to information and consent [31]. Latvian legislation was based on the principle of "presumption of consent," meaning that if a person did not express any objections to donation during his or her lifetime, his or her organs could be removed. However, there were no mechanisms to properly inform relatives about this.

The European Court of Human Rights has found that Article 8 of the European Convention on Human Rights, which guarantees respect for private and family life, was violated. The Court concluded that the Latvian authorities did not ensure adequate protection of Svetlana Petrova's rights to preserve the bodily integrity of her deceased son, namely in the matter of removing his organs without her consent. Thus, the European Court found that the actions of the Latvian authorities violated Svetlana Petrova's right to privacy [32].

When considering these cases, it is very important to take into account the national context of the state. For example, according to EU data for 2010, Latvian residents have the most negative attitude toward organ transplantation in the entire European Union. Eurobarometer survey data show that only 25% of people in Latvia allow their organs to be used for transplantation after their death [33].

There are several other similar decisions. For example, in the case of *Elberte v. Latvia*, 2015, the applicant applied to the ECtHR after tissues were removed from her deceased husband's body for scientific research and medical use without her knowledge and consent. The case concerned a possible violation of Article 8 of the European Convention on Human Rights, which guarantees respect for private and family life. The European Court found a violation of Article 8 of the Convention, finding that Ms. Elberte's right to respect for private and family life was violated by the unlawful removal of tissue from the body of her deceased husband. The Court emphasized that the Latvian authorities had failed to ensure adequate protection of the applicant's rights, in particular, given the lack of proper procedures and policies to guarantee consent or inform relatives in cases of organ or tissue removal [34]. The judgment emphasizes the importance of taking into account the rights and wishes of both deceased persons and their relatives in the use of biological materials after death.

Another case that we believe deserves attention is *Polat v. Austria*, 2021. This case does not concern transplantation, but organ removal, but is important in the context of understanding the attitude of the ECtHR to the need to follow the principle of privacy. In this case, a baby born prematurely died two days later from a rare disease. The doctors decided to perform an autopsy to clarify the diagnosis, despite the religious objections of the parents, who wanted to hold a funeral according to Muslim rites that require the integrity of the body. However, the autopsy was performed without their consent, and most of the chil-

d's organs were removed. The applicant learned about this only during the funeral. It should be noted that according to the Law on Organ Transplantation, as amended in 2012, the removal of organs and tissues is allowed only with the explicit consent of the person concerned or, in the case of death, his or her next of kin [35]. The state has an obligation to take into account the cultural and religious beliefs of relatives in matters of transplantation and autopsy. Austrian law did not contain an effective mechanism to protect the right of relatives to object to autopsies for religious reasons. The Court found that the lack of an individualized approach to such cases violated the principle of due regard for private and family rights.

The Court confirmed that under the Convention there is no absolute right to refuse an autopsy. The autopsy was carried out lawfully, but the Court recognized that the applicant's position was not taken into account during this process. It also noted that while states have a certain degree of discretion in determining the balance between private and public interests, conducting an autopsy against the will of the family requires maximum respect for the rights of their members. Thus, the authorities failed to balance the relevant competing interests, namely: the state's duty to protect public health and the applicant's rights under Articles 8 and 9 of the Convention [36].

In other words, the ECtHR attaches great importance to the right to privacy. Through its judgments in various cases, the court emphasizes the importance of this right and the need to protect it, especially in contexts where it may conflict with other

rights and interests. The ECtHR regularly considers cases that raise questions about the balance between the right to privacy of an individual and the broader public interest. The right to privacy often becomes a key issue in these decisions, emphasizing its importance within the framework of European human rights protection.

From the analysis of these decisions, we can identify several systemic problems of national legislation that do not meet the ECtHR standards:

- Lack of a proper mechanism for informed consent of relatives in countries with a presumption of consent to transplantation.
- Insufficient control over the procedure of removal of organs and tissues, which leads to violations of the rights of families of deceased donors.
- Ignoring religious and cultural beliefs in transplantation-related processes.

It is important to note that this issue is still relevant. This is evidenced by the latest practice of 2023. For instance, case "Mayboroda v. Ukraine", 2023 involves Mrs. Lyudmyla Mayboroda, who had her kidney removed during a surgical procedure without her informed consent. She was unconscious at the time, and the removal of the kidney was not communicated to her immediately post-operation. The case centers on the alleged violation of Article 8 of the European Convention on Human Rights, concerning the right to respect for private and family life. It is particularly worth noting that the organ was not simply removed.

According to Art. 47 of the Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care" [37]., the use

of transplantation of anatomical materials to humans is carried out in accordance with the procedure established by law. In addition, Art. 14 of the Law of Ukraine “On the Application of Transplantation of Anatomical Materials to Humans” [38], provides for the need to obtain consent for organ transplantation. That is, unlike many EU countries, in Ukraine a person must officially agree to become a donor after death. In addition, this Law provides for voluntary and free organ and tissue donation. It also establishes a state register of donors, which records a person’s will to donate.

However, this law has serious gaps that lead to human rights violations. First of all, there are no clear mechanisms to monitor compliance with the procedure for obtaining consent from relatives in the case of posthumous donation. In addition, the Law is characterized by insufficient detail on the protection of personal data of donors and recipients. This is especially noticeable in terms of anonymity during transplantation. The limited legal framework for transplantation from living donors can also be emphasized. In the context of the case of *Mayboroda v. Ukraine* [39], it should also be noted that Ukraine lacks adequate mechanisms for legal protection of patients in cases of organ removal without their consent. Although the law stipulates that transplantation is possible only with written informed consent, the mechanisms for monitoring compliance with this rule remain insufficiently effective.

Having examined the applicant’s complaint about the failure to protect her right to informed consent, the European Court in this case took into account the absence of any structured response of the state au-

thorities to the applicant’s allegations that the “risk” of nephrectomy should have been discussed with her before the operation. The European Court noted that, as an alternative, the applicant’s relatives should have been consulted before the removal of her kidney - which, as it appears, was closely related to the absence of any national or local guidelines, standards or formalized medical documentation and procedures that would ensure proper implementation in practice of the general legal provisions on the right of patients to informed consent.

The European Court concluded that the respondent state had failed to fulfill its positive obligation to introduce an adequate legal framework to protect the applicant’s right to informed consent. The European Court of Human Rights found that there was a lack of an appropriate regulatory framework to protect *Mayboroda*’s right to informed consent, and this absence of guidelines and formalized procedures constituted a breach of Article 8 [39]. Although the issue here concerns not transplantation but removal, we still consider it relevant to our study, as it demonstrates violations of the right to privacy in various medical aspects. This gives us the right to state that the court has found cases of violation of the right to privacy both in the case of removal of organs and tissues for transplantation and removal for medical reasons.

The case law of the European Court of Human Rights emphasizes the importance of the right to informed consent in the field of organ and tissue transplantation, as well as the need to respect human dignity in these processes [40]. The ECtHR emphasizes the obligation of states to ensure that medical professionals carefully assess the pos-

sible consequences of medical procedures for the physical integrity of patients and provide detailed information to patients or their relatives, allowing them to make an informed decision about consent to medical intervention.

4. Discussion

The authors paid special attention to the work of the Ukrainian researcher V. Turianytsia [6], her article is an analytical study that focuses on the development and evolution of human rights, especially with an emphasis on the fourth and fifth generation of these rights. The article analyzes the current processes of civilizational development of mankind and discusses the relationship between theoretical and practical aspects of these rights. Particular attention is paid to the moral and ethical aspects of the fourth generation of rights, which are and will be transformed into the issues of the fifth generation of rights. Globalization processes, scientific and technological progress, philosophy of law, religious canons, moral and cultural traditions are taken into account. This article was useful for your research because it offers a comprehensive approach to analyzing the development of human rights, including recent trends and challenges. It can also reveal how current global trends and innovations affect the development of new generations of human rights and their practical application.

The work of Y. Zborivskyi [8], is important in the context of our analysis of the human right to organ transplantation. The author examines the legal, medical, and ethical aspects of the right to transplanta-

tion, and also highlights the issues related to the realization of this right. Particular attention is paid to the relationship of the right to transplantation with other human rights, including the right to life, medical care, and health care. The article also discusses the concept of donor and recipient informed consent, its importance in the transplantation relationship, and the role of healthcare professionals in ensuring that informed consent is obtained. This article provides an analysis of the legal aspects of transplantation, with a focus on personal non-property rights, including the right to privacy. It helps to understand how the right to transplantation interacts with other human rights and what are the legal requirements and ethical standards in this area.

The issue of maintaining the confidentiality of transplant participants and the cybersecurity of medical data was raised in the work of American researchers E.D. Perakslis, S. J. Knechtle, B. McCourt, R. Lynch and B.L. Doby [41]. In the current organ transplant system, there is often no specific guidance in many countries on how organ transplant organizations should handle personal data and ensure the privacy of both donors and recipients. With recent plans for a major overhaul of the transplant system, the authors propose a feasible method to improve the quality of transplant data and protect the autonomy of individuals participating in the system.

Transplantation is an important medical discovery. However, it is important that the latest medical treatments do not violate other fundamental human rights. Transplantation involves sensitive medical data, so protecting this information is important to preserve patient confidentiality. It is ne-

cessary to ensure that transplantation decisions take into account ethical principles, including respect for human dignity and autonomy. Moreover, maintaining a balance between the right to privacy and transplantation helps to avoid legal problems related to the violation of the rights and freedoms of individuals. A balanced approach in transplantation promotes socially responsible use of medical resources, taking into account the interests of both individual patients and society as a whole.

It is worth emphasizing that in its judgments in the cases of *Petrova v. Latvia* and *Elberte v. Latvia*, the European Court of Human Rights found that the lack of clarity in national legislation on organ and tissue transplantation led to a violation of the rights set out in Article 8 of the European Convention on Human Rights, which protects the right to private and family life. This underscores the importance of proper legislative regulation and protection of human rights at the national level in matters related to transplantation [22]. That is, first and foremost, the clear wording of national legislation is the key to striking a balance between protecting the right to privacy and ensuring transplantation. If the issue of confidentiality in organ transplantation is properly regulated in national legislation, it will significantly reduce the risk of violation of the right to privacy. Effective legislation that clearly defines the procedures for collecting, processing and using medical data of donors and recipients will create a transparent and secure system that takes into account both medical needs and the rights of individuals. Accordingly, countries can avoid human rights violations and increase trust in the transplant system.

A number of steps can be taken to improve the legislation in the field of organ transplantation.

1. Clear rules on consent to donation. Establish clear consent requirements for donors and their families, including in the case of deceased donors. Legislation should clearly define how consent to donation should be given - whether it is written consent, electronic consent, or through registration in special donor registries. Potential donors should be fully informed about all aspects of donation, including possible risks, procedures and consequences of organ donation. In cases where the donor is unable to give consent (for example, in the event of death), the procedure for obtaining consent from relatives or legal representatives should be clearly defined. If the deceased expressed a wish to become or not to become a donor during his or her lifetime, these wishes should be taken into account. It is also very important to establish special rules for donor consent for minors, ensuring the protection of their rights and interests.

2. Protection of personal data. First of all, it is necessary to ensure that clear rules are established for the storage, processing and transfer of medical data of donors and recipients. In addition, it is advisable to ensure proper cybersecurity of institutions that store such data. For example, by implementing encryption technologies and secure databases to prevent unauthorized access. Access to personal data should be limited to authorized persons with appropriate permissions.

3. Ensure transparency of the process. In this context, we consider it appropriate to ensure the availability of information on

transplantation procedures and policies to the public and potential donors and recipients. Also, the principles and criteria used to select donors and allocate organs should be made public, ensuring fairness and objectivity of the process. The competent institutions should establish mechanisms to monitor and evaluate decision-making processes in the field of transplantation, including ensuring the possibility of reviewing and appealing these decisions. It is also important to ensure open and honest communication with patients and their families about all aspects of the transplantation process. Again, this transparency should not go beyond ensuring the right to privacy.

4. Improving medical standards. The key role is to establish high medical and ethical standards for the assessment, collection and transplantation of organs. In particular, the development and implementation of updated clinical protocols to ensure high quality of medical care. Organizing specialized trainings and courses for doctors and nurses, ensuring that they are familiarized with the latest methods and technologies in transplantation, will also be an important measure to ensure the right to privacy in the field of transplantation.

Establishing a system for continuous monitoring of the quality of transplantation services and interventions, allowing for timely detection and correction of possible problems. These measures will help ensure that transplantation procedures are performed in accordance with the highest medical standards, ensuring the effectiveness and safety of patients. Prospects for further research may include analyzing the impact of the latest digital technologies, such as artificial intelligence, on personal data pro-

tection in the medical field. In addition, further research could include how different countries balance the right to privacy with the needs of organ transplantation.

5. Conclusion

The evolution of human rights demonstrates a shift away from a state-centered worldview focused on sovereignty and national interests to a more globalized and integrated approach where the protection and promotion of human dignity and rights at the international level is a core value. Organ and tissue transplantation is a defining medical achievement that saves lives and improves the quality of life for many people around the world. This practice can be considered life-saving given its potential to treat critical illnesses and conditions leading to organ failure. Accordingly, the right to transplantation can be seen as an integral part of the fundamental right to life, which includes not only the right to be alive, but also the right to access medical services that can significantly improve or save lives.

On the other hand, organ transplantation raises a number of ethical, legal and social challenges. Of greatest concern is the illicit trade in organs and transplant tourism, which jeopardize the rights and safety of the most vulnerable populations, especially in low-income countries. The illegal removal of organs is a gross violation of fundamental human rights, including the right to bodily integrity and dignity. It also violates the right to privacy, as personal medical information is often used without the consent of the individual.

It is also important to keep in mind that the right to privacy includes not only the protection of personal data, but also the right of an individual to control the use of their biological tissues and organs. Thus, healthcare professionals must adhere to ethical standards of informed consent, ensuring that patients fully understand all potential risks and benefits of transplantation. In response to these challenges, the international community and individual countries are developing regulatory mechanisms aimed at ensuring transparency and fairness in the process of organ transplantation. For example, the Convention on Human Rights and Biomedicine and other international documents lay the groundwork for ethical and legal removal and use of organs, etc.

The ethical dilemmas in organ transplantation, particularly with regard to donor and recipient privacy, involve several key aspects. First, there is the need to protect the personal information and medical data of both parties, which has a significant impact on their right to privacy. Secondly, there are questions about informed consent, especially in cases where donors or recipients may not fully understand the medical risks or consequences of the procedure. In addition, ethical challenges include balancing the need for organs for transplantation with the protection of donor rights. These dilemmas need to be carefully considered and ensure compliance with ethical standards and legal norms. Clear national legislation can help to find the appropriate balance. Specific steps that should be taken include: clear rules on consent to donation; protection of personal data; ensuring transparency of the process; and improving medical standards.

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