

Presumed Consent: Public Opinion and Bioethical Challenges

In terms of bioethics, organ transplantation can be considered a fringe activity today.

On the one hand, it is a new, hi-tech medical procedure that takes us “beyond” the traditional ideas of what is possible and acceptable as an outlook for “improving” and saving human beings, something that makes us proud of the latest biomedical achievements. On the other hand, transplantological practices continue to raise bioethical questions concerning the acceptability, appropriateness and ethics of actions taken in the context of saving (extending) human life, donating organs, etc., becoming an epicentre of moral collisions and debates about the boundaries of human intervention in natural (or divine) providence.

When we speak of transplantation in the context of saving an individual human life, ethical questions become even more acute and urgent as they are aggravated by psychological factors, the realities of knowledge/ignorance and the preferences and wishes of specific persons involved in the transplantation process (the donor, the recipient and their next of kin).

One of the most ethically challenging issues related to transplantation practices today is the procurement of organs and tissues from deceased persons, particularly the position of “presumed consent” to posthumous organ donation adopted by Russia.

There are three key positions on posthumous donation in today: “presumed consent,” “explicit consent” and the so-called mixed system (combining some elements of presumed and explicit consent). It is also possible to talk about routine organ removal, where a deceased person’s body is considered state property and, therefore, organ removal decisions are guided by the interests of the governments and society. This model of organ removal for transplantation purposes existed in the 20th century; however, in modern society, which places a special value on human rights, routine organ removal is perceived as an absurd practice.

Under international principles, the selection of a specific model falls under the authority of the state. The WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation (Sixty-Third World Health Assembly, 21.05.2010, Resolution WHA63.22) clarifies: “Whether consent to procure organs and tissues from deceased persons is ‘explicit’ or ‘presumed’ depends upon each country’s social, medical and cultural traditions, including the manner in which families are involved in decision-making about health care generally. Under both systems any valid indication of deceased persons’ opposition to posthumous removal of their cells, tissues or organs will prevent such removal”.

Adopted by a number of countries (such as Denmark, the Netherlands, Lithuania and Romania, among others), the “explicit consent” system stipulates that cells, tissues or organs may be removed from a deceased person if the person has expressly consented to such removal during his or her lifetime. Depending on the law in force the country, such consent may be made orally or recorded on a

donor card, driver's license, identity card, in their medical record or in a donor registry. When the deceased has neither consented nor clearly expressed opposition to organ removal, permission should be obtained from a legally authorized person, usually a family member. Lithuania provides an example of "explicit consent": under Lithuanian law, informed consent to posthumous organ or tissue removal is required and a system of donor cards is in place. Any legally competent Lithuanian citizen may fill out an official form available at any Lithuanian medical institution or online at ntb.lt to express consent to posthumous organ removal (in whole or in part).

Another group of countries has adopted the position of "presumed consent" (Austria, Belgium, Bulgaria, the Czech Republic, Norway, Poland, Portugal and Russia, among others). This model is also a law in Belarus. The notion of "presumed consent" dictates that all adult citizens of a country "by default" consent to the removal of any of their organs after death for transplantation purposes. Of course, expressing opposition to posthumous organ removal during one's lifetime is a way to make sure that this does not happen. Non-consent is recorded in the "Uniform Registry of Transplantation." In the Republic of Belarus, for instance, this possibility is provided under Article 10-1 of the Law "On Organ and Tissue Transplantation": "Legally capable citizens may submit to a public healthcare institution at the place of their residence (or place of temporary abode), as well as to any other public healthcare institution where they receive medical care, a written refusal of organ removal for transplantation after death. With regard to minors, except those who have acquired full legal capacity under the established procedure, and persons declared legally incapable under the established procedure, such refusal shall be submitted by their legal guardians. With regard to persons incapable of making an informed decision due to their health, such refusal shall be submitted by their spouse or a close next of kin." Under the law and applicable regulations, citizens may file a refusal to consent to the removal of their organs for transplantation purposes upon death with any healthcare institution. Refusals are subsequently forwarded to the Uniform Registry of Transplantation (Article 10-2 of the Law), where they are recorded and entered into a database. The Uniform Registry of Transplantation was established in May 2013 at the Organ and Tissue Transplantation NCAR attached to the 9th Clinical Hospital healthcare institution in the City of Minsk. As of 01.12.2017, the Registry contained 2351 applications from persons who had expressed their opposition to removal of organs and (or) tissues for transplantation after death under the established procedure. Organ removal from a deceased donor is not permitted if the person had opposed such removal during his or her lifetime under the established procedure; nor is organ removal permitted if a public healthcare institution "had received a written refusal to organ removal for transplantation filed by the spouse of the deceased donor or, if there is no spouse, by a close next of kin or a legal guardian of the deceased donor" before organ removal (Article 11 of the Law of the Republic of Belarus "On Organ and Tissue Transplantation").

The question of the "positives" and "negatives" and the "correctness" or "incorrectness" of the "presumed consent" and "explicit consent" systems is often

one of the most hotly debated bioethical problems of transplantation. However, both have their “positives” and “negatives,” and both impose certain obligations on the organizers of the healthcare (transplantation) systems and the bioethics community.

The “positives” of the “presumed consent” system essentially include three arguments. The first one is based on the notion that adopting the presumed consent system provides the healthcare system (i.e. the state) with the biggest possible number of donors (since, unless explicitly stated, a person is automatically considered to have consented to the removal, despite their personal beliefs, etc.). While inhumane and shallow, this argument is often cited by both the proponents and the opponents of “presumed consent.”

The second argument, cited in the context of the “convenience” of presumed consent, is organizational – the state does not have to bear the costs associated with setting up a system for filling out/storing/recording donor cards (or their equivalents).

The third argument in favour of the “presumed consent” model is used less frequently. It is fairly serious, however, as it concerns the specific features of modern human mentality. It is worth noting that contemporary culture often makes thinking about death a “taboo.” The renowned French anthropologist Philippe Ariès attempted to describe the anthropology of society through the lens of its attitudes towards death, writing that modern society “ignores death” and erases it from its culture. Ariès called the modern attitude towards death as the “reversal of death.” The fear of death reached such a degree in the 20th century that it has been sequestered from collective consciousness and contemporary society appears to ignore it. “Death has become a misfortune and an obstacle; attempts are made not only to take it out of society’s sight but also to hide it from the dying themselves so as not to make them miserable. So, it can be said that we live in an era of ‘invisible death’” [Philippe Ariès, *The Hour of Our Death*].

In keeping with Philippe Ariès’ writing (concerning the subject matter), it is possible to say that we pretend that there will be no death and that we are reluctant to take care of “after-death” matters (such as posthumous organ removal). Psychologically, most people today are unwilling to consider death-related matters or draw up relevant papers (such as a refusal of organ removal after death) while they are still alive, which is due to a subconscious unwillingness to remind themselves of their own mortality in such an obvious way. In such a “psychological” context, the “presumed consent” to posthumous organ removal for transplantation is more acceptable to most people.

However, all the “advantages” of adopting the “presumed consent” model have a flip side. If we do not take this flip side into account, we will be in complete violation of the bioethical principle of personal autonomy and human rights. First, all members of society must be absolutely and totally aware of the existing position. Second, an altruistic attitude towards organ donation (to posthumous donation in this case) needs to be constructed within society. If we do not create an environment in which citizens are informed about organ donation, the position of “presumed consent” with regard to posthumous organ donation, the option to

refuse to become an organ donor after death and the role of next of kin in this process, we will be in violation of the person's right to dispose of their body as they so choose and express their will. If we are serious about human rights and personal autonomy, we must acknowledge that every person has the right to information (particularly information that concerns them directly) and to the recognition of their position. Furthermore, everyone has the right to make their own decisions: "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers" (Article 19 of the Universal Declaration of Human Rights). If we fail to educate the public (as well as every citizen) on the issues of organ donation, posthumous donation and the existing "presumed consent" position, we are essentially helping spread myths, rumours, inaccurate information and a lack of awareness.

The first step towards resolving the issue of public awareness and the readiness to accept "presumed consent" is an assessment of the level of public knowledge in the field of posthumous organ donation. In preparation for a full-fledged study, the author has carried out a pilot project – an anonymous poll of university students in the cities of Minsk and Brest about their knowledge of posthumous organ donation. The poll covered 214 students representing four specialist fields: medicine (40 people), philosophy (40 people), law (72 people) and biology (62 people), whose professional interests are more or less linked with ethics (philosophers), human rights (lawyers) and transplantation theory and practice (medics and biologists).

The poll asked eight questions that could be broadly divided into two parts: the first part relating to knowledge and self-assessment of their level of knowledge about posthumous organ donation, and the second part relating to what needs to be explained to the public as a matter of priority to foster awareness of and an altruistic attitude towards organ donation and how this can be achieved.

Poll Results

When asked to describe their attitude towards posthumous organ removal (Question 4), most of the respondents replied that "the removal or non-removal of organs must depend on the beliefs the person held during their lifetime" (73%); 16% selected the reply "after death, a person's organs must be removed for transplantation"; 4% believe that "after death, a person's organs should not be removed for transplantation"; and 7% held no opinion in this subject. The replies are remarkable in that they show that an absolute majority of the respondents approached the question from the point of view of personal autonomy and the need to protect human rights.

In response to the question "Are you aware of the existing position of the Republic of Belarus on the posthumous removal of organs for subsequent transplantation?" (Question 5), 47% pointed out the "presumed consent" regime that exists in the country. However, a rather high percentage of respondents (36%) thought that "explicit consent" was in place instead. Even more worryingly, 9% checked "routine organ removal," an option added by the author more as a

provocative response, as this position does not exist anywhere in the world today. A total of 8% replied honestly, checking “I don’t know.” Medical students provided most of the “correct” answers (70%), while philosophy students came in last (40%). Such a distribution is clearly worrisome, as it demonstrates a lack of public awareness of posthumous organ donation within a “presumed consent” environment and, consequently, it shows that the efforts made by transplantation organizers and coordinators, medical workers, bioethicists, etc. to raise public awareness have been insufficient.

Question 6 was dedicated to self-assessment by the respondents of their knowledge of some of the most challenging issues of posthumous organ donation. While the students assessed their own knowledge about who can be a donor, how to refuse to become a donor after death, and whether next of kin may refuse to allow organ removal from a relative (after his/her death) sufficiently strongly (around 70%), the awareness of a complicated matter of posthumous organ donation by minors did not exceed 50% (29% among philosophy students!). The “provocative” question on whether “it is possible to sell/buy an organ in Belarus” was a good demonstration of how entrenched myths (for instance, about underground organ transplant surgeons) and a lack of awareness of the laws and realities of existing transplantation practices in Belarus are in the public conscience (self-assessment by the respondents of their own knowledge on this matter did not exceed 40%).

In formulating part two of the questionnaire, the author sought to identify transplantology/organ donation knowledge areas that are of the biggest interest to the respondents and the methods of disseminating this knowledge that should be made a priority. Most responses were related to an interest in the legal implications of organ donation (53.5%), as well as to knowledge about the successes of and challenges facing the development of transplantology in Belarus (49.7%). In the “Details” section, the students explained that they were “particularly interested in the latest data from public opinion polls on organ donation (transplantation),” and stated that information on those matters “must be accessible and easy to understand”.

Responses to the question on how better to inform the public on the matters of transplantation were as follows: 1) through mass media; 2) through meetings with organ transplant surgeons and experts in bioethics; and 3) through public service announcements and social media. According to a majority of the students polled, obtaining the relevant information in classes and lectures is not as important (28% of the respondents replied “through university classes” and less than 10% responded “at school”). Accordingly, we can conclude that as healthcare organizers and experts in bioethics analyse the matters of public awareness of organ donation and the formation of an altruistic attitude towards organ donation, they somewhat overestimate the importance of educational institutions in this process and underestimate the role of meetings with professionals (possibly online, as part of webinars, etc.) and the impact of public service announcements and social media.

Thus, our pilot poll has allowed us, above all, to get a general impression of public knowledge of posthumous organ donation issues. The results of the poll make it worth thinking about intensifying efforts to educate the public on those issues while emphasizing the importance of human rights, the individual's ability to make important decisions and the need to foster an awareness of the altruistic nature of posthumous organ donation.

Second, the poll "shed light" on some hard to understand matters related to posthumous organ donation and, regrettably, on a sizeable role that myths and fake information play in shaping students' ideas about posthumous organ donation.

Third, the poll helped identify the most important channels and the most engaging questions for raising public awareness of and improving education on organ donation.

In conclusion, it is worth noting that, unfortunately, the joint efforts of healthcare organizers, transplantation coordinators, experts in bioethics, etc. to raise public awareness of and improve education on organ donation are insufficient today. Special emphasis should be placed on creating a positive image of organ donation and making people aware of its importance. I believe that a similar expanded poll of the Belarusian population is necessary, complete with a subsequent detailed analysis of its results, which could serve as a basis for a large-scale research project on the bioethical aspects of transplantology. The data obtained as a result of such an analysis would help coordinate and improve the operations of transplantology services and substantially increase the prestige of organ donation among the public, raise awareness, strengthen altruism, prevent improper situations (including judicial precedents), improve relevant legislation, etc.