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SOCIAL BASES FOR THE DIALOGUE ON DECEASED ORGAN DONATION

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This article assesses the changes in the coverage of the problem of organ donation in Russia. The boundaries of the dialogue on posthumous organ donation are outlined, taking into account the current organ donation model in Russia. The paper defines the concept of social capital, the sociology of organ donation and their significance for the development of deceased organ donation (DOD). Steps to promote the DOD concept in Russia are proposed.

Keywords: deceased/posthumous organ donation, social capital, sociology of organ donation.

INTRODUCTION

Transplantation is the gold standard treatment for end-stage diseases of internal organs and is performed routinely [1–3]. At the same time, the concept of organ transplantation itself remains an attractive object of ethical reflection due to its paradoxical nature. It is the only type of medical care, where saving the life of one patient is, in most cases, inextricably linked to ending another patient's life. Organ shortage remains the main challenge of modern transplantation. The current situation is clearly illustrated by the latest reports from domestic and foreign publications. According to the 15th report of the Registry of the Russian Transplant Society, 2,555 transplants were performed in Russia in 2022 [4], and there were 8,378 people waitlisted for donor organs (2019 data from the Report by Academician Sergey Gautier, the chief freelance transplant specialist at the Ministry of Health of Russia [5]. According to the Health Resources and Services Administration of the United States of America (USA), 42,000 transplants were performed in 2022 in the USA and there were 104,000 people on the transplant waiting list [6]. Data from a recent publication by A.J. Matas, on the pages of JAMA Surgery, which reports that the transplant waiting list in the US for the past 20 years increased by 83%, while the number of transplants for the same period only doubled [7]. The latest statistical report for 2022 by Eurotransplant International Foundation, which unites 8 EU countries, shows that 6,454 transplants were performed in the year and that 13,277 patients were on the transplant waiting list [8].

Attempts to overcome the persistent organ shortage are shaping the modern image of transplantation, which in less than 70 years of its existence, has transformed from an experiment into the most complex type of organized medical care [9]. This has been made possible by the general progress in medical science, emergence and continuous improvement of immunosuppressive therapy protocols, introduction of new criteria for death based on neurological signs, expansion of criteria for the suitability of donor organs for transplantation, establishment and development of the concept of perfusion rehabilitation of donor organs, introduction of the institute of transplant coordination, and complex legal and administrative changes that have evolved into a national model of donation [4, 10–15]. The success of donor programs today depends, among other things, on the perception of the concept of deceased organ donation by the public.

This study of literary sources is aimed at defining the boundaries of the dialogue on deceased organ donation between medical professionals and non-professionals, assessing the influence of social capital on the development of donor programs, and initially marking the boundaries of such a phenomenon as sociology of posthumous organ donation.

ON THE BOUNDARIES OF DIALOGUE ABOUT DECEASED ORGAN DONATION AND TRANSPLANTATION BETWEEN MEDICAL PROFESSIONALS AND NON-PROFESSIONALS

The desire to become an organ donor is based on basic principles of bioethics, such as altruism, acting in the interest of the common good, justice, personal autonomy, integrity of the body, and non-harm [16]. Altruism, meanwhile, stands out as the main principle of bioethics when it comes to organ donation. In his seminal work "The Gift Relationship: From Human Blood to Social Policy", British sociologist Richard Titmuss concludes that voluntary, or altruistic donation reflects a sincere

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desire to help, and therefore such donors are free from the fear of being deceived and, through their behavior, contribute to the strengthening of social justice and are a kind of buffer for actions aimed at exploiting human resources [17]. Altruism is also defined as prosocial behavior and motivation to do good unselfishly, sometimes at the risk of life, and sometimes with the willingness to sacrifice oneself for the sake of others [18]. Therefore, an altruist does not need to be persuaded to become an organ donor, but should be educated so that he or she is left in no doubt about the altruistic nature of the act of organ donation.

An appropriate legal basis is needed in order to have a dialogue about cadaveric donation. In Russia, it is represented by Law № 4180-I "On Transplantation of Human Organs and(or) Tissues" of December 22, 1992 and Article #47 of Federal Law № 323-FZ "On the Fundamentals of Health Protection of Citizens in the Russian Federation" dated November 21, 2011, which contains important clarifications about the possibility of lifetime will and the right of a spouse or close relatives to refuse organ donation if the deceased has no lifetime will [19]. The amendments introduced in 2016 to the Federal Law № 323-FZ "On the Fundamentals of Health Protection of Citizens in the Russian Federation" dated November 21, 2011, outlined the boundaries within which it is possible to conduct a dialogue about cadaveric donation and transplantation between medical specialists and non-professionals. The need for such a dialogue will be confirmed below.

ABOUT THE PLACE FOR DIALOGUE ON POSTMORTEM DONATION AND TRANSPLANTATION

The ambiguous public perception of organ donation and transplantation is eloquently demonstrated by the results of recent sociological studies. In particular, in the results of a study by the STADA Group Health Report, which is being conducted for the fifth time by the consulting and marketing agency Kantar Health in 9 countries (Germany, Belgium, France, Great Britain, Italy, Poland, Russia, Serbia and Spain) with the participation of 18,000 people, about 2,000 in each country, it was shown that the existing model of donation in Russia, in the form of presumption of consent, is criticized by 64% of respondents, 65% at the time of the survey have not yet decided whether to be donors or not, and only 20% of respondents consider organ donation as their moral duty. This last indicator resonates favorably with the results of another well-known and for a long time the only available survey conducted by the Levada Center in 2013, where less than 10% of respondents indicated that they were willing to become a donor for a stranger [20, 21].

In countries where there was a presumption of refusal at the time of the study, such as Germany and the United Kingdom, only 36% and 38% of citizens, respectively, were registered as organ donors on specialized online resources. On the German Organspende, a special donor card can be ordered in plastic, or a paper version can be printed from the comfort of one's home [22]. The British register as organ donors or opt out by filling out special forms on the official portal of the National Health Service of Great Britain [23]. At the same time, 63% of respondents in Germany and 75% of respondents in the UK reported that they would be willing to become deceased donors automatically [20]. The UK's move to a presumption of consent model in May 2020 is likely to highlight the failure of the previous model, as reported on the official government resource: "*with widespread public support for deceased organ donation at 75–80% of the population, only 38% have opted in. This means families are often left with a difficult decision when a loved one dies*" [24], which has a negative impact on donation rates [24], which has a negative impact on donation rates.

In the United States, where the "informed consent" model is in place, 170 million people are registered as organ and tissue donors, approximately 51.2% of the population as of August 22, 2022 [25]. A recent article by Matas reports that the number of registered organ donors has increased to nearly 60% of the population in exactly one year but points out that there are many explantations from unregistered donors [7]. A search for up-to-date statistics on the number of explantations from unregistered donors proved to be of little use; all search queries lead to resources that offer people to register as organ donors. A 2014 publication from the National Bureau of Economic Research cites data from 2010, 2011, and 2012, when explantation rates among unregistered donors was 54%, 57%, and 55%, respectively, for brain-dead donors, and 42%, 38%, and 39%, respectively, for donors with sudden irreversible circulatory arrest. It is noteworthy, however, that the authors of the publication obtained these data, as indicated, by personal conversation [26]. A news article on the Newsday resource, in turn, reports that in New York City alone, almost 80% of donated organs were obtained from unregistered donors in 2022 [27]. In annual reports by the official government resource United Network for Organ Sharing [28], the national Organ Procurement and Transplantation Network [29] and the nonprofit organization Donate Life America [25] do not include data on unregistered donors. The true reasons for the lack of statistical information on the receipt of donor organs from unregistered donors are unknown; probably, this is due to the current model of donation in the United States, aimed at maximizing the number of registered donors, for which large-scale promotional campaigns to popularize posthumous organ donation are launched, which is financed both at the state level and with the participation of over 100 different charitable organizations [25]. This intensive educational policy over the past 12 years has ensured record rates of postmortem donation in the USA, where 42,800 transplants were performed in 2022 [29]. It will be shown below why this approach can hardly be adapted to the domestic model of deceased donation.

According to 2021 data from the authoritative analytical platform Statista, the United States leads the world in terms of the number of donors per million population (41.6), with Spain in second place, with a slight lag (40.8) [30].

The "Spanish Model" of donation and transplantation originated in 1989, underwent major changes in 2007 and 2018, and has been considered the gold standard worldwide for the last 15 years [31]. The main elements of the Spanish Donation Model include: 1. A well-developed legal framework and technical support, 2. A three-tiered system of deceased donation coordination: national, regional, hospital, 3. A special profile of transplant coordination: partially employed ICU physicians and nurses as transplant coordinators, not involved in transplantation, appointed and reporting to the clinic management; their main task is to ensure postmortem donation with active involvement in its promotion, training of colleagues, interaction with the media and research activities, 4. Transplant coordinators are employed in clinics participating in donor programs, 5. The Spanish National Transplant Organization acts as a support service, 6. Continuous quality audit of the posthumous organ donation procedure, both external and internal, 7. Special attention to educational programs, 8. Close attention to the media and a special policy of interaction with them, 9. Financial reimbursement for clinics for participating in the donation process [32].

In May 2023, the journal Transplant International published a review article "Ten Lessons from the Spanish Model of Donation and Transplantation", whose authors summarize: "*Changes in the national donation and transplantation system of any country can be achieved by adapting elements of the Spanish Model, thus avoiding more complex measures.*" [31].

The work of the team of authors led by V. Papalos provides a careful analysis of the donation system in Spain, detailing the "components for success", where, in addition to changes in the legal framework, creation of an institute for transplant coordination, expansion of donation criteria, and development of clinical protocols and guidelines, working with public opinion and donor families to create "a culture of trust and confidence in donation and transplantation programs" is mentioned; also emphasized on is the importance of a thorough and ongoing training of healthcare professionals in the following areas: 1. Fundamentals of transplant coordination, 2. ICU training, 3. Training for emergency medical technicians, 4. Educational courses for neurologists in vascular centers, 5. Courses for non-medical specialties, 6. Separate educational programs on communication with relatives of patients, discussion of the procedure of consent to cadaveric organ donation in critical situations; correct conversation with media representatives, 7. Educational courses for media representatives [31, 32].

When comparing the best deceased donation models, their nominal status becomes apparent. Regardless of the current model of donation, the attention of the country's residents is actively being attracted to this problem, only the approaches differ. In Spain, a measured educational work is being carried out; a competent specialist can be consulted on the problem of postmortem donation at any time, consistent interaction with the media is carried out, and due to constant and accessible training, a high level of professionalism of medical specialists and representatives of non-medical specialties involved in deceased donation is maintained. This approach can be characterized as "soft" and/or "transparent", one of its main advantages being the invisible strengthening of social ties in society and closer interaction of seemingly unrelated social groups when it comes to posthumous organ donation, interaction in silence and for the common good.

In the United States, the practice is different; the model of mandatory informed consent for organ donation determines the need to actively "seek" such consent. In an article by A.B. Sterry, in the Cambridge Quarterly Journal of Health Ethics, it is reported that if a person waiting for a driver's license is asked directly if they would like to be a deceased donor, they are more likely to say no, not because they are against the concept, but because of the feeling of being forced to do something they have not thought through; the report cites the example of Chile, where the number of postmortem donors decreased by one-third after the introduction of the mandatory informed consent model [33]. This is probably why more than a hundred charities in the United States are engaged in postmortem organ donation education, as well as government and non-government foundations with multimillion-dollar advertising campaigns. Organ donation promotion programs have been criticized as being biased and often lacking a scientifically proven basis, secondly, providing false or incomplete information regarding risks for potential donors, and thirdly, having an obvious propaganda overtone [34]. Let us turn to Russian practice.

In recent years, unprecedented changes have occurred in the Russian practice of promoting deceased organ donation. According to the Report by Academician Sergey Gautier, the chief freelance transplant specialist at the Ministry of Health of Russia, no less than 80 speeches in the authoritative media were made in 2020 alone, and the formation of positive public opinion about organ donation and transplantation was singled out as a separate area of work [5]. In the Internet era, online resource "Organ Donor = Life Donor", available at https://donorstvo.org/, the official platform of the Ministry of Health of the Russian Federation, which is constantly moderated, contains weekly statistics on operations performed, latest news on organ donation and transplantation, articles on current topics, interviews with leading national experts and, at the time of writing, contains about 70 news publications [35]. In recent years, the problems of perception of postmortem organ donation and attitude towards it have come to the attention of sociologists, now at the level of individual studies in small samples [36], but this already marks the vector of interaction between transplant specialists, sociologists and the society as a whole.

SOCIAL CAPITAL AS THE BASIS FOR DECEASED ORGAN DONATION

Social capital, in the first approximation, is defined as an indicator of the quality of social ties in society, for example, when there is a need to come to the aid of strangers.

The term was introduced by the French sociologist Pierre Bourdieu in 1980 and, in accordance with the author's definition, was considered as "the sum of the resources, actual or virtual, that accrue to an individual or a group by virtue of possessing a durable network of more or less institutionalized relationships of mutual acquaintance and recognition" [37]. The concept was then supplemented by the American sociologist James Coleman, who considered social capital as "a public good formed by all members of society and positively influencing it, and this influence determines the need for cooperation within society, as it is in the personal interest of each of its members [38]. Finally, political scientist Robert Putnam proposed his version: "social capital is the inherent properties of society, such as trust (primarily), social norms and networks that contribute to greater social cohesion due to cooperation for the common good" [39].

In a recent study of the impact of social capital on posthumous organ donation, Hans Schmiets observes that a posthumous organ donor does not become one for someone; it is a gesture of pure altruism toward society as such, based on trust in the health care system in general and the current donation model in particular [40].

Sociology of organ donation

There are few studies devoted to the sociology of postmortem organ donation. In fact, the term is coined by Laura L. Machin, a professor at Lancaster University Medical School, a sociologist and health care ethics researcher. Drawing on the works of Richard Titmuss, she discusses the sociology of postmortem organ donation as a system of interaction between professionals and representatives of civil society, based on altruism, a sense of solidarity, social cohesion, and anonymity [41, 42].

CONCLUSION

The organ donation system established in Russia is steadily developing, as evidenced by the steady increase in the number of operations performed year after year [4]. Thanks to breakthrough changes in the information field of Russian transplantation, we can state that the conditions for dialogue between specialists and members of the society on postmortem donation have not only been created, but the dialogue is already ongoing at a high level and in the right direction. The authors assume that the social capital of Russian citizens is sufficiently developed such that they can be interacted with in a partnership manner. In order to give specific outlines to the concept of sociology of posthumous donation as a means of its promotion in our country, the following steps are necessary: 1) Conducting more sociological research on focus groups (medical students, doctors of different specialties, specialists involved in donor programs both at large centers and in the regions); 2) Developing unified information and educational materials on the basis of the results obtained; 3) Transmission of knowledge on deceased donation as a form of social interaction aimed at developing social capital, and thus society, to regional donation and transplantation centers.

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