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ATTITUDES, PERCEPTIONS AND DETERMINANT FACTORS IN ORGAN DONATION

Lorena TĂRUȘ¹, Cristina GAVRILOVICI²

Abstract

The significance of organ donation comes from the need of giving unconditionally and further to linger this gift. In our days giving an organ becomes giving life, giving power, creation and re-create a new identity. But obviously, when you touch life, you touch God, society and all of the cultural traditions from the environment that you are coming from. The attitudes and the perceptions are the result of some factors and a unique combination between them, for each individual. Some individuals will be more attached to the church, so the religious element will have a much higher importance for them, when others will think more pragmatic, considering the medical parameters, the transplant system and its effectiveness. Therefore this paper has the purpose to approach the attitudes, perceptions and the opinions towards organ donation and the transplant. The most important elements will be described, which, from a multicultural perspective they reflect upon the decisions about donation and transplant. We will insist on their role in the process of transplant and we will highlight the interactions between them.

Keywords: organ donation, transplant, organ donation determinants, cultural factors, religion

Introduction

When discussing the dimensions of the transplantation phenomenon, focussing on the actors involved or trying to analyse methods for increasing the rate of donation, the debate has a common denominator – the attitude concerning organ donation. This includes the arguments that underpin the decision to donate. No matter whether it is about beliefs, information, social or demo-

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graphic indices, trends promoted by the background culture, opinions of family members and friends, altruism, media campaigns, the donation system itself, legal aspects, all these contribute to and reflect upon the rate of donations. The attitude concerning organ donation is in fact a social construction composed by different by different ethical, religious, psychological, legislative issues rooted in the society itself.

In 2013 to 2014 the number of patients who died whilst on the Romanian transplant list was 810 (<http://www.transplant.ro/Statistici/W.L.%20form%20ROMANIA%202013.pdf>). Romania has one of the lowest rates of organ donation in Europe: 3,1 per million population willing to donate deceased organs in 2012. At the opposite side, Spain has one of the highest rates of donation: 35.6 people per million population in 2012. (http://ec.europa.eu/health/blood_tissues_organs/docs/ev_20131007_rd3_en.pdf)

This article aims to present and discuss the factors that have been identified and proven through empirical research as the most influential in the issue of organ donation.

Frequent factors influencing the attitudes towards organ donation

Organ donation has a multifactorial character, and the process itself involves legal and medical factors, issues related to health policies, investments and infrastructure in the healthcare system, mentalities, as well as religion and education (Roels & Rahmel, 2011: 350–367). It seems that barriers to organ donation are present in every state, irrespective of its level of development. Each state has its own specificities, traditions and customs, and therefore successful public campaigns supporting donation should not come in conflict with these issues. Roels and Rahmel (2011) have identified an intention to standardise as much as possible a general framework in order to change attitudes towards donation and to increase the rate of donation. Such a framework would need however to be filtered and adapted for each individual state. The authors emphasise that one aspect of the general public campaigns is the fact that they often do not address the cultural micro-diversity and therefore can prove ineffective (Roels & Rahmel, 2011: 350–367).

Irving et al (2014) point out that making an assumed and informed decision, expressing one's own initiative to donate, as well as the way the transplantation system works in general are of equal importance. Across Europe, it has been shown that such a decision is influenced both by *the positive media impact* concerning donation, as well as by aspects related to *religious beliefs*. (Irving, Chadban, Jan, Rose, Tong, Cass, Wong, Allen, Craig, Howard, 2014: 617–624). There is a whole decision-making mechanism consisting of a number of more or less visible factors that lies behind these reasons

The family

The family is most often mentioned as having an important say in an individual's decision to donate organs. The donation process is perceived as a „family experience”, no matter who who authorize the consent (Harald, Emeric, László, Katalin, Gabor, Brînzaniuc, 2011). Discussions held with family members, between families and medical staff, the family's degree of information, as well as the quality of the relationship between the medical personnel and the family of a potential donor influence the organ donation decision (Ashkenazi, Klein, 2012: 304-311), turning any uncertainties concerning organ donation into a *pro* or *con* decision. In many transplant centres the decision and the analysis of arguments are left to the family.

Numerous factors have been found to be associated with the families' decisions to grant consent for donation, including positive beliefs and attitudes toward organ donation and prior knowledge of the patient's wishes regarding donation, either through a signed donor card or a prior discussion about donation with the patient. Discussions around topics such as the costs of donation, the impact of donation on funeral arrangements, and the option for the family to choose which organs to donate were also found to be directly related to the decision (Sander& Kopp Miller, 2005: 154–163).

Although the general impression is that the decision is made together with the family, the study made by Nizza et al (2014) states that the behind the family's decision is in fact placing the responsibility for one's own body to one's friends and family (Nizza, Britton, Smith, 2014). Not taking a decision about possible post-mortem harvesting of organs also creates confusion, causing feelings of guilt among the dear ones. As the (dead) donor is not in a position to sign a consent form for donating his/her own organs, the donor's next of kin often feels the burden of such a decision on behalf of their loved one.

The family may be the most important factor in the organ donation decision, representing a private universe, which manages in its own way its resources, beliefs and decisions. It is actually in the hospital when family members become so close, in order to be able to face the imminent death of the loved ones. For the donor's family, the fact that somebody else's life could be saved with the “gift of life” may become a genuine anchor for coping with his/her death and provides this unfortunate event with a “band-aid” solution (Eckenrod, 2008: 1061–1063). However, in the long-term many families were satisfied with the decision to proceed with the donation.(Eckenrod, 2008: 1061–1063) The perception that the life of their loved one is continued through the recipient gives new meanings to the lives of the family members. The fact that their loss resulted in something good for someone else increases the donor family's capacity to cope with their loss (Eckenrod, 2008: 1061–1063).

It is interesting to note however that involving families may also be perceived as a threatening factor for the individual's autonomy. Most transplantation systems are opt-in systems, thus giving priority to the wishes of the next -of -kin.

Therefore, placing the burden of such a decision on the family's shoulders may undermine the patients' autonomy. They may have objected during the course of the patient's life, but families can give post-mortem anatomical gifts upon request. The wishes of deceased are more likely to be respected if they have been previously discussed with during lifetime with the family (Traino, Siminoff, 2013: 294–300). Even in the cases in which they have agreed on the transplantation issue, this does not guarantee a positive outcome, since seeking consent for organ donation often results in family distress when feelings of guilt and sorrow are prevalent. Van Leiden et al (2010), has shown that in almost half of cases even when the potential donor was already registered as a donor, the relatives refused to donate organs (Van Leiden, Jansen, Haase-Kromwijk, Hoitsma, 2010: 677–682).

On the other hand, an opt-out system may be considered morally objectionable because it may harm the members of the patient's family if they disagree with the medical criteria for death. If there is disagreement with the medical opinion, physicians should respect that and give the family time to accept that the person is dead according to well-established and contemporary criteria. Therefore a transplantation system that places the family in middle of all decision processes will undermine the patient's autonomy.

Education

The education is found in many studies as a *factor* strongly connected to the intention to donate: according to Ashkenazi and Klein, "the higher the education level, more the desire to donate increases" (Ashkenazi, Klein, 2012: 304-311). Similarly, Mossialos et al (2008) show that young people with longer education and better informed about their country's current legislation concerning donation tend to be more open towards donating their organs (Mossialos, Costa-Font, Rudisill, 2008: 8-48).

Individuals with higher educational levels had more favourable attitudes toward donation but did not have more knowledge of donation as compared to those individuals whose highest degree was a high school diploma or equivalent. Those with higher education were more willing to donate their organs and tissues (Sander & Kopp Miller, 2005: 154–163).

It appears from these results that when people are knowledgeable about organ donation and feel positively toward it, they may be more confident in approaching family members about donation. The opposite, the misconceptions derived from lack of information are an important barrier for deciding in favour of donation. A study by Lee et al (2010) shows that, although they consider the act of donation as a very important one, most individuals included in the study were not informed properly, nor did they seek to find details that would clarify and help them understand the act and process of organ donation (Lee, Midodizi, Gourishankar, 2010: 223–229). One consequence of the lack of information is the perception according to which the donated organs would be assigned to

recipients who do not deserve them, who had unhealthy lifestyles, or that the transplant would spread the HIV infection. Other common misconceptions involve fear of bodily disfigurement or fear that potential donors will not receive the same life-saving measures as others. There are mistaken beliefs that signing a donor card or granting consent for donation on a driver's license is all that is necessary to ensure a person's wishes, that brain death is reversible, that rich and famous people receive preferential treatment on the transplant waiting list, and that most religions are generally opposed to donation. Many also incorrectly believe that there is an age limit on organ donation, that people with medical conditions cannot be donors, and that a donor's family will have to pay extra medical bills associated with donation (Sander & Kopp Miller, 2005: 154–163). Accurate knowledge of how to make arrangements to donate, the role of next-of-kin, and the body's normal appearance after donation as well as the willingness to accept a donated organ have been found to be positively associated with the intention to donate (Saub, Shapiro, Radecki, 1998: 407–417).

Quite often, the unrational motivations become important obstacles in organ donation. Fears, apprehensions, individual totally unrealistic projections weigh more in the decision to donate an organ than any explanations based on pertinent arguments and laid out in comprehensible language. The medical proof, the example of other donors, the saved lives become motivations that fade when faced with the inability to accept death or with irrational thoughts such as “attracting death upon oneself” or “predicting it” when signing a donor card (Nizza, Britton, Smith, 2014), for instance. The complexity of human nature cannot be squeezed in standard frameworks, the psycho-emotional factors being crucial in the decision to donate.

Apart from education, communication between medical personnel and patients proves to be an important factor as well. The attitude of the medical staff and the level of willingness to provide complete information that every patient can understand are issues that reoccur under various shapes. A positive attitude on the part of medical staff may positively influence the the family' decision, as healthcare professionals are the first who must provide pertinent and clear information to the wider public (Harald, Emeric, László, Katalin, Gabor, Brînzaniuc, 2011).

Demographic factors

Age is considered to changes one's personal view along with education. Mossialos, Costa-Font and Rudisill (2008) suggest that young individuals, presumed to be far from the moment of death, are more willing to donate their organs (Mossialos, Costa-Font, Rudisill, 2008: 8-48). Old age has a negative influence on the willingness to give consent for organ donation (Schulz, Nakamoto, Brinberg, Haes, 2006: 294-302). Organ donation also depends on the *gender* of the potential donor. A stronger intention to donate among women was highlighted by Wu and Lu (2010), who found that women are more willing to donate and have less

negative attitudes than men (Wu & Lu, 2010). A similar aspect was identified by Harald et al (2011), who describe the fact that women are more open to discussing this topic with their families, this not being, however, a clear starting point for the desire to donate (Harald, Emeric, László, Katalin, Gabor, Brînzaniuc, 2011).

Cultural factors

Cultural factors are often perceived as barriers for organ donation. The mentalities and the tradition an individual identifies with make organ donation either a generous act or something that is unacceptable. The Chinese views will be shaped by the three main religions – Confucianism, Buddhism and Taoism – that strongly refers to bodily integrity. Although cutting-edge technology has grown and entered successfully in this region, the transition towards reinterpreting religious beliefs occurs slow enough, as expected. Yu Cai (2013) stresses this aspect by saying that “despite the availability of transplantation technology, the Chinese have not managed to simultaneously develop and ensure culturally relevant practices that would support organ donation.” (Cai, 2013) We are talking thus about a culture that requires adaptation to everyday challenges, an adaptation that must be achieved in a top-down approach.

Culture strongly influences the decision to donate, and this is visible even among individuals belonging to the same country, but to different regions. For instance, the French Swiss regard donation as a “normal” act, whereas the Italian Swiss take the decision to donate after discussing it in the community, while the German Swiss, although they seek information about the various aspects of the donation process, they frequently give a negative answer, emotion - driven, refusing to interact with other donor card carriers or to meet people involved in the transplantation process. (Schulz et al., 2006: 294-302)

Mythology and superstitions present in a certain community or region, also impact the local culture. Transmitted and modified in time, from one generation to the next, in the shape of stories with a subjective-emotional interpretation, they strongly impact the attitude towards donation. The authors of a study focussing on the impact of cultural diversity on donation found that the concerns related to the act of donation partly originate in “cultural myths or superstitions transmitted from generation to generation or in the stories of individuals from the community” (Wong, 2010: 1439-1444). “Culture” is a factor composed by a variety of conscious influences or by influences accepted without any strong foundation. “Culture” also refers to the mentalities of a region, to the mythology or the superstitions of a community, to the level of development of a state or even to the type of society that shapes the individuals. We can see, however, that in case of an individual belonging to a community other than the community of origin, the attitude will be the one imprinted in early life rather than the one of the current host community, which may be completely opposite.

Religion

As culture consists of a multitude of spiritual elements, it will most often bear the mark of the majority religion in a certain area. The cultural traits frequently overlap with the religious ones. Research on donation includes many times the religious issues, but a clear influence of religion on organ donation has been established apparently only in Muslim beliefs (Türkyilmaz, Topbas, Ulusoy, Kalyoncu, Kiliç, Çan, 2013: 864–868; Uskun & Ozturk, 2013: 37–41; Randhawa, Kinsella, Brocklehurst, Parry, Pateman, 2012: 743-51; Ozer, Ekerbicer, Celik, Nacar, 2010: 3363–3367). Christianity has many confessions, therefore we cannot speak of an unanimous opinion. However, Christians believe in eternal life, and death is merely a passage to another life. Transplant is permitted, but the decision is left to the patient or to his/her family. The organs must not be removed until death has been established unequivocally (Puchalski & O’Donnell, 2005: 114-121).

Religion is perceived sometimes as a barrier in the decision to donate, since all medical practices that affect bodily integrity are considered unacceptable. Despite the fact that organ and tissue donation is supported by all major religions, individuals often cite religious beliefs as their reason for choosing not to donate. Compared to Caucasians, a greater percentage of African American and Hispanics feel that organ donation is against their religion, although there are no documented religious conflicts with organ donation and transplantation within these cultures (Sander & Kopp Miller, 2005: 154–163). Bruzzone et al (2008) carried out a quantitative study on the acceptability of the opt-out system and noticed that although the faith leaders were supportive of organ donation, they did not agree with adopting an opt-out system. Christians and Judaic representatives tended to be more willing towards transplantation than other religious exponents (Randhawa, Brocklehurst, Pateman, Kinsella, Parry, 2010: 36–44) points out that no religion strictly forbids organ donation or the acceptance of organs, irrespective of whether the donors are alive or deceased. Also, no religion forces anyone to donate or to reject a donated organ. No religion considers the cadaveric organs as a social resource, or donation as a religious duty (Bruzzone, 2008: 1064–1067). On the other hand, the Muslims (Türkyilmaz et al., 2013: 864–868) state that no religion has a unitary vision, as everywhere there are differences within regions, nations or societies.

The media

The experts on organ transplantation have shown that the way organ donation is *communicated*, *promoted* and *made visible* is very important. All three elements are mentioned to a certain extent in research (Mossialos et al., 2008: 8-48) both by potential donors and by decision-makers or stake holders in the transplantation system. Generally, there is little knowledge about organ donation in population at large. The concepts of “brain death” or “cadaveric donor” are strange or unclear for them, and this causes skepticism in granting consent for

post-mortem harvesting of organs. Therefore, the lack of knowledge should not be placed only on the shoulder of the the potential donor. These information as well as the communication skills are the responsibility of those who are in charge with the transplantation system, the need of organs and the registration of donors. Currently faced with a lack of information among the general public, the decision-makers place the transplantation as a a priority. Lee et al (2010) conclude in their study that “accurately educating and informing the public would be a first step towards increasing the rate of donation and changing mentalities. Eliminating and correcting the assumptions concerning the preferential allocation of organs to rich recipients or the supposed lack of appropriate medical care for potential donors are crucial aspects in any campaign. Irrespective of whether they decide to donate or not, individuals must make an informed decision.”(Lee et al., 2010: 223–229)

When media has a positive interest in organ donation campaigns, this can have a significant effect on organ donation rates (Bastami, Matthes, Krones, Biller-Andorno, 2013: 897–905). Therefore, public information campaigns aiming to inform and to influence the attitude towards donation would be a solution for increasing the rate of transplants.

Conclusions

The attitude towards organ donation consists of a number of factors, each of them represented in a different extent in the decision to donate organs. The multitude of stake holders and factors involved in donation and transplantation underline the complexity of the phenomenon as well as and role of individual and the society in bringing up to front this issue.

Research on the attitude towards donation is an effort that has to continue. New elements can be revealed among the personal circumstances when the individuals have to make a decision of such great importance for themselves and their families. The inflencing factors may remain the same, may radically change, or they may take on other implications. The common ground identified as a result of this brief breakdown is the insufficient knowledge concerning the main aspects involved in donation and the weak representation of the act of donation in some societies (Gavriliuță, 2013: 169-182).

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