
THE SOCIAL ACTORS IN ORGAN TRANSPLANTATION

Lorena Tăruș*

*'Alexandru Ioan Cuza' University of Iași, Faculty of Philosophy and Social-Political Sciences,
Carol I Blvd., Nr.11, 700506, Iași, România*

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Abstract

Currently, organ transplantation is being analysed by specialists in a multitude of fields. How can we discuss the issues of transplantation nowadays without being redundant? How can we deal with aspects that have so many implications in the light of a new approach, one that includes all the others and still remains open to the innovations that keep appearing in this domain? This paper highlights social actors of donation and transplantation and their role in a sociological context.

Keywords: organ donation, transplantation, social actor, church, religion

1. Sociological aspects concerning organ donation and transplantation

Organ donation and transplantation are a major challenge in today's society. Both the medical world and other professions are sources of new approaches to the issue, depending on the elements that intervene in discussions or in practice. Whereas for medical professionals things are clear-cut, and the practitioners are familiar both with the phenomenon and with its implications and dimensions, for those who do not work in the medical profession, these aspects are (still) unknown or at least unclear. For the man in the street, organ donation and transplantation is not a current issue, and people relate very little and often not at all to this issue. Even when collecting views and opinions concerning this phenomenon from the general population [1], it is easy to identify the low degree of familiarity with the latter and the lack of sufficient arguments supporting the opinions stated.

As a multidisciplinary issue, organ donation and transplantation seem to have all the possible interpretations and meanings. However, this domain keeps attracting controversies and new approaches. In other words, how and why can we talk about organ donation and transplantation nowadays? What perspective on donation and transplantation would not be permeated by the claims of one domain or another? Is there a formula for interpreting organ donation and transplantation in a manner that would integrate the multitude of opinions and arguments concerning it?

* E-mail: lorrenna_maria@yahoo.com

The perspective presented here aims to deal with organ transplantation as a social phenomenon and to highlight the categories of social actors that interact during the donation and transplantation process. The extent of organ transplantation in the multitude of existing discourses makes it a complete social phenomenon [2].

Seen in this way, we can say that the issues of donation and transplantation could become a topic with a profoundly sociological character. From a sociological point of view, organ transplantation is currently a challenge of (post)modernity. Transplant science has managed great changes over a very short time interval, concerning the removal or postponement of suffering and the discovery of wellbeing, the rediscovery of the body and the re-familiarisation with its 'performances'. Medical technology is visibly ahead of the spiritual aspects; it is easy to see, as Father Chirilă underscores, that "the scientific and technological advances have often got ahead of dogmatic and moral analyses" [3]. Therefore, the intersection of the transplantation phenomenon with all the domains that do not belong to the field of Medicine is the reason for its complexity and for the need to view it also through a sociological lens.

Organ transplant is a complex social phenomenon consisting of a number of phenomena investigated by a diversity of areas of research, from the medical to the ethical and theological. Highlighting the social actors that intervene in the transplantation procedure would mean outlining their roles and identifying the weight of each of these roles. Accepting and assuming these roles is one of the first steps on the evolution of the system.

By following the thread of the social actors that have a role in the economy of transplantation, we find that, first of all, organ donation and transplantation are contrary to religious precepts. Organ transplant pushes the limits of life ever further, as if defying any call from man's divine nature to accept and understand his suffering. On the other hand, Father Pavel Chirilă reminds us that "healing is at once a divine and a human act. Why? Because it is Christ suffering inside the patient, it is Christ working inside the doctor and it is Christ working in priest's prayers and in Church Sacraments." [4] Consequently, the task is to find voices that would apply the teachings of Christianity to the modern technologies of body re-evaluation and reinterpretation. Are such voices isolated or could they come together in one opinion concerning organ donation and transplantation and even provide support in this direction? Where and how to capture such concrete views and opinions? To begin with, sociological research can have an approach that would go towards this intersection of Church with organ donation. When searching for studies or research work on organ donation from a religious perspective, the perspective narrows considerably, as most of them refer to religion just as a reason in favour or against organ donation. Thus, there is a very small number of studies that reflect a clear and assumed religious vision [5-8], fact that proves the weak presence of Church voices that have something to say in this respect. However, "in a setting in which Medicine and Theology are discussed, research always finds its place.

There are countless questions being asked – and they must not be eschewed – about research under the incidence of Christian values.” [9]

In this respect, after identifying the categories of actors that have significant roles in the issues of organ transplantation, our paper will attempt to outline the role of just one social actor – the Church. At the same time, this paper points out the lack of sociological research juxtaposing the Church and organ donation in the Romanian space. The following sections intend to sketch out a few possible premises for such research.

2. Social actors in organ donation and transplantation

The attitude towards organ donation is in fact a social construction consisting of a number of aspects and dimensions (ethical, religious, psychological, legislative, etc.). For each dimension there are social actors, who are more or less visible and who play various roles in a society’s transplantation system.

Sociologist Raymond Boudon states the fact that “in order to explain a social phenomenon, one must find individual causes, that is to understand the reasons social actors have for acting the way they act and believing what they believe” [10]. Also, the author underlines that “it can be just as difficult to find the reasons that led an actor to a certain act, either because the actor does give explanations or because the actor belongs to a culture we are not familiar with” [0, p. 26]. Identifying an attitude involves, according to the above, the motivations that form the foundation for the acts and actions of individuals who are profoundly different between themselves and who have different roles and different statuses.

Identifying the actors involved in the transplantation system and describing the roles they play can result in a viable strategy for increasing the rate of organ donation. Categorising the actors involved in the transplantation system and describing their roles can and should lead to a growth in their awareness about the need to become actively and visibly involved in a responsible manner. On the other hand, we may identify the actors involved in the process of organ donation and in increasing the rate of donation, we may highlight the specificities of a certain geographical area, but most of the time all these remain mere discussions, without applicability in reality.

Being focused mainly on the factors that determine the willingness to donate, research tends to push to the background the ‘social actors’ who have a say and a role in the practice of organ donation and transplantation. By synthesising the research concerning the determining factors in the decision to donate [11-15], we can outline the categories of actors that could become spokespersons in proposing clear and well-structured directions for increasing the rates of donation in most societies that face a low donation rate.

The importance of identifying the actors of transplantation is underlined by the author Rhonda Shaw, who points out that stressing the position these actors have in the organisation of the transplantation system (donors, recipients,

physicians, transplantation coordinators, transplantation specialists, public policies experts, hospitals, activists in the transplantation are and governmental agencies) can reveal the degree of influence and the perspective each of these groups has on the processes of donation and transplantation [16].

The actors that play a role in the process of organ donation and transplantation is a society come both from the political upper echelons as well as from professional categories who have the power to issue directives and provide explanations or arguments to those who do not have enough information in order to make decisions. Motives such as saving the life of another, selflessness, the improvement in the quality of life of the organ recipient are just a few aspects that can be put to good use by the groups of actors who aim to put in place a strategy for increasing the rate of donation.

A first category of actors in the economy of organ donation and transplantation is that of recipients. Organ donation and transplantation are vital for those who require an organ. Waiting lists have much more members than the number of organs available, and this is the general situation everywhere in the world. The patients on the list are waiting every day to become organ recipients, to have transplant give then back their lives and quality of living. In the equation of organ donation and transplantation, the recipients are the category of actors that show in numbers the current situation of transplants. If we look at waiting lists – that is the lists of potential recipients – we see that the number of effective recipients indicates a very small number of actor patients who had the chance to receive an organ [<http://www.transplant.ro/Statistici/W.L.%20form%20ROMANIA%202013.pdf>, accessed 15.01.2015].

The category of organ receivers includes in its turn individuals who experience post-transplant adaptations in ways that differ from one person to another. The outcome is not always a happy one, in which the patients carry on their life after transplantation naturally and without mental and emotional consequences. After transplantation, “the life of a foreign organ raises the issue of its integration in the host, which is an issue both if immunity tolerance and/or psychological appropriation” [17]. The aspects relates to identity after receiving an organ, the resumption of social activities, the existence of family support for living through a period with a high emotional load are directions that some societies go as far as to tackle in support groups! [<http://www.transplantliving.org/community/support-groups/>, accessed 17.01.2015]

The category of actors that require an organ for transplantation can yield information concerning waiting lists, the required number of organs, and even testimonials concerning life in such circumstances, when everything boils down to having to rely on a donor who has just lost his or her life. The waiting, the feelings of guilt, the awareness of the fact that they will receive an organ belonging to another person are factors that weigh down on these transplantation actors. Looking at the research including patients who had already received an organ, Margareta A. Sanner discusses the acceptability of an organ when the necessity to receive it is projected in one’s imagination [18]. The view is

opposite to the usual one, and the recipients are only potential ones, as any of us could be. When not raising identity issues or issues concerning changes in terms of emotions, individuals perceive the situation of donation in a relaxed manner, as they place themselves outside the issue. The focus will be on the origin of organs and less on the imminence of death when patients have only this solution left if they are to stay alive. Thus we can see that the extreme circumstances the recipients are in, can only be highlighted when the individuals have experienced such extreme situations. Such projections can, at most, result in an increase of enrolment in the donor register. The diversity of nuances concerning organ recipients is however much broader and causes the issue to step over the boundaries of other reflection domains. Sometimes they concern aspects pertaining to the recipients' beliefs and spirituality. The testimonials given reluctantly by recipients after a transplant experience show that their feelings, emotions and even their spiritual life are more intense and take on new dimensions after the transplant.

The donors are the second category directly involved in the transplantation process, at the other end of the procedure. Transplantation is achievable only when donors exist, irrespective of the way the organ is supplied. When we talk about donors, we have in mind both potential donors and individuals who have already donated organs or who have expressed their agreement for the post-mortem harvesting of organs, or who are enrolled in a donation database. The number of potential donors in the database is incomparably smaller than the number of organs needed. [<http://www.transplant.ro/Statistici/W.L.%20form%20ROMANIA%202013.pdf>]

Human donors may be alive or deceased. Among living donors, oftentimes we find the lack of any regret concerning the decision to donate, a firmness of decision and its acceptance, the lack of expectations following donation and the inclination to donate again if necessary [19]. These are the donors who have made a firm decision, and altruism and helping others are at the basis of said decision. Although the decision of living donors involves the same factors as the granting of consent for their organs to be harvested post-mortem, in the latter situation the decision-making process is much more elaborated and reflected upon. Family, education level, age, gender, religion, background culture will influence more strongly the individuals who give consent for their organs to be harvested after they have ceased to live in order to save other lives.

Next of kin form a category that involves on one side of the barricade the donor's next of kin, and on the other side the recipient's next of kin. This category is not presented in any detail in literature, but due to the fact that it is directly connected to the main actors of the procedure and that they are in their immediate vicinity, they may reveal other aspects concerning donation and transplantation. Although attention given to the next of kin is regarded as optional, just a few simple questions concerning them may generate new ethical dilemmas.

The donor's next of kin are "those in the entourage of the donor, who are affected by the decision to donate" [20]. The discussion around them aims to clarify their degree of involvement in the decision-making process, by signing or refusing to sign the consent form for donation. The deceased donor's next of kin may request information concerning the recipient, and ethics should answer the question of whether such a request for information is legitimate or not. Meanwhile, the next of kin of a living donor experience situations that may include major complications or even the death of the donor [20]. How will these individuals perceive donation, especially if they have tried to influence the donor in one direction or another? How will they relate to the medical system? How will they experience these situations, which they have not anticipated?

The recipient's next of kin are "those in the proximity of the recipient" [20, p. 32]. Certain aspects concerning the life of an individual who may have been for a long while on a waiting list can be captured from the perspective of those who have lived in the proximity of an organ recipient. Although their role can be discussed in general, individual cases provide a much more accurate description of the meaning the recipient's next of kin have. In this sense we mention the cases in which kidney transplant operations fail and the patients must return to dialysis, situations that cause depression in the patient and situations that are difficult to manage in the recipient's next of kin. Therefore, "the presence of a person in the proximity of a donor, who can help in the difficult post-transplantation moments, is important" [20, p. 32].

The medical team/personnel carry, first of all, the responsibility for communicating and interacting with the first two categories of actors. The interrelation between medical personnel and recipients or potential donors is based on a body of theoretical knowledge and on acquiring the competences and practical skills filtered and adapted according to intuition, as well as the skill of knowing how to interact with patients, who are burdened by their personal history [16].

Medical personnel has, first and foremost, the difficult task of expressing in plain language the fact that, without a transplant, the patients cannot continue their lives in a normal manner or even at all. The discourse is even more fraught when a possible donation from a brain dead patient is approached. Those in charge of the transplantation process find themselves in the situation of finding the ideal key for discussing such issues with the family who is grieving over the loss of a loved one. The dynamic of the family must be analysed, in order to have the possibility to anticipate the reaction to such a request. A discussion opened too early can lead to reluctance and rejection from the part of the family, or it can even cause a misunderstanding of the request or indignation when facing such an approach. The family may feel an obvious insensitivity to the crisis the potential recipient goes through. Mistrust from the family is in this case a natural reaction. The family members are still under the shock of the loss they have suffered [21]. Complementing the medical history with the social one is an opportunity to help the family reflect on the trauma and overcome it. However, reality shows that medical personnel, the transplantation teams, will

never get to know all the family dynamics and history. In most cases the decisions are made as a result of the physicians' assessments, without knowing the detailed situation of each case [21]. It is easy to see that the dimension of communication between the medical team and the family means a great pressure places on the actors finding themselves in the situation of acting as mediators between the death and suffering of some individuals and the recovery of a whole universe for other individuals. The category of social actors involved in the medical side of transplantation has a difficult role, which it has to be able and willing to adapt from patient to patient.

The education system is a collective actor, but it is almost imperceptible in the economy of the transplantation system. The research made on the intent to donate point out that the education factor has a great influence on the decision to donate. If we talk either about education level or about degree of information, we see that behind the education factor we have the education system of a certain space. The lack of information concerning decisions related to the end of life and the lack of interest for seeking such information are markers of education level. Ashkenazi and Klein have shown in a study that "the higher the education level, the more increased the wish to donate" [12]. The relationship between the willingness to donate and the level of education has been described in another study, which states that "young people with more years of education and with more information about the current legislation of their country concerning donation tend to be more willing to donate their organs, the way they are open towards granting consent for a relative to donate" [13].

We may count prejudice ad part of the same area and becoming barriers in pro-donation decisions. One proof concerning prejudice as a result of lack of information, highlighted in a study, is related to the allocation of organs, which go to "beneficiaries who do not deserve them and who have head unhealthy lifestyles; besides, there is the fear of HIV transmission" [15]. The examples come to underline the important role the education system plays in a society. The information research activity for personal decisions made in the know and accepted depends to a great extent on the type of education available in a certain area. This is one reason why we may consider the education system as being a significant actor in the issue of organ donation and transplantation.

The multi-factorial character of the donation process makes it difficult and slow, to the disadvantage of the patients on waiting lists in need on an organ. Roels and Rahmel showed in a study made in the European Union that throughout this process, legislation crosses paths with the medical teams, with the investments and infrastructure of the healthcare system, with mentalities, as well as with religion and education [14].

The political and economic system of a state may be considered an actor in the organ transplant equation. It is the one who can harmonise healthcare policies in the matter of organ donation and transplantation, in a position to fund the system and assign resources, as well as create 'collaborations' between national donor registers in order to create an international database.

The inexistence in the EU of a common legal framework concerning donation [14] points however towards an actor who has not managed to find the common denominator of all the countries in order to create a common database concerning donation. In terms of politics, some researchers have tried to find out whether political affiliation and a higher degree of social interaction lead to a decision in favour of donation [13]. The community may have some weight in the choice to donate, as the donation act may be seen as a community contract with the others. Mossialos has shown that the higher the degree of social involvement, the more inclined the individuals are to donate their organs. As they experience a strong social inclusion and the feeling of belonging to the various groups they are a part of. These individuals believe they have a moral duty to replay this inclusion and interaction by donating organs. The role of this segment reflects, as we can see, both on the donation process and on the entire system, as well as on the population of a community. But in order to be able to talk about the political/economic/lawmaking segment as genuinely playing a role as an actor in the process, this segment needs to be visible, perceptible by the individuals.

The donors, the recipients and other individuals that play various roles in the transplantation process and system can come together as common voices in various associations, organisations, therapeutic communities, etc. Some of their aims concern increasing the effectiveness of the system, or the beneficial effects of testimonials and follow-up reunions of operated patients, or mutual support through the discussion and publication of special medical cases, etc. Irrespective of the nature or the aim of their activity, the influence of such groups may prove useful and effective for improving the transplantation system.

The discussion of factors that belong to the transplantation system and/or process reveals both the complexity of the phenomenon and the levels on which it can be analysed. Transplantation is a multidimensional phenomenon, and the actors and factors that intersect in the intention to donate are varied and manifold. It is difficult to take any position in relation to some of them. At the same time, the intention to get things moving or a willingness to improve the effectiveness of the transplantation system are ambiguous. Nevertheless, whenever an actor from the decision-making system shows an interest in effective change, the situation appears different.

The decision to donate involves all these factors and identifying the actors behind them may prove difficult, confusing or useless. Meanwhile we find common actors, imperceptible actors or actors that may generate changes in several areas.

Church and religion have a very important role in society, especially in the current context, in which “Science and technology have become such strong realities, set in the hands of man, that we can talk rightfully, about playing God” [22]. This play, however, can become downright in those societies in which religious traditions and customs are intertwined with the local culture or are even partly identified with it. Drawing the limits of technology and seeking religious answers to today’s problems turn out to be concerns that are necessary for the

good operation of a community. Thus, with various degrees of religious integration in one's personal trajectory, each type of society will also seek out the answer of religion to the issue of organ donation and transplantation [12]. Although religion may be an individual factor in the subjective decisions concerning donation and not only, individuals seek out the official opinion expressed by the institution of the Church they belong to. When comparing the religious factor, which may be very private for the individual, with the institutional one, that of the Church, other reflection topics come to the surface: "does the Church see itself as an opinion-maker in the issue of donation?", "does the Church have and acknowledge a certain point of view in this direction?", "can we talk about an up-to-date Church, engaged in discussing today's challenges?". These are just a few of the premises that make us think that the Church is an actor that should be dealt with in a separate work.

3. Conclusions

The discussion about organ donation is far from having exhausted all its dimensions. Due to its social, economic, legal, ethical, moral and religious implications, organ donation proves to be a total social phenomenon. We are therefore dealing with a social phenomenon, with actors, challenges and many levels of discussion in a pluridisciplinary context that has more or less visible anchors in concrete planes.

The attitude towards organ donation consists of a number of factors and actors, each of them present in a different manner in the decision of organs donation. Finding the actors that contribute to the attitude towards donation is an effort that has to continue. New nuances and elements can appear in personal circumstances when the individuals have to make a decision of such great importance for themselves and their families. The multitude of actors and factors that are involved in donation and transplantation underline both the complexity of the phenomenon and the whole host of individual or collective social representations concerning them.

When viewed as a social phenomenon, organ transplant is clearly in a dynamic of change, in a relativist framework, which may change depending on the elements that make it up. The social actors in the economy of organ donation and transplantation are just one segment of a phenomenon that can change its parameters radically, sometimes in a very short period of time.

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