

Anonymity of organ donors under discussion

Dibattiti in Nefrologia

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ABSTRACT

The World Health Organization declares in its *Guiding Principles on Human Cell, Tissue and Organ Transplantation* that organizations must ensure that the personal anonymity and privacy of donors and recipients are always protected. Hence, most of the European transplantation programs forbid any form of direct contact between the family of the deceased donor and the transplant recipient. The anonymity is guarded to protect both parties against potential abuse, manipulation or financial pressure.

However, legislation on anonymity of organ donation has come under discussion in the last few years, especially in Italy where the National Committee for Bioethics has recently positioned in favor of allowing organs donor families and transplant recipients to meet, if both parties wish to. Most donor families need to “complete” the biography of the deceased and make peace with their decision to consent to the donation; on the other hand, a considerable proportion of recipients wish to acknowledge the role that the donor and their family played in saving their lives and make peace with having a part of the donor sustaining their life, while not feeling guilty. Thus, a resilient model built on confidentiality, autonomy and freedom to make informed choice should be considered in those countries where a change in the transplantation law is currently debated.

KEYWORDS: transplant laws, anonymity, organ donor families, transplant recipients

Introduction

The World Health Organization declares in its *Guiding Principles on Human Cell, Tissue and Organ Transplantation* [1] that organizations must ensure that the personal anonymity and privacy of donors and recipients are always protected. Hence, most of the European transplantation programs forbid every form of direct contact between the family of the deceased donor and the transplant recipient. The anonymity is guarded to protect both the donor family and the recipient against potential abuse, manipulation or financial pressure.

However, as society evolves, priorities and demands are completely different from what they were only a few years ago. Thus, organizations should adapt to the changes experienced by society and try to meet its demands.

According to some studies, up to 90% of organ donors' families express a wish to get some information about recipients [2,3,4]. When talking about recipients, results are not equally consistent, indicating that a portion of them wants direct contact, while others prefer anonymity [3,4]. In many European countries transplant coordinators send a letter to donor families to thank them for the act of donation and to share the transplant outcome of the patient or patients who received an organ from their beloved one, but without including any information on identity. In some other European countries, contact between transplant recipients and the donors' families is possible only indirectly, by means of anonymous letters of appreciation. Only in the United States and Israel transplant recipients and donors' families can get to know each other, with organ procurement organizations acting as an intermediary.

In Europe, the current practice seemed sufficiently satisfying for both the transplant recipients and the donor families. However, in the last few years, the legislation on anonymity of organ donation has come under discussion, especially in Italy where the National Committee for Bioethics has recently positioned in favor of allowing organs donor families and transplant recipients to meet, if both parties wish to [5]

Analysis

In addition to wanting to help others, donors' families have their own needs, which include wanting a positive outcome, having hopes for the future, and receiving confirmation that their decision made a difference and was appreciated. This helps them to make sense of what they experienced and to engage in new tasks, roles, and responsibilities, while rebuilding their lives without the deceased. The family post-death relationship with the deceased, and their ongoing narrative, are entwined with the knowledge that parts of their loved one are still "alive". In this sense, their bereavement may include a sense of attachment to the organs or to the recipients, who embody the significance of their decision. A desire to honor their loved one and ensure that they are remembered as a person may contribute to a need to share information about the donor. Information about transplant outcomes and recipient progress is also valued and families appreciate opportunities to correspond with or meet recipients, exchanging information that contributes to their narrative [2].

In contrast, there are also donors' families that do not want any contact with their transplant recipients, arguing that their identity is not important to them and that they do not want to relive such a painful experience.

But what happens when the expectations of those who want information are not met? Researchers feel that exaggerated expectations can sometimes contribute to the risk of

disappointment and may influence the two parties' ability to cope when contact is made and either of them does not meet the expectations of the other [6,7]. For example, donors' relatives may imagine the recipients to be of a similar age and gender as the donor, with some parents saying that they consented to donation so that other parents would not have to suffer what they lived. What they may not know is that, while heart donors are often males aged between 18 and 27, a big proportion of heart transplant recipients are males in their 50s or 60s. In the case of liver transplant, more than half of the recipients experience early acute rejection, while 20% to 30% of them experience late acute or chronic rejection, which may require re-transplantation if untreated [8]. Also, reported rates of overall alcohol recidivism following liver transplant ranged from 3% to 95%, and recipients classified as excessive or heavy drinkers ranged from 10% to 21% [8,9]. Based on these findings, in the cases in which contact is considered, obtaining preliminary information about the other party could contribute to realistic expectations and reduce the risk of disappointment, which can be difficult to cope with.

If we explore the point of view of the recipients, we find that a portion of them want direct contact, while the others prefer anonymity. The main reasons given for wanting to make contact are being able to learn more about the donor and thanking the donor's family in person [3,4,10]. In the study conducted by Annema et al. [3] in the Netherlands, 53% of liver recipients agreed or strongly agreed with the principle of anonymity of organ donation and 35% indicated that they did not wish to have any information about their donor. Although almost 30% of the respondents felt that contact with the donor family should be possible, only 19% of the respondents actually favored direct contact with their donor's family. In Belgium, 70% of liver transplant recipients were satisfied with the laws protecting anonymity and were concerned that relaxing them would contribute to anxiety, to a feeling of being obliged to do something in return for the donated organ, and a feeling of guilt [4].

A study from Israel, one of the only two countries all over the world that permits contact between donors' families and recipients, showed that 29% of the transplant recipients made contact with the donor's family; of these, 89% reported benefitting from the contact and 49% reported negative experiences [11].

Most of the donors' families and recipients who wish to obtain information about each other are satisfied with anonymous correspondence as a way of communicating, even when the option of direct contact is available [3,12]. Researchers have found that even when both donors' relatives and recipients wish to communicate, many do not make contact themselves and are hesitant to do so until receiving correspondence from the other [13, 14]. MacKay [15] also notes that only about 14% of donor families who received a letter wrote back.

However, many others, including those who do not wish to make contact themselves, feel that anonymity should not be enforced by law and believe that individuals should have the autonomy to decide for themselves [3].

Conclusions

Most donor families wish to "complete" the biography of the deceased and make peace with their decision to consent to the donation; also, a considerable proportion of recipients wish to acknowledge the role that the donor and their family played in saving their lives and make peace with having a part of the donor sustaining their life, while not feeling guilty. But there are also donors' families and transplant recipients that do not want any contact with each other at all. Thus, a resilient model built on confidentiality, autonomy and freedom to make informed choice should be considered in those countries where a change in transplantation law is debated. Perhaps

it could be a model in which donors' relatives and recipients are represented by third parties that serve the interests of the individuals they represent, while also ensuring that the whole transplantation system is protected. These third parties could be chosen according to the peculiarities of each system. Dicks et al [2] propose a possible model in which donors' relatives are represented by donation agencies and recipients by transplant centers. Families and recipients decide the terms of their contact with each other. When there is a party requesting contact, it is asked to respect the conditions set by the other. The authors claim that in this way the benefits of contact can be maximized. When difficulties arise, the organizations involved try to resolve them and, when either party get disappointed, try to assist them or find alternatives to meet their needs.

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