



RESEARCH ARTICLE

BETWEEN THE TWO PARTIES TO A DECEASED DONOR TRANSPLANT: ANALYSIS OF A TRANSPLANT COORDINATOR'S ETHICAL POSITION BETWEEN THE RECIPIENT AND THE DONOR'S FAMILY

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ABSTRACT

Topic: When an organ is harvested from a dead donor, how should transplant coordinators handle the issue of contact between the donor's family and the organ recipient?

Methods: The authors—qualified by extensive practical experience and philosophical investigation—conduct a systematic discussion of the problem, setting out both the bioethical issues and the practical dilemmas which have to be faced and resolved.

Results: They then recommend a strategy for coordinators to decide both their own thought-through stance on the issue and how they will respond in practice to the needs and wishes of the parties.

Conclusions: The professionals handling the transplant process need tailor-made training in the bioethics relevant to the challenges likely to confront them. This training must go beyond theoretical and ethical guidance to include simulations designed to disclose each staff member's own personal belief system and make them aware and reflective of their individual biases.

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INTRODUCTION

Advances in transplantation have taken this field of medicine great strides forward but have left the professionals having to find answers to many critical ethical issues. Transplantation ethics is a philosophy that incorporates systematizing, defending and advocating concepts of right and wrong conduct related to organ donation. As the demand for organs increases, it is essential to ensure that new and innovative laws, policies and strategies of increasing organ supply are bioethical and are founded on the principles of altruism and utilitarianism. In the field of organ transplantation, role of altruism and medical ethics values are significant to the welfare of the society (Danovitch, *et al*, 2013; Lacetera, *et al*, 2014; Dalal, 2015). Organ transplantation centers have expanded and increased in the last 20 years as transplant recipient outcomes have improved steadily and transplantation has moved from experimentation to treatment of choice for several indications. Transplantation presents difficult ethical and legal challenges for the transplant community and society. These include declarations of death, consent to donation and allocation of a scarce societal resource, i.e. transplantable organs.

Policy and practice reflect the law, societal beliefs and prevailing values (Caplan, 2014). A bioethicist contributes to a transplant team by clarifying values held by various stakeholders or embodied in decisions and policies, conducting clinical consultations, developing and interpreting policy and researching the ethics of innovations for rationing and increasing available supply of organs for transplantation. The bioethicist's interdisciplinary education, preparation, experience and familiarity with ethics, law, sociology and philosophy and skills of mediation, communication and ethical analysis contribute to addressing and resolving many issues in transplantation (Messina, 2015; Justo-Janeiro *et al*, 2015; Steinberg, 2015). The major source of organs for transplant today in Israel is tissue recovered from deceased donors, a source which depends on the deceased person's family agreeing to the organ donation. This consent is the outcome of a complex interaction between the family and the transplant coordinator, (Kramer, 2001) an interaction which involves much more than medical procedures. There are intense emotions involved and also the individual belief and value systems of all the parties — the dead person's family, the professionals who must manage the transplant process, and the potential recipient. At the core of the process is the transfer of an organ from a dead donor to a recipient under threat of death.

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It should come as no surprise that, in such circumstances, the organ is invested with profound symbolisms, far beyond its physiological value. For the donor's family it renders their loss and grief some positive meaning; for the recipient it is a life-saver and the end of suffering which has, in most cases, been his/her reality for a long time (Ono *et al.*, 2008). In Israel the families of potential deceased donors have to decide on the donation at the very moment they are informed of their relative's sudden death. The great majority of donations are not directed by the family to a particular person and, in such cases, the family are not told to whom the organ will go. In most cases, therefore, there has been no pre-transplant contact between the donor and/or the donor's family and the recipient and neither knows who the other is. It is the policy of Israel's National Transplant Center, as of most European states, to preserve the anonymity of both sides to this transaction. This practice derives from a commitment to confidentiality, which in turn derives from respect for the dignity of the individual and a commitment to patients' wellbeing (Trafford and Stanton, 1988). 'Contact' is defined for the purposes of this paper as any interpersonal interaction which creates some form of connection. It may take the form of a letter, a telephone conversation or face-to-face meeting. It would also include the transplant coordinator giving the recipient and donor family information about each other or passing a letter of thanks from the recipient to the donor family. In practice, face-to-face meetings are rare and almost all come about as the result of the independent initiative and resolve of the two sides (Branwell, 2008).

The advantages of bringing donor families and recipients into contact

Recently published studies on this issue which have endorsed bringing the two sides together state that contact can be made at different levels, all of which can help recipients cope with the fact of their transplant and donor families with their bereavement. They argue that contact with the recipient has a positive effect on the donor family's mourning process by rendering new positive meaning to the tragedy of their loss. Seeing the success of the transplant gives them a good feeling and satisfaction about their decision to donate the organ (Colarusso, 2006; Lopez Martinez *et al.*, 2008). The first step towards this satisfaction is their being told by the transplant coordinator that the surgery has succeeded. Until this information arrives the grieving family feel stressed and impotent at not knowing the fate of the organ(s) they have donated. Not being given this information can be frustrating and cause them to feel disrespect, even anger, for the recipient (Holtkamp, 2002). The announcement of success, perhaps followed by a letter of thanks from the recipient, works a positive effect on the delicately-balanced relations between the two parties (Ono *et al.*, 2008). Should the family receive no 'return' from the recipient for their great gift, they turn with even greater urgency to the transplant team for information as to the fate of their gift (Sanner 2001; Walter *et al.* 2003). As for the recipient, their benefit from contact with the donor family is the opportunity to express their gratitude for the donation and, through them, get to know the person who has saved their life. The root of this need to say 'thank you' is the gut urge to shake off the sense of guilt for having one's life saved by the death of another (Clayvill, 1999). Close relations between recipient and donor family also predict a more successful recovery from transplant surgery, as well as giving a sense of 'closing the circle' (Goetzmann *et al.*, 2009).

The Ono *et al.* study (2008) quotes both organ recipients and donor families saying that they wished to maintain long-term contact with each other.

The disadvantages of bringing donor families and recipients into contact

Studies that have come out against the two sides making contact argue that the donor family has ambivalent feelings toward the recipient. They have the satisfaction of a successful good deed but at the same time the anger of having a stranger given the life their family has lost (Riley and Coolican, 1999) and in meetings this anger can uncomfortably encounter the organ recipient's joy and relief. Should the transplanted organ be rejected this can arouse a renewed mourning (Cornell and Howard, 2008). The contact can also stimulate the donor family to exaggerated expectations of the recipient, which can end in severe disappointment at the recipient's treatment of them (Rodrigue *et al.*, 2008). Recipients, for their part, can be troubled by feelings of guilt at owing their good fortune to the misfortune of another and so be reluctant to meet the donor's family (Inspector *et al.*, 2004).

If they do meet, this can add to the recipient an extra sense of 'burden' at their responsibility to nurture and do well with the donated organ, something that does not make the recovery process any easier. A further possible psychological burden is the feeling that they owe the donor family some form of 'return' for their life-saving gesture. They can also be drawn into the family's mourning process. Neither of these developments aid recovery and rehabilitation (Sanner, 2001). The balance of the discussion over the last decade or so is nevertheless in favour of contact (Lewino *et al.* 2001; Colarusso, 2006). To the above debate there has been added more lately the dimension of exchange theory. Sociologists regard this relationship between donor family and recipient as an exchange of gifts but differing from a 'gift relationship'. In the latter the gift is given face-to-face but in the context of an organ donation the two sides are anonymous and in communication before the transplant only via the healthcare professionals' mediation. Bringing the sides together can fill in the missing element of face-to-face contact and make the connection closer to that of a gift relationship (Ben-David-Bror, 1997).

But in the context of an organ transplant not only does a physical transaction take place but also an exchange of more abstract qualities—life and death—and this parameter helps understand the different feelings of the two parties to the transaction (Vernale and Packard, 2007). Sociologists are concerned with the benefit each side gets from the gift (Mauss, 1954; Fox and Swazey, 1978). In exchange theory the gift giver expects an immediate or later reward, that the 'debt' will be eventually repaid. From the point of view of exchange theory the distinctive quality of an organ donation is its non-mutuality. It is the donor family that does all the giving and once only, whereas the recipient does all the receiving and possibly more than once and over many years. Thus the donor family may well feel that they lack the reward/benefit an important gift should bring. The recipient, on the other hand, may feel the lack of mutuality no less keenly and wish to make some sort of return to the donors. Meeting with them to express gratitude and acknowledgement and maintaining the connection over time can be this 'return'. However, research into the applicability of exchange theory to transplants (Sque,

2005; Shaw, 2009) argue that the theory cannot explain all the emotionality and dilemmas that transplant from a deceased donor awakes.

Transplant team attitudes

The transplant team can exert critical influence by the information and opinions they impart. The transplant coordinator occupies an especially crucial position in that she can carry messages between the two sides, for instance, a letter of thanks from the recipient. Over the years the attitudes of the transplant team to contact between donor family and organ recipient have undergone a sea-change from outright opposition through indecision to strong and active support for it but the debate among the professionals is still unresolved.

The transplant team often hesitate about passing information to one side about the other, sometimes from lack of experience, sometimes unsure whether the information will be really beneficial. The dilemma is a keen one because of the professionals' fear of unforeseeable developments and their wish to help patients reach the decision that is right for them (Trafford and Stanton, 1998). A 2009 survey by Dobbels *et al.* of liver recipients in Belgium, where the law insists on the anonymity of both parties and forbids contact, found that no less than 90% of the recipients were unhappy at being denied the opportunity to say thank you. As against this Ono *et al.* found in 2008 that 74% of coordinators opposed contact for fear of the stormy emotionality it aroused. This attitude in turn is refuted by donor families and recipients who claim that the coordinator owes them the duty of mediation, from a minimum of providing anonymous information about the other side to a maximum of arranging face-to-face meetings, and that this mediation is vital to the success of their mutual relations (Baines *et al.* 2001; Landon, 2004).

The transplant coordinator is perceived by both recipient and donor family as placed between them by the 'system' for the purpose of contact. She is the one who knows, who is in command of all relevant information and so she is, and is perceived as, critical whether it be to promoting or preventing contact. It occasionally happens that one or both parties express a wish to meet or to make some form of contact and this then raises the dilemma of how the professionals should respond and what their moral duty is in denying or bringing about such contact. Donor family and recipient have the unquestioned right to decide what is good for themselves on this issue.

Is it the professionals' part to act according to what they want? When the recipient wants to make contact and the donor family does not, or vice versa, what is the coordinator's moral duty and how should she /he advise and inform each side? In this paper we outline a way for transplant coordinators to devise a position on the advisability of the donor family and the recipient making contact on the basis of two factors, their perception of the advantages and disadvantages of such contact and their sense of their own moral duty in the circumstances.

Analysis

These questions also challenge professionals to examine closely the factors that potentially impact their own decision-making. One such key factor will be how each staff member perceives his/her own role and another factor will be the principles of bioethics.

(a) Staff members' personal role perception and group decision-making

This role perception can take one of two opposite forms: either (a) that the recipient is the preferred object of the staff's care and his/her wellbeing their primary goal, or (b) that the donor family and their emotional needs are the first priority and the staff are duty-bound to concentrate on these needs. If the staff believe that the success of a transplant is measured by the recipient's wellbeing then they will tend to side with his/her interests. Should the recipient's and the donor family's wishes clash then staff will tend to take the recipient's side. Their perception of their relations to the recipient will also tend to bring this about. They will see this therapeutic relationship as seamless and aimed at achieving two goals, short-term and long-term. In the short-term, to obtain an organ for transplant, in order to save their patient's life. In the long-term, the target is to keep the transplanted organ working well. As the staff see things, their relations with the recipient challenge them to work steadily and optimistically with him/her and with tight unity for a sustained period of time. Their sustained professional support, they are convinced, will bear fruit — the recipient will not reject the implant, his/her quality of life will dramatically improve and he/she will respond with admiration and acknowledgement of the professionals who have saved their life — consequences that satisfy the expectations of both recipient and staff. Given this perception of their role, if the recipient shows interest in connecting with the donor family, the team will make an effort to bring this contact about. If the recipient shows no such interest the team will ignore the possibility of contact.

Should, on the other hand, the staff see it as their duty to focus on the donor family's needs and give them emotional support, then they will tend to display empathy, respect and support for the family and for their readiness to give the gift of life to a stranger. In cases like these the donor family enjoys the staff's exclusive and unqualified support and staff try to align their judgment with the family's. Their perception of their relationship with donor family and recipient will change accordingly. Whereas in the preceding paragraph staff saw their relationship with the recipient in the long-term, in the situation described here staff envision a short-term relationship only, limited to obtaining the family's consent to an organ donation, and they will expect the intensity of the relationship to decline with time.

They will be well aware that the family are struggling with the simultaneous pain of personal loss and having to make the hard decision whether to donate organs or not, and this at a time when they are feeling devastated. Staff will also align themselves with the family to the extent that they perceive that professional support will help them cope with their mourning. The above two contrary positions clearly affect and alter the conduct and intuitions of individual professionals. An important point is that the coordinator's relations with the recipient will be intensive and profound and long-term in comparison to their contacts with the donor family, which can be brief and confined to the single meeting at which the decision to donate or not donate is taken. The effect of this may tend to persuade coordinators that their main responsibility is to the recipient and the success of the transplant. In both cases, however, each individual staff member must remain self-aware so that they meet their ethical and professional obligations to both sides.

They must take care to show empathy and sensitivity to the party who they do not feel to be the first target of their professional care.

Bio-ethical theory and principles relevant to the relations between donor families and organ recipients

The coordinator's role in making or baulking contact is characterized by conflict between bio-ethical principles such as the recipient's or the donor family's autonomy, on the one hand, and doing only good to both sides, especially when the two parties disagree as whether there should be contact or how much. Beauchamp and Childress (1989) identify the bioethical principles which govern transplant coordinators. There is the principle of beneficence which obliges the coordinator to give care which does actual good, the principle of non-maleficence, which requires doing no harm to patients/clients and not to deceive them by providing inaccurate or misleading information. A patient's/client's autonomy also has to be respected, which obliges the coordinator to allow recipient and donor family to decide what is good for them and to take their own decisions, even where these are opposed to the coordinator's own beliefs, culture and professional skills. Finally there is the principle of justice committing the coordinator to give equal respect to the rights of all sides and to allot resources equitably (Page, 2013).

Autonomy

The principle of autonomy requires respect for the decision-making capacity of competent adults. Kant holds that autonomy is the essential ground of the dignity of human nature and of every rational being (Kant, 1997: Justo-Janeiro, *et al.* 2015). He combines the ideas of rationality and dignity as follows: "... a rational being himself must be the ground for all maxims of action, never merely as a means, but as a supreme condition restricting the use of every means, that is, always as an end... and the dignity of man consists precisely in his capacity to make universal law, although only on the condition of being himself subject to the law he makes." Patients are autonomous to the extent that it is their own personality and values which decide their choices. One of the grounds for the high value accorded to autonomy is that patients know better than anyone else what is 'good' for them. They use their judgment and knowledge of their past to decide what is best for them and have the ability to take and carry through a decision consonant with their own individual universe. Respect for patient autonomy is now fully integrated into modern medical practice: it is out of regard for autonomy that staff provide patients all the information they need to make informed independent choices and to give 'informed consent' (Pellegrino, 1994) to every treatment and every interaction which forms part of that treatment.

Beneficence and Maleficence

The principle of Beneficence requires that any treatment given do some actual good, bring some visible benefit and improve the patient's wellbeing and quality of life. The source of this principle is Benthamite Utilitarianism (Bentham, 1789) which holds that actions are right when they conduce to the benefit of a majority. It directs us, when choosing between alternative courses of action, to choose that which will bring the greatest happiness to the greatest number. Utilitarianism judges deeds by results, by the extent to which they achieve their stated

goals, and not by the importance of their intrinsic values. Ends can justify means. In this light, if the goal of a transplant team is to obtain an organ and successfully implant it then all the team's actions will be measured by the good they bring to the organ recipient. However, such a judgment carries with it a number of ethical difficulties, among them the denial of the donor family's wishes, should they clash with the recipient's. Also, if the goal is to bring the greatest happiness to the greatest number and the donor family is more numerous than the single recipient then the theory should decide in favour of the donor family, even at serious cost to the recipient. This 'arithmetical' Utilitarian approach has attracted a lot of criticism as simplistic and merely arithmetical when the very nature of the situation evokes far more complex considerations. The retort of the supporters of Utilitarianism is that its calculation is not simplistic: that the harm done to the neglected recipient is also a component of the equation. The harm done can be grave, the recipient's depression for instance, or their neglect of the chemotherapy which is preventing rejection of the implant, so that giving preference to the donor family's interests becomes in the end non-utilitarian. In this light, the guiding principle for a Utilitarian transplant team would be 'to prevent harm', that is, not to infringe on an individual's rights further than is required to prevent harm to others. Thus the principles of Utilitarianism and its critique serve to highlight the dilemma facing a transplant team but do not help resolve it. The debate, however, has underlined the fact that it is the team's ethical duty to be very careful in devising its position.

DISCUSSION

How is the principle of autonomy likely to influence the staff's stance on the donor family's or the recipient's attitude to making contact? At first glance, it would seem to generate fuel for conflict. However, appreciating that the autonomous choice of both donor family and recipient will be based on information supplied them by staff for this purpose establishes a good basis for staff decision-making. Both the staff's objects of care (donor family and recipient) may have wishes and desires without the knowledge and information to back them up. They may also not know exactly what they want to happen. What they want at any particular stage of their coping with this sudden crisis in their lives may well derive not from knowledge as much as from their current emotional state. So, to respect the autonomy of both sides, staff must supply both with all relevant information about the possible positive and negative repercussions of establishing contact. They also need to open the eyes of both parties to the emotional and mental needs that can be aroused by such contact. The key objectives are to give both sides the basis for taking an informed and grounded decision so that each individual involved feels able to take personal responsibility for the decision arrived at. Critical to realizing this aim will be the professional carers' expert knowledge and their communications skills in imparting this knowledge (Beauchamp and Childress, 1994; Trey, 2015 Faber, *et al.* 2016).

Utilitarianism, beneficence and maleficence require them to answer the following questions about the stand they eventually take on this issue of contact:

- Does establishing contact embody any risk to one of the parties? What is this potential risk?

- Does establishing contact embody benefit to one of the parties? What is this potential benefit?

To answer these questions reliably, on the basis of informed assessments, the team has (a) to get to know both sides very well and (b) to ensure they have the information to take not an intuitive but an informed stand. Utilitarianism requires staff to assess the two sides' ability to withstand the results of the stance each has taken.

autonomy to the principle of beneficence, being absolutely convinced that their judgment is the right one. Key questions here are: When does one side's "good" justify violating the other's autonomy? and When does one side's "good" justify violating its own autonomy?

In conclusion: What do professional bioethics demand of transplant staff with respect to encouraging/ discouraging contact between the donor family and the organ recipient?

Table 1. A Phased Model of Bioethical Decision-Making

Staff's Duty to Donor Family and Recipient	
Principles Autonomy	<ul style="list-style-type: none"> • Review the two parties' initial stance on encouraging/discouraging contact. • Examine the motives (expectations) behind this stance. • Assess both parties' changing emotional needs. • Give respect and legitimation to both parties' wishes.
Do good	<ul style="list-style-type: none"> • Mediate between the parties if both want contact. • Supply pertinent information on the potential benefits/ risks of making/not making contact. • If both parties want contact, work to bring about a successful interaction by 'balancing' expectations. • Offer both parties emotional support in any situation that comes about. • Supply information that can help each individual make up his/her mind. • Assess the capacity of each individual to cope with the consequences of the stance they take. • Assess the limitations of every individual on both sides. • Detect seeds of conflict early and try to prevent it, whether the two parties reach an agreed stance or remain divided.

Should the parties eventually decide in favour of establishing contact, staff must also give guidance as to how to set up and manage this, making sure, as far as possible, that the expectations of donor family and recipient remain realistic. And, despite all the precautions they take, the team must still prepare themselves for unwanted outcomes, such as their patients' disappointment, sharpened pain and renewed sense of loss. Further, they must consider that the one strategy — to discourage contact, for instance — can do both good and harm, according to the stance each side takes on the issue.

Conflicts between autonomy and beneficence

Autonomy can come into conflict with beneficence when patients disagree with the recommendations which staff believe are in the patient's best interests. For example, the team is convinced that the contact with the donor family will benefit the recipient but he/she rejects the idea. Also the opposite: the recipient is convinced that he/she should contact the donor family but the team is convinced that it would be counter-productive. In both these cases the team has to balance potential risks against informed autonomy and they might choose to cede to the patient's autonomy in order not to harm their relationship with them by refusing their wishes. Other situations might generate dual conflict. For instance, the team is convinced that the family should avoid contact with the recipient for its own good. The family understands the professionals' thinking and agrees but the recipient insists on the contact and, indeed, for him/her contact presents no danger. Is this a case where the team may decide? May they decide in one party's favor? Does concern for the family justify rejection of the recipient's autonomy? Does concern for the recipient's autonomy justify violating the family's interests? In situations of conflict of opinion between staff, recipient and donor family sooner or later the staff will take a final decision as to which of the two sides they wish to support, whose autonomy will give way to the other's interest. In other words beneficence has to favour one side over the other. A situation can also arise where family and recipient both agree on wanting to make contact but the staff are opposed, for instance because the transplant has failed. In this case the professionals sacrifice both sides'

It seems to us that the clash between siding with the donor family or the recipient is no more resolvable than any other collision of values which cuts the ground from under ethical impulses. Nor is a strategy of 'Wait and see' feasible. Instead, close study of bioethical principles reveals that the way out of the conflict is for staff members, not to take a single clear-cut and unchanging stand on the issue but to adjust their stance to each interaction between themselves and the two parties. This is a case where bioethical principles do not generate any one decisive recommendation. They rather lead to a phased process, whereby the staff stance at each stage is shaped by the results of the previous stage or stages and the staff's ethical conduct and observance of bioethical principles are kept under constant review. The phases of this process are set out in Table 1.

The discussion conducted over the course of this paper leads to the conclusion that the professionals handling the transplant process need training in a number of specific skills. We recommend:

- That staff keep themselves up-to-date with the latest scientific knowledge in the field so as to meet their duty of providing full information to family and recipient.
- That transplant teams be given tailor-made training in the bioethics relevant to the challenges likely to confront them. This training must go beyond theoretical and ethical guidance to include simulations designed to disclose each staff member's own personal belief system and make them aware and reflective of their individual biases.
- To design this training so that it also develops awareness of –
 - The types of conflict this paper has described and of the processes by which staff perceive and judge a situation and come to a decision.
 - The staff's influence on the beliefs, attitudes and choices of donor family and recipient. Donor family and recipient need to be made aware of the values which are propelling their choices about making contact and other issues. One of the staff's key

functions is to disclose to each family member/recipient the personal values and beliefs shaping their judgement so that they can review their situation with deeper understanding of what is to their true benefit.

- For the sake of critical group thinking, forums should be set up for the professionals within which they can raise ethical issues and difficulties and debate ways and means for the effective and informed management of all challenges. These same forums, which may be face to face or internet-mediated, can also be thrown open to family members and organ recipients.

To set up professional-led support groups designed to enable family members/recipients to put questions about any issue troubling them, including the issue of contact.

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