

The Rights of the Relatives within the Deceased Organ Donation Process

Nadia Primc

Institute of History and Ethics of Medicine
Faculty of Medicine, University of Heidelberg
primc@uni-heidelberg.de

Derechos de los familiares durante el proceso de la donación de órganos de cadáver

ABSTRACT: Within the process of organ donation, the healthcare team has to interact closely with the relatives of the potential donors. If the family opposes an organ donation, the transplant coordinator has to decide whether he should continue with the donation process. Two ethically challenging questions need to be discussed. Do relatives have the right to override the patient's decision to donate or not to donate? Should they be allowed to decide in cases where nothing is known about the patient's wishes concerning organ donation? It will be argued that the family has the right not to be distressed. However, this doesn't give them the right to override the potential donor's decision. Neither does it give them the right to decide for or against a donation in the case that nothing is known about the donor's wishes concerning organ donation.

KEYWORDS: organ donation – medical ethics – rights of the relatives – conscription of organs – professionalisation of the transplant coordinator

RESUMEN: Como parte del proceso de donación de órganos, el equipo de atención médica tiene que interactuar estrechamente con los familiares de los donantes potenciales. Dos situaciones éticamente difíciles necesitan ser debatidas. ¿Tienen los familiares el derecho de anular la decisión del paciente de donar o no? Si la actitud del donante potencial es desconocida, ¿deberían tener los familiares el derecho de decidir a favor o en contra de la donación? Se sostendrá que el único derecho que debe ser atribuido a la familia es el derecho a no ser angustiada. Sin embargo, esto no les da el derecho de anular la decisión del donante potencial. Tampoco les da derecho a decidir a favor o en contra de una donación en caso de que no se sepa nada acerca de la voluntad del donante.

PALABRAS CLAVE: donación de órganos - ética médica - derechos de los familiares - reclutamiento de órganos - profesionalización del coordinador de trasplantes

1. Introduction

The ethical debate on cadaveric organ donation usually focuses on the potential donors and the patients on the waiting list (Hilpert, 2016, 83; Farrell/Quigley 2012, 292). However, the families of the potential donors play an essential role in clinical practice, too. The healthcare team and the transplant coordinators have to interact closely with the family members before, during, and after the organ donation. The prominent role of the relatives in clinical practice sharply contrasts with the marginal role they play within the ethical debate.

When it comes to the perspective of the relatives, several ethical topics need to be discussed. However, the present considerations have to confine themselves to briefly addressing the following normative questions: do the families and relatives have any genuine rights within the donation process? Do they, for example, have the right to override the patient's¹ decision to donate or not to donate? Should they be allowed to decide in cases where nothing is known about the patient's wishes concerning organ donation?²



The major part of the paper will try to answer these questions. In a concluding remark, an outlook will be provided on some general conclusions for clinical practice, that follow from these considerations. But first, a brief characterization of the German Transplant Act (TPG)³ and the associated practice of organ donation in Germany will be given, as this stresses the ethical relevance of the above-mentioned questions.

2. The practice of organ donation in Germany

A clarification of the rights and duties of the family is especially important for countries like Germany that have opted for an extended consent system, a version of the opt-in system. In Germany, in 9 out of 10 cases the family has to take a direct or indirect decision for or against organ donation (Breidenbach, 2011, 120), as the potential donors don't have any organ donor card or advance care directive. In 2015, this made up 88 % of the officially reported cases (DSO, 2016, 50).⁴

The German Transplant Act distinguishes three different constellations that legally allow for a cadaveric organ donation (Breidenbach, 2011, 19 f.). The first and simplest case is a donation that is based on explicit consent of the donor, for example an organ donor card or advance care directive (Sec. 3 TPG). An organ donation is legally impermissible if the patient has documented his unwillingness to donate (Sec. 3 para. 2 TPG). Second, the German Transplant Act states that if the patient has not written down any wishes concerning organ donation, the family or a closely related person has to be asked whether any statement or wishes concerning organ donation are known (Sec. 4 para. 1 TPG). If so, then the physicians should, just as in the first case, respect and follow the reported wishes of the patient.⁵

However, this is not always done in practice. In the case of opposition, the relatives are often given the right to override the patient's documented or presumed willingness to donate, although the German Transplant Act suggests doing otherwise.⁶ The transplant coordinators feel uncertain about how they should handle those cases, whether they should insist on the legal requirements, or whether they should retreat from continuing with the donation process. Hence, it is a question of ethical importance for the clinical practice of the transplant coordinators, whether the relatives should be given the right to override the patient's willingness to donate (De Wispelare/Stirton, 2016, 157 ff.).

Third, if nothing is known about the wishes of the patient concerning organ donation, a donation is still possible if the next relative (or a closely related person) gives his consent. The next relative has the possibility to decide for or against a donation on the basis of his own personal principles and values, although he has to respect the presumed wishes of the patient (Sec. 4 para. 1 TPG).⁷ In this special case – which in 2015 made up 18 % of the officially reported cases in Germany (DSO, 2016, 50) – the relatives are given the right to decide in a more or less heteronomous⁸ way on the physical integrity of the potential donor's body. This seems to be in conflict with the underlying concept of the opt-in system, namely that an organ donation – in order to be a donation and not a compulsion – has to be based on the donor's consent or wish⁹ to donate (Farrell/Quigley 2012, 290 ff.; Hurley, 2011, 217). The German opt-in system permits organs to be taken, although the patient had not expressed his willingness to donate and maybe would not have wanted to donate, if the family decides to do so and if there is no information available as to any willingness or unwillingness to donate. The same applies, for example, to the current UK legislation, which passes the authority for decision making on to the relatives if the patient's wishes are unknown (NHS Blood and Transplant 2013, 16 ff., 24 f.)

This third constellation causes considerable discomfort within clinical practice too, as some transplant coordinators hold the view that within an extended consent system (and in contrast to an opt-out system) an organ donation should always be based on the patient's documented, reported or at least inferred willingness to donate. Hence, this third constellation points to the second question mentioned above, namely whether the relatives have the right to decide when nothing is known about the patient's wishes.¹⁰

These considerations underline the ethical importance of the question of the families' rights. It should be clear that this question has importance for other countries too, as the relatives are often allowed to override the patient's decision to donate, irrespective of whether an opt-in or an opt-out system is implemented on a national level (Wilkinson, 2011, 76; Shaw/Elger, 2014). Family refusal is considered to be the 'biggest 'step down' in loss of potential donors in the whole of the donation pathway' in the United Kingdom (NHS Blood and Transplant 2013, 6), where 43 % of the families oppose a cadaveric organ donation. The refusal rate is even higher for Black, Asian and Minority Ethnic communities, where 66 % of the relatives oppose an organ donation (Organ Donation Taskforce 2013, 6, 29). In the United

States, the family refusal rate sums up to 54 % (Ralph/Chapman/Gillis/Craig/Butow/Howard/Irving/Sutano/Tong 2014, 923). As an older empirical study of the practices of the organ procurement organisations in the US suggests, there are 'implicit ethical disagreements about whose wishes should be followed' (Wendler/Dickert 2001, 329).

3. The perspective and rights of the relatives

What rights should the family be given? Do they have the right to decide on the physical integrity of the potential donor's body? The two above mentioned constellations, i.e. the case of a family that opposes the patient's documented or reported willingness (or unwillingness) to donate, and a situation where nothing is known about the potential donor's attitudes towards organ donation, will be discussed separately, beginning with the first.

3.1. Do the relatives have the right to override the patient's decision to donate or not to donate?

In his discussion of this specific question, Wilkinson claims that the only genuine right the relatives have is the right not to be distressed. Distress is a bad thing in itself, and the situation of a cadaveric organ donation is challenging enough for the family, as they are about to lose a beloved person. Overriding the family can cause them a lot of distress (Wilkinson, 2011, 67). Hence, it could be argued on the basis of this right that they should be given the possibility to oppose an organ donation, even if the patient has documented his willingness to donate.¹¹

Indeed, it has to be regarded as morally important not to distress the relatives of a seriously ill patient. The healthcare team and the transplant coordinators should do their best to avoid causing distress to the family (UK Donation Ethics Committee 2016, 2). Nevertheless, it does not follow from these considerations that the right not to be distressed entails the right to decide whether an organ donation should be performed or not. For example, it is usually not seen as permissible to base the decision to suspend a life-sustaining treatment or not on the goal of minimizing the distress for the family. Rather, the focus should be primarily on the patient's personal values and presumed interests (apart from the question of

a medical indication). The same applies to cadaveric organ donation. The right not to be distressed demands, for example, that the transplant coordinators should be professionally trained to approach the relatives in a sensitive way¹² and to comfort them as much as possible, as long as this quest for consolation and relief does not conflict with other significant duties and rights, for example the patient's right to self-determination or the physician's moral obligation to tell the truth.

It could be debated whether the avoidance of distress is a right in itself or just something that is morally important. Of course, the answer to this question partly depends on the ethical position one takes, whether one views moral rights as something that includes an entitlement to legal rights, something whose violation calls for an intervention of the State, or something whose violation could (in some cases) be merely blameworthy, to name just a few possibilities. The present considerations are based on the last option, namely, that moral rights are closely connected to the notion of blameworthiness, but are not something that is necessarily linked to legal entitlements, although the latter applies to a number of rights, too. The avoidance of distress is part of the professional duties of the transplant coordinator, i.e. part of the skills that should be promoted within the professional training of the transplant coordinators and the healthcare team. The counterpart of this duty is the family's right not to be distressed. This means that the relatives are entitled to ask for a professional and sensitive interaction on the part of the transplant coordinator, that the transplant coordinator should be professionally trained to meet these demands and that he is blameworthy if he does not meet them.

Some might find the term virtue more suitable to describe the idea that the healthcare professionals should do as much as they can to minimize distress for the family. Above all, this seems to perfectly fit the claim that this is a part of the skills that should be promoted within the healthcare team. Certainly, the acquisition of such a skill is very similar to the acquisition of virtues. Both can only be attained by training and practice, and not just by implementing a rule or ethical principle in every single case. However, the aim not to distress the family should not be regarded as a virtue, if a virtue is understood as something that is laudable, as an excellence of character or the soul of a person, but not something whose lack involves the notion of blameworthiness. According to the present reasoning, not to minimize the

distress of the family within the donation process, although one has the possibility to do so, is something that should be regarded as blameworthy and hence avoiding distress of the family must be seen as a duty.

By accepting that the family has the right not to be distressed, one does not have to admit that this right has the same importance as all the other rights, for example the right to live, the right to physical integrity, or the right to self-determination, which are all closely interconnected. The family's right not to be distressed cannot be used to override the patient's right to self-determination and his documented willingness (or unwillingness) to donate. That one has to go along with the patient's right to self-determination does not mean that the family does not have the right not to be distressed. We are often confronted with situations in which several rights cannot be fulfilled simultaneously because they are opposed to each other, especially within the medical context. The inability to fulfil all of our obligations does not suspend individual rights that cannot or will not be fulfilled.

For example, many patients have a legitimate right to the life-saving treatment of an organ transplantation. But we are not able to meet all the moral entitlements because of the scarcity of the resource. This inability to ensure the patients' rights does not imply that their right to a life-saving donor organ is suspended. Their rights have to be balanced against one another in order to establish an ethically justifiable allocation mode. By balancing the rights against one another, none of the rights are suspended. This becomes clear if we imagine a situation where suddenly enough donor organs were available. One certainly has to agree that in such a situation we would be morally obliged to give every single patient a donor organ, also those patients who, in the preceding situation of scarcity, would have been denied a life-saving donor organ. The right to the life-saving donor organ does not disappear and pop up again depending on the number of donor organs available at a specific moment. The patients suffering from a severe organ failure all have these rights and these rights need to be traded off against one another.

To come back to our present topic: The same applies to the relatives' right not to be distressed. It has to be balanced against the patients' right to self-determination and to bodily integrity. Given the high value of the latter, the right not to be distressed cannot in itself be used to override a patient's known decision for or against an organ donation. This reasoning perfectly applies to other situations within the medical

context, as the right not to be distressed is generally not regarded as strong enough to override a patient's decision for or against a medical treatment.

Do the relatives have some other rights that need to be considered? Wilkinson too briefly considers some other aspects that could be used to override the patient's willingness or unwillingness to donate, namely respect for family bonds and for religious or cultural diversity (Wilkinson, 2011, 71 ff.). The establishment and cultivation of family bonds is generally supposed to be of major importance for the flourishing of individuals and society as a whole. From the point of view of social ethics, the protection and strengthening of family bonds¹³ has to be regarded as morally important, or even a fundamental right. A similar line of reasoning can be applied to the right to live according to one's own religious and cultural values and beliefs.¹⁴ Although both of these issues have to be regarded as morally important and should be respected within clinical practice, this argument cannot be used to give the family the right to override an individual's decision for or against a medical treatment or an organ donation. That the family is generally asked whether the organs of their relative should be donated is primarily because the family is believed (wrongly or not)¹⁵ to know best the wishes and the religious or cultural background of their relatives. Hence, it is primarily out of respect for the autonomy of the patient that the family should be consulted (Wilkinson, 2011, 74 ff.) and not because the family has the right to override the patient's willingness or unwillingness to donate.

That these issues have to be discussed mainly in terms of the autonomy of the potential donor can be exemplified by the case of Elijah Smith, a 21-years-old who died in a traffic accident in Ohio, USA in 2013. Elijah had registered as a donor when he applied for his driver's licence. His parents opposed an organ donation when they learned that his organs would be taken while their son was still on mechanical ventilation. They argued that Elijah 'did not fully understand the choice he had made' (Manning, 2013), implying that he would not have consented to donate if he had known what donation after brain death really means. The hospital sided with the parents. Lifeline, the local organ procurement organization, filed a complaint in court and one day later received permission to continue with the donation process (Crane, 2013).

In this case, the only ethically valuable argument to stop the donation process would have been that the patient's right to self-determination and bodily integrity would

be abrogated by an organ donation. That means that Elijah would not have wanted his organs to be taken under such circumstances, either because he did not accept the concept of brain death, or would not have wanted his family to suffer from the donation process. Both lines of reasoning ultimately rely on the patient's right to self-determination and not the family's right to decide for or against a donation. As the UK Donation Ethics Committee suggests, they shouldn't be classified as a genuine overrule but as 'new evidence regarding a patient's refusal to donate' (2016, 2).

3.2. Do the relatives have the right to decide if the patient's wishes are unknown?

The previous considerations have discussed situations that involve a documented, reported or inferred willingness (or unwillingness) to donate. We now have to consider situations in which nothing is known about the patients' attitudes towards organ donation. Does the right not to be distressed give the family the right to decide for or against a donation in cases when the potential donor's wishes are unknown? If one does not know what the patient did want or would have wanted, erring is inevitable. Hence, the answer to the question partly depends on whether one claims that 'taking organs from someone who opposed donation is worse than failing to take the organs from someone who wanted to donate' (Wilkinson, 2011, 87). If this is true, then one should not give the family the right to decide on their own. The best option would be to not take the organs.

However, Wilkinson takes the latter claim to be unjustifiable, as 'invading someone's dead body against that person's wishes' does not 'infringe his right to bodily integrity [...] when the invasion is a result of following a reasonable best guess about the person's wishes.' (Wilkinson, 2011, 88). According to Wilkinson, taking organs from someone who opposed donation is just as bad as failing to take organs from someone who wanted to donate – if one follows the best guess available. 'The best guess about a person's wishes need not be reliable or well-informed – just better than the alternatives' (Wilkinson, 2011, 87). Wilkinson further argues that, given the fact that there are several patients waiting for a donor organ, we should take the organs of the patients whose wishes are unknown. According to Wilkinson's line of reasoning, the family should not only be given the right to decide. Given the uncertainty of the patient's wishes and the recipients' right to the life-saving

treatment, the family should always opt in favour of a donation if nothing is known about the patient's wishes (Wilkinson, 2011, 90 f.).¹⁶

Wilkinson's line of reasoning strongly focuses on our right to self-determination, which seems to be similarly violated whatever side we err on. What Wilkinson does not consider is that the right to self-determination gives us the right to offer our organs and to overtly express our willingness to donate, but it does not found a right to our organs actually being taken. The right to self-determination, as it is used within the discussion of cadaveric organ donation, especially designates a negative right, i.e. the right to decide on and to defend one's own bodily integrity. Hence, if the organs are not taken although the patient wanted to donate, none of his rights are violated. If his organs are taken although he opposed donation, his right to bodily integrity is violated. Contrary to Wilkinson's claim, the two scenarios do differ and cannot be judged as equal with regard to the possible wrong being done to the potential donor.

Of course, the two options differ in some other important aspects, too. In one case, we have more organs to distribute among the patients on the waiting list. To violate the bodily integrity of a person against their presumed wishes in order to save somebody else is something that is not seen as morally permissible. If one wants to argue that the right to self-determination and to bodily integrity no longer applies to brain-dead persons, and that, hence, the relatives should always opt in favour of a donation if nothing is known about the patient's wishes, one would have to defend the conscription of organs from the dead – a position that is highly contestable and (at least until now) not supported by social consensus. Wilkinson offers a profound and valuable criticism of the central arguments for a conscription of organs, so that there is no need to recapitulate them in detail here (Wilkinson, 2011, 102 ff.). Just a few points have to be stressed.

First of all, any serious attempt to argue in favour of a conscription of organs from the dead will have to defend the right to take somebody's organs, whatever the objections of the patients and relatives. This entails that no exceptions should be allowed out of religious or cultural reasons, or because some people do not personally accept the concept of brain death (Wilkinson, 2011, 107 f.). Everything else would, in practice, come down to an opt-out system, with the possible addition that the people who are opting out will also be excluded from the distribution of

donor organs (see Wilkinson, 2011, 116 f.). The latter could not be regarded as an argument for the conscription of organs, but solely as an argument for the implementation of a restrictive opt-out system. From the point of view of such a restrictive opt-out system, the two above-mentioned scenarios would still differ in an ethical, substantial way. The patient's right to self-determination and bodily integrity is violated if his organs are taken, although he opposed donation (out of religious, cultural, or personal reasons). None of his rights are violated if his organs are not taken although he would have wanted to donate.

Second, by defending a conscription of organs (with no possibility to opt out), one would have to argue that the bodies and the organs of brain-dead people (and the non-heart-beating donors) have to be regarded as a mere material resource, that as such can be made the object of distributive justice, just as any other material resource (Wilkinson, 2011, 108 f.). This might perfectly fit the view of a scientific realist or a defender of some variation of biochemical reductionism, who could both argue that nowadays the only defensible view of the human body is the one propagated by the contemporary biomedical sciences. Nevertheless, these are highly contestable positions too, such that they cannot be easily used as a justification for the conscription of organs. This line of reasoning could, for example, be easily contested by adopting an instrumentalist position that regards 'scientific theories not as literal and/or accurate descriptions of the natural world, but instead as mere tools or 'instruments' for making empirical predictions and achieving other practical ends' (Stanford, 2006, 400).

Third, it might be objected that in the case of autopsy, too, the bodily integrity of a dead person is violated, although the person concerned maybe would not have wanted this done. To dispel these concerns, it has to be stressed that, from an ethical point of view, every single autopsy has to be carefully justified, for example, by referring to the serious possibility that a criminal act, medical malpractice, or a contagious disease is related to the death of the person. These are all cases that involve a possible threat to members of society or society as a whole. The State has the duty to protect the fundamental negative rights (the right to life and the right to bodily integrity) of its citizens. To do this, the State should, in some cases, be allowed to violate the bodily integrity of a dead person. To perform an autopsy without an actual and absolute necessity to do so has to be regarded as an impermissible violation of the person's right to bodily integrity, just as in the case of organ donation.

Of course, the State has the duty to protect the negative rights of the patients on the waiting list, too. These negative rights encompass, for example, the State's duty to implement an adequate transplantation system, i.e. that the donor organs – once they have been donated – are allocated in a fair and efficient way. But these negative rights do not encompass the (positive) right to one or more of the organs of a brain-dead person (or a non-heart-beating donor) *before* these organs have been voluntarily donated. Of course, the recipients also have a positive right to the life-saving transplantation and, hence, to any organs *already donated*.

To sum up this section: it cannot be argued that the relatives should always opt in favour of a donation if nothing is known about the patient's wishes. The latter would presuppose to defend the conscription of organs – a position that has to be regarded as highly contestable.

4. Concluding remarks

What conclusions for the clinical practice of organ donation can be drawn from the preceding considerations?

First, and as already mentioned above, the families' right not to be distressed and to be approached in a professional and sensitive way calls for a further professionalisation of the transplant coordinator – a process that has already been implemented to a great extent in countries like Spain and the United Kingdom and has just been initiated in Germany a few years ago.¹⁷ In 2015, the German Medical Association implemented a new curriculum that enables physicians to qualify as a transplant coordinator. The training program encompasses 40 hours, out of which 8 hours are dedicated to the topic of how to talk to and interact with the relatives ('Gesprächsführung'). Nevertheless, no specific requirements are made concerning the specific interactive or ethical skills that are supposed to be promoted within those training units or the methods of instruction to be implemented (Bundesärztekammer, 2015). Furthermore, the qualifications of the transplant coordinators are regulated on a federal level such that until now the curriculum is not mandatory and the qualification programs may vary on a national level.

The qualification of the transplant coordinator should be based on an appropriately structured training program that gives them the possibility to develop the relevant professional interactive skills, for example in the form of a real-time simulation of the deceased donation process (Wood/Buss/Buttery/Gardiner, 2012), additional teaching techniques involving the use of simulated patients (or rather simulated relatives), the attendance of organ donations led by experienced transplant coordinators, and the use of different supervision techniques, to name just a few. The advancement of comparable training programs is essential, as these professional skills can only be acquired by practice, not just by being informed of the legal, medical, and ethical issues concerning cadaveric organ donation – a feature that these professional skills share with the traditional concept of virtues.¹⁸

It has to be stressed that such a structured training program *should not solely be driven by the aim of maximising the number of donor organs*.¹⁹ The respect of the rights of the patient and his or her relatives has to be given a genuine place within the goals and the fundamental structure of these training programs.

Second, as the family does not have the right to oppose the patient's willingness to donate, they should be approached in an appropriate way if the patient has documented his willingness to donate. 'It is important to avoid any suggestion that the family's permission is also required' (NHS Blood and Transplant 2013, 15). The transplant coordinator should not approach them by asking whether they consent to a donation. Rather, he should, in a first step, inform them of the documented willingness to donate and that the healthcare team will do its best to satisfy the wishes of the patient and to assist the relatives within this difficult situation. The family should be given enough time to come to terms with the challenging situation and obtain all the information they need and seek about the process of organ donation. But what if the family continues to oppose it? It has been argued that the family does not have the right to override the patient's documented or reported willingness to donate. Does this mean that the transplant coordinator has to ignore the family's opposition and continue with the donation process, whatever the cost?

The physicians certainly have a duty to do as much as they can to ensure that the patient's will to donate will be obeyed. (UK Donation Ethics Committee 2016, 2/ Organ Donation Taskforce 2013, 7). They have in particular the moral obligation to investigate the reasons for the family's opposition, whether they think that the

documented willingness to donate no longer applies to the patient's wishes, or whether they oppose solely out of personal reasons. 'An initial strong refusal to consider donation could mask a misunderstanding' (UK Donation Ethics Committee 2016, 19). The process of addressing the family's reasons for refusal should not be cast in terms of 'persuasion' of the family (see for example Shaw/Elger, 2014; 2013), as this might (unconsciously) encourage the healthcare team to cross the line of the mere provision of and request for information and compromise the family's right not to be distressed.

If the family continues to oppose organ donation, additional aspects have to be considered. It can be argued that the duty to continue the donation process against the vehement opposition of the family would be too much of a burden for the healthcare team. The family does not have the right to override the patient's will to donate. But neither does the patient have the right to his organs actually being taken under all circumstances. Hence, the transplant coordinator would not offend the potential donor's rights if he decides that the continuation of the donation process represents too much of a burden for the healthcare team.

This justification differs from the one that is usually given for the interruption of the donation process due to opposition by the family. The latter is generally justified by pointing to the impending negative effect on the number of organs donated. According to this line of reasoning, the transplant coordinator can refrain from continuing the donation process out of concern for the recipients, i.e. the patients waiting for a donor organ (see for example Wilkinson, 2011, 78 ff.). Although the patients on the waiting list certainly have a right to the life-saving donor organs, it is not clear that the healthcare team of the potential donor also has a moral obligation towards the patients on the waiting list. They should be primarily concerned with the well-being and the rights of their own patients (and their relatives). Some strong ethical arguments call for a strict separation of the realms of organ donation and organ allocation within clinical practice.²⁰ In order to avoid any conflict of interests, the decisions of the transplant coordinator should primarily be based on a consideration of the interests and rights on the donor side. The physician in charge also has a professional responsibility for the healthcare team involved in the care of the potential donors. It is through this responsibility that he can decide not to continue with the donation process against the vehement opposition of the family, namely, if this would fundamentally conflict with the ethical self-conception of the healthcare team.

Another line of reasoning that would give the physicians the right not to continue with the donation process has already been mentioned above and relies on the right to self-determination of the potential donor. The physician could, in principle, legitimately refrain from a donation if he receives the well-founded impression that the donor did not know about his family's opposition and would not have wanted them to be traumatised by a donation. Nevertheless, there are several caveats associated with the concept of a presumed wish. It is always difficult for the physician to assert whether the reported statements or wishes of the patient are trustworthy or strong enough to deduce the patient's willingness or unwillingness to donate, or that the patient was really ignorant about the family's opposition and would not have wanted them to be distressed that much. Hence, the first line of reasoning, referring to the physician's responsibilities for his healthcare team, has to be preferred.²¹

Fourth, it has been argued that the family is a social unit that deserves special protection because it is essential for the flourishing of individuals and society as a whole. The recognition of the family as a special unit and of the right to found a family entails that, as a society, we give them the possibility to care for each other and to regulate their own affairs. Although the right and duty to care for each other does not give them the right to decide whether an organ donation should be performed or not, these do entail the obligation of the family members towards each other to do as much as they can to help the transplant coordinator to find out what the wishes of the potential donor might have been.

Fifth, it could be asked whether the present considerations are against any form of an opt-out system, as in the latter case one cannot always be sure whether the potential donor really wanted to donate or just forgot to opt out. Strictly speaking, the present considerations solely discuss the family's right to decide on the bodily integrity of the possible donors. Whether society or the State has the right to implement an opt-out system and to demand from every citizen that he should actively opt out if he does not want to donate is a complex question requiring further examination. One could possibly argue in favour of an extended opt-out system, which gives the family the possibility of informing the transplant coordinator of the presumed wishes of the potential donor. But it would certainly be ethically questionable to take the organs of a patient who has no known relatives, as in this case the transplant coordinator has no way of finding out about the presumed wishes of this patient.

Bibliography

- Beauchamp, Tom L. and Childress, James F. (2009): *Principles of biomedical ethics*, New York, Oxford University Press.
- Breidenbach, Thomas (2011): Organ donation and transplantation in Germany, in: Jox, Ralf J.; Assadi, Gaïa; Marckmann, Georg (eds.): *Organ transplantation in times of donor shortage*, Cham; Heidelberg; New York; Dordrecht; London, Springer, pp. 115 – 125.
- Bundesärztekammer (2015): *Curriculum transplantationsbeauftragter arzt*, http://www.bundesaerztekammer.de/fileadmin/user_upload/downloads/pdf-Ordner/Fortbildung/Curr-Transplantationsbeauftragter-Arzt.pdf (last access date, 11/10/2016)
- Crane, Misti (2013): Dispute over organ donation brings attention to defining death, *the columbus dispatch*, July 22, <http://www.dispatch.com/content/stories/local/2013/07/22/dispute-over-organ-donation-brings-attention-to-defining-death.html> (last access date, 11/10/2016)
- Deutsche Stiftung Organtransplantation (2016): *Jahresbericht 2015 organspende und transplantation in deutschland*, <http://www.dso.de/servicecenter/downloads/jahresberichte-und-grafiken.html> (last access date, 11/10/2016) (cited as DSO)
- De Wispelaere, Jurgen and Stirton, Lindsay (2016): advance commitment: rethinking the family veto problem in organ procurement, in: Jox, Ralf J.; Assadi, Gaïa; Marckmann, Georg (eds.): *Organ transplantation in times of donor shortage*, Cham/Heidelberg/New York/Dordrecht/London, Springer, pp. 157 – 166.
- Farrell, Anne-Marie and Quigley, Muireann (2012): organ donation and transplantation, in: Chadwick, Ruth (ed.): *Encyclopedia of applied ethics*, London, Elsevier, pp. 288 – 296.
- Grammenos, Dorothee/Bein, Thomas; Briegel, Josef; Eckardt, Kai-Uwe; Gerresheim, Götz; Lang, Christoph; Nieß, Christopher; Zeman, Florian; Breidenbach, Thomas (2015): Einstellung von potenziell am organspendeprozess beteiligten Ärzten und Pflegekräften in Bayern zu organspende und transplantation, *Deutsche Medizinische Wochenschrift*, vol. 129 (24), pp. 1289–1294.
- Hilpert, Konrad (2016): The theological-ethical dimension of organ transplantation in the context of contemporary discussions, in: Jox, Ralf J.; Assadi, Gaïa; Marckmann, Georg (eds.): *Organ transplantation in times of donor shortage*, Cham/Heidelberg/New York/Dordrecht/London, Springer, pp. 83 – 88.
- Höfling, Wolfram (ed.) (2013): *Transplantationsgesetz. kommentar*, Berlin, Erich Schmidt Verlag.
- Hurley, Thomas (2011): The meaning of gift in organ transplantation, in: Jensen, Steven J.: *The ethics of organ transplantation*, Washington D.C. The Catholic University of American Press, pp. 217–231.
- Manning, Allison (2013): Family loses fight to keep son's organs from donation, *the columbus dispatch*, July 12, <http://www.dispatch.com/content/stories/local/2013/07/11/Judge-ordered-family-to-let-brain-dead-son-donateorgans.html> (last access date, 11/10/2016).
- NHS Blood and Transplant (2013): *Approaching the families of potential organ donors, best practice guidance*, http://www.odt.nhs.uk/pdf/family_approach_best_practice_guide.pdf (last access date, 03/12/2016).
- Organ Donation Taskforce (2013): *Taking organ transplantation to 2020, a detailed strategy*, http://www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_long.pdf (last access date, 03/12/2016).
- Ralph, Angelique; Chapman, Jeremy R.; Gillis, Jonathan; Craig, Jonathan C.; Butow, Phyllis; Howard, Kirsten; Irving, Michelle; Sutanto, Bernadet; Tong, Allison (2014): family perspectives on deceased

- organ donation: thematic synthesis of qualitative studies, *American Journal of Transplantation*, (14), pp. 923 – 935.
- Shaw, David and Elger, Bernice (2014): persuading bereaved families to permit organ donation, *Intensive Care Medicine*, 40 (1), pp. 96 – 98.
- Shaw, David and Elger, Bernice (2013): Evidence-based persuasion. an ethical imperative, *JAMA*, 309 (16), pp. 1689 – 1690.
- Stanford, Kyle p. (2006): Sarkar, Sahotra and Pfeifer, Jessica (ed.): *The philosophy of science. an encyclopedia*, New York/Abingdon, Routledge, pp. 400 – 405.
- UK Donation Ethics Committee (2016): *Involving the family in deceased organ donation. A discussion paper*, http://www.aomrc.org.uk/wp-content/uploads/2016/07/Involving_family_deceased_organ_donation_0416-2.pdf (last access date, 03/12/2016).
- Wendler, Dave and Dickert, Neal (2001): The Consent Process for Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?, *JAMA*, 285 (3), pp. 329 – 333.
- Wilkinson, T. Martin (2011): *Ethics and the acquisition of organs*, Oxford, University Press.
- Wood Charlotte, Buss Charmaine, Buttery Andrew and Gardiner Dale (2012): Evaluation of deceased donation simulation, *Journal of the Intensive Care Society*, vol.13 (2), pp. 107–114.

Notes

1. In order to avoid the question about the status of brain-dead patients, the term ‚patient‘ or ‚potential donor‘ will be used to refer to persons considered to be suitable candidates for the cadaveric organ donation. Although the German Transplant Act (TPG) restricts cadaveric organ donation to brain dead patients (Sec. 3 para. 2 TPG), the discussion also applies to the non-heart-beating donors.
2. A systematic review of several qualitative studies of the perspective of families within the cadaveric organ donation process is given by Ralph/Chapman/Gillis/Craig/Butow/Howard/Irving/Sutano/Tong 2014.
3. The German Transplant Act, called ‚Gesetz über die Spende, Entnahme und Übertragung von Organen und Geweben‘ or briefly ‚Transplantationsgesetz‘ (TPG), came into effect in 1998 and has since been revised in 2012 and 2013 (Breidenbach, 2011; Höfling 2013). The revision of 2012 made the nomination of a transplant coordinator mandatory for every hospital performing cadaveric organ donation (sec. 9b TPG). The assistance of the relatives is specified as one of the responsibilities of the transplant coordinator (sec. 9b para. 2 TPG). Nevertheless, the qualification of the transplant coordinators and their position within the hospitals are regulated on a federal level by the so-called ‚Landesausführungsgesetze‘ and may vary considerably within Germany.
4. The officially reported cases are all the cases reported to the ‚Deutsche Stiftung Organtransplantation‘ (DSO), the German Organ Transplantation Foundation (DSO, 2016, 41). The DSO is, among other things, responsible for the organization of cadaveric organ donations, but not for the allocation of the organs. Organ donation, the allocation and the transplantation of organs are legally separated in Germany (Breidenbach, 2011, 115). The hospitals are supposed to report all potential donors,

- i.e. those patients that are deemed suitable for a donation, to the DSO – irrespective of whether in the end a donation will be carried out or not (Breidenbach, 2011, 116). It nevertheless has to be assumed that not all potential donors or brain-dead patients are officially reported, which can occur, for example, for logistic reasons (especially in small hospitals).
5. If one takes these cases to be those that are officially reported to have been decided on the basis of the presumed wishes or of the patient, than they made up at least 40 % in 2015 (DSO, 2016, 50). The real number could be somewhat higher, as the DSO separately records the cases that are decided on the basis of an oral statement. Typically, these statements are reported by the relatives of the potential donor. It has to be doubted that the distinction between an oral statement and a presumed wish can always be drawn sharply in practice. Did the patient really express his willingness to donate during his lifetime (*'I would donate my organs, if they can be used!'*) and how long ago did he say this? Or, has the willingness to donate just been inferred (*'I think that more has to be done to fight the shortage of donor organs!'*), such that this shouldn't be regarded as an expressed but rather as a presumed willingness to donate?
 6. See also Höfling, 2013, 255 ff.
 7. This is why the relative has to have been in personal contact with the patient during the last two years, to make sure that the presumed wishes of the potential donor will be respected (Sec. 4 para. 2 TPG).
 8. The characterisation of these decisions as heteronomous has to be understood as being in opposition to the autonomous decisions of the patient himself and the decisions taken by others (relatives, physicians) in the interest of the patient or his well-being. The latter could be characterised as paternalistic (Beauchamp/Childress 2009, 215 f.).
 9. The difference between the patient's consent and his wish to donate can be formulated as follows: consent includes the willingness to donate having been overtly expressed in written, oral, or some other form (for example through gesture). Having the wish to donate doesn't necessarily presuppose that this wish has been overtly expressed (see for example Wilkinson, 2011, 82 f.).
 10. The reason that nothing is known about the patient's wishes as to organ donation could be that there is nothing to be known because the patient never thought about organ donation, or that his wishes were never 'communicated to those deciding on organ retrieval' (Wilkinson, 2011, 82).
 11. Wilkinson discusses this question and denies that the right not to be distressed is able to found a right to override the patient's willingness to donate. However, Wilkinson claims that physicians should be allowed to refrain from an organ donation if the family opposes it, out of concern for the negative implications for the image of transplantation medicine and the number of organs donated (Wilkinson, 2011, 77 ff.). Although I agree with Wilkinson that the right not to be distressed cannot be used to override the patient's decision, I cannot follow him in some of his subsequent reasoning.
 12. One of the several promising possibilities to train the professional skills, that are necessary for interaction with the relatives during the deceased donation process, consists in the real-time simulation of the deceased donation process (Wood/Buss/Buttery/Gardiner, 2012).
 13. The term *family bonds* should of course encompass the very diverse forms those bonds can nowadays take (for example married, unmarried, homosexual, transgender couples, stepchildren and all sorts of social parenthood) and should not be restricted to the ideal of a married heterosexual couple.
 14. The right to form a family is explicitly mentioned in the Universal Declaration of Human Rights (UDHR) of the United Nations (Article 16, see also Article 12 UDHR). Similarly, the disposal of cultural rights and religious freedom is regarded as fundamental to the development of an individual person's personality (Article 18; Article 22 UDHR)

15. That the families are not always right in what they think are the presumed wishes of their relatives has been shown by several empirical studies within the context of the intensive healthcare and the end of life decisions (Wilkinson, 2011, 65). There seem to be no comparable studies testing the accuracy of the relatives' guesses about the potential donor's attitude towards organ donation (see also Wilkinson, 2011, 66).
16. But as already noted above, Wilkinson claims that the physicians should be allowed to refrain from an organ donation if the family opposes it (Wilkinson, 2011, 77 ff.).
17. In 2012, the nomination of a transplant coordinator became mandatory for every hospital performing cadaveric organ donation (sec. 9b TPG).
18. The simple provision of information on the legal, medical and ethical aspects of organ donation seems to be a desideratum in another professional group, namely the healthcare teams that are typically confronted with the issue of organ donation (for example in intensive care units), as a recent survey suggests (Grammenos/Bein/Briegel/Eckardt/Gerresheim/Lang/Nieß/Zeman/Breidenbach 2015).
19. The aim to maximise the number of donor organs is often mentioned as the main reason to call for a sensitive and ethical sound interaction with the relatives (Ralph/Chapman/Gillis/Craig/Butow/Howard/Irving/Sutano/Tong 2014, 933/Organ Donation Taskforce 2013, 15).
20. In order to avoid a conflict of interest, the German Transplant Act tries to make sure that the persons involved in the donation process are, as far as possible, not engaged in the allocation or transplantation of those organs (see Breidenbach, 2011, 115)
21. De Wispelaere and Stirton discuss a special form of advance commitment, involving the designation of a second consentor, that could be used to resolve, or at least reduce the conflicts arising from the family veto. They argue that the presence of such a living second consentor would make it easier for the family to agree to a donation and that this model also has the potential to relieve emotional stress on the medical staff (De Wispelaere/Stirton, 2016).