

# The role of the relatives in opt-in systems of postmortal organ procurement

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**Abstract** In almost all opt-in systems of postmortal organ procurement, if the deceased has not made a decision about donation, his relatives will be asked to make it. Can this decision power be justified? I consider three possible justifications. (1) We could presume the deceased to have delegated this power to his relatives. (2) It could be argued that, if the deceased has not made a decision, a proxy decision has to be made in his best interests. (3) The relatives could have a standing of their own because they are singled out from the parties whose interests are being affected by the decision by the special relation they had to the deceased. None of these arguments turns out to be convincing.

**Keywords** Opt-in system · Organ donation · Presumed consent · Proxy decision making · Special relations

## Introduction

Legal systems of the procurement of postmortal organs for transplantation are usually classified into opt-in and opt-out systems. Systems of both types aim to respect the decision of the deceased person, whether his decision is to donate or to refuse donation, or to hand over the decision to his relatives (or to some other person). The basic difference between these systems of organ procurement concerns what they take to be the *default*: what will happen when the deceased has not made any decision at all. In pure opt-in

systems the default is that no removal of organs will take place, in opt-out systems that it will take place.<sup>1</sup> In almost all systems commonly known as opt-in systems, however, the actual default is that the decision will be made by the family of the deceased, hence a threefold classification would be more accurate than the present one.

In this paper I want to discuss the role of the relatives in so-called opt-in systems, where the actual default is that they decide. My basic question is whether this choice of default can be justified. As a matter of fact, however, the relatives have a similar role in opt-out systems as we know them. For in such systems the default—removal of the organs—can be defeated in two ways: by the refusal of the deceased person, registered before her death, or by the actual refusal of the family. In some cases this power of veto is recognized by the law, in other cases it isn't, but in actual practice it is recognised virtually always and everywhere.<sup>2</sup> Hence that the next of kin have the last word is the most common, almost universal, feature of the existing systems of postmortal organ procurement.

That the relatives have the last word in all systems, however, doesn't mean that after all there really is no difference between opt-out and opt-in systems as we know them.<sup>3</sup> For even for the way in which they normally use this power it may be relevant what the default is. This may be relevant in itself, but also because of the information it provides indirectly about the preferences of the deceased.

<sup>1</sup> Japanese law requires the consent of the donor for declaring him dead at the moment of brain-death, and hence for the removal of his organs. Lebanese law requires the consent of both the deceased and his relatives.

<sup>2</sup> It is legally recognized in most countries with an opt-out system, but, for example, not in Austria and Italy. For France and Spain see note 11.

<sup>3</sup> As some authors suggest, e.g. Gevers et al. (2004).

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(“He could have refused but he didn’t”). For that reason I will concentrate my discussion on the purest case, which is the role of the relatives in opt-in systems. Having decided whether any justification can be found for taking the decision power of the family as our default, I will then go on to consider the possible justifications of this power as a defeating consideration.

I do not embark on this investigation with a revisionist mind. For such a common feature one expects to be able to find a rationale and it would not be unwelcome to find it. What I have to report, however, is failure in this respect on the whole. The only, rather modest status of the family which turns out to be justifiable is a power of veto in the one kind of opt-out system which can claim to satisfy fully the requirement of consent (Sect. “[First conclusion: the vain pretentions of opt-in systems](#)”).

### Possible strategies of justification

In considering the possibilities of justifying a decision-making power of the relatives within the framework of opt-in systems, we can start by noticing an obvious objection to attributing any such power to them. The common presupposition of the opt-in systems is that, *ceteris paribus*, nothing can be done to the body of a person, not even her dead body, without her consent. Indeed, this is often, albeit mistakenly, supposed to be an implication of the basic human right to bodily integrity. (Wilkinson 2007).<sup>4</sup> My right to dispose of my own body follows from the special relation that exists between me and my body, a relation which fundamentally changes, but does not end with my death. It changes because I am no longer co-existent with my body, but it does not end because as a living person I have a special stake in what happens to my body after my death, for example that it will be treated with respect. It is basically a negative, not a positive right: it prohibits other people to do things with my body without my consent, but it doesn’t give me the power to claim positive efforts from them.

If, however, my relatives are allowed to permit the removal of my organs after my death when I have not made any explicit decision about this matter at all before I died, such decisions seem to violate the requirement of consent.

The same objection can of course be made to opt-out systems as such. This objection can be and has been met in three different ways, which, it will turn out, are possibly available in an analogous way for defending the decision powers of the family in opt-in systems.

<sup>4</sup> As he says, the right to bodily integrity is one of our basic rights because we are embodied beings, but my dead body is no longer the embodiment of ‘me’. He also rightly points out that a right to bodily integrity would not rule out the overruling by the family of a decision to donate, because it is only a negative right.

The three ways of defending opt-out systems differ in the importance they attribute to the requirement of consent. According to the first justification the requirement of consent can be overridden by other important counter-vailing interests. This is recognized by all legal systems which permit post-mortem autopsies of bodies, on the orders of some legal authority, in the interests of criminal justice, without prior consent. It could be argued that the requirement can equally well be overridden by the urgent interests of patients suffering from organ failure in receiving organs for transplantation. In that case the availability of the opt-out option can be seen as a kind of compromise: even if the system doesn’t require consent, it stops short of relying on coercion. In that respect it still differs fundamentally from conscription systems.<sup>5</sup>

According to the second and third justification of opt-out systems there is no need to override the requirement of consent. According to the second justification the requirement can be satisfied. For even if consent has not actually been given, it can at least be ‘presumed’, if the opt-out option has not been used. In the English-speaking world opt-out systems of organ procurement are even usually referred to as ‘presumed consent’ systems. This is unfortunate, for it overlooks the possibility of the first and third justification. The first justification as a matter of fact may have been the most prominent justifying ground for the introduction of such systems in most European countries.

Whether or not a presumed consent defence is available for opt-out systems, turns out to depend on the proper conception of ‘consent’. According to some theorists consent is basically a mental state: to consent to some action means to prefer it to all feasible alternatives. On this conception it makes sense to provide evidence of what a person would have preferred, if she is no longer there to tell us. On the alternative conception of consent it is a public act of authorisation which gives another person a right to do something which he hadn’t before. To consent is to publicly exercise a power of authority in determining other peoples’ rights and duties. On this conception consent can only actually be given, not presumed. If no proper act of authorization has taken place, consent has not been given, whatever we may infer, and infer correctly, about the preferences of the agent. I have elsewhere defended a public act conception of consent, and will presuppose in this paper that it provides us with a decisive argument against presuming consent (den Hartogh (forthcoming); cf. Wertheimer 2003).

According to the third justification it can be allowed that to consent is to publicly exercise an authority. However,

<sup>5</sup> Many opponents of ‘presumed consent’ see hardly any difference with conscription, e.g. Veatch (2000), Etzioni (2003), Bell (2006), and Godbout and Caillé (1992).

situations may arise in which it is impossible for a person to exercise her authority. An exemplary case occurs when a person is transferred to a hospital in a comatose condition after a stroke or an accident, and we have to decide whether or not to reanimate her. We can no longer ask her what we should do, hence we have no alternative but to attempt to act in her best interests as we can best ascertain these to be. In such a case we are not overriding the requirement of consent; it simply doesn't stand in our way (den Hartogh submitted).<sup>6</sup>

These three strategies of defending opt-out systems can analogously be used for justifying the decision power of the next of kin in opt-in systems. I will consider all three of them, beginning with the second strategy (Sect. “[Presumed delegation](#)”), and then proceeding to the third (Sect. “[Donation by procuracy?](#)”) and the first (Sects. “[A gift from the next of kin?](#)” and “[The weakest party](#)”).

### Presumed delegation

Opt-in systems presuppose that your rights over your own body make it unacceptable to take your organs without your consent. But if that is correct, how should we judge opt-in systems as we know them? As we saw in Sect. “[Introduction](#)”, almost no country in the world has a pure opt-in system<sup>7</sup>: if you have not registered any decision, your relatives will be asked to make the decision in your place. How can we justify this power? In particular, how can we reconcile it with your right to make decisions concerning your own dead body? The only remotely plausible way seems to be: by presuming that people who make no decision themselves, consent to the decision to be made by their relatives. From this perspective the existing opt-in systems themselves turn out to be a kind of

<sup>6</sup> I have argued there that there are decisive differences between this case and taking organ removal as our default. I will draw upon that argument in Sect. “[Donation by procuracy?](#)”, but do not presuppose its validity.

<sup>7</sup> See note 1. It is also worth noting that in opt-in countries it is either legally allowed (UK) or common practice (the Netherlands) not to request consent for the following procedures: to go on with artificial respiration until brain death sets in, even if this does not serve any interest of the dying patient himself, and to take steps for preserving the organs, in particular in the case of potential non-heart beating donors (see Bell 2006). Such steps are also taken without prior consent in the programmes, recently introduced in the USA, for retrieving organs from people who have suddenly died from cardiac arrest outside the hospital (Dubois 2009). In the description Wall et al. (2009) give of this procedure it is justified in terms of presumed consent. Requesting consent in the few minutes before ischemic damage occurs is often not feasible, and if it is feasible, many family refusals would probably occur. But if these considerations justify proceeding without actual consent, why is such consent required for taking out the organs? Cf. Verheyde et al. (2009).

presumed consent systems. What they ‘presume’ is consent to delegation: a person does not himself lift the barrier blocking access to his private domain, but he authorizes someone else to lift it.

Such systems are open to the same objection to presuming consent that I mentioned in Sect. “[Possible strategies of justification](#)”.<sup>8</sup> Presumed consent is false money, for what it presumes is only preference, and preference is not consent. It is a remarkable fact about the organ donation debate that so many authors (and parliamentarians) criticize presumed consent systems, often vehemently, as being incompatible with ‘the right to self-determination’, without noticing that the system they support is vulnerable to the very same basic objection.<sup>9</sup> It is based on a counterfeit.

Actually the legal situation is often even worse. The argument of this section concerns opt-in systems which give each person a number of options to choose from, including the option of refusal, and only presume delegation if she doesn't make use of any of those options. But many of the so-called opt-in systems we know do not even satisfy this description. In the UK, in Ireland and in some Swiss cantons it is relatively easy to register consent, in a Donor Register or by filling in a donor card, but it is much more difficult to register refusal, which might require a living will, signed in the presence of witnesses. In the United States both donor cards and state registries usually have the same limited range of options, although in most states one can also tick yes or no on one's driver's license. In some US states, moreover, hospital teams just have to make a reasonable effort to discover a registered will or locate next of kin: if the efforts are unsuccessful, they are free to proceed as they wish (Morris 2002).

Such systems violate everyone's right to decide about their own bodies, including even the right of those who register their willingness to donate. Your right is, justifiedly or not, not fully respected if non-removing of organs is not taken to be the default, but your right is even less respected if it is made difficult for you to register refusal at all. In a system in which refusal would not be assumed as the default and could not be registered at all, consent would lose all meaning. In terms of your authority-right such a system would really be on a par with a conscription system, since it would depend on the will of other people whether your organs would be taken or not.

<sup>8</sup> It may be possible for them, however, to meet the burden of proof, for evidence may be available showing that most people who didn't register a decision themselves, will be happy to have the decision made by their relatives. For the Netherlands see Taelis and van Raaij (2008).

<sup>9</sup> Veatch (2000, p. 161) recognizes that decision by the next of kin is problematic from the point of view of the right of self-determination, but not that it is precisely as problematic as presumed consent and for the very same reason.

The same of course is true of a procurement practice in which, whatever the law says, the next of kin can effectively decide to donate, even if the decision of the deceased to refuse donation is recorded on a valid document. This is reported to be the practice of no less than 43% of the American organ procurement organizations (Wendler and Dickert 2001).

### Donation by procuracy?

It is often suggested that the relatives have a *proxy* right to decide in cases in which no decision of the deceased is known—they are donors by procuracy. In that case they would be duty-bound to make the decision they think he would have made. The suggestion is implied by another argument which has often been made, for example by the legislator of the Dutch Law on the Donation of Organs of 1998. According to this argument opinion surveys show that many more people are actually prepared to donate than have registered a positive decision. In order to create the opportunity that the positive attitude of these people will be acted upon, we give their relatives the right to consent to the taking of the organs. It is obvious that this argument presupposes that the relatives will decide in the spirit of the deceased. They are supposed to be *delegates*.<sup>10</sup> The case, as I pointed out in Sect. Possible strategies of justification, can be compared to the situation arising when a decision has to be made about medical treatment of a patient who is unable to consent himself. In that case many legal systems give a right of proxy decision making to his relatives.

However, such situations differ from the present one in two respects. If a person gets unconscious as a result of an accident, there is usually no time at which he is able to make a decision concerning his treatment himself. He may only be able *ex ante* to provide general instructions, for example about resuscitation, which necessarily leave a large scope for interpretation. (May et al. 2000, 326–327) Moreover, as a matter of fact no legal system requires to ask people to make such an *ex ante* decision. But in most opt-in systems (at least in North America and Europe) the government actively invites all citizens to register a

decision, in a national Donor Register, on a donor card, on a driving licence, or in other ways. If such countries had a pure opt-in system, in which not taking the organs would be the default, they might still have the same mechanisms for consent, albeit not for refusal. In that case every adult person would have all the opportunity he needs to express his consent, or his delegation of the decision to others, and there would not be any need for proxy-decision making at all. Hence that supposed need cannot be a good reason for choosing another default. Similarly, if a person has made no will, on his death we dispose of his inheritance in accordance with default rules provided by the law; we would not consider asking his relatives whether he might have preferred to deviate from those rules.

In the second place, we should ask why so many people do fail to register a preference. Some people are not sufficiently interested in the issue to spend time on making up their minds; in particular, they don't want to be confronted with their own mortality. A much larger number of people are unable to make up their minds. Yes, they are in favour of transplantation medicine because of the extent to which it improves patients' chances of survival and their welfare. But this rather abstract general attitude is counterbalanced by a number of doubts concerning their own individual cases: the burden for the relatives, some mistrust of doctors, the wish to leave the dead body intact for some time, and more or less vague religious objections. Interestingly, these doubts tend to be expressed, not as beliefs to which one clearly subscribes, but only as 'feelings'. (Tael and van Raaij 2008)<sup>11</sup> So it seems that the very failure to register normally indicates either indifference or ambivalence. The person either wasn't interested in making a decision, or unable to make it because of conflicting considerations. If that is the case, by asking her relatives to decide in her spirit we are asking for the impossible. Her spirit has been characterized by indifference or ambivalence, so it can be represented neither by consent nor by refusal. It could be better represented by tossing a coin than by asking the relatives.

So from the point of view of people's right to decide about their own bodies, the idea of proxy decision-making is doubly problematic: there is no need to give anyone that task, and it is normally an impossible task to execute.<sup>12</sup>

<sup>10</sup> That has often been reported to be the public's general view of the proper role of the relatives (Farsides 2000, with further references). In the German transplantation law of 1997 it is explicitly stipulated that this is the task of the relatives; they have to be asked whether the deceased made any relevant statement during his life, and if not what they presume his will to have been. In France and Spain the law prescribes to ask the relatives for confirmation of the consent of the deceased, though in practice they are asked to consent themselves (Nowenstein 2008). Actually, although for most relatives their view of the preferences of the deceased is the most important consideration, it is not always the only or decisive one—far from it (Farsides 2000. Siminoff et al. 2007; Sque and Payne 1996; Sque et al. 2008).

<sup>11</sup> According to Sque et al. (2008) a similar ambivalence between general pro-donation views and (in particular) concerns about the wholeness of the dead body characterizes many relatives.

<sup>12</sup> The next of kin also have the right to demand an autopsy. However, there are considerable differences between this decision and a decision on donation, which makes it difficult to regard this as a precedent. For instance, for lack of relevant information the deceased is unable to take any binding decisions on an autopsy before his death, not even in the form of a veto. In the case of autopsy, therefore, there is every reason to assign the task of representing the deceased's interests to the next of kin after his death.

Moreover, although many relatives earnestly try to decide in the spirit of the deceased, the significant extent to which, as we know, their decision actually is determined by other considerations provides us with an additional reason not to entrust them with this problematic task. If the family refuses to permit the refusal of the organs because they have not been treated with sufficient concern and respect by medical staff, they are, however, understandably, punishing the wrong people.<sup>13</sup>

In many cases families apparently refuse to consent to donation because they believe that they have no right to dispose of the deceased's organs if he hasn't given his consent personally (Eaton 1998; Nationaler Ethikrat 2007, 24).<sup>14</sup> For them the requirement of consent means that refusal is the default. But that is the very position the lawgiver wanted to avoid by empowering them to make a proxy-decision. Obviously the lawgiver fears that a pure opt-in system would substantially reduce the number of organs available for transplantation even in comparison with the present situation of pressing scarcity. But it is doubtful whether that problem really is surmounted by supplementing the system with proxy decision-making. Instead of accepting refusal to be the default, the system asks the relatives to reconsider, but in a context in which *they* naturally continue considering refusal to be the default. People who find it difficult to arrive at a decision may be all too happy to leave it to their next-of-kin, but they only inherit the problem and may 'solve' it in a similar way. "They seem[ed] to regard 'no' as a non-decision" (Sanner 2007; cf. Siminoff et al. 2007).

### A gift from the next of kin?

If the decision power of the family cannot be derived from the authority or the interests of the deceased, this leaves us with only one option for justifying that power: the relatives could have a proper standing of their own. Their decision-power on that view is not to be derived from the authority people have over their own dead bodies, neither by presuming consent nor by supplementing it by proxy-decision making.

Which arguments could we provide in favour of this independent authority? It is sometimes suggested that the requirement of consent rests on an individualistic model of decision-making which is not really accepted by people, even in an individualistic society: most people who register

a decision do so on the basis of collective deliberation with their relatives, and it is the same group, the family, who as such is making the final decision when the person has died. (Boddington 1998, in a tentative way; Lauritzen et al. 2001) Hence we should not consider the individual rights of the deceased but the group right of his family. But this argument confuses the power to decide with a "model of decision-making". There is not the slightest inconsistency in a person having the power to make a certain decision and her actually doing so in close consultation with others or even delegating the decision to them. We need not deny that agents are neither self-reliant nor self-transparent, and hence in their decision-making necessarily depend on others in all kinds of ways (explored in the literature on relational autonomy, as summarized in Mackenzie and Stoljar 2000) in order to go on insisting that certain decisions are up to the agents themselves and not to those others. A recognition of the social embeddedness of 'autonomous' agents does not commit one to hold only families and other groups to be empowered to make decisions regarding those agents. Occasionally the family is reported to decide to which of its (usually junior) members the task is assigned of donating a living kidney to another family member in need of it, but we consider this objectionable because it makes the individual into a mere means for the promotion of the collective interests of the family. So, even if we accept that people normally make such decisions, to register as a donor or to refuse registering, in consultation with their relatives, we are still in need of a justification of the independent authority of the family when no such decision has been made.

To start with, we could point out that donation usually demands a greater sacrifice from the next of kin than from the donor. At a moment that they are still in shock about the incident which took the life of their partner or child, they see their loved one taken into the operating theatre while he does not yet look as if he is dead, and have to wait until he returns in the shape of a real dead body. Sometimes they have to wait for this during the time that artificial respiration is continued until brain death has been confirmed. And they subsequently have to live with the memory of the whole course of events. (Klassen and Klassen 1996; Mongoven 2003, 92) "The true gift comes from the family" (Siminoff and Chillag 1999; cf. Lauritzen et al. 2001).

A first question about this view is whether it does sufficient justice to the point of view of the relatives themselves. Generally speaking, their main concern is what the deceased would have wished. And even if they then consciously decide otherwise, they do not usually do this because they are giving priority to their own interests, but, for example, because they want to protect the deceased's body and thereby his 'person' in a certain sense (Sque et al.

<sup>13</sup> According to Radeck and Jaccard (1997) perceived support of the medical staff is a pivotal factor in consent decisions, cf. Siminoff et al. (2007).

<sup>14</sup> If the relatives cannot agree among themselves, taking out will also be refused, and the same happens when the burden of decision making is too much for the relatives under the circumstances.

2008). Insofar as the next of kin are able and willing to bear responsibility for the decision, therefore, they mainly focus on the deceased's interests as they see them at that moment. They do not claim their personal interests to be protected by their authority.

This does not alter the fact that the deceased's interests are also *their* interests. It could seriously encumber their bereavement and grief process if they felt afterwards that they had failed their loved one at such a crucial moment. However, if we allow them to have an interest which requires to be protected by rights which overrides the authority of the deceased, they are not the only ones who may have such interests. We have also to consider the interests of the patients suffering from organ failure and waiting for a donor organ, and it can hardly be denied that these interests are greater. Transplantation for them may make the difference between life and death, or between a relatively normal and a miserable life. Even when we take into account the possibility of failure of the operation and the adverse side-effects from the immunosuppressants necessary for survival, the overall balance is clear.

But, it could be argued, it is not only a question of who has the greater interests, for the next of kin have special ties with the deceased that also entail special mutual care and responsibility for one another's needs. This special relationship gives those involved the right to concern themselves more with each other's interests than with those of anonymous strangers. It could be argued that this special relationship still has this significance when one of the people involved in it has died, which is why it is proper to give the next of kin priority over potential recipients of the deceased's organs. They are being asked to make a sacrifice, and they are the ones to decide whether or not they wish to make it.<sup>15</sup>

This seems to be the basic argument for the independent authority of the relatives. How should we assess it? Both of the premises on which it is based are indisputable: the next of kin have a genuine interest in the decision on donation, and they (usually) have a special relationship with the deceased. And I do not at all wish to deny that this special relationship has a moral significance. In his *Enquiry concerning Political Justice* (1793), William Godwin, the founding father of both utilitarianism and anarchism, discusses the dilemma facing me if I am only able to rescue one person from a house on fire: either Archbishop Fénelon (a philosopher who Godwin greatly admired), or his chambermaid, who also happens to be my wife, mother or benefactress. According to Godwin, it is a requirement of 'pure, unadulterated justice' to save the philosopher:

"What magic is there in the pronoun 'my', to overturn the decisions of everlasting truth? My wife or my mother may be a fool or a prostitute, malicious, lying or dishonest. If they be, of what consequence is it that they are mine?" However, anyone seriously able to subscribe in this way to an impartial principle is not capable of forming close intimate relationships. Therefore, we are not to be criticised for giving particular care and attention to people with whom we have a special relationship; on the contrary, if we did not do this we would demonstrate that we have no sense of the true significance of this relationship. The simple pronoun 'my' does indeed have magic.<sup>16</sup> That, indeed, may be the moral basis of the whole practice of living donation. (Hilhorst 2005).

But is this a sufficient reason for allowing the next of kin to decide? There are two reasons to have doubts. In the first place, even if we allow the special claims implied by special relationships, it does not follow that they simply eclipse all other claims. Let us grant that the donor may multiply his own interests and those of the people with whom he has a special relationship by a given factor before he weighs up these interests against the recipient's needs. The moral magic of the pronoun 'my' is in that case already included in the criteria for the existence of a duty to help others in an emergency. This corresponds to the common understanding of the duty as it has been classically expressed by Thomas Aquinas: "Those who fail to give a gift are in danger of committing a mortal sin: from the recipient's point of view, if a clear and urgent need becomes apparent and no helper appears and from the giver's point of view, if he can spare that which is not necessary to him in view of his present situation..." (*Summa Theologiae*, 2ae, q. 32, a. 5, quoted from Schenderling 2003) Even on this loaded weighing of interests, the needs of the patients seem paramount. After all, research has shown that the donation process has no lasting psychological consequences for the surviving relatives, not even if they have doubts about the donation afterwards. (Cleiren and van Zoelen 2002).

Moreover, our duties vis-à-vis the patients may not be exhaustively described by conceiving of them as duties of rescue. For everyone of us can during his lifetime get organ failure to an extent at which he can only be helped by a transplantation, and therefore everyone of us benefits from the existence through time of a pool of organs available for that end, by the assurance it provides of assistance in a possible future emergency (Cleiren and Van Zoelen 2002). Contributing to that pool therefore means participating in a

<sup>15</sup> This important argument is rarely found in the literature. It is briefly outlined by Engberts (2005).

<sup>16</sup> This should not be interpreted as criticism of utilitarianism in general; utilitarians are able to acknowledge the importance of special relationships and make allowances for them.

collaborative arrangement for mutual benefit, and therefore could be seen as an obligation of fairness.<sup>17</sup> And special care relationships are not taken into account in forms of cooperation for mutual benefit in which contributions and profits are directly coordinated. Those who voluntarily contribute less have fewer rights: the reasons why they contribute less are not important. We cannot evade our duty to participate in dyke surveillance during a gale on the grounds that the gale also poses a threat to our bicycle sheds or those of our children or neighbours.

So even if we agree that the relatives have relevant interests and their interests should generally be given extra weight because of their special relationship to the deceased, it does not follow that these interests should be given priority in this particular case. Even if we only have duties of rescue to the patients with organ failure, their interests seem to deserve priority. If, in addition, we have duties of fairness to them, their interests need only be weighier than those of the relatives to be paramount. And they are.

It could be objected that this counterargument only shows that the relatives should use their authority to decide by giving priority to the interests of the recipients, not that they don't have the authority. This brings me to the second reason why the present argument for the independent status of the relatives fails. The appeal to their interests, and the additional weight those interests acquire from their special relationship to the deceased, does not establish that they have any authority. Dead bodies are not usually considered to be property that can be inherited. But even if proprietary rights to dead bodies were to pass to family members through inheritance, the duties we have discussed would still be attached to these rights. It is true that, even if it is allowed that these duties exist, it is an open question to what extent they should be regarded as enforceable. If they should not, we would have the right to refuse to register as a donor despite the fact that this decision is liable to moral criticism. However, the same cannot apply to our next of kin. Even if we had the right to set aside our duty for the sake of their interests, it does not follow that they also have the right to set aside our duty for the sake of their own interests. The interests of the family are a consideration to be given its proper weight, but it does not follow that they are protected by rights and powers of decision. (Wilkinson 2007, 34).

Suppose it did follow. In that case the relatives would be entitled to this position of authority because a greater sacrifice is required from them than from the deceased himself. But if that were the case, the relatives should also be entitled to veto the deceased's own decision to register

<sup>17</sup> More needs to be said to establish that duty, cf. den Hartogh (2011), with further references.

as a donor. This kind of double veto is legally recognised in countries such as Great Britain. However, it is widely accepted, and in some countries, including the USA and the Netherlands, legally established that registering a willingness to donate not only means that consent has been given for donation, but also that the relatives must respect this consent.<sup>18</sup> In that event, the relatives cannot invoke the special relationship they had with the deceased. But this means that they cannot directly derive any right to decide from this special relationship, since they would then be able to exercise this right with respect to the deceased, too. If the special relationship does have any significance, this is only because the deceased conferred this significance on it before his death. He must have done so explicitly. If the next of kin are only entitled to the right to decide because the deceased has conferred this right on them, default cannot lie in delegation.

### The weakest party

There is one more argument in favour of this placement of the default that I would like to discuss, in particular because it sheds an interesting light on the meaning of default as such. Choosing the default is of immense importance in contract law. Marie Jacob has interestingly pointed out that the default in that domain is often determined in such a way as to protect the interests of the party with the weakest negotiating position. The reason is that if the other party wants to depart from the default, he will be obliged to open explicit negotiations in this respect, which will invariably involve additional costs. (Jacob 2006).

Jacob is of the opinion that in the case of organ donation, the patients in need of help have a stronger negotiating position than the deceased.<sup>19</sup> But she entirely

<sup>18</sup> In the Netherlands only 40% of the population concur with the proposal not to ask for the consent of the next of kin if the deceased is a registered donor. (Friele and Kerssens 2004, 18) The Dutch Organ Donation Act nevertheless has an explicit provision of this kind since 2006. Most American states have similar laws, as well as Canada, Australia and Switzerland, and of opt-out countries Belgium. But as a matter of fact in none of these countries a persistent refusal by the family to go along with the registered decision of the deceased to donate will be overruled, and such refusals regularly occur, in the Netherlands in 8% of the cases. In the USA only 12% of the OPO's will in such a case overrule the refusal of the family (Wendler and Dickert 2001).

<sup>19</sup> Her argument is that patients are supported by the institutional power of the hospitals, but this is by no means automatically the case. In many cases it is the task of the intensivists who were responsible for the care of the deceased to ask the next of kin to consent to donation, and they tend to identify with the relatives, not with the organ recipients, see Sect. "Donation by procurement?"

disregards the position of the family in the issue. In practice, all over the world the next-of-kin have the last word, and if only for this reason, the question of which party's negotiating position should be strengthened should primarily be considered in relation to relatives and patients. Of these two parties, patients waiting for an organ are clearly in the weaker position. All they can do is wait and see which way the decision will go, whereas the next of kin can make their voices heard there and then. As long as their relative is still alive, they are entitled to information on his treatment. If this relative is not a registered donor, in many jurisdictions their permission already has to be obtained in the case of preparatory measures for the preservation of the organs. Furthermore, the next of kin are in such a difficult situation anyway that we dislike the idea of confronting them with the additional burden of asking them to consent to donation. (As well as with all the relevant information that may be highly confusing, such as the concept of 'brain death'.) Given the situation, it is almost in bad taste to point out their moral duties to them, whether or not such duties exist. In many cases, the doctors who ask for their consent have just had to relinquish their efforts to save their partner or child, and rightly feel jointly responsible for ensuring that the family are able to come to terms with this death as much as possible.<sup>20</sup> All these circumstances contribute towards giving their interests at least the weight they deserve to be given, and probably more.

It follows from this argument that we can even recommend transferring the default to 'donation', *without* invoking the moral desirability of donation, let alone any moral duties. If we ask ourselves how the interests of all parties concerned are actually weighed up in the decision-making process, we see that patients waiting for an organ run the greatest risk of insufficient justice being done to their interests. This also emerges from the actual results of the process, with its alarming rates of family refusal.

Even if there were a reason for allowing the next of kin to decide if the deceased himself has not registered any decision, this does not mean that we should deliberately keep this option open. The whole idea that we not only ask the next of kin for a gift simply because we have no choice, but even make a point of seeking the opportunity to be able to do so, is highly problematic. It is preferable to refrain from asking people for help in an emergency if these people themselves are in dire straits: this is not fair to either

the givers or the recipients (Spital 1996).<sup>21</sup> For this reason alone, we should prefer systems in which the decision is made in advance, in terms of the consent of the deceased or the needs of the recipients, or some combination of these considerations.

### First conclusion: the vain pretensions of opt-in systems

Opt-in systems claim to respect the requirement of consent, which they hold to be implied by the authority of people in regard to their own bodies, including their dead bodies. This is the basic justification of such systems, in all countries which resist the introduction of opt-out systems, in spite of the evidence that these yield better results, in terms of the number of postmortal organs becoming available for transplantation.

It is true that opt-out systems as we know them are not fully compatible with the requirement of consent. But exactly the same is true for almost all opt-in systems, and for exactly the same reason. When no legally valid decision of the deceased has been registered and the next of kin decide nevertheless to donate, the requirement is violated even if the decision is made in the spirit of the deceased. For in such cases no actual consent has been given, and there is no need for supplementing actual consent by proxy consent. No-one who accepts such systems can consistently object to opt-out systems. As we have seen, some opt-in systems are even guilty of more grave violations of the requirement than at least some opt-out systems, because they make it more difficult either to have one's refusal of donation registered, or one's registration effective.

There is an additional point to be made which reinforces this conclusion. The requirement of consent is supposedly implied by the right to make decisions about one's own body, even after one's death. But the number of options you are actually given to choose from is extremely limited. You can decide to be buried or to be cremated, you can perhaps present your body to be used in medical education, and you can be a donor. That's about it. You cannot normally decide to have your body mummified and set up in the hall of your *alma mater*, you are not allowed to be laid down in a small boat to be delivered to the infinite ocean, and you cannot give permission for your mortal remains to be fed to the tigers in the zoo. Most of these limitations are

<sup>20</sup> Which is one good reason why he should not be the person who opens the issue of donation with the family. Streat's (2004) plea in favour of the family's right makes this perfectly clear by showing how an intensivist experiences the situation: the person who registered as a donor is dead, potential organ recipients are far away and he is confronted with the family and their grief. Cf. Nowenstein (2005, 180–182) about the attitudes of French doctors.

<sup>21</sup> According to research by Sque et al. (2008) and Siminoff et al. (2007 973), resp. 41 and 44% of the next of kin decide to refuse consent to donation because the circumstances have already put such a strain on them that they are unable seriously to consider the request for consent. It is hard to reconcile this finding with the statement of Sque et al. that being asked for donation does not create an additional burden for the family.



uncontroversial because they follow from the harm principle: dead bodies left alone are a danger for everyone coming into contact with them. Other limitations are justified on the offence principle: they forbid actions which are supposed to show a lack of respect, not only for your person but for humanity as such. This is also the main reason given for the strict prohibition to give your body or part of it to others on condition of any valuable reward.<sup>22</sup> But in addition to these limitations, in most countries the only conditions you can stipulate for being a postmortal donor concern the specific organs you permit to be removed. You are not allowed to limit the class of possible recipients, either to a person or to a class of persons, not even to a harmless class like children. In this respect your position is that of an individual seller facing a monopsonistic buyer. You are being offered a standard form, and your options are only to sign or not to sign.

These limitations of your authority-right need to be justified. It may be possible to provide such justifications for each limitation, but then it may equally be possible to justify taking out organs as the default, even if that would involve another limitation. If one category of limitations cannot simply be blocked by appealing to our ‘right of self-determination’, neither can the other. People who reject opt-out systems as infringing their right but accept that organs cannot be sold and donation cannot be directed, owe us an explanation why this particular inroad on that right is so different from all the others.<sup>23</sup>

If we insist on the requirement of consent for organ donation, opt-in systems as we know them are equally incompatible with that requirement as opt-out systems as we know them. However, it may be possible to design an opt-out system in such a way that it is fully compatible with the requirement of consent, and in that case the same is true about a system in which delegation to the family is the default. In such systems every inhabitant of the country who has not registered a decision is clearly and regularly informed of what will happen when she dies leaving organs suitable for transplantation: removal of the organs (in the case of an opt-out system), or a decision by the family. And, as second condition, it must be easy for everyone to change her registration, by filling out a short form, and

sending it postfree or online to the registration office.<sup>24</sup> If a person does not use that option, we are allowed to take her to give her consent to acting as the default prescribes: that is not a presumed but a tacit consent, and tacit consent can be genuine actual consent (den Hartogh (forthcoming 2)).

In the present climate of opinion in countries accustomed to an opt-in system and its (false) claims, a suitably modest proposal might be to introduce as the default in such a system of tacit consent that the organs will be removed unless the family persistently objects. It may be true that this is acceptable anyhow to the majority of people who do not explicitly consent. That fact, as I argued, is not enough by itself to warrant concluding that they (“presumably”) consent to delegation, but under the conditions stated it may justify a legal provision to that effect. For within limits of reasonableness and fairness the law can stipulate what counts as consent. That system has two advantages in comparison to the usual opt-in systems: it always provides the relatives with at least some information about the preferences of the deceased, and it legitimizes approaching the relatives in a non-neutral way, asking them to give reasons for their objection, not for their consent.<sup>25</sup>

It may even be possible to offer a more principled justification for this approach by appealing to the social embeddedness of autonomous decision-making. In the literature on relational autonomy it is suggested that a necessary (or at least a supporting) condition for such decision-making is that the agent has some particular attitudes towards himself, attitudes of self-esteem and self-trust, and that a necessary (or at least a supporting) condition for such attitudes to persist is social recognition of the agent by others, in particular by his close relatives and associates. (Mackenzie 2008; Anderson and Honneth 2005) In order to maintain the social relations needed for autonomous decision-making people therefore would justifiably prefer to be supported in the major decisions they make as regards their own life by their relatives, and this preference tends to give these relatives some informal standing in the decision-making process. If this is correct, it does not justify ascribing a formal standing to the relatives irrespective of the agent’s actual consent, but it may justify

<sup>22</sup> See the characteristically fine discussion in Feinberg (1985, 72–75). For the prohibition other reasons are often provided, e.g. the possibility of exploitation or resulting inequalities of access, but such effects can be prevented by institutional arrangements. That the sale of organs is seen as degrading seems to me the reason most basically motivating the opposition to it, perhaps in addition to the idea that the profit motive would crowd out altruistic motives.

<sup>23</sup> See den Hartogh (2002, pp. 67–71) for a criticism along these lines of the consent theory of political obligation. If these limitations on our options can be justified by other considerations without requiring consent, why is consent necessary?

<sup>24</sup> A system like this is at present being discussed both in Germany and in the Netherlands. See Nationaler Ethikrat (2007); Coördinatiegroep Orgaandonatie (2008).

<sup>25</sup> It is open to discussion whether or not we should retain in that system the option to register as a donor explicitly. This only makes sense if the law does not allow the relatives to overrule that decision. The effect might be that some of the people who now decide to register will not do so anymore, and in those cases the number of family refusals may be increased. But this may be more than compensated by the decreased number of family refusals in the case no registration had been made. See den Hartogh (2008, pp. 102–106).

giving such a standing a default status in the legal recognition of a form of tacit consent.

### Second conclusion: the role of the relatives

If, on the other hand, it is accepted that the requirement of consent is not absolute, it does not follow that your next of kin could be given the power to decide whether or not to allow the removal of your organs for transplantation when you have died. For it cannot be shown that the interests of the relatives have a greater moral weight than the urgent needs of patients waiting for an organ.

Undoubtedly the relatives have special interests in what happens to the body of the deceased. The donation procedure interferes in complicated ways with the process of taking leave, and they are the ones who have to live on with the memory of that process. That is why the procedure should be adapted optimally to their needs, and why they should be properly informed about the procedure and be given adequate support during it. But it is hard to see how even the maximal protection of these needs could imply a power to decide about donation, overruling the claims of the patients on the waiting list. It may even be true that in requesting them to decide we unnecessarily create an additional burden for them.

So how do we explain the almost universal grant of at least a power of veto to the relatives? It is often pointed out that an overruling of substantial resistance of the next of kin would risk creating a scandal in the media which could do great harm to the general willingness to donate. But this presupposes already the general feeling that such resistance has a claim to be respected, and it is that feeling which is in need of a justification.

I have not been able to find this justification. My provisional conclusion therefore is that the fact that next of kin are granted the last word in so many countries, sometimes contrary to statutory regulations, is not based on an adequate moral justification, but on the sole fact of their presence on the scene and the special consideration for their circumstances required at that moment. (May et al. 2000; Bucklin 2002) “(T)heir state of mourning gives them the right to oppose the harvesting of the newly dead.” (Nowenstein 2005, 181, summarizing the views of French intensivists) The doctors who make the request, usually the intensive care physicians who have been responsible for the treatment of the deceased as well, rightly feel a role conflict between their traditional role of providing as much comfort to the relatives as possible and the duty to make the request. This role conflict often causes them to shy away from upsetting the relatives by “begging for body parts” (Sanner 2007).

Even if no justification can be found, we should perhaps regretfully permit transplant doctors to abandon the

removal of suitable organs if the relatives have strong unsurmountable objections to it. But that will be done out of consideration for their distress, in a situation in which they already have to cope with the (often sudden) death of their partner, child or sibling, and in full awareness of the wrong we thereby do to patients suffering from organ failure. It should not be done in recognition of a right to decide.

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