Tacitly consenting to donate one's organs

den Hartogh, G.A.

Published in:
Journal of Medical Ethics

DOI:
10.1136/jme.2010.038463

Citation for published version (APA):
den Hartogh, G. (2011). Tacitly consenting to donate one's organs. Journal of Medical Ethics, 37, 344-347. DOI: 10.1136/jme.2010.038463

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Tacitly consenting to donate one’s organs

Govert den Hartogh

ABSTRACT

The common objection to opt-out systems of postmortal organ procurement is that they allow removal of a deceased person’s organs without their actual consent. However, under certain conditions it is possible for ‘silence’—failure to register any objection—conventionally and/or legally to count as genuine consent. Prominent conditions are that the consenter should be fully informed about the meaning of his or her silence and that the costs of registering dissent should be insignificant. This paper explicates this thesis and discusses some possible objections to it: (1) it cannot possibly be guaranteed that each citizen is aware of the meaning of silence; and (2) the system is slightly manipulative because it exploits a common defect in autonomous decision-making.

It is generally assumed that people have the authority to decide, with respect to their own bodies, what other people are allowed to do. This authority does not only concern their living, but also their dead bodies, although it may be mistaken to take the second authority to be implied by the same basic right to bodily integrity as the first one. If this authority is granted, it follows that organs should not be removed post mortem for transplantation ends without the consent of the deceased. Opt-out systems of postmortal organ procurement, however, do not seem to respect this requirement, for they allow the removal of the organs unless the deceased (or his family) has explicitly objected. This is the main reason why countries such as the USA, the UK, Germany and The Netherlands still hold on to an opt-in system, even though, according to the majority opinion of experts, opt-out systems have better results in terms of organs becoming available for transplantation. It is remarkable that the actual opt-in systems adopted by those countries are vulnerable to the very same objection, because in cases in which the deceased has neither registered his consent nor his refusal they allow his relatives to make the decision. The fact that opt-in systems are also open to it, however, by itself does not invalidate the objection to opt-out systems.

There are several possible ways of meeting it. The most obvious way is to recognise the requirement of consent, but to hold that it can be overridden by pressing moral considerations, as all legal systems acknowledge when they allow autopsies to take place without the consent of the deceased. An alternative defence of opt-out systems suggests that even if in a particular case we have no compelling evidence of the consent of the deceased, we may have reason to ‘presume’ it. Actually, in the English-speaking world opt-out systems are generally known by the proper name of presumed consent systems. The appeal to presumed consent, however, turns out to be based on a mistaken conception of consent. If to consent to donation meant desiring it or preferring it to non-donation, it would make sense to act on the mere probability of such a desire, but if the requirement of consent is implied by our authority to make our own decisions, we have to exercise it by actually making such decisions. Consent, in this view, is not a mental state but a public action with normative consequences. On a mental state view there might be no safe side to err on, but on the public action view there is: it is wrong to act without consent, but not to abstain from action in spite of consent. One does not get a claim of having one’s organs removed merely by consenting to it.

In this paper, I want to consider an alternative way of justifying at least some possible opt-out systems, leaving it open to what extent actually existing ones can be justified in this way. According to this argument, when certain conditions have been met, the very fact that a person has not registered a refusal to have his organs removed provides us with sufficient evidence of consent. Such tacit consent should not be taken as a species of presumed consent, but as a form of genuine valid consent, fully legitimate even on a public action conception of consent. In giving their consent tacitly people are exercising their authority to make binding decisions about the fate of their mortal remains.

THE APPEAL TO TACIT CONSENT

Consider the following variant of the opt-out system. On reaching the age of 18 years each citizen is sent a letter asking him to register a decision concerning donation in the national donor register. The options include consent, refusal and delegation, to one’s relatives or to a specific person, or perhaps even a conditional consent, giving the relatives a right of veto. If one fails to respond, the invitation is repeated a year later. If one still fails to respond, one is informed of being registered as a donor, and of

As Wilkinson says, the right to bodily integrity is one of our basic rights because we are embodied beings, but my dead body is no longer an embodiment of me.

Doctors may have a duty to act on consent, but that will be a duty to the recipients of organs, not to the donors. I have elaborated the argument in this paragraph elsewhere. Probably none: not enough has been done to make sure that citizens know what will happen to their organs when they die without having registered any decision, and people do not commonly understand each other’s failure to object as a way of consenting. The German Ethics Council interprets the system described in the next section as embodying presumed consent, and even mistakenly (see note 1) concedes that it encroaches on the deceased’s bodily integrity, arguing, however, that this can be justified by the interests of the recipients.
the way to revise one’s registration (by filling out a short form on paper or on-line). At regular intervals (let’s say once in 5 years) one is informed again of one’s status and of the possibility of revision. A system like this is at present being discussed both in Germany and in The Netherlands. The German Ethics Council calls it a two-tiered procurement system, the first tier consisting of an open choice between registration options, the second one of being registered as a potential donor on not making any choice at all. The name suggests that it is only an opt-out system on account of the second tier, but this is somewhat misleading. For already in the first tier, when all options can be chosen, it is relevant to know what the default is.

In such a system a person who does not register anything, neither consent, nor refusal, nor delegation, can indeed be considered to give his tacit consent to the post mortem removal of his organs. Consent can be given in many ways; on auctions a small movement of one’s little finger is sufficient. What counts as consent may be to some extent naturally given, but in addition it is largely a matter of convention, and it is often authoritative determined by the law. Situations in which ‘silence’—an opportunity to respond is given but not taken—is interpreted as consent by law or custom are very common. If my bank informs me that I will no longer receive balance sheets unless I declare that I prefer to get them, and I do not object, I am considered (not ‘presumed’) to have consented to not receiving them any more. If I am repeatedly informed that I will be registered as a donor unless I make an explicit choice for an alternative and I fail to make that choice, my silence properly counts as consent, if the law says it does. It has been objected that even if people know their registered status, they may not be interested enough to give the matter more than a fleeting consideration. An objection rests on a misunderstanding of the requirement of ‘informed’ consent: if people choose to disregard the information before consenting, that is up to them, it does not invalidate their consent. To insist on an extensive consideration of the pros and cons would be a form of paternalism in the name of autonomy.

That tacit consent can be a form of genuine consent can be verified by inspecting the necessary conditions for the validity of any form of consent. The competence of the consentor and the voluntariness of his consent clearly create no special problems. An important condition is that the consenting person should be fully aware of the issue and of his options. In the case of tacit consent this means in particular that he should know what it means to remain silent. Moreover, he should also know that others know this, and vice versa; in other words, the meaning of a failure to dissent should be a matter of common knowledge. (This condition is insufficiently stressed in the literature.) This requirement of common knowledge holds in all cases, not only in cases in which the interpretation of an act or omission as constituting or implying consent is given by custom or law. In the end it is the fire that counts, not the match. In a newspaper I came across a letter from a reader who compared the government that would introduce a tacit consent system to a person who sends goods to people which they have not asked for, then requiring them to pay for the goods or return them. But in that case the omission to return the goods is not commonly known to constitute or imply consent, nor would it, for obvious reasons, be desirable to introduce such common knowledge by legislation.

The consenting person should also have easy access to all relevant information about his options and the consequences of taking any of them. (As I suggested, it is up to him to decide whether or not to digest that information.) Another condition worth mentioning is that the person should be given a reasonable period of time, with a clear terminus, for making and expressing his decision, silence counting as the appropriate expression of one possible choice. Finally, the costs of registering dissent should be low, or even insignificant. In the case of explicit consent this is normally the case, although even then only contingently. (It may be very difficult to do nothing.) My claim is that an opt-out system like the variant I described satisfies all those requirements for interpreting abstaining from registering objections as genuine, albeit tacit consent.

Because proper tacit consent is a form of genuine consent, the tacit consent system actually is a mandatory choice system. It has the advantages but not the disadvantages of the no-default system usually referred to by that name. It has been claimed that ‘the essential ethical advantage of required response is its undiluted loyalty to the value of individual autonomy’, but this is equally true of tacit consent. It registers a relevant decision of every adult citizen or resident. With one exception, to be discussed presently, it guarantees that the relatives have some information about the preferences of the deceased, which the present opt-in systems do not give them in the majority of cases. That is the item of information they consider themselves the most relevant one for their decision. In addition, they do not have to make a decision at all if they do not feel up to the task, but unlike the standard mandatory choice system the tacit choice system does not rely on sanctions that are likely to be interpreted as forms of détourment de pouvoir and hence invite people to refuse donation out of resentment.

People have an authority-right to control the entrance into their personal domain, including their bodies, but if they are properly informed about someone’s wish to enter it and only need to say ‘no’ to prevent the execution of that wish, they have all the control they need. Therefore, a tacit consent system fully respects their authority-right.

It is true that in some cases special reasons may exist for insisting on explicit consent. In some countries for such reasons formal written consent is required for any invasive medical procedure to be undertaken. (Note, however, that ‘invasive’ in this context refers to the living body.) For similar reasons we would not be content with tacit consent for allowing the donation of living organs. In such cases the dangers of erring on the unsafe side appear to loom very large, either because of the probability or of the catastrophic consequences of error, or both. On some other issues it may be controversial whether for such reasons explicit consent is or should be required. The post mortem removal of organs is not one of
those issues. If, for example, people have religious reasons for being very much opposed to having their organs removed, a system such as the one I described gives them all the opportunity they need for acting on such reasons.

CAN THE CONDITIONS FOR TACIT CONSENT REALLY BE SATISFIED?

It could be objected that no system can guarantee that really everyone will know his status: some people do not open their letters, in particular when they have been sent by government agencies, others are unable to read, or can read only in languages that will not be used in the invitation to register.31 It should be noted that most of these people in such matters rely on the assistance of others, otherwise they could not function in a modern society at all, but for some of these people it is true that the conditions for ascribing tacit consent to them will not be satisfied. We could reply that such problems occur in opt-in systems as well: illiterate people are unable to register as a donor, even if they would prefer that option if they knew they had it.31 The force of this reply depends on the mental state conception of consent I rejected. The right to make decisions concerning one’s body is a negative authority-right, and this means that in regard to consent there is a safe side to err on: abstaining from taking out the organs is the proper default. If you do not know that you have the option to register as a donor, your right is not violated, as it is sometimes suggested.22 23 You only lack an opportunity to exercise it. However, impure opt-in systems as we know them, as well as mandatory choice systems, really are necessarily confronted with the same problem, and to the same extent: the very same persons who lack the capacities and the external assistance to get to know that silence means willingness to donate will not come to understand either that it means delegating your decision to your relatives, even if every possible measure has been taken to inform them about that.

It should simply be conceded that the objection points to a real problem for any system of tacit consent. Short of introducing a new register with data about the relevant capacities of reading and understanding of all inhabitants (suggested by Neades,24 probably in the spirit of a reductio ad absurdum), there may be other means of identifying most of these people. If the default of the system is interpreted as: I consent to donating unless my relatives object, the relatives will usually know that the deceased did not understand this, but the problem cannot fully be solved. This problem, however, is not special to this domain. The fact is that the modern state has no alternative but to arrange its relations to its citizens on the presupposition (the presumption) of minimal literacy. It cannot excuse illiterate people for not paying taxes, violating the law unwittingly and so on. Educational policies should aim at promoting literacy, and assistance should be freely available for the remaining illiterate individuals; that is all the state can do.

THE JUSTIFICATION OF TACIT CONSENT

Another common objection to the choice of organ removal as the default is that it violates your right to self-determination because you are obligated by this choice to spend some minutes of your valuable time on filling out a donation form.25 It is, however, an inflation of the notion of ‘rights’ to use it in this context. What the objection refers to is a presumption of liberty: there should be good reasons for restricting the liberty of citizens. This presumption should be clearly distinguished from the right to make decisions concerning one’s body, dead or alive. It is quite common for citizens to be burdened by chores in the general interest; to fill out a form and return it post-free or online must be one of the least burdensome. Surely the interests of patients with organ failure provide ample justification for such a requirement.7 The mere fact that registering dissent is not altogether cost free does not amount to a form of coercion or pressure that might possibly invalidate the consent given by abstaining from it.

A final objection is the following. If opt-out systems generally tend to have better results than opt-in systems, even when the burdens attached to registering consent and refusal are hardly distinguishable, this has to be explained by the general relevance the choice of the default has in people’s decision-making. In deliberation people need clear and decisive reasons for deviating from the default, and in cases in which it is difficult to weigh the reasons pro and contra they will usually stick to the default. This explains the fact that the number of consenters in opt-out systems with the largest number of dissenters exceeds the number of consenters in opt-in systems with the largest number of dissenters.26–28 It also explains why the rate of family refusal in cases in which no explicit decision by the deceased has been registered is much lower in opt-out than in opt-in systems. This fact, however, means that even if abstaining from dissent can be said to amount to valid consent in a particular system, such tacit consent will tend to be less fully rational than valid consent in an opt-in system. If that is true, it might be said that by choosing the removal of organs as the default, a government to some extent manipulates its citizens in the interests of harvesting organs.29 xii

One way of dealing with the objection would be to grant it. Yes, maybe there is some moral cost involved in choosing organ removal as the default, even in a tacit consent system. That moral cost can, however, be outweighed by the benefits of the greater number of organs becoming available for transplantation.29 xiii

I believe that a stronger reply is available. We may welcome that greater number of organs without considering it to be the justifying ground for our choice of the default. The possible bad consequences of having one’s organs removed are normally very limited, both for the deceased (although I do not deny that such consequences may exist) and for his relatives, and this means that one normally has a strong moral reason to make one’s organs available for transplantation to people with organ failure. That is enough for taking removal to be the default. The manipulation objection fails, because such a system presents no hindrance at all for people to be clearly and fully aware of the existence of that moral reason, and act on it by consenting, explicitly or tacitly. Even if they are only dimly aware of it, it is to be preferred that they act on it.

If patients with organ failure have a moral claim on us to make our organs available to them after our death, but a conscription system, for reasons of principle or practicality, is not an option, we should at the very least adopt organ removal as the default. That need not even be a restriction or limitation of people’s authority-right to decide about their own dead bodies.

*People who fail to open their letters can be said to do so at their own peril. The real problem is lack of ability, not unwillingness.

*Note again that the objection equally applies to opt-in systems as we know them, which identify the decision by the family as the default.

*As Hausmann and Welch27 recognise. Note that this particular argument appeals to the benefits for other people, not for the consenters themselves. The argument for changing the default is not really a case of ‘libertarian paternalism’ at all, as it is presented by Thaler and Sunstein.28
Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES