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ORIGINAL ARTICLE

Can we turn down autonomous wishes to donate anonymously?

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Summary

Imagine a Samaritan living kidney donor, who some time ago has anonymously donated one of his kidneys to a patient on top of the waiting list. He now contacts the transplantation centre once again, to donate part of his liver. The Centre, startled by this idea, refers him to the regular screening procedure for all Samaritan donations. It turns out that his wish is well-informed, voluntarily made and that he is competent to decide. We acknowledge that a donor's wish should not be followed in all cases, even though this wish is a clear expression of his own free will. However, a refusal must be based on sound moral reasons and it is less clear what reasons these might be. We outline the most common arguments for refusal, assess these arguments in terms of strengths and weaknesses, and show which arguments, if any at all, are most promising. We conclude, firstly, that we should only assess risks (which include motivations), not judge relationships, and secondly, that it is not a transplant centre's mission to carry out a donor's life project.

Introduction

Developments in organ transplantation continue to raise new ethical issues. One trend, ascribable to persistent scarcity, is a small but significant increase in Samaritan kidney and liver donations. Several studies show a remarkable willingness in the general population to donate [1,2]. Our centre in the Netherlands has developed a successful programme in kidney donations that includes altruistically motivated donations to strangers [3]. It challenges our normative views with respect to related and unrelated donor-recipient relationships and the adequacy of sincere

donor wishes. In earlier days a genetic relation was presumed and required, both medically and morally, and was set apart from 'unrelated' relationships. When the medical requirement was removed, close emotional ties between donor and recipient became more common and ethically accepted. The view that (genetically) unrelated cases should be subjected to additional assessment was considered unjustified. Although, for instance, Germany still holds on to a restrictive policy, a special authority in the United Kingdom was discharged [4]. Today altruistic donations to strangers represent a new challenge, in particular in cases of partial liver donation between adults.

Imagine a living kidney donor who, after having donated a kidney anonymously, also wants to donate part of his liver. In the clinic we increasingly come across similar individuals who have equally strong wishes to donate anonymously for a second time, e.g. part of a liver, or lung. What to do with them? (Even more problematic cases have turned up: the wish to donate part of the liver and the second kidney, just before dying, within the context of a euthanasia procedure.) We will not go into the details of all these cases, but we presuppose in this article, for the sake of argument, that the outcome of the screening, regular for all Samaritan donors, does not disclose any contraindications. Our centre, like most other centres, has strict informed consent and psycho-social assessment procedures [5]. In principle, we require anonymity between donors and recipients both before and after the donation. Moreover, we assume that fair procedures of allocation are safeguarded. Now suppose that screening shows that the potential living liver donors do not suffer from any psychiatric disorders, and that no psychological condition is found that obstructs decision-making or invalidates the wish to donate. The donors are well-informed about the procedure, its risks and consequences, and competent to decide. The question that concerns us is: Should the transplant centre accept fully autonomous donors such as these? What reasons can a centre, can surgeons, bring forward that would justify a refusal? Which arguments make sense and have enough weight to discredit the offer? This article should be read as a quest for an answer, by looking at the arguments with an open mind.

To start with, we look at arguments that either refer to third-party interests or to the donor's best interests. We then try to make sense of two specific arguments: one that sets constraints on donor autonomy, another which takes the centre's responsibility and further societal interests into account. We argue that a refusal should not be based on a difference between related (nonanonymous) and unrelated (anonymous) cases. Rather we should screen risks, not relationships. In addition, we should keep in mind, referring to the (limited) mission of the centre that we need not and should not carry out a donor's life project.

Third parties

Directly involved, firstly, are the potential recipients of the offered organ. It seems that they will only be affected in a positive way. In line with society's commitment to protect and sustain health, recipients can substantially benefit from the donation and this provides us with a strong reason to accept the donation.

Secondly, the interests of those who are closely related to the donor, e.g. a husband, small children, an old mother, might be at stake. In particular the interests of those in a vulnerable position, heavily dependent on the donor, may give us a priori moral reasons to discourage the donor to donate and abstain from transplantation. This may emerge as a moral contraindication that should be distinguished from the requirement of family support that primarily is concerned with the wellbeing of the donor [6]. We assume that in the cases mentioned above no such decisive moral reasons exist.

Thirdly, one may refer to the interests of the transplant centre itself, and point, for instance, to reputational risks. We will come back to this later.

Fourthly, the surgeon in charge may put forward personal convictions, even conscientious objections (for instance based on personal views with respect to the risk-benefit ratio, or the absence of a donor-recipient relationship), as a reason to decline the offer. However, from a centre's perspective, a health care perspective, a surgeon's personal views are irrelevant. If a doctor has conscientious objections – let us suppose that one has reasons to honour these – he should not obstruct the wish, but hand over the case to a colleague. This is good common practice. Personal considerations can in themselves not provide a good reason for refusal.

The donor's best interests

Reasons to refuse the donation that refer to the donor's best interests can be called paternalistic, that is: neglecting a competent person's will or even acting against it. In the case presented, it would mean that although one has no doubts about the wish being fully informed, voluntary and well-considered, the transplantation team nevertheless judges that the donation is against the donor's best interests. It is hard to see how this paternalistic argument ('We know better than the donor') can have sufficient weight to justify a refusal. An autonomous person can and should be allowed, in the end, to make his own judgement, by balancing benefits, harms and risks. As long as we have any doubts we may intensify the screening and postpone the donation. This type of (temporary) 'weak' paternalism is justified, given the possible weighty harms and risks of a partial liver transplantation. We may

then choose to stay on the safe side. But as soon as adequate clarity is provided, we can no longer play this card.

The donor's wish: a professional, context-relative perspective

A different argument remains, that says that doctors cannot grant every wish, however, strong and sincere, that individuals have. Views on what is professionally acceptable and accepted may then provide them with justifying reasons for dismissal. Is this argument, that imposes constraints on a doctor's acting on a donor's wishes, strong enough to justify a ban on unrelated donations?

In medical practice a person's wish in itself cannot be decisive. Even if a person has consented, one can do harm to him [7]. Doctors always have the responsibility to make their own professional judgements, in which other considerations than the patient's wish is taken into account as well. In everyday practice one can find a whole range of constraints on individual wishes: in clinical situations (no futile treatment), medical research (only minimal harm), euthanasia practices (unbearable and hopeless suffering), cosmetic surgery (no mutilating operations), transplantation (no living heart transplants), etc. These norms express and reflect both societal and medical-professional normative views on what wishes should be granted and what wishes should be declined. These norms are put in place to protect patients' interests as well as societal (third-party) interests.

In the context of living liver transplantations one may try to pinpoint a difference between related (nonanonymous) and unrelated (anonymous) situations, and take that as a reason for turning down a donor's wish. However, in the Netherlands as elsewhere, we accept donations between related adults (genetically, emotionally), provided that the wish is fully voluntary and the risks are justifiable. Accordingly, it is hard to see why one should not accept 'unrelated', anonymous living liver transplantations. Harms and risks, medical and others, seem to be the same in both groups, as has been shown in many studies at least in donors of living kidneys [5,8]. This outcome has made us confident about our programme that includes Samaritan offers: anonymous 'altruistic' kidney donations to 'strangers'. (On the issue of risk, and additional risks of a second donation, see below.) A remark on this terminology: The question of what terms we should use is a normative issue in itself. We take the view that even in so-called unrelated, anonymous cases some strong kind of (human) relationship may exist between a forthcoming donor and a group of potential, unknown recipients that is morally highly significant. Reasons clearly motivated by the wellbeing of an (although anonymous) recipient express this commitment [9,10]. So, if we accept 'related' wishes, why should we not accept the 'unrelated' ones? A difference in circumstance of a nonmedical kind, is commonly considered irrelevant. This feature should not play any role in our decision-making. It is difficult to understand that the sole fact that an unrelated donor does not bring her own recipient, can be a proper reason for refusal [11]. Likewise, it is difficult to understand that the absence of a particular kind of relationship should be medically relevant for judging the wish.

In short, the fact that someone has a wish to donate does not in itself provide a sufficient ground for granting that wish. However, fairness and consistency require that if a wish may be granted in one case, it cannot be forbidden to grant it in similar cases that differ from the first one in nonmedically relevant aspects only. If this reasoning makes sense, this implies that current professional medical ethics cannot refuse donor wishes of an 'unrelated' kind in situations where it does accept 'related' wishes.

Reputation: a health care perspective

We do not think that the centre's own interests, e.g. its reputation taken as self-interest (and often reflecting a defensive attitude) should overrule the donor's wish and the significant benefits for the potential recipient. But taken as a sincere concern for the possible implications of mishaps and accidents during or after the operation, these interests should be taken seriously. The possibility that the donor will suffer severe long term complications, with drastic consequences for the living liver donation programme as a whole, e.g. suspended operations, wide public debate, and doubts about the integrity of the surgeons, forces us to weigh the benefits of the transplantation against these considerable drawbacks. These wider interests may carry enough weight to decline exceptional donor offers, in the interests of both future donors and future recipients in the transplantation programme. Such an argument makes a refusal based on third-party interests understandable and reasonable, and can therefore provide a proper ethical basis for a centre's policy of restraint or an ethics advisory board to advice dismissal.

But how convincing is this argument in the end? Why should one assume that these harmful consequences will occur in unrelated cases of living liver transplantations (and not in related cases), when surgeons – medically and professionally speaking – proceed in the same way they do in related cases? As said, harms and risks for donor and recipients are essentially the same in both cases. Why then, should one fear repercussions and detrimental effects?

The explanation could be that doctors, who seek and expect societal support for their practices, are uncertain about societal expectations in unrelated, exceptional cases. An unwelcome outcome can arouse intense emotions and

public anxiety. The reason for refusal would then not lie in the transplantation itself (which seems as ethically justified in unrelated cases as in related cases), but in the fact that unrelated liver transplantations, including donating a second time, are even more rare than related transplantations and therefore probably lack sufficient societal support. This could give the centre a reason to stay at the safe side and decline the donor's offer. The decision, whether to accept or refuse exceptional donations, then, is put in a wider context and taken as a social responsibility. It is not primarily seen as a medical-professional issue that is in the hands of doctors, but conceived as a societal and political one: society should tell (a government should tell the public) whether or not it can give its support to these new practices. As we have argued, however, it is difficult to find ethical objections to the donations per se when we have already accepted cases with comparable risks. We rather should change public opinions and unjustified biases [12].

The difference between related and unrelated donations reconsidered

If one fears societal repercussions in unrelated, anonymous cases, would this not suggest that there *is* a significant difference between related and unrelated cases, and, contrary to what we claimed above, a highly relevant difference in ethical respect?

Some authors have argued that the initial justification for living donations in general lies in the unique fact that the donations take place within the context of a special relationship, e.g. between family members, spouses, intimate friends and emotional liaisons. The question of proportionality, the balancing of benefits and risks, should be understood in this context [13,14]. This special relationship does not only make the often strong wishes to donate, and the motivations behind them, understandable, it also gives us the (only?) proper reasons for justifying the transplantations. Within this particular context one can 'assume in advance' (Govert den Hartogh, personal communication) the special concern that the related donor has for this recipient's health. This special circumstance would give surgeons, so it is claimed, the proper, moral reason to take risks, cut in a healthy body and accept exceptions to moral and professional rules that normally forbid this. Presented in this way, it follows that unrelated cases differ substantially from the cases rooted in special relationships. Therefore, unrelated cases should be considered in their own right and require their own justification, so the argument goes.

We prefer to portray the situation differently. Both experience and research in cases of unrelated, anonymous living donation have shown, at least for kidneys, no significant difference between related and unrelated cases in terms of motivations and outcomes (see above). Motivations and reasons to donate turn out to be equally understandable in unrelated cases and these kidney donations do not involve greater harms and risks. That is the reason that in living kidney donation, unrelated donations are considered justified and has become common practice. In our view, the special relationship between donor and recipient is not the morally relevant key feature that provides a justification for living transplantations. Of course, related cases differ in several respects from unrelated cases. But what is morally relevant, is the concern that the donor has for the needs and suffering of others, regardless of their relatedness and regardless of their (non)anonymity, as documented in many studies [1,9,12]. Therefore, we should not judge unrelated cases by the norms of related cases, and reject them on the ground that unrelated cases lack a special known recipient, lack particularity in relations, lack reciprocity, etc. As philosophers as Peter Singer and Michael Walzer among others have pointed out, moral progress does not consist in the introduction of any new principles so much as in the expansion of the circle of their beneficiaries. What started out as concern for relatives and a limited group of close fellow humans has come to its logical conclusion in the concern for all mankind. This concern for others underlying a person's wish to donate makes unrelated cases similar to related cases. Most striking is the example of Ismail Khatib who agreed to have his son's organs donated to children (in Israel), after his young son Ahmad was shot and killed by Israeli forces in the Jenin refugee camp in 2005.

Livers and kidneys: risks require careful screening

What makes living donations of partial livers so much more problematic than living kidney donations, is the much higher risks of death (10-fold) and of severe complications for the liver donor [6]. But this feature is equally problematic for related and unrelated cases. Living liver donations require even more careful screening, psychologically and morally, than kidney donations. It is not sufficient that, all things considered, donors generally speaking, are autonomous persons. One should ascertain that a donor makes a consistent, enduring, reliable, well-considered judgement in the particular situation at stake. Just as we consider and judge the appropriateness of the reasons and motivations of a patient in other cases, we should also screen a donor's reasons and motives in cases of transplantation. The wish to donate should be understandable for the transplantation team, and reasonable, at least in the context of the donor's own views and convictions. Moreover, the donor's expectations should be realistic enough to make us sufficiently confident that the outcome will be

acceptable to him. Rather than thinking in terms of 'benefits for the donor' (as is commonly done in the prevailing literature), we prefer 'significance' and 'meaning' for the donor as more adequate concepts, that refers to particular, personal and social identity-defining characteristics. These concepts capture the reasons a person has to donate more adequately [10]. As we have already mentioned, unrelated donors express their motives just as related ones, in all kind of sincere and authentic ways (loyalties, duties, personal experiences with illness, attitudes towards life and death, etc.). In many ways they seem to be strong and independent individuals [8]. Moreover, as is often mentioned, unrelated, anonymous donations are less susceptible for compulsion and coercion than related cases.

In a case where part of a liver is offered after a prior kidney donation, this second offer gives us additional reasons to screen motivations and expectations extremely carefully. With respect to the risks, we should require that the donor has fully recovered from the first transplantation and is in a condition of optimal health, to not accumulate risks, thus avoiding complications that can be prevented. However, to preclude the offer beforehand, either on paternalistic grounds, or by referring to the distinction between related and unrelated cases, seems unjustified. In our view, risks and harms for the living liver donor are either acceptable or unacceptable, and from a medical perspective we cannot consistently say they are acceptable in related cases but unacceptable in unrelated cases. It would be equally unacceptable to argue that healthy research subjects can be enrolled in medical research and subjected to much higher risks and harms for the sake of their sick family members than in the absence of this family. As argued, such non-medical features of a case are irrelevant.

Assessing risks: autonomy is not decisive

What risks and harms are acceptable? Answers depend on who you ask. Risks and harms for whom: surgeons, donors, recipients, society? Moreover, some persons are more risk adverse than others. Perspectives and views about risks and harms differ, among donors as well as doctors. Any judgement about risks and harms involves an idea of proportionality. Risks and harms are always weighed against perceived gains, which are also subjected to perspectives taken and views held.

As already asserted, we should not leave the judgement solely to the, although fully autonomous, donor. The sole wish to give a living heart to your sick daughter cannot be the only and sufficient reason for a transplantation, since other important (societal) interests and views are also at stake. Autonomy is not the only relevant moral principle [15]. Likewise, we should not make the strength of a donor's wish, or the strength of his intimate relationship, and his view on proportionality (e.g. the urgency to save a family member's life), decisive for our judgement about harms and risks. What counts as acceptable risk in medical research is not left to the research subjects themselves any more than what counts as a safe speed limit is left to individual car drivers.

Nor do we think that medical practitioners as such can provide us with a decisive, normative view on what counts as acceptable and not acceptable. Is a death risk for the donor of 0.05% for kidneys or 0.5% for livers proportional, or should the cut-off point rather be set at respectively, 1% and 5%, or 10% and 50%? This is an issue open for debate, but it is clearly not (solely) a medical issue, for which surgeons possess a set of well-developed normative criteria. It is, in the end, a societal and political issue. Again, we assert that the risks and harms of related and unrelated donations should not be judged differently. If one has doubts about living liver donations, either as a first or a second donation, one should question related donations as well.

To find answers for what counts as acceptable one should go back to what we perceive as the ends of transplantation as a medical practice. The mission of transplant centres, as we see it, is to fulfil the needs and relieve the suffering of patients in need of an organ. This ideal should guide their decisions and constrain doctors' options. It is not the other way around: centres should not carry out the life projects of donor/recipient couples or adhere to the life projects or personal ideals of individual donors. Transplant centres do not serve donors, but merely seek to work together with donors. The special concern for the need and suffering of others (irrelevant of who they are) should be the only basis for centres and donors (regardless who they are) to work together to alleviate the suffering and overcome the need. Benefits for the donors, their relationship to the recipients or the strength of their wishes, should not be in the equation of what is an acceptable, proportional risk-benefit ratio as many studies suggest by pointing to the benefits for the donor [16]. Instead, we judge the sincerity of their wishes to cooperate with the mission of the transplant centre, and our understanding of their wishes, their situation and motivations, makes it possible to assess the involved risks to the donor. But what counts as acceptable risk, proportional to the benefits for the recipients, is a different issue that should be dealt with in its own terms.

Conclusion

In sum, we have found no valid ethical objections to close off options for 'unrelated' living liver donations, including donating twice or more. The wish to donate (anonymously) to a 'stranger' should be taken seriously, when it

is motivated by the concern for the special need and suffering of others. Screening should be carefully executed, and reasons and motivations should be reasonable and realistic. Refusals cannot be legitimately motivated by personal convictions or by paternalistic arguments. Only wider, third-party interests may give a reason for foregoing the offer, in particular fear for (societal) repercussions.

We conclude that unrelated donations cannot be turned down a priori and that society should take a stand and support related and unrelated living liver transplantations equally (or reject them both). What counts as acceptable risks and harms is, in the end, not a medical-professional issue, but a social and political one. We have argued that in the case presented, given the fully informed, voluntarily and well-considered wish, surgeons may in principle accept the offer, because related and unrelated cases do not differ ethically in any relevant way. Surgeons and transplantation centres may also refuse the offer, and rather stay on the safe side, when they have doubts about society's support for their practice and fear (probably) reactions and severe drawbacks for their programme. Doctors do not have a duty to perform unrelated donations, but they are ethically allowed to do so. Their mission is to help patients, and not to be led by donor projects.

The conclusion to act according to the donors' wishes in the absence of any contraindications is backed up by recent positive outcomes in Samaritan donations. The ethical consideration seems to have shifted for good reasons from 'in case of doubt, abstain' to a more future-oriented perspective: 'give donations the benefit of the doubt'. We should add that transplantations under new, more experimental circumstances should be monitored, assessed and reviewed carefully within an accurate study or medical protocol, to obtain more thorough and trustworthy data. Moreover, we suggest that daily practice may be improved by a better decision-making process, e.g. by the participation of a psychiatrist, the meeting of all relevant parties in the clinic, the involvement of the donor in the decision-making, and, finally, full transparency with respect to the arguments for acceptance and refusal, in which benefits, harms and outcome scenarios, are explicated.

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References

1. Landolt MA, Henderson AJZ, Gourley W, *et al.* ''They talk the talk'': surveying attitudes and judging behavior about living anonymous kidney donation. *Transplantation* 2003; **76**: 1437.
2. Popp FC, Eggert N, Hoy L, *et al.* Who is willing to take the risk? Assessing the readiness for living liver donation in the general German population. *J Med Ethics* 2006; **32**: 389.
3. Roodnat JI, Zuidema W, Van de Wetering J, *et al.* Altruistic donor triggered domino-paired kidney donation for unsuccesful couples from the kidney-exchange program. *Am J of Transplant* 2010; **10**: 821.
4. Choudhry S, Daar AS, Radcliffe Richards J, *et al.* Unrelated living organ donation: ULTRA needs to go. *J Med Ethics* 2003; **29**: 169.
5. Kranenburg L, Zuidema W, Erdman R, *et al.* The psychological evaluation of Samaritan kidney donors: a systematic review. *Psychol Med* 2008; **38**: 177.
6. Wright L, Ross K, Abbey S, *et al.* Living anonymous liver donation: case report and ethical justification. *Am J of Transplant* 2007; **7**: 1032.
7. Medical Ethics Today. *Medical Ethics Today: Its practice and Philosophy*, 2nd edn. BMJ Publ Group, London, 2004. Available from www.bma.org.uk.
8. Massey EK, Kranenburg LW, Zuidema WC, *et al.* Encouraging psychological outcomes after altruistic donation to a stranger. *Am J of Transplant* 2010; **10**: 1.
9. Daar AS. Strangers, intimates, and altruism in organ donation. *Transplantation* 2002; **74**: 424.
10. Hilhorst MT. Directed altruistic living organ donation: partial but not unfair. *Ethical Theory Moral Pract* 2005a; **8**: 197.
11. Evans M. Organ donations should not be restricted to relatives. *J Med Ethics* 1989; **15**: 17.
12. Hilhorst MT, Kranenburg LW, Zuidema W, *et al.* Altruistic living kidney donation challenges psychosocial research and policy. *Transplantation* 2005b; **79**: 1470.
13. Spital A. Justification of living-organ donation requires benefit for the donor that balances the risks: commentary on Ross *et al. Transplantation* 2002; **74**: 423.
14. Ross LT, Glannon W, Josephson MA, Tristlethwaite JR. Should all living donors be treated equally? *Transplantation* 2002; **74**.
15. Holm S. Not just autonomy. *J Med Ethics* 1995; **21**: 332.
16. Roff SR. Self-interest, self-abnegation and self-esteem: towards a new moral economy of non-directed kidney donation. *J Med Ethics* 2007; **33**: 437.