Introduction
Living organ donation has increased considerably owing to deceased organ donor shortage and improvements in the safety of surgical procedures. Nevertheless, living donation remains a unique situation in which physicians must put a healthy person’s life at risk to improve a patient’s health or prevent this patient’s death. This highly unusual burden for physicians could have two opposite but equally undesirable consequences. To avoid an internal conflict, a physician might decide that his main loyalty lies with the recipient and therefore only superficially explore the donor’s willingness to donate. Alternatively, she might interpret any donor ambivalence as unwillingness to donate, for fear of being accessory to any form of coercion. Although the problem is universal, solutions vary. In some institutions, clear separation of donor and recipient care provided by two different teams is considered sufficient to guarantee the validity of living donors’ consent. In other instances, evaluation of potential donors by a third party is requested or even required. In some countries such as France (1) and Italy (2), it is even a legislative requirement. In Switzerland, legislation did not address organ transplantation until very recently. The law promulgated in 2005 does not require third-party evaluation of competent and consenting adult donors. Non-related donation is not prohibited by law but we do not know of any cases of donation in which the donor and the recipient had no personal tie whatsoever. In our institution, the Clinical Ethics Committee was mandated a few years ago by the medical director to evaluate the validity of donor consent to live liver – but not kidney – donation. The reason for this difference is that live kidney donation is considered an established procedure. This probably reflects the fact that the Ethics Committee is considered by our institution to be an additional safeguard to ensure the validity of donor consent, justified by a higher donor risk in the case of liver donation. This could of course be challenged: an encounter with third-party assessors may also be an extra opportunity for the donor to think through his decision, and this could benefit candidates to kidney donation also. In this paper, we address a few questions and reflections that have arisen as a result of our practice in evaluating potential live liver donors, with particular emphasis on the precise scope of third-party evaluation.

What is the role of the third party?
The premise of living organ donation has been stated in a consensus paper by the Live Organ Donor Consensus Group in 2000: «The person who gives consent to be a live organ donor should be competent, willing to donate, free from coercion, medically and psychosocially suitable, fully informed of the risks and benefits as a donor, and fully informed of the risks, benefits, and alternative treatment available to the recipient.» (3) Obviously, many of those aspects require medical expertise and must remain the task of the medical team in charge of evaluating
the donor. This is especially evident regarding the medical suitability of the donor. However, subtle ambiguities may arise regarding so-called «psychosocial» suitability during third party evaluation. The exclusive scope of a third-party evaluation is to verify whether the donor is free of coercion and has been fully informed of the risks incurred by donating. In our institution, we decided that it would be impractical and undesirable for the entire Ethics Committee to carry out the living donor’s consent validation. We felt that our task would involve delicate conversations and that we should create a secure environment in which difficult questions could be discussed and emotions handled tactfully. Therefore, two members of our Committee conduct those interviews. It could happen – indeed it has – that we feel the potential donor to be psychologically fragile. Should this weigh in on our final assessment? We strongly believe not: the psychological evaluation must be performed by the psychiatrist attached to the transplant team. But it is important to acknowledge that the temptation to overstep our mandate, and decide against donation on psychological grounds, exists. Further, although there are several guidelines on living donor evaluation and more specifically on psychosocial evaluation, (3–8) they are silent on the topic of consent validation by a third party.

Table 1 details the topics that are deemed important in evaluating the voluntariness to donate by the Multi-Organ Transplant Program of the University Health Network in Toronto. (8) The first item pertains to the subject’s motivation to donate. We contend that insofar as there is no financial interest, a committee such as ours should not establish itself as a judge of motivation, provided there is no financial reward. Donor autonomy commands that any altruistic motivation be respected. Insofar as the motivation is altruistic, there can be no «good» or «bad» motivation to donate. Unrealistic expectations, however, may exist and must be addressed and corrected. The desire that the recipient be cured is, for example, a completely respectable motivation, but the potential donor must be aware that the procedure may fail or even result in the recipient’s death.

Thus, the second role of the Ethics Committee is the verification that complete and truthful information has been delivered to the donor. This should not be confused with assessing whether the potential donor understands the risk, which will be dealt with in a further section. The objective, here, should be limited to checking the information received, since ethics committees and their members do not have the expertise to provide that information themselves. There is evidence from the literature that the information delivered to the donor on short-term risks is fairly consistent, whereas there considerable variation can exist regarding communication of long-term risks such as hypertension and proteinuria. (9, 10) Although this may be a problem for evaluating the quality of the information received, it is in our opinion a minor one. Indeed, the main issue is whether the donor has been informed that the surgical procedure entails a mortality risk, however small.

Table 1. Topics addressed in assessing potential donors’ will to donate an organ

| 1. Motivation to donate            |
| 2. Social situation and family constellation |
| 3. Economic situation              |
| 4. Relationship with the intended recipient |
| 5. Decision-making around the proposed donation |
| 6. Evidence of solicitation of donation, the people and circumstances involved |
| 7. Comfort level in declining the request to donate |
| 8. Comfort level in presence of family or others involved in proposed donation |
| 9. Evidence or suggestion of a material reward for organ donation |

Is informed consent possible in living donation?

Two opposing opinions are defended in the ethical literature on living donor consent. Indeed, the nature of the decision whether or not to donate is quite different from the usual decisions a patient must make for himself. First, the main benefit is for another person, while the risks are for the donor herself. Second, there is a strong moral sense of duty involved, particularly when a parent and child are involved. This sense of duty is largely internalized by most individuals; although it may be merely a social norm for others, it can nevertheless be strong enough to be difficult to oppose for fear of appearing selfish. Even the internal pressure exerted by the donor’s feelings of guilt—the donor might die if she does not donate—is difficult to distinguish from altruistic motives. (11) However, it should be acknowledged that there is an odd tension between the rigorous insistence that emotional entanglements compromise autonomous informed choice and the often voiced argument that live donation is possible because there is some degree of benefit for the donor. Indeed, this benefit is necessarily of an emotional and social nature and it is difficult to see how emotions could be simultaneously an ethical problem and a justification.
sharing the illness of a close relative is an extremely stressful and emotional experience. The dominant model of informed consent relies on rationality and values, not emotions. Therefore, some authors contend that informed consent is almost impossible to attain in live donation, all the more so if the donor involved is a parent and the transplantation envisaged life-saving. In an interesting paper, Knibbe et al. report that «Many parents in our interviews state that living donation for their child was not a matter of choice. Because of their intimate relation with the child who was in danger, they simply had to donate, if possible.» But, in reference to the framework of moral agency, they consider that such intimate family relations are a strong motivating factor, not a coercive one. At the other end of the ethical spectrum, strong defenders of autonomy such as Aaron Spital argue that none of those constraints weigh enough to invalidate donor consent: «It is important to remember that informed consent and autonomy are not the same. It is respect for autonomy we seek to protect, and informed consent is but one way to accomplish it. Consent that is not fully informed may still be valid if it expresses a competent person’s free choice.» An extreme example of absence of choice is fulminant hepatic failure which adds the pressure of urgency to the interpersonal obligations. Even in that instance, Spital considers that «we have no right to categorically deny parents the opportunity to save their child’s life». Although a full philosophical discussion of autonomy and moral agency is beyond the scope of this paper, it should be mentioned that principle-based formulations of bioethical theory have been criticized precisely because of the prominent role given to personal autonomy. There are other frameworks that join relational experiences to individuality, arguing that relationality actually facilitates rather than limits autonomy. (16)

In addition to this sense of moral obligation, we have observed another feature potentially disturbing for valid consent. When discussing the fatality risk involved in the procedure, we many times heard statements such as: «This simply won’t happen to me, or I don’t even want to think about it.» Some proponents even ask us for reassurance: «It’s a really small risk, isn’t it?» Also, evidence suggests that donors decide very quickly and are often not even all that interested in the information provided by doctors: «the majority of donors voluntarily immediately upon hearing of the need without any time delay or any period of deliberation.” (17)

Be that as it may, we do not in that particular respect see a fundamental difference between that situation and everyday clinical decisions that patients have to make, in which they often exhibit exactly the same behavior. Is a surgeon going to renounce a potentially life-saving procedure because the patient appears unconcerned about the risks? True, live donation is a life-saving procedure for someone else and this is a crucial difference. Nevertheless, there is no empirical evidence that this might radically change a person’s way to make decisions. It is likely that some individuals will remain risk-adverse and others risk-prone, whether the intervention’s main potential clinical benefits are for themselves or for others.

What of the physicians’ responsibility?
None of those questions would have the slightest relevance if modern medicine – hence physicians – had not made live donation possible. Therefore, physicians bear an important responsibility in making «proposals that are hard to refuse». The term proposal is here metaphorical, since studies show – and this is also our experience – that potential donors often learn that live donation is a possibility from non medical sources. One premise of living donation cited in a previous section deserves serious attention here: «Donors should not be called on to donate in clinically hopeless situations.» (3)

This statement is important but it may be too restricted. Indeed, there are very few truly hopeless situations. Consequently, physicians may be legitimized to resort to live donation even in situations with a dire prognosis. We believe that assessing the risk-benefit balance for the donor and recipient is the single most important duty of the physician in charge of the donor. The same amount of risk to the donor may be acceptable to transplant a child with a genetic disorder that will be cured by transplantation but questionable for grafting a 60-year old person with hepatic cancer. Ideally, care of the donor by a team completely separate from that caring for the recipient should enable a fair view of this balance of burdens. Unfortunately, as in our center, such a separation is often practically impossible. What relationship, if any, does this discussion have with our main topic, i.e. the role of the evaluation of donor consent validity by the Ethics Committee? Third-party evaluation must not be an alibi (18) for the transplant team. In our view, this represents an additional argument for a precise definition of the Ethics Committee’s role: verifying the information received by the donor and his freedom of choice. All other considerations, including the difficult weighing of risks and benefits, belong exclusively to the team or teams in charge of the donor and recipient.

Our experience in evaluating donor consent validity
We have some degree of experience in those evaluations but it is admittedly small: delegations from our committee have interviewed around 20 potential live donors since our insti-
In all cases, we were able to verify that the donors had been given complete and detailed information, at least regarding the short-term risks. As already discussed, we do not require that the donor appear «duly anxious» to acknowledge that the information has been given and received. In most cases, the donor had had ample time to reflect and was completely decided, even if this did not preclude the expression of anxiety in some subjects. But there were two cases in which the interview revealed many unmet concerns and clearly resulted in donor retraction. One was the situation of a 30-year old subject willing to donate to his father who required a transplant for post-hepatitis B cirrhosis and hepatocarcinoma. He had already received all the relevant information regarding his own health hazard, but the sudden realization that the prospect of curing his father was not certain appeared to make him revise his decision. It is probable that he had already been told as much in other circumstances, but the neutral setting and the intervention of two persons totally uninvolved in the process probably helped him to really hear it. The second case was more unusual: our committee was solicited for a case of kidney transplantation because the evaluation of the 50-year old potential donor had disclosed an unusual anomaly that caused controversy between the transplant team and the consulted hematologist. The anomaly was a monoclonal gammopathy of undetermined significance, which carries a 10% risk of transformation into a multiple myeloma, which in turn may be complicated by renal failure. We were asked to meet this person. According to the transplant team, although perplexed by that unforeseen complication, she was thoroughly determined to go through the process of donating her kidney to her ex-husband. Again, as we progressed through the interview, it became increasingly apparent that she was in fact very worried about the consequences for her own future health. We asked her whether she was ready to sustain the slightest risk to her future health in the process of donation and she gave a very clear negative answer. However, she was afraid of endorsing the responsibility for the inevitable disappointment her consent withdrawal would cause to the potential receiver. We therefore informed the leader of the transplant team that we had decided that donation was in that case inadvisable. Those anecdotes do not amount to evidence, but they do show at least that some donors change their mind after evaluation by a third party. Whether their second decision was a better one is open to question. But the mere evidence of a possible decision change argues against the invalidation of consent due to emotional entanglement: if emotional ties really amounted to coercion, such changes should be impossible.

**Conclusion**

Our limited experience confirms some of the concerns expressed about live donor informed consent. Donors tend to decide rapidly and minimize or sometimes even disregard information on risks to themselves, particularly mortality. Freedom of choice may be limited by the strong emotional ties between donor and recipient. Despite this, we concur...
with the opinion that neither of these factors impairs donor autonomy. Nevertheless, we believe that an evaluation by a third party, in our setting members of a Clinical Ethics Committee, is warranted to verify that motivations for donation are altruistic, that full and truthful information has been provided to the potential donor and that no undue pressure is being exerted. For this assessment to be a true opportunity for the donor to think through his decision, we propose a neutral and secure environment, allowing space for discussion and questions. We recommend that third-party assessors restrict their objectives to those precise tasks and take particular care not to take over part of the donor evaluation by the transplant team, such as psychosocial evaluation. Institutionally, it is important to clarify explicitly that third party evaluation does not evacuate the responsibility of the transplant team regarding live donor evaluation. Indeed, the most difficult assessment is the balance of risks to the donor and potential benefits to the recipient and this can only be performed by the transplant team. Finally, our limited experience provides some empirical evidence that the incorporation of third party evaluation in the process of live donor evaluation may allow at least some donors to further reflect and elaborate their decision.

Acknowledgments: The author gratefully acknowledges the contribution of Dr. Samia Hurst who accepted the challenging task of correcting the English for this manuscript.

Conflict of interest: none to declare.

Zusammenfassung

Die Validierung der Zustimmung zur Lebendspende durch Ethikkommissionen: Ist sie von Nutzen?


Résumé

La validation du consentement au don vivant par un comité d’éthique: est-ce utile?

Des soucis concernant le consentement des donneurs vivants au don d’organe ont été exprimés dans la littérature. Les donneurs tendent à décider rapidement et à minimiser parfois ne pas considérer des informations sur les risques pour eux-mêmes, en particulier le risque de décès. La liberté de leur choix pourrait être limitée par les liens émotionnels forts qui existent entre donneur et receveur. Cependant, plusieurs approches éthiques ont été invoquées en soutien au consentement des donneurs, comme l’agence morale, le respect de l’autonomie, ou l’autonomie relationnelle; nous sommes d’accord avec l’opinion selon laquelle aucun des facteurs cités n’est suffisant en soi pour invalider l’autonomie du donneur. Cependant, nous pensons que l’évaluation par le tiers qu’est un comité d’éthique est utile pour vérifier que: i) les motivations du donneur sont altruistes; ii) une information complète et véridique a été fournie au donneur; et iii) aucune pression induite n’est exercée sur le donneur. L’évaluation par un comité d’éthique ne doit pas évacuer la responsabilité de l’équipe de transplantation dans l’évaluation d’un donneur vivant: la pédagogie la plus difficile dans ces cas est celle des risques pour le donneur et des bénéfices pour le receveur, et elle ne peut être réalisée que par l’équipe de transplantation. À la fin de cet article, nous présentons des données empiriques limitées suggérant que l’inclusion d’une évaluation par un tiers dans le processus de l’évaluation des donneurs vivants pourrait permettre à certains candidats de réfléchir davantage et d’élaborer leur décision, et dans de rares cas pourrait les mener à reconsidérer leur décision de devenir donneur.

Correspondence

Prof. Arnaud Perrier
Division of General Internal Medicine
Geneva University Hospitals
24 rue Micheli-du Crest
CH-1211 Geneva 14

e-mail: arnaud.perrier@unige.ch

Manuscript submitted: 19.01.2009
Revisions submitted: 19.03.2009
Accepted: 20.03.2009
References


