# Consent and Living Organ Donation

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*Abstract*

This paper focuses on voluntary consent in the context of living organ donation. Arguing against three dominant views, I claim that voluntariness must not be equated with willingness, that voluntariness does not require the exercise of relational moral agency, and that, in cases of third-party pressure, voluntariness critically depends on the role of the surgeon and the medical team, and not just on the pressure from other people. I therefore argue that an adequate account of voluntary consent cannot understand voluntariness as a purely psychological concept, that it has to be consistent with people pursuing various different conceptions of the good, and that it needs to make the interaction between the person giving consent and the person (or people) receiving consent central to its approach.

## Introduction

Sarah is fifteen years old and suffers from cystic fibrosis, a genetic disorder that damages a person's lungs and reduces the quality and length of her life considerably. Currently, there is no known cure. As Sarah's condition is worsening, her parents James and Debby consider donating parts of their lungs to her, which would greatly improve her condition, and they approach the medical team about this. Since cystic fibrosis requires a bilateral lung transplantation, Sarah would need both of her parents as donors. James and Debby undergo tests and will soon receive the results. (This case is fictitious but close to clinical practice[1].)

Whereas some people feel very gratified if they can donate and help their child, others are extremely frightened and secretly hope not to be compatible. In interviews, the latter admit to be "scared to death" and "terrified all the way down"[2, 3]. Yet, many of the most frightened eventually feel compelled to donate because they see themselves as under a moral obligation, experience pressure from social expectations, or are subject to explicit third-party pressure. Empirical evidence shows that, in one form or another, "[p]ressure to donate is a reality"[4, 5, 6, 7, 1].

This situation poses an urgent question: when, if at all, do donors give *voluntary* consent? Voluntariness is key because it is a necessary condition for valid consent, i.e. necessary for consent to make transplantation surgery permissible. Moreover, the standards for consent must be very high: people would consent to a procedure that is risky, highly

intrusive, and lacking in any medical benefit for them. Should it turn out their consent is involuntary, this would be devastating for clinical practice.

Although I will not be able to present a comprehensive account of voluntary donor consent, I will make three substantial points in this paper, arguing against three dominant views in the literature on living organ donation. I will claim that (1) voluntariness is not the same as willingness, (2) voluntariness does not require the exercise of relational moral agency, and (3) in cases of third-party pressure, voluntariness critically depends on the role of the surgeon and medical team, and not just on the pressure from other people.

## 1. Voluntariness is not willingness

Suppose the tests reveal that both James and Debby are eligible to donate. But whereas Debby is happy to proceed, James is extremely frightened and would strongly prefer not to undergo transplantation surgery. Unfortunately, if James refuses to donate, Sarah will continue to suffer severely or even die. So, he eventually consents. Is his consent voluntary?

Al-Khader proposed that we "determine the degree of willingness or unwillingness" of potential donors in order to "screen out donors who are acting under duress" and therefore fail to give their consent voluntarily[6]. Thus, Al-Khader and those who followed him[8, 9, 10, 11, 12] hold that consent is involuntary if a person's unwillingness to donate, i.e. his reluctance, aversion, or fear, exceeds a certain threshold. Al-Khader and others made unwillingness central to their view because they consider unwillingness to indicate a conflict with important interests of a person and they claim that, if such conflict is great enough, a person's decision ceases to be truly his own and becomes involuntary. Hence, if James's reluctance is too great, his consent is involuntary.

But this view cannot be right. Suppose James's pressure comes from seeing himself under a moral obligation to donate, i.e. suppose James is like the following donor from an interview survey: "I felt I was obliged to do it. I wanted to do it. There was really no choice. It was all about trying to save my daughter. They could have whatever they needed"[2].

In such a case, James is strong-willed and self-determined. He does not let himself be carried away by his fear, but distances himself from it and acts on his moral decision to donate. To this extent, he is autonomous, and the reluctance that accompanies his acts does not diminish his autonomy. Quite the contrary, it is a sign of autonomous agency as it shows that he is able to manage different preferences.

But if reluctance does not undermine autonomy, it cannot undermine the voluntariness of consent either. This is because, in the context of consent, autonomy and

voluntariness are closely linked: voluntariness is a condition of the validity of consent, and such conditions are supposed to protect the autonomy of the person giving consent. Hence, conditions of valid consent can only be violated if there is a flaw in the protection of a person's autonomy, but not otherwise. Therefore, for consent to be involuntary there has to be an infringement of a person's autonomy. Thus, as reluctance is consistent with autonomy, it is also consistent with the voluntariness of consent.

Therefore, voluntariness is not the same as willingness and involuntariness is not the same as reluctance. The voluntariness of consent cannot be understood as a purely psychological concept, reporting on the inner states, desires, or preferences of the consenting person. Any adequate account of voluntary consent needs to focus more closely on the ethical role that voluntariness plays, i.e. the role of a necessary condition of making surgery permissible.

In response to this critique, however, proponents of the willingness-view may argue that my assessment of James's willingness was incomplete. They could claim that, although James's first-order preference against donation decreased his willingness, he also had a second-order preference, or even moral commitment, not to let his fear determine his decision, and this preference *increased* his willingness. Moreover, since this was a higher-order preference and one that James seemed to have reflectively endorsed, James's decision was *authentically his own* and therefore, on balance, perfectly willing. Thus, by claiming that people consent willingly when their decision is 'authentic' in this sense, proponents of a willingness-views can explain James's consent as voluntary after all, despite his fear and great reluctance.[1]

Unfortunately, this response comes at a price. Suppose James has always prioritised his own physical well-being over that of others and therefore lacks a reflectively endorsed second-order commitment in favour of donation. Yet, upon seeing his daughter suffer, James steps out of his usual character, experiences moral pressure, and decides to donate. In such a case, James's decision is not authentic, because it is not (already) supported by a reflectively endorsed second-order preference or commitment. However, it is not the result of some questionable moral compulsion either. His instant decision to break with his prior framework of values can still be deliberate, autonomous, voluntary, and worthy of respect. In fact, when people radically revise their value framework in unprecedented circumstances, they exercise what Rawls called a "moral power"[13]. and doing so is an integral part of people's autonomy. Therefore, the requirement of authenticity may ask for too much: people need

[1] Thanks to an anonymous reviewer for suggesting such a potential response.

not always support their decision with an already reflectively endorsed second-order preference in order to make autonomous and voluntary decisions.

Hence, we should not only reject the simple equation of voluntariness and willingness but also avoid a more sophisticated view based on claims about authenticity. Although my argument against authenticity-views may not be decisive, given the comprehensive debate about them in the literature, it highlights a problem that is particularly relevant for the context of living organ donation: most living donors find themselves in situations that are unprecedented for them and, as scholars pointed out, these are exactly the situations that pose the greatest challenge to authenticity-views[14].

## 2. Voluntariness does not require exercising relational moral agency

Mare Knibbe and colleagues might offer a better explanation as to why James's consent is voluntary. Knibbe *et al* discuss the case of a fearful mother and says that the mother's consent to donating an organ for her child is voluntary because it "is an expression of who she is *as a mother*"[3]. Thus, Knibbe *et al* consider the woman in her *parental role* rather than seeing her only as an *isolated individual*. In fact, Knibbe *et al* specifically argue that the flaw in many accounts is the adherence to a picture of the "'moral agent' as being self-interested, independent and free from emotional bonds, commitment and duties"[3]. Such a picture, Knibbe *et al* argue, must have necessarily led to the false view that any pressure opposing self-interests must reduce a person's autonomy and voluntariness.

Alternatively, Knibbe *et al* suggest that "the interpretation of living donor voluntary consent must be based on a *relational view of the moral agent*"[3], as opposed to an unduly individualistic picture (see also[15, 16, 17]). This relational view holds that "relations are seen as constitutive of moral agency"[3], which means that the capacity to act from moral reasons, and being autonomous for that matter, requires that individuals actually have and promote valuable relations with others[17, 18]. Accordingly, the pressure which James and the mother experience does not negate voluntariness precisely because James's and the mother's consent expresses who they are *as parents* and promotes valuable relationships with their families.

Knibbe's account is insightful and I agree with her that people who exercise their relational moral agency consent voluntarily. But I disagree that exercising relational moral agency, so understood, is necessary for voluntary consent. To see why, consider the following case:

***Estranged Father*** Bob has a sixteen-year old daughter, Carry, whom he has not had contact with since she was born. Upon hearing that she needs a kidney, he feels great moral pressure to donate and consents to surgery. Donating a kidney will not promote the relationship to his daughter, as her family made clear that there would be no contact afterwards, and it will even worsen Bob's relation to his current family, as they would need him healthy to support another child.

In some respects, Bob is like James: his daughter needs an organ, he is frightened about surgery, and he feels morally compelled to donate. In other respects, Bob is unlike James: donation worsens rather than promotes valuable relationships and Bob therefore fails to exercise his relational moral agency as Knibbe *et al* describe it.

However, considering Bob's consent involuntary for this reason is false. The requirements of consent must allow people to pursue a variety of different conceptions of the good and not just one that requires the promotion of existing relationships. This is because respecting a person's autonomy requires respecting people's own and often unique values. In *Estranged Father,* Bob still acts from his firm moral conviction, pursues his own conception of the good, and genuinely exercises his autonomy. His decision may even be perfectly authentic and express what is most important to him. Hence, even if Bob experiences pressure that does not lead him to promoting valuable relationships, his consent can still be voluntary.

In response, however, Knibbe *et al* could adjust their view and claim that actually promoting valuable relationships is not required as long as Bob discharges a genuine moral obligation owed to his daughter Carry. Discharging such a parental obligation may be sufficient to fulfil one's role *as a parent* and live up to the standards of relational moral agency, more widely conceived. Thus, on this modified view, Bob's consent is voluntary as long as the pressure Bob experiences stems from sound moral reasoning.

To test this view, suppose Bob is mistaken. Although he still thinks he is morally obliged to donate, e.g. because he still thinks that he ought to compensate for his past failings as Carry's father, and therefore continues to feel moral pressure, he is in fact *not* morally obliged, e.g. because the interests of all people involved would be better served with another donor and Bob would wrong his other family when being absent during the donation. If so, Knibbe's modified view would consider Bob's consent involuntary, as he fails to fulfil the standards of relational moral agency, and imply that just as factual mistakes invalidate consent, moral mistakes do so too.

I am doubtful about this modified version. Generally, a patient's false belief invalidates consent only if the kind of belief that the physician is obliged to correct by

disclosing relevant information. Consider factual mistakes, e.g. false beliefs about significant risks of a medical procedure. Due to their medical expertise, physicians ought to correct these factual mistakes and disclose relevant medical information. If they fail to do so, such mistakes invalidate consent. By contrast, physicians do not have a comparable *moral* expertise and thus are not in a position, let alone under an obligation, to ensure their patients' sound moral views. In fact, in several US legal cases, it was held that medical professionals only need to disclose what is 'inherent' in a medical procedure, where 'inherent' means "inseparable from the procedure itself"[19]; and whether undergoing a procedure is morally required is certainly not 'inherent' in this sense. In addition, physicians will lack the required background information about their patient's life to make a moral judgment in the first place. Therefore, moral decisions, including potential mistakes, remain within the patient's own responsibility rather than the physician's responsibility and therefore do not determine whether the physician can permissibly perform a medical procedure. But if so, these mistakes cannot invalidate consent either, as validity is precisely about determining the permissibility of a medical procedure.

However, even if one remains unconvinced about my argument and still thinks that moral mistakes do invalidate consent, one should still not assume that they render consent *involuntary*. Generally, mistakes undermine consent by violating the requirement that consent be *informed* rather than the requirement that consent be *voluntary*. As Wertheimer pointed out, we achieve greater conceptual clarity when we separate voluntariness (as the requirement concerning the absence of controlling influences and certain types of pressure) from information (as the requirement concerning the absence of false beliefs)[20].

Hence, I conclude: exercising relational moral agency is not necessary for voluntary consent and moral mistakes, if they are relevant at all, should be seen as affecting the requirement of information rather than the requirement of voluntariness.

## 3. In cases of third-party pressure, voluntariness depends on the role of the surgeon and the medical team

Finally, let me move on to a more direct form of pressure. Suppose James considers waiting for a cadaveric organ an acceptable option and therefore no longer feels morally obliged to donate. However, his wife Debby tells James that she will divorce him and fire him from the family company unless he donates. Divorce and unemployment would leave James in a very poor financial situation and even make him homeless. James eventually consents but only to prevent Debby from carrying out her threat.

In such cases, scholars in the literature all hold that the voluntariness of consent depends solely on Debby's influence: if Debby's influence is sufficiently severe, consent is involuntary and invalid[8, 9, 10, 11, 21, 22].

But I think this view is mistaken and I will defend the claim that in cases of explicit third-party pressure the voluntariness of James's consent depends, at least sometimes, on how the surgeon and the transplant team reacts to the situation. However, to defend this claim, I will firstly need to focus on a slightly different question, namely whether the surgeon and their team could ever permissibly proceed with surgery in such a case. Consider the following case.

***Respect*** James's family knows about his physiological compatibility as a donor and keeps pressuring him. After James informed the surgeon about his situation, the latter agrees with James to contact his family. They meet for a family conversation where the surgeon explains the viability of cadaveric donation and emphasises the importance of making the decision to donate free of pressure. Yet, the family cannot settle the issue and medical team is unable to alleviate James's situation. James eventually requests that the surgeon proceed with the donation. On the basis of the overall situation, he says donating is best for him. He insists that the surgeon no longer offer any help, contact his family, or interfere with his private decision.

Refusing James as a donor would disrespect James's part or role in deciding how to proceed. It would give short shrift to his perspective and unduly impose standards on him he does not share. It would thereby also put him in a situation that is, according to his own evaluation, worse for him. Accepting James's decision to donate on the other hand would respect his part in deciding what to do, at least in the interaction between him and the medical team, and it would allow him to pick the option he considers best for him under the circumstances. Furthermore, having offered any possible help for James, the surgeon and their team did not fail to discharge obligations owed to James. For these reasons, I argue, the surgeon can permissibly proceed with the surgery. Contrast this scenario with another case:

***No Help*** According to the hospital's policy, a person will be identified as an *incompatible* donor due to physiological, psychological, or other reasons. 'Other reasons' are broadly understood and include people's requests to be identified as incompatible when pressured by others. The exact reasons for incompatibility will be kept confidential within the medical team and not released to anyone except the tested person. At the moment, only James knows about his physiological compatibility as a donor. His family has not been informed yet and James does not want them to know. He asks for a general statement of incompatibility. Issuing this statement would be in line with

the hospital's policy and James's family would subsequently withdraw their pressure. Yet, the surgeon, although knowing about James's situation, deviates from the usual policy and only issues a specific statement on physiological donor compatibility. James's family keeps pressuring him and he subsequently consents to donation.

In this case, the surgeon could have helped James very easily. It was possible and feasible for him to provide James with a general statement of incompatibility. Yet, the surgeon decided to deny James this opportunity to escape the threats from his family. The surgeon thereby unduly controlled the circumstances in which James had to make his decision and made him worse off, compared to an otherwise possible scenario. For these reasons, it would be impermissible for the surgeon to perform the surgery.

*No Help* and *Respect* do *not* differ in terms of third-party pressure. In both scenarios, James consents to surgery only because Debby pressured him. However, they differ in terms of the surgeon's reaction: whereas the surgeon and their team did everything he could in *Respect*, the surgeon in *No Help* failed to help James where doing so was possible and feasible. Therefore, if my evaluation is correct and performing surgery is impermissible in *No Help* but permissible in *Respect*, permissibility cannot always depend on third-party pressure. The permissibility of surgery can depend on the surgeon's reaction to the situation.

This result can inform judgments about the voluntariness of James's consent. This is because the debate on living organ donation unanimously accepts what we can call. The *Permissibility Principle*, i.e. the view that performing donation surgery can only be permissible if consent is voluntary[23]. Thus, if permissibility requires voluntariness, and if performing surgery is found permissible, then James's consent must have been voluntary. This line of reasoning can be described a simple modus ponens: (1) X is a necessary condition of Y (e.g. voluntary consent is a necessary condition for permissible surgery). (2) Y is given (e.g. surgery is permissible). (3) Therefore, X (e.g. James's consent is voluntary).

In order to account for the conclusion in (3), we need to adopt a certain account of voluntary consent. Such an account can start with the premise that voluntary consent requires that the person's decision-making is not controlled by others. But then, one needs to claim that control over a person's consent can take different forms: *global control* is the control coming from outside the interaction between the person giving consent and the person receiving consent, e.g. pressure from third parties like Debby. By contrast, *transactional control* is the control coming from within the interaction between the person receiving consent and the person giving consent (including the medical team more generally), e.g. if

the recipient of consent of their team threatens the consenter, or if he keeps him in his predicament where it would be possible and feasible to help, as was the case in *No Help*.

In order to accept the *Permissibility Principle* and the evaluation of the different scenarios of James's situation, we need to adopt the view that the voluntariness of consent depends on *transactional control* rather than *global control*. In *Respect*, James's consent is voluntary because it was not transactionally controlled, whereas James's consent is involuntary in *No Help* because it was in fact transactionally controlled.

Hence, the voluntariness of consent depends on how the recipient(s) of consent, e.g. the surgeon and their team, react(s) to the situation and not just on the influence exerted by third parties. The influence of third parties, and their strength and illegitimacy, may inform what the person receiving consent is obliged to do, but may not directly negate the voluntariness of consent.

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