Transparent Vessels?: What Organ Donors Should Be Allowed to Know about Their Recipients

Richard H. Dees

After a long search, Jonathan has finally found someone willing to donate a kidney to him and thereby free him from dialysis. Meredith is Jonathan's second cousin, and she considers herself a generous person, so although she barely knows Jonathan, she is willing to help. However, as Meredith learns more about the donation process, she begins to ask questions about Jonathan: "Is he HIV positive? I heard he got it using drugs. Has he been in jail? He's already had one live donor, so what happened to the first kidney? Did he forget to take his drugs or something?"[1] The transplant center must, then, decide if Meredith is, in fact, entitled to answers to these kinds of questions. According to the Consensus Statement on the Live Organ Donor, "It is incumbent on the transplant center to provide full and accurate disclosure to potential donors of all pertinent information regarding risk and benefit to the donor and recipient."[2] But whether answers to the Meredith's questions count as "pertinent information regarding the risk and benefit" is the issue at hand.

I will argue that the donor has the right to know enough about her recipient to assess the risk to herself and the prospects for a successful donation, but that she is not entitled to any further information, no matter how much she wants it. In other words, the donor has the right to information that will objectively affect the likelihood that the transplant will succeed, but she should not be allowed to invade the privacy of the recipient beyond that point. In particular, I will argue that a donor is not entitled to information about anything, like his criminal record or past drug use, that has not been shown to affect outcomes, but that she should be told if the recipient is positive for HIV and if he has lost a previous organ due to non-compliance, because these factors do seem to make a difference. Donors have a right to make decisions with all the information they need, but recipients need not make their lives completely transparent.

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I. The Rationality of Donation

Live organ donors are special people: they are willing to sacrifice a part of themselves, at some risk to themselves, for the benefit of another person. But before a live donation makes sense, a potential donor like Meredith has to have good reason to believe that the risk she is taking is worth it to her. I do not mean this claim in a narrowly self-interested way: part of what will make it worthwhile for her is the prospect that she will make the life of her recipient better. To make her decision, then, the donor should comprehend two sets of facts: the risks to herself and the benefits to her recipient. First, she must understand what the risks to herself will be. In agreeing to the surgery, the donor is, after all, taking a small, but real risk with her own health: so, for example, there are 3.1 donor deaths in every 10,000 kidney donations,[3] and up to 22 percent have at least some complications.[4] Indeed, organ donation is the one of the few procedures in medicine in which a perfectly healthy person is intentionally made sick by doctors. For that reason, each donor in the U.S. is screened by a team of providers who are not connected with the recipient, and an independent living donor advocate is assigned to the donor to protect her interests and to ensure that she understands the procedure and its implications, both for herself and for her recipient.[5]

For the donor, three kinds of risk must be considered. First, obviously, there are medical risks. Those risks depend much on her own health — on what diseases she has and on what diseases she is likely to contract. So the medical team should evaluate Meredith for conditions that the surgery may exacerbate, either conditions she has, like hypertension, or conditions that she is at risk to develop, like diabetes.[6] Second, the team must assess whether the donor has sufficient social supports to ensure that her medical and emotional needs can be met, both before and after the surgery. Third, the team must assess the psychological risks to the donor. Those risks depend on the mental health of the donor and on her expectations about the results. Meredith would put herself at some risk if, for example, her feelings about the donation depend too much on the actual results, if she feels coerced into offering to donate, or if she needs Jonathan to be eternally grateful to her. Many things can go wrong in a donation, and the donor should feel that she has done a good thing even if the donated organ never works or if the recipient suffers complications from the surgery, and she needs to think it is worthwhile even if the recipient does not prove to be grateful.[7] In other words, Meredith needs to see her donation as an unconditional gift, the value of which lies in the giving.

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The second set of facts the donor must understand is how likely it is that her donation will benefit the recipient. Since the donor is taking an unnecessary risk with her own health, a live donation makes sense only if the expected benefit to the recipient is great. Indeed, if the donor is not emotionally close to the recipient, we might want an even greater benefit, since the quality of donor's life will not improve as a direct result of the improvement in the recipient's quality of life.[8] Usually, such a determination is easy to make: waiting for cadaveric organs leads to further medical deterioration, temporizing therapies like dialysis carry their own risks, and live organs typically produce better outcomes than cadaveric.[9] However, the donor should also understand that the recipient has alternatives: dialysis can continue, a cadaveric organ may be found, and another donor may come forward. So the donor should understand that she is not literally the recipient's only hope. Nevertheless, a live donation is likely to benefit the recipient greatly. Only in circumstances in which the surgery itself or the drug regimen that follows it would exacerbate the patient's physical conditions is a transplant expected to produce no benefit at all. But how significant a benefit the donation is likely to produce depends on whether the patient has other diseases and whether he can live with the regimen of restrictions and medicines that are needed to sustain a transplant. If Jonathan suffers from an unrelated heart disease which will continue to debilitate him even with a transplant and which will kill him in less than two years, then the transplant might benefit him some, but not very much; indeed, for that reason, such patients are not usually listed for either live or cadaveric transplants. If Jonathan has a poor history of compliance with medical requirements, then the chance that he will lose the organ because he fails to take his immunosuppressants is high. Again, the organ is only likely to benefit him for a short period of time. Or if Jonathan does not have sufficient social supports, he may be unable to get the care he needs after the operation, and the transplant is more likely to fail. In each of these cases, the benefits to the recipient are not enough to outweigh the risks imposed on the donor.[10]

II. Models of Assessment

Obviously, both the donor and the medical teams for both the donor and the recipient should have a role in determining whether a particular donation is worthwhile. At minimum, the role of the transplant teams is to assess the exact medical and psychosocial risks to the donor and the recipient. At minimum, the role of the donor is to understand those risks and either to agree to them or to decline to donate. A key ethical question is who should be responsible for framing the risk-benefit profile of a potential donation. In other words, the question is, who will decide what facts are relevant to the decision to donate and what risks are worth taking? In particular, if the donor is responsible for making that determination, then she must be given whatever information she deems necessary for that assessment. But if the transplant teams are responsible, then their members need only provide the donor with the information they think is relevant to the decision.

Ordinarily, questions about what information to provide to the donor do not arise. Usually, a potential donor knows a lot about her recipient: when the recipient is a spouse, a sibling, or a close friend, the donor will usually know a great deal about him, and so she will have a good idea about whether he will be a good steward of her organ. Yet Meredith and Jonathan's situation is becoming more common. Now donors may be mere acquaintances: distant cousins, church members, or long-lost friends found on Facebook. Indeed, some donor-recipient pairs are complete strangers, either because the donor is making a Good Samaritan gift or because the donor is part of a paired-donor exchange in which she will donate to a recipient on the understanding that a loved one will receive a donation from someone else. But even in the case in which the recipient and the donor are close, the recipient may not share many of the details of his medical condition or of his life in general. Since potential donors like Meredith may not know everything about recipients like Jonathan that they would like to know, the donor's medical team will need to decide what information about the recipient should be provided to the donor. But what that information should be depends on whether the medical teams or the donor sets the agenda for the transplant decision.

A. Medical Teams as the Agenda Setter

If we think the medical teams should set the agenda, then we place on them the obligation to ensure that the risks and benefits of the surgeries are reasonable for both the donor and the recipient. To say that the medical teams are the arbiters does not, of course, exclude the donor: as the consensus statement makes clear, she still has the right to know the risks and benefits for both herself and her recipient so that she may decide if the donation is worthwhile for her. Obviously, she must have all the information she wants about the risks to herself. The only question is what particular information she is entitled to have about the recipient.

The medical team assigned to the recipient has the obligation to ensure that he is medically suitable for a transplant: that he has no medical barriers to the surgery itself, that he can physically withstand the surgery, and that he does not have other diseases that will cause him to die soon after the surgery. According to the Clinical Practice Committee of the American Society of Transplantation, transplant teams should not approve a recipient who does not have a reasonable chance to live for at least five years after the transplant.[11] In addition, the team has an obligation to ensure that the recipient is psychologically prepared to undergo not only the rigors of surgery, but also the tremendous demands of postoperative care, including the recovery and the continuing need to take immunosuppressant drugs and to adhere to a strict medical regimen. If the team feels he has a good chance of failing to comply, then the recipient should not be approved. On this model, then, only the recipient's medical team is responsible for determining whether or not the recipient is a suitable candidate for a live transplant.

So, in our example, they would decide if anything in Jonathan's past, like a criminal record or his HIV status, shows he is psychologically incapable of doing what he needs to make the transplant a success.[12] Since non-compliance led to the rejection of Jonathan's first kidney, they will likely require Jonathan to undergo a rigorous psychological evaluation and a trial period of compliance before they allow him to be eligible to receive another kidney.[13] So while some of these facts have bearing on whether Jonathan is a suitable recipient, none of them is directly relevant to Meredith's decision.

On the other hand, the members of the donor's medical team are primarily responsible both for providing the donor with information about the donations process and for weighing the risks to the donor. So they will exclude the donor if they determine that that donation might has a significant chance of causing her lasting physical harm. So they will reject a donor with, say, a high risk of diabetes or cardiovascular disease,[14] and they will do so even if she understands those risks and yet insists that she is still willing to donate. In addition, her team will exclude her if they determine if she has inappropriate expectations about what the donation will do for the recipient and about what her relationship with recipient will be after the surgeries, again, even if the donor understands and accepts the psychological risks. In effect, then, her team decides if the risks of the donation are low enough to make it worthwhile. They set the maximum level of risk to which the donor will be subject. The donor, of course, can decide that the risks as presented to her are too great. But her medical team can judge that above a certain level of risk, the transplant is not acceptable, no matter how much the donor wants to take the chance.

The donor's situation is in some ways parallel to that of a potential subject of medical research where there is no benefit to the individual, but there may be potential benefit to others — the researcher, science, and society.[15] For research, we think it appropriate for the professionals — the Institutional Review Board and the researchers — to set real limits on what risks the subjects are allowed to take for the sake of even the most worthwhile research. Indeed, certain kinds of research are not permitted because they pose too much of a risk to the subjects, even if they are more than willing to assume that risk. These protections are strongest for vulnerable populations, like children and patients with dementia, who are incapable of making decisions for themselves. And while organ donors are not vulnerable in the way that children who participate in a vaccine study are, potential donors often face enormous pressures, either explicitly or implicitly, from families and, more subtly, from doctors. So they too have some vulnerabilities, and so they deserve some protection from the system.

On this model, then, since the professionals do the most of the heavy work of risk assessment, the donor does not need to know any specific information about the recipient. She only needs general information about the risks of the surgery and of the post-surgery period, perhaps with some general information about how recipients who are in the same general class as her recipient fare. So, for example, Meredith should be told that, typically, recipients of second transplants fare worse that those receiving their first transplants.[16] In fact, within five years, about 20.6 percent of live donor retransplants fail, as compared with the 16.8 percent of first transplants.[17] So while Meredith might change her mind if she knew one thing or another about Jonathan, that information is not the kind that *should* make any difference to a donor who is mostly interested in helping the recipient. So, Meredith might want to know if Jonathan's grandparents were illegal immigrants from Mexico or if he had an extramarital affair, but neither fact is relevant to the risks of the transplant, and her medical team should not think it must supply such information simply because she wants it. The donor is entitled to any information about the possible risks and benefits of the transplant for patients like her recipient, but nothing more. If the Jonathan's medical team thinks he is at a significantly higher risk than those given in these averages, then the team should not approve him for the transplant in the first place.

Thus, on this model, the medical teams act to protect the donor from needless risk and the recipient from unnecessary intrusions into his privacy. Obviously, this model forces the donor to rely heavily on the assessments of the medical teams. Those teams, we might argue, contain the appropriate people for making the assessment: they are the professionals who have experience with donors and recipients, they can understand the intricacies of the professional literature about risk, and so they are best positioned to assess that risk appropriately and then to provide the appropriate information to the donor and the recipient. Making such assessments is part of their job description. So to place that responsibility on the donor, we might argue, would shirk their professional responsibilities.

Placing the agenda in the hands of the medical team is how, in fact, transplant programs are structured in the U.S. The assumption in the Consensus Statement, for example, is that the transplant teams will provide the risk assessment.[18] Indeed, the statement concludes by emphasizing the autonomy of the medical teams to refuse to do any transplant "if it [*the team*] believes it will do more harm than good."[19] Such a structure puts both the responsibility and the power in the hands of the medical teams.

B. Donor as Agenda Setter

However, precisely because the previous model places so much power in the hands of the medical teams, many will see it as overly paternalistic. It assumes that the medical teams should decide what counts as a harm and what counts as a good and that they should determine how best to weigh them. Others will argue that the transplant teams are too vested in promoting transplants to assess the risk for the donor. In either case, many would argue that we should, instead, place our trust in the donor herself. To respect the donor and the gift she is willing to provide, we might argue, we should give her as much autonomy as possible. For that reason, we might argue, she should set the agenda for the donation. Since she is risking her health for the sake of another, she should have the right to control the process. For most medical procedures, informed consent requires that the medical team provide nearly any information that the patient wants. So, the medical team has an obligation to provide not only general information about the risks and benefits of the procedure and the alternatives, but also any other information that the patient wants to help her make her decision. If anything, we might argue, we should give a kidney donor more information than we would give to an ordinary patient, simply because she is not making a decision that will improve her own health.

Of course, the information she may want for this decision, unlike others, is information about another person. But, we might argue, if the recipient wants the donor to provide this valuable gift, then he must be willing to provide whatever information the donor wishes to have. On this model, then, the donor is entitled to any information *she* thinks would be relevant. Indeed, the logic of the position is that since her autonomy controls the process, she can ask not only for whatever medical information she thinks important (e.g., past medical compliance, HIV status, past transplants, and reasons for their failure), but also for whatever non-medical information she thinks might affect her decision (e.g., criminal record, employment history). To proceed, then, the potential recipient would have to be willing to waive whatever privacy rights he has to his medical records and provide the donor with whatever information she demands. In surveys, a majority of both donors and recipients think that donors should have much of this information. Specifically, more than 50 percent thought that the donor should know if the recipient has diabetes, hepatitis, and a history of drug and alcohol abuse, and more than 75 percent thought the donor should know if the recipient had lost a transplanted organ due to medical noncompliance.[20]

The donor model leaves no room for the privacy of the recipient, and so it promotes the autonomy of the donor at the expense of the autonomy of the recipient. Indeed, requiring such disclosures places an enormous burden on the recipient. Since he may die or, at minimum, suffer greatly without the donation, such requests are inherently coercive. The fact that a potential recipient may be willing to give such information does not change the fact that asking for it demands from him things which he might prefer not to share and which he has no reason to share. Indeed, it underlines how coercive such requests are that the recipient may feel that he has no choice but to comply with them.

On this model, then, Jonathan would have to tell Meredith that he is HIV positive, that he was once arrested for a minor shoplifting charge, that his first marriage dissolved after he had an affair, and that he lost his first kidney because he failed to keep taking his immunosuppressants after six months because they made him nauseous. He is, of course, free to refuse to tell Meredith any of these things, but of course, she would then be free to refuse to donate to him.

Even on this model, of course, the medical teams would still play an important role. The members must insure that the donor understands both the risks and the benefits for herself and her recipient and that she understands the information about medical and non-medical factors and how they affect — or do not affect — the probability that the transplant will succeed. The team must counsel the donor about the psychological impacts of her decision and inform her about what they think the likely impact of her donation will be on both herself and her recipient. The team must, then, provide the donor with all the information that the donor requests, and they must also help her to appreciate what that information means.

However, on this model, the medical team should *not* decide what level of risk is acceptable or what factors are relevant to the donor's decision. That determination would be left to the donor alone. The team should say, "We think your recipient is likely to live X years with Y quality of life. Given the risks to your own health, both now and in the future, do you want to give him an organ under these terms?" Such an approach leaves as much of the decision as possible to the donor. It places the highest value on her autonomy: she is given the power to take as much risk for herself as she wants, as long as she fully understands what could happen both to herself and to her recipient. Just as people can take on the risk of skydiving — an activity that is more risky that kidney donation[21] — she can judge the risk with which she feels comfortable. And, by the same logic, she can determine what information she requires to make her decision.

C. Further Considerations

While the donor model does the most to respect the autonomy of the donor, in doing so it violates other values that, I think, cumulatively outweigh it. Three considerations are crucial.

First, the donor model leaves no room for the privacy of the recipient, and so it promotes the autonomy of the donor at the expense of the autonomy of the recipient. Indeed, requiring such disclosures places an enormous burden on the recipient. Since he may die or, at minimum, suffer greatly without the donation, such requests are inherently coercive. The fact that a potential recipient may be willing to give such information does not change the fact that asking for it demands from him things which he might prefer not to share and which he has no reason to share. Indeed, it underlines how coercive such requests are that the recipient may feel that he has no choice but to comply with them. When Meredith wants to know, say, whether Jonathan has been in prison or whether he has ever had an adulterous relationship on the grounds that she is trying to determine if he will be a good guardian for her kidney, she is essentially making a personal judgment about whether he "deserves" to have her organ.

In effect, if not in intent, Meredith is asserting control over Jonathan. Indeed, placing so much emphasis on what he deserves frames the donation in unhelpful way. If the organ is a gift and the benefit of the gift is in the giving, then focusing too much on how much the recipient "deserves" the gift sets up a bad psychological dynamic. Focusing the donor's attention on the recipient's behavior turns a magnanimous gift whatever the outcome into a contingent gift, whose value depends on whether it is well received.

Think of birthday presents. The best are those that come from a deep connection between the giver and the recipient. They are based on a knowledge of what will be good for the recipient — even if that judgment is simply one about what will give the recipient pleasure. A good gift should not have an agenda attached to it; the gift should not be a means of getting the recipient to change. And while the gift is given with an eye to the good of the recipient, the gift is still a good one even if it fails to have its intended effect, for whatever reasons. I hope the DVD I give will be enjoyed by my brother, and I have some good reason to think he will like the version of "The Marriage of Figaro" that I have chosen, but the gift is not a failure if it gets damaged in shipping or if he does not like voice of the soprano playing Susanna. I give him the DVD, not because he deserves it, but as one way of expressing the care I have for him with the hope that he will benefit from it. Likewise, the gift of an organ is done out of the expression of care, and as such its worth should not be depend too greatly on its effect. Of course, no gift is ever really so pure, and the gift of an organ is particularly fraught with complexity, since the stakes for both the donor and the recipient are so high. Indeed, it is a gift that can never be repaid, and so it places a real psychological burden on the recipient and, for that reason, on the donor as well.[22]

The medical teams, obviously, cannot alter this fundamental dynamic, but they can try to make the gift relationship that emerges from the transplant as uncomplicated as possible, both by counseling the donor and the recipient and by screening them to minimize the number of dysfunctional pairings.[23] For obvious reasons, the donor and the recipient are often too close to their own situations to have the proper perspective on these issues. Even when these issues are explained, they will often be unable to step away from themselves enough to see how these dynamics apply in their own situations. So even in the best of circumstances, a third-party perspective is crucial. Generally speaking, the medical teams are better positioned to look at the issues objectively. For that reason alone, we have some reason to prefer that the teams set the agenda for the transplant process.

The second reason we should not let the donor set the agenda is, ironically, that such a model would place too much burden on the potential donor. By bowing completely to the donor's autonomy, we also place the decision entirely in her hands with all the weight that such a decision entails. We thereby make it harder for her to act freely. If the donor is being asked to give an organ to a loved one, she might be very reluctant to tell that loved one that one extra year of life is not worth the sacrifice of her organ. She might feel that she would — or ought to — do anything to keep that loved one alive, no matter how little he gains by it. On the other hand, she might feel that she cannot think of herself as a generous person unless she goes through with the donation. In either case, she may be unable to weigh the risks and benefits objectively. Weighing such matters is a task we can and should leave to the professionals.

Third, precisely because the members of the medical teams occupy their positions as professionals, they have duties that the donor does not, duties to *everyone* involved in the transplant, duties that we should not expect others to fulfill. First, they have a duty to the donor. That duty is to protect her interests and to ensure that the likely outcome for the recipient is promising enough that it is worth the risk to her, even if she is willing to take a higher risk. Second, they have a duty to the recipient: to find a suitable organ for him if possible and if a transplant will benefit him. But the medical teams also have a third duty: to the system as a whole. They have an obligation not to let donations go forward that the donor would have good reason to regret or that places too many burdens on the system, given the limited expected benefit. So while they have a vested interest in the transplant process, that very interest encourages them to be cautious, since transplant programs can be damaged greatly by poor outcomes. They thus have a duty not to participate in an undertaking they think is too risky for the donor.[24] Indeed, this point has broader implications about their responsibilities to the health care system in general, obligations that we can only expect to be met by the health care professionals. The teams, unlike the donor or the recipient, have a responsibility to create and follow rules that ensure that valuable medical resources — not only money, but also time and organs — are not used on procedures that are unlikely to produce long-term benefits for all involved. So even if Jonathan desperately wants a transplant that is unlikely to benefit him much and Meredith is willing to go along with it, the transplant team should not indulge them. Their time and the resources of the health care system as a whole could be better spent. Even the organ has a better use — in Meredith, if nowhere else.

III. Particular Information in Context

Even this framework, however, does not resolve the question about what exactly the donor should be able to know about her recipient. While the transplant teams have an obligation to ensure that the donor does not take on too many risks, they cannot dictate the circumstances under which the donor will think her sacrifice is worthwhile. So even if the donor is not entitled literally to any information about the recipient that she wants, she is entitled to know information that is relevant to the medical success of the transplant. Certainly, the team should provide the donor with generalized information about the odds that a candidate like her recipient will have a successful transplant. So, as I have already noted, everyone agrees that Meredith should be told that the odds that Jonathan's second transplant will fail are higher than the odds were that his first transplant would fail.[25] Meredith's autonomy is thus still important. After all, the donation goes nowhere if she is unwilling to start the process. To say that her autonomy is not the only value at stake here does not imply that it has no significance.

Within this framework, then, we can directly address whether Meredith should have access to particular information about Jonathan's medical condition and, in particular, to information about his HIV status and whether he lost a prior transplant due to medical noncompliance. Generally, unless the information would affect the outcome of the transplant, it is irrelevant to the decision she has to make, so Meredith has no need to know it, and the transplant teams should resist such a request. However, in the two particular questions at hand, the issue is more complicated.

On the first question, the best evidence is that even HIV+ patients whose situation is well-controlled do marginally worse than HIV- patients with kidney transplants. Although patient survival rates are comparable in HIV+ and HIV- patients, HIV+ patients suffer from graft rejection somewhat more frequently, so that the graft survival rate for them is comparable to that patients over 65 years of age. Such results are hardly surprising, given the difficulties of treating someone with a potential immunodeficiency with immunosuppressants.[26] However, both patient survival and graft survival rates are high, and so the transplants are well worth doing. With more experience with immunotherapy in these patients, many think the differences will be eliminated.[27] Moreover, given the stigma that has been attached to HIV status and the special status that HIV status has in many state laws, we should certainly be wary of requiring disclosure. Nevertheless, the current evidence is that HIV status does affect the odds for a successful transplant, and for that reason it should be disclosed to the donor. Indeed, a modest majority of both donors and recipients think that the donor should be given information about the recipient's HIV status,[28] and so for now, transplant teams should provide such information.

P.D. Bright and J. Nott suggest that the medical team can finesse this issue by telling Meredith that Jonathan has a higher risk for graft failure than other recipients, specifying as best they can what the increased risk is, but without specifying the reasons for the increase. They would thus give Meredith the information she needs without invading Jonathan's privacy more than strictly necessary.[29] But such a solution is, in practice, too clever. Telling a donor that the recipient has increased risk and then attempting to conceal the reasons seems shifty. It is, I think, more likely to lead to suspicion and distrust, rather than to a better decision process. Attitudes towards HIV are gradually improving,[30] so we can hope that any donor refusals will be based on the increased risk and not on donor attitudes. However, since the information is relevant to the medical decision to donate, trying to conceal it is simply not credible.

On the question of disclosing past non-adherence, the behavior bears directly on whether the recipient is going to be a "good guardian" of the donor's kidney — not in some abstract sense in which the donor wonders if the recipient will live a good life, but in the sense that the donors wonders if the recipient is capable of doing what is necessary to insure that the organ will function. Unfortunately, the evidence on this question is rather thin, and what is available is somewhat mixed. On the one hand, even previously non-compliant patients who have been carefully screened still lose their second kidneys due to medical non-compliance more often than other patients, and they seem to have worse outcomes:

> Recipients with a history of overt NA [non-adherence] do have more repeat NA behavior, more acute rejection, and more graft loss to repeat NA, as well as overall trends toward worse outcomes compared to retransplant recipients without a history of overt NA.[31]

On the other hand, the overall graft survival rate is not significantly worse,[32] and the new transplant usually does provide the recipient with a significant benefit.[33] While the rate of non-compliance is higher among those who were previously non-compliant, even among those who are carefully screened, a large majority are medically compliant with their second transplant. So while the benefits of the transplant are less certain than those of other patients, they are still highly likely to succeed. Thus, the fact that a patient has lost a kidney from non-compliance is not by itself a reason to prevent them from receiving a second kidney, but that fact does affect the likelihood that the transplant will ultimately be successful. In these kinds of cases, the recipient's transplant team has an obligation to insure that the recipient has been carefully screened and counseled to insure that they are likely to adhere to their regimen. But since even in these cases, the risks of failure are still higher than for other patients, the donor's team should inform the potential donor of this part of the recipient's medical history.

So the donor is entitled to know facts about the general health of the recipient, about whether he has adequate social supports, about whether this transplant is a first transplant or not, about his HIV status, and about whether he lost a previous transplant because he failed to comply with his medical regimen. She does not, however, have a right to any other information.

This information will, of course, place some extra burden on both Meredith and Jonathan. Jonathan's team must ensure the he has demonstrated a commitment to a better outcome in his second transplant before he is allowed to go forward. In doing so, that team can give Meredith some confidence that their donation will have a good chance of success. But since Jonathan's history affects the odds for the transplant, Meredith should be told. The alternative — not to inform the donor at all and to rely completely on the team's own assessment of the recipient — is itself fraught with moral dangers. If Meredith were not told of Jonathan's history and he subsequently lost his transplant through neglect or abuse, Meredith would have good reason to be angry and to feel betrayed, not only by Jonathan, but also by the transplant teams that allowed the donation without giving her a choice in the matter. Indeed, a large majority of both recipients and donors think this information should be provided to donors,[34] and so both have a clear expectation that it will be provided. Since such information is, in fact, relevant to the success of the transplant, we have good reason to tell a donor if her recipient lost a previous transplant due to medical non-compliance.

Conclusion

The decision to donate an organ is one that must be made carefully with a close collaboration between the potential donor, the recipient, and the transplant teams. In general, the donor is entitled to information that might affect the success of the transplant. While donors must understand that organs are rejected for many reasons and that they should not be wedded psychologically to the ultimate success of the donated organ, their decision to donate makes no sense at all unless they can reasonably expect that it will benefit the recipient. Information about factors that bear on the likely success of the donation are, then, relevant. So the donor is entitled to know facts about the general health of the recipient, about whether he has adequate social supports, about whether this transplant is a first transplant or not, about his HIV status, and about whether he lost a previous transplant because he failed to comply with his medical regimen. She does not, however, have a right to any other information: she need not be told specific details of his health condition, his criminal record, or any of his other personal characteristics. The autonomy of the donor is important, and so she must be given information that is relevant to her decision, but the privacy of the recipient deserves some respect as well. He should not be forced to abandon all privacy simply because he is desperate for the help of another.

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References

1. In my example, the donor is female and the recipient is male, and for clarity, I will refer to the generic donor as female and the generic recipient as male. While the points of the paper obviously apply to donors and recipients of either gender, my choice is not random: about 60 percent of live donors are female, and about 60 percent of recipients of live donations are male. See Organ Procurement and Transplant Network (OPTN), *OPTN/SRTR Annual Report 2010*, at Tables 2.9, 5.4d *available at* <http://srtr.transplant.hrsa.gov/> (last visited February 22, 2013).
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3. D. L. Segev, A. D. Muzaale, D. Abimereki, B. S. Caffo, S. H. Mehta, A. L. Singer, A. S. E. Taranto, M. A. McBride, and R. A.

Montgomery, "Perioperative Mortality and Long-term Survival Following Live Kidney Donation," *JAMA* 303, no.10 (2010): 959-966, at 965.

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   For simplicity's sake, I will limit the discussion to kidney donations. Most of the discussion will apply to other live donations as well. However, the risks involved in other donations are often higher. So, for example, the risk of death for liver donors is 17 per 10,000. See A. D. Muzaale, N. N. Dagher, R. A. Montgomery, S. E. Taranto, M. A. McBride, and D. L. Segev, "Estimates of Early Death, Acute Liver Failure, and Long-term Mortality among Live Liver Donors," *Gastroenterology* 142, no. 2 (2012): 273-280.
5. See Live Organ Group, *supra* note 2.
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7. M. A. Dew, C. L. Jacobs, S. G. Jowsey, R. Hanto, C. Miller, and F. L. Delmonico, "Guidelines for the Psychosocial Evaluation of Living Unrelated Kidney Donors in the United States," *American Journal of Transplantation* 7, no. 5 (2007): 1047-1054; K. L. Lentine, M. A. Schnitzler, H. Xiao, D. Axelrod, C. L. Davis, M. McCabe, D. C. Brennan, S. Leander, A. X. Garg, and A. D. Waterman, "Depression Diagnoses after Living Kidney Donation: Linking U.S. Registry Data and Administrative Claims," *Transplantation* 94, no. 1 (2012): 77-83.
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9. See OPTN, *supra* note 1, at Tables 5.8cd, 5.10cd.
10. See Live Organ Donors, *supra* note 2; T. Steinman, B. Becker, A. Frost, K. Olthoff, F. Smart, W. Suki, and A. Wilkinson, "Guidelines for the Referral and Management of Patients Eligible for Solid Organ Transplantation," *Transplantation* 71, no. 9 (2001): 1189-1204.

    These examples are all relatively clear, but many more are not. However, we might think that some quality of life issues may be important. So, we might be inclined to transplant a parent of young children, even though that parent is likely to live only two years, on the grounds that the time spent with his children will be greatly valuable both to himself and to his children.

    In addition, some of the issues here demonstrate the real disparities between the poor and the rich in the transplant system. Many of the disadvantaged have a history of poor medical compliance because they lack the resources – both financial and social – to follow a complicated regimen. Indeed, the most disadvantaged may have few friends or relations who can help see them through the transplant process, and for that reason, they may be unlikely to do well with a transplant.
11. See Steinman, *supra* note 10 at 1193.
12. R. Formica, W. Asch, K. Wagner, and S. Kulkarni, "Kidney Transplantation and HIV: Does Recipient Privacy Outweigh the Donor's Right to Information?" *Clinical Journal of the American Society of Nephrology* 5, no. 5 (2010): 924-928; P. D. Bright and J. Nutt, "The Ethics Surrounding HIV, Kidney Donation, and Patient Confidentiality," *Journal of Medical Ethics* 35, no. 4 (2009): 270-271.
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14. See Ad Hoc Subcommittee, *supra* note 6, at 2302-2303 and 2298; OPTN, *supra* note 6.
15. See C. Elliott, "What's Wrong with Living Heart Transplantation?" in *A Philosophical Disease* (New York: Routledge, 1999): 103-120, at 105-106.
16. J. C. Magee, M. L. Barr, G. P. Bassadonna, M. R. Johnson, S. Mahadevan, M. A. McBride, D. E. Schaubel, and A. B. Leichtman, "Repeat Organ Transplantation in the United States, 1996-2005" *American Journal of Transplantation* 7, no. s1 (2007): 1424-1433; and P. S. Rao and A. Ojo, "Organ Retransplantation in the United States: Trends and Implications," *Clinical Transplants* (2008): 57-67. But see S. Barocci, U. Valenta, Fontan, A. Tagliamacco, G. Santori, M. Mossa, E. Ferrari, G. Trovatello, C. Centore, S. Lorenzi, D. Rolla, and A. Nocera, "Long-Term Outcome on Kidney Retransplantation: A Review of 100 Cases from a Single Center," *Transplantation Proceedings* 41, no. 4 (2009): 1156-1158.
17. See OPTN, *supra* note 1, at Table 5.10d.
18. See Live Organ Group, *supra* note 2, at 2920.
19. *Id.*, at 2925 (emphasis added).
20. The percentage of potential recipients who thought donors should have this information is, in every case, higher than those of potential donors. For HIV status, 58 percent of potential donors and 67 percent of potential recipients thought the donor should be told. For loss of organ due to noncompliance, 75 percent of potential donors and 84 percent of potential recipients thought the donor should know. J. R. Rodrigue, K. Ladin, M. Pavlakis, and D. A. Mandelbrot, "Disclosing Recipient Information to Potential Living Donors: Preferences of Donors and Recipients, Before and After Surgery," *American Journal of Transplantation* 11, no. 6 (2011): 1270-1278, at 1274.
21. An average of about 21 people die each year in skydiving accidents in the U.S., 6.7 deaths for every 10,000 skydivers, while an average of less than two people died each year from kidney donations, 3.1 deaths for every 10,000 donations. See United States Parachute Association, "Skydiving Safety," *available at* <http://www.uspa.org/AboutSkydiving/SkydivingSafety/tabid/526/Default.aspx> (last visited February 22, 2013) and Segev, *supra* note 3, at 965.
22. N. Scheper-Hughes, "The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants," *American Journal of Transplantation* 7, no. 3 (2007): 507-11.
23. See Dew et al., *supra* note 7; N. B. Levy, "Psychological Aspects of Renal Transplantation," *Psychosomatics* 35, no. 5 (1994): 427-433.
24. See Elliott, *supra* note 15, at 118-1119.
25. See Magee et al., *supra* note 16; Rao and Ojo, *supra* note 16; Barocci et al., *supra* note 16.
26. P. G. Stock, B. Barin, B. Murphy, D. Hanto, J. M. Diego, J. Light, C. Davis, E. Blumberg, D. Simon, A. Subramanian, J. M. Millis, G. M. Lyon, K. Brayman, D. Slakey, R. Shapiro, J. Melancon, J. M. Jacobson, V. Stosor, J. L. Olson, D. M. Stablein, and M. E. Roland, "Outcomes of Kidney Transplantation in HIV-Infected Patients," *New England Journal of Medicine* 363, no. 21 (2010): 2004-2014, at 2008; and J. E. Locke, R. A. Montgomery, D. S. Warren, A. Subramanian, and D. L. Segev, "Renal Transplants in HIV-Positive Patients: Long-Term Outcomes and Risk Factors for Graft Loss," *Archives of Surgery* 144, no. 1 (2009): 83-86.
27. See Stock et al., *supra* note 26, at 2012; Locke et al., *supra* note 26.
28. See Rodrigue et al., *supra* note 20, at 1274.
29. See Bright and Nott, *supra* note 13, at 271.

30. The *Washington Post*/Kaiser Family Foundation, *2012 Survey of Americans on HIV/AIDS, available at* <http://www.kff.org/kaiserpolls/upload/8334-T.pdf> (last visited February 22, 2013).
31. See Dunn et al., *supra* note 13, at 1345. An unfortunate truth is that many cases of non-adherence are related to problems that the recipients have paying for the immunosuppressant drugs and to the difficulties they have in maintaining such a regimen. See R. W. Evans, W. H. Applegate, D. M. Briscoe, D. J. Cohen, C. C. Rorick, B. T. Murphy, and J. C. Madse, "Cost-Related Immunosuppressive Medication Nonadherence among Kidney Transplant Recipients," *Clinical Journal of the American Society of Nephrology* 5, no. 12 (2010): 2323-2328); F. Dobbels, R. Van Damme-Lombaert, J. Vanhaecke, and S. De Geest, "Growing Pains: Non-adherence with the Immunosuppressive Regimen in Adolescent Transplant Patients," *Pediatric Transplantation* 9, no. 3 (2005): 381-390. Such problems point to another significant disparity between rich and poor in the transplant system. However, the data available are not detailed enough to determine if such patients are more or less likely to lose a second transplant than other non-adherent recipients.
32. See Dunn et al., *supra* note 13, at 1341.
33. *Id.*, at 1345.
34. See Rodrigue et al., *supra* note 20, at 1274.