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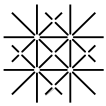
Institut für
Bio- und Medizinethik

**A Report on the Ethics & Law of Challenging Cases in
(Crossover) Living Donation**

David M. Shaw

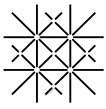
Institute for Biomedical Ethics, University of Basel

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Executive Summary

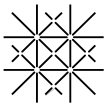
This report considers the request from Swisstransplant expert group to change the law so that “orphaned” or “empty” recipients and former kidney donors who go on to develop renal insufficiency can be prioritised for an organ on the deceased donation waiting list. Orphaned recipients are intended recipients in crossover kidney donation who do not receive an organ as anticipated, even though their partner provides an organ; some people who donate one of their kidneys go on to develop kidney problems after donation.

The ethical analysis reveals that the proposal to prioritise orphaned recipients is problematic, primarily because of concerns about justice and non-discrimination. Although the justification offered for the request claims to be based on justice, it is a narrow conception of distributive justice that neglects broader issues of social justice and fairness. While it is true in some cases that there is no net loss of organs from this prioritisation, granting orphaned recipients the priority currently accorded only to those who are in urgent medical need of a kidney would discriminate against those on the waiting list and who remain unprioritised despite potentially greater medical need. Furthermore, the reason for granting this prioritisation would be grounded in an initial advantage already enjoyed by orphaned recipients; they are fortunate enough to have a family member or friend willing to donate an organ, while (most of) those on the waiting list do not. Therefore, prioritising orphaned recipients would give an unfair advantage to someone who already had an advantage, while unfairly penalising those potentially in greater medical need who enjoy no such advantage. The discriminatory effects of implementing the proposal seem disproportionate considering the relative rarity of orphaned recipients.

In the case of former donors who develop renal failure, prioritisation may seem less discriminatory. However, it remains unclear what the justification would be for granting prioritisation of a former donor over a non-donor who is in greater medical need of a kidney. The surest way to avoid discrimination is to only permit prioritisation in cases of medical urgency.

The legal context in Switzerland only reinforces the conclusions of the ethical analysis. The Swiss Constitution, the Transplantation Act and its related ordinances all place great emphasis on non-discrimination, and more specifically on precisely which criteria can be used in allocation of organs without discrimination occurring. Implementation of the Swisstransplant expert group’s request would require not only changes to the Allocation Ordinance, but also to the decisive criteria stipulated in the Transplantation Act itself, and even (arguably) the Swiss Constitution itself.

In conclusion, the proposal as it stands should not be implemented as it would be unethical. Alternatively, it is possible that milder prioritisation within a tiered or points-based waiting list (or prioritisation in another chain) might succeed in avoiding the risk of discrimination, but the Swiss law is so restrictive that these alternatives might run into legal obstacles even if deemed ethical.



Chapter 1: Introduction and Context

1.1: Living and paired donation in Switzerland

Donation of organs from living people rivals deceased donation in terms of the number of donors per year in Switzerland. In 2014 and 2016, the number of living donations exceeded the number of deceased donations.¹ While it has the disadvantages of potential medical risk to the donor, and a reduction in the type of donatable organs (only the kidney and/or part of the liver), living donation has the advantage of avoiding the challenges surrounding consent posed by deceased donation.² Living and deceased donation are both governed by the Transplantation Act and associated ordinances.^{3 4 5}

In Switzerland, two types of living donation are possible. The first is directed donation, where a donor provides an organ for a family member or friend, and thus knows the identity of the (intended) recipient. The second is non-directed donation, where a person donates an organ without knowing who will receive it. This type of living donation is also known as “altruistic” donation because, in contrast with directed donation, the donor will not benefit (directly) from the recipient receiving the organ.

Paired, or crossover donation combines directed and non-directed donation, in a sense. A donor can only provide a kidney to a family member or friend if he or she is a tissue match. Often, despite genetic relatedness, tissue testing reveals that (for example) a woman cannot donate to her daughter. In such cases, paired donation can provide a solution. Here, a donor who is not a match for his or her chosen recipient is ‘paired’ with another non-matched donor and recipient pair. Instead of donating to her daughter (because she is not a match), the mother donates to a stranger in need of a kidney, and the stranger’s donor donates to the daughter. Thus the recipient is directed, but the donation comes from a different donor, and the donor’s recipient receives a kidney from a stranger (the non-directed aspect). When this works, all parties benefit: two people who wanted to donate to a relative or friend but could not do so due to for example a tissue mismatch are able to donate to strangers instead, but the intended recipient still receives a matched kidney.

1.2: The issue of orphaned recipients

However, paired donation does not always go as planned. In some cases, an organ might not be transplanted due to an unexpected abnormality not seen before explantation or the organ might be harmed during transport. Either way, the consequence is that (to take the previous example again) the mother has donated a kidney and it has been transplanted into a recipient, but her daughter has been unable to receive the ‘paired’ kidney. Such situations are difficult because the donor might feel that she has been cheated through no fault of her own; she wanted to help her daughter but due to bad luck was unable to do so. Under the current context in Switzerland, the ‘spare’ kidney is allocated to someone else on the waiting list for an organ, but the “empty recipient” does not receive any priority in terms of finding a substitute kidney. In

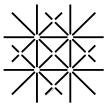
¹ Federal Office of Public Health. Chiffres relatifs au don et à la transplantation d’organes en Suisse. <https://www.bag.admin.ch/bag/fr/home/zahlen-und-statistiken/zahlen-fakten-zu-transplantationsmedizin/zahlen-fakten-zur-spende-und-transplantation-von-organen.html>

² Shaw DM. The Consequences of Vagueness in Consent to Organ Donation. *Bioethics*. 2017 Jul;31(6):424-431. doi: 10.1111/bioe.12335. Epub 2016 Dec 28.

³ Federal Act on the Transplantation of Organs, Tissues and Cells (810.21). 2004.

⁴ Ordinance on Crossed Transplantation (810.212.3). 2017.

⁵ Ordinance on the allocation of organs. 810.212.3. 2017



addition to this being a difficult situation (though a very rare one), doctors can find it difficult to explain this potential situation to people considering entering the paired donation programme.

It has therefore been suggested that empty recipients should be given priority for allocation of an organ from the deceased donation pool. Specifically, the Swisstransplant Crossover Living Donor Expert Group has recommended that empty recipients should be given “urgent” status, meaning that they will be allocated an organ more quickly than “non-urgent” patients on the waiting list. The main justification for this proposal is that it would be unjust to deny priority to empty recipients: the donor in the ‘empty pair’ has provided an organ to the overall pool of organs, and it seems unjust not to compensate for the loss of the organ that was anticipated in exchange. Chapter 2 of this report provides an ethical analysis of this proposal; Chapter 4 considers the legal context of the request.

1.3 The issue of living donors with renal insufficiency

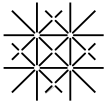
Another foreseeable but unintended consequence of the living donation programme more generally is that altruistic and directed donors who provide an organ for someone else sometimes go on to develop renal insufficiency themselves; the risk of this has been estimated at 1 donor per 3000. This is one of the key risks of becoming a living organ donor; while most people live healthily using only one kidney, others have related health issues after donation. Currently, living donors who now need a new (or ‘extra’) kidney receive no special treatment; if they cannot find a living donor willing to donate, they are placed on the waiting list for a deceased organ.

Accordingly, it has been suggested by Swisstransplant expert group that living donors who go on to develop renal insufficiency should also be given priority on the waiting list for organ allocation. As in the case of empty recipients, the main motivation is justice: these patients have donated organs and helped recipients, and it seems just (according to the proposal) to compensate the risk they took by getting them a new organ quickly, even if this means disadvantaging other people on the waiting list who are not given priority. Chapter 3 of this report provides an ethical analysis of this proposal; Chapter 4 considers the legal context of the request.

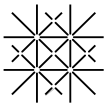
1.4 The Swisstransplant expert group proposals

The proposals of the Swisstransplant expert group have been briefly sketched above, but it will be helpful to give them in full here, along with the proffered justification. Currently, Article 13 of the ordinance concerning allocation of kidneys states that medical urgency particularly applies where “a patient who can no longer be dialysed is at immediate risk of death” (“Eine unmittelbare Bedrohung des Lebens liegt namentlich vor bei Patientinnen und Patienten, bei denen eine Dialyse nicht oder nicht mehr möglich ist”). Notably, the Swisstransplant expert group proposal omits the word “medizinische” before “Dringlichkeit”, perhaps anticipating that the proposed new types of urgency are not medical, but social.

The specific proposals are to add two new situations that also qualify as “urgent” in addition to the current definition in Art. 13 of the ordinance. First, with regard to empty recipients, the Swisstransplant expert group proposes: “a recipient in a pair within the KPD [kidney paired donation] program is left empty, although his partner already has donated a kidney (orphaned recipient)”. Second, with regard to living donors who go on to need a new kidney themselves, the proposal is: “a person who has previously donated a kidney in Switzerland and has reached a stage of renal insufficiency requiring dialysis” (“Eine Person, die vorgängig in der Schweiz eine Niere gespendet hat, hat eine dialysepflichtige Niereninsuffizienz erreicht”). Thus, in



addition to the existing definition of medical urgency as “imminent risk of death due to renal insufficiency”, the definition of urgency would expand to include “requires dialysis but once donated a kidney” and “requires dialysis but is an orphaned recipient”.



Chapter 2 – Ethical analysis: Prioritisation of Orphaned Recipients

2.1 Integrity of the paired kidney donor system

This chapter provides an ethical analysis of the Swisstransplant expert group proposal regarding empty or orphaned recipients. There is little published literature on the issue of orphaned recipients, with the possibility discussed only in passing in some transplant guidance^{6 7} and academic papers.^{8 9 10} The Swisstransplant expert group makes two key claims: that prioritising orphaned recipients is required by justice, and that doing so will “restore trust in the integrity of the crossover program”. Before considering the justice claim in light of potential benefits and harms, let us examine the one regarding integrity. Is it true that the integrity of the program is threatened without prioritisation of orphaned recipients? If it is not, and any loss of trust is based on a misunderstanding, changing the allocation system might be unnecessary.

It is true that orphaned recipients who are prioritised would greatly appreciate this, as they would get an organ faster, and it might increase their confidence in the program. But in fact, the actual (rather than perceived) integrity of the program is not compromised by the current system. Pairs who enter a crossover program have the prospective risks and benefits explained in detail, and one of those risks is that something might go wrong. The fact that an acknowledged low-risk possibility actually occurs in no way threatens the integrity of the program; that would only be true if the risk was not mentioned at the outset. The feelings of hurt and betrayal experienced by orphaned recipients and their donors are very real, but that does not necessarily mean that they have been treated unjustly.

It is also important to bear in mind that potential recipients of organs donated by deceased donors are sometimes disappointed when it seems that an organ has been found but something goes wrong, either because the organ turns out to be unsuitable or because the recipient is too unstable to receive the organ and it goes to someone else. Yet this is not claimed to threaten the integrity of the deceased donation system, and no-one is suggesting that people who miss out on an organ in this way should be given (an increase in) priority over others on the waiting list. Why are the ethics of the situation perceived differently in the case of orphaned recipients? There are two obvious factual differences that might be thought to explain this asymmetry. First, one situation concerns living donation, and the other deceased donation. However, that distinction alone cannot explain the perceived difference; if something goes wrong in altruistic living donation and the intended recipient cannot receive an organ, it will go to someone else, and there is no suggestion of giving priority to the original intended recipient. One difference, however, is that the orphaned recipient always knows that something has gone wrong, while only a few potential recipients on the waiting list have their hopes dashed because something goes wrong. Therefore, the distinction must concern the nature of paired donation itself. As suggested by the Swisstransplant expert group, the issue appears to be one of thwarted expectations and fair play; by getting her donor to give an organ, an expectation was generated that an organ would be received in return. This is a unique feature of paired

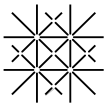
⁶ British Transplantation Society. Guidelines for Living Donor Kidney Transplantation. 2018. https://bts.org.uk/wp-content/uploads/2018/01/BTS_LDKT_UK_Guidelines_2018.pdf

⁷ Australian Paired Kidney Exchange Program Agreement to participate for donors and participants. <https://stgrenal.org.au/sites/default/files/upload/Transplant/Agreement-to-Participate.pdf>

⁸ N. Cowan H. A. Gritsch N. Nassiri J. Sincore J. Veale. Broken Chains and Reneging: A Review of 1748 Kidney Paired Donation Transplants. <https://doi.org/10.1111/ajt.14343>

⁹ Rees MA Kopke JE Pelletier RP et al. A nonsimultaneous, extended, altruistic-donor chain. *N Engl J Med* 2009; 360: 1096–1101

¹⁰ Paolo Ferrari, Willem Weimar, Rachel J. Johnson, Wai H. Lim, Kathryn J. Tinckam, Kidney paired donation: principles, protocols and programs, *Nephrology Dialysis Transplantation*, Volume 30, Issue 8, August 2015, Pages 1276–1285



donation, which does differentiate it from deceased donation and other types of living donation. But the fact that paired donation involves an agreement that involves a degree of risk of failure is not sufficient to justify giving people left aggrieved by the resulting situation a claim over organs that would normally go to people unable to enter such an agreement in the first place.

Part of the reason for the misperception of what is fair in this situation may be due to the proximity of actors in living donation, relative to those in deceased donation. In those rare cases where a crossover donation goes wrong, healthcare professionals have to deal with the raw emotions of those who feel they have been cheated of an organ. This results in the understandable impulse to grant them priority for an organ from a deceased donor. But the only reason that this seems fair is because those professionals neither know nor have to face those already on the waiting list who may be disadvantaged by helping orphaned recipients in this way. In other words, doctors are morally close to orphaned recipients and their family members, but morally distant¹¹ from those who would be disadvantaged by the Swisstransplant expert group's proposal.

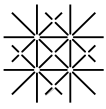
2.2 Justice

The foregoing discussion concerns some moral intuitions about whether orphaned recipients should be given priority for allocation of organs from the deceased donor pool. I have suggested that these intuitions are based on a misconception and there are no more grounds for giving priority to orphaned donors than there are for giving priority to potential recipients who do not receive a deceased organ. But even if we think there are grounds for giving priority to orphaned recipients, these grounds might not be sufficient, given that giving them priority means de-prioritising patients who may have been on the waiting list for many years, might be in greater medical need of an organ, and were not lucky enough to have a potential living donor in the first place. For all these reasons, the Swisstransplant expert group's proposal runs into serious difficulties when considered from the perspective of justice. This is rather ironic, given that justice is the main stated motivation for the perceived change. As discussed above, the situation of the orphaned recipient does seem unjust at first sight and in isolation, but that moral intuition may well be mistaken.

Let us return to the central claim behind the proposal. It is claimed that it is unjust that a donor-recipient pair has provided an organ but not received one. In a sense, what was intended as a reciprocal directed donation has been transformed into an altruistic donation; the donor donated, but the recipient did not receive. This means that the "trade" has not been honoured, which does seem unfair in the isolated context of this intended arrangement. The Swisstransplant expert group also argues that giving priority to orphaned recipients does not disadvantage those on the waiting list, because the orphan's donor did donate an organ, reducing the waiting list by one, so there is no net loss of organs. However, this argument relies on a narrow transactional conception of distributive justice, and there are wider conceptions of justice that must also be considered. From a wider perspective, then, what do social and procedural justice have to say about the situation of the orphaned recipient?

On the one hand, we have a situation where someone in need of an organ was fortunate enough to have a living donor. Unfortunately, the donor was not a match; but fortunately, a crossover donation was a possibility. Unfortunately, the recipient does not receive the organ as intended. On the other hand, we have a situation where many people are on a waiting list for a deceased organ. They might need to wait many years for one, and only those who are at risk of imminent death because dialysis can no longer help them

¹¹ Shaw, D. and Gardiner, D. (2015), Moral distance and distributive justice: how the increase in organ donation is helping us make better ethical decisions. *Anaesthesia*, 70: 10-13.

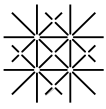


are given priority for kidneys, in line with medical necessity. Given these two situations, is it just to accord priority to the orphaned recipient?

The Swisstransplant expert group argues (i) that it is actually a requirement of justice to give the orphaned recipient priority, because of the perceived injustice of denying an organ to someone who legitimately expected to receive one from the crossover and whose donor did donate; and (ii) that the orphaned recipient's donor contributed an organ so there is no net loss for the waiting list. Let us consider the first of these arguments first. The orphaned recipient expected to receive an organ, but has been denied one through no fault of his or her own. Is this sufficient reason to grant priority over people who have been on the waiting list for years? It does not seem sufficient. The only reason that the orphaned recipient expected to receive the organ was because he or she was lucky enough to have a living donor with whom to enter the crossover program. While it is unfortunate that the organ was not transplanted, and this might seem unjust, it would be a much greater injustice to let the orphaned recipient leapfrog people who have no potential living donor, may have been on the list for years, and might well be in greater medical need of the organ that goes to the orphaned recipient. As the Swisstransplant expert group suggests, one concern is that orphaned recipients might be perceived as gaining an unfair advantage because they had a living donor, thus increasing inequality between them and patients on the waiting list who do not have potential donors; this in turn might lead to a feeling of discrimination). "But this is not just a feeling; it is a fact that granting priority to orphaned recipients would discriminate against some patients who were already on the waiting list and are in greater medical need.

Does the second argument, that the orphaned recipient's donor contributed to the pool by removing someone from the waiting list, mitigate these concerns of social justice? To some extent, it does. It is true that the net number of organs needed for those on the waiting list remains the same under the prioritisation scenario; thus the orphaned recipient would not be "stealing" an organ from those waiting, considered as a group. However, the orphaned recipient would still be leapfrogging people who had been on the waiting list longer, which would not be possible if he or she did not have a living donor. As such, the orphaned recipient would be permitted to skip the queue because he or she "paid" with his or her donor's kidney. Worse, in some cases the orphaned recipient would not even be on the waiting list yet, meaning that it would not simply be 'leapfrogging', but swooping in to the top of the list ahead of those who may have been waiting for years. This is clearly not fair or just, even before we consider the finer detail of what is actually happening in such a situation. The 'spare' kidney from the crossover donation will go to someone who is a match on the waiting list. Ideally, that would be someone who urgently needs a kidney, but it might be allocated to someone who is a better match but less urgent. In such a case, the orphaned recipient who is given priority over (almost) everyone else on the waiting list will be taking a net kidney from the group of those most in need of one, because the spare kidney has gone to someone who did not urgently need it, but the orphaned recipient could receive one that could otherwise have gone to someone who does urgently need it. The flaw here in the Swisstransplant expert group's proposal is to think of the waiting list as one group of people when in fact it is comprised of (at least) two; those who are non-urgent, and those who are urgent. Furthermore, only very few patients urgently need a kidney, medically speaking, meaning that the vast majority of those on the waiting list would indeed be being discriminated against.

Another issue with the "net neutrality" argument is that it only applies where the intended recipient is unstable and the kidney does actually go to someone on the waiting list. But as the Swisstransplant expert group's proposal makes clear, that is only one scenario: the other three are that the kidney is nontransplantable, that the kidney is lost, or that the kidney is not removed. In all three of these cases, there is no gain of an organ for those on the waiting list, so prioritisation would result in a net loss of one organ for those on the list. Prioritisation is even more discriminatory in such circumstances. (Note that the kidney might be transplantable into another patient in some scenarios unless a surgeon rejects it.) Curiously, the



proposal summarises the benefits and harms for all these scenarios under the status quo, but not under the proposed change in priority for orphaned recipients, presumably because providing detail would reveal the net loss of organs to the waiting list pool under the three other scenarios. (The crossover program is anticipated to yield an additional 40 transplants every year, which does take people off the waiting list, or prevents them from eventually going on to it. This is good for those on the waiting list, as it means they might get an organ more quickly. However, this does not change the fact that it would be discriminatory in most cases to give orphaned recipients priority when they are in less medical need, or at least have not been waiting so long.)

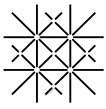
Another issue is the use of “feelings” in argumentation concerning justice. For example, it can be argued that people would generally feel that prioritisation results in some justice being achieved, but that there would be also be a feeling of discrimination against patients on the waiting list. As stated above, however, feelings and intuitions can be mistaken, and any consideration of justice should attempt to be as objective as possible. While the Swisstransplant expert group correctly states that the status quo does not discriminate against waiting list patients, what is missing is any admission that the proposal would discriminate against waiting list patients; all that is conceded is that there is a potential perceived inequity.

But even if the ‘spare’ kidney goes to someone who urgently needs it, according priority to the empty recipient remains unjust and problematic in terms of clinical ethics. As already stated, “urgent” means “medically urgent”. By giving priority to orphaned recipients, a new type of urgency is added: it is not medical, but the Swisstransplant expert group might describe it as “urgent in terms of perceived fairness”. We have already seen how this perception is likely to be mistaken, but even if it does seem just to grant priority to orphaned recipients because of the crossover agreement that was entered, we must consider the ethics of granting clinical priority to those who are (likely to be) in less clinical need.

John Rawls is famous for his well-known Theory of Justice.¹² Part of that theory is the Difference Principle, which states that any distribution must not leave the worse-off worse off. In terms of Rawls’ Difference principle, those who are lucky enough to have a living donor are among the socially best-off among those in need of an organ: they enjoy a particular good that is denied to most others. Those who do not have a prospective living donor are thus worse-off than those who do. By granting priority to those who are already better-off (even if they are not as well off as those who have a successful kidney crossover), the Swisstransplant expert group’s proposal violates the difference principle and is thus unjust. And that is even before we consider who is worse off and better off in terms of medical necessity. As stated above, giving priority to orphaned recipients puts them into the same category as those who will die imminently if they do not receive an organ. Most orphaned recipients are not in that situation, and if they were, they would be accorded priority in any case. Rather, they are likely to need an organ non-urgently, and probably less urgently than many people on the waiting list. Once again, granting priority would disadvantage those who are already medically worse off (though not in all cases). (One can also apply Rawls’ thought experiment of the Original Position to the issue of whether orphaned recipients should be prioritised. Behind the ‘Veil of Ignorance’, people choosing the rules for society – or in this case organ allocation – would not know whether they would need an organ. But they would know that they are much more likely to be a patient on the waiting list than to be an orphaned recipient, increasing the likelihood that they would favour strict medical urgency criteria being applied without exception.)

There is also another sense in which granting prioritisation to orphaned recipients would be unjust. In support of the proposal, the Swisstransplant expert group states that there might be a “feeling of injustice and inequity, invested a LD [living donation] without pay back”. While it is true that there was an expectation

¹² Rawls J. A Theory of Justice. 1971. Cambridge, MA: Harvard University Press.



that an organ would be provided to the orphaned recipient, this language comes rather close to suggesting that this was a trade in organs and that compensation is due for the loss. Any talk of “organ trade” with regard to crossover donation is unfortunate, but justifying the potential deprioritisation of patients in greater medical need in order to compensate for the loss of “pay back” is extremely ethically problematic.

The Swisstransplant expert group also points out that prioritisation does take place in other countries, but three points should be borne in mind here: first, in countries such as the UK, prioritisation only takes place within relatively tight tiers on the waiting list, which is quite different from letting orphaned recipients ‘leapfrog’ to the top of the list. Second, the fact that other countries permit prioritisation does not mean that it is ethically correct to do so; they might be making a mistake. Finally, even if they are not making a mistake, the legal context in those countries may be quite different from that in Switzerland, with its strong emphasis on non-discrimination.

Finally, there is support for the argument that prioritisation in this context would be unethical and unjust. In 2007 the Health Council of the Netherlands produced a report on a related but slightly different topic: Living Donor List Exchange, where an incompatible donor-recipient pair donates to someone on the waiting list and in turn is prioritised for an organ from the deceased donor pool. In essence, LDLE is what would happen (inadvertently) when a crossover donation goes wrong and the orphaned recipient is prioritised to receive an organ. The Dutch report was quite clear on the ethically problematic nature of such arrangements:

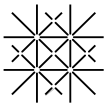
Justice in a formal sense involves the consistent treatment of all according to predefined rules and without respect of persons. This requires that people are dealt with on the basis of universally applicable impartial criteria. Universal applicability means that criteria are not individualised. Impartiality rules out expecting any reciprocal acts other than those that may reasonably be expected of everyone to whom the criterion applies. LDLE does involve such reciprocation and does not therefore appear to qualify as formally just: not everyone has a relative or friend who is willing to give up a kidney for them and it is not appropriate that the relatives and friends of kidney patients should feel under a moral obligation to donate. It follows that giving priority to patients who are able to provide a donor for someone else is unfair.¹³

2.3 Alternatives: Ethical Analysis

One alternative to granting prioritisation for a deceased donor organ to orphaned recipients would be to give them priority for the next altruistic living donor. But this solution does not avoid all the aforementioned ethical objections; other people are in greater medical need, and they should not be disadvantaged by the social advantage enjoyed by the orphaned recipient who had someone willing to donate. (A better solution as implemented in the USA, might be to prioritise orphaned recipients into the next available pair in a crossover chain, which would be more likely to avoid the charge of discrimination. Open chains are not used in Switzerland, and are unlikely to be adopted.)

Another alternative to granting orphaned recipients “urgent” status would be to give them more “points”, granting them slightly higher priority. This is what happens in some other countries; for example, in the UK, orphaned recipients are given higher priority within the tier they are in on the waiting list. This solution is less discriminatory than the Swisstransplant expert group’s proposal to grant urgent status, and thus might

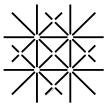
¹³ Health Council of the Netherlands. Living Donor List Exchange: an addition to the Dutch living kidney donor programme? The Hague: Health Council of the Netherlands, 2007; publication no. 2007/11.



seem preferable from the perspective of justice. If it were practical to implement it in Switzerland, this solution could be seen as a compromise between the unjust labelling of orphaned recipients as urgently in need of a kidney, and the perceived injustice of not compensating the orphaned recipient in any way. A potential paradox here may be insurmountable: the advantage given to the orphaned recipient via prioritisation must not be too great, or it would be seen as discriminatory. Therefore, the potential benefit to the prioritised recipient might by necessity be so small that it does not seem sufficient compensation for the situation he or she is in.

However, it remains the case that the points/tier solution would still discriminate against other patients over whom the orphaned recipient gains an advantage in terms of waiting time for an organ. Whether this disadvantage is proportionate to the benefit brought about by the organ provided by the orphaned recipient's donor is difficult to establish in general terms. From a utilitarian perspective, this might be seen as appropriate, but utilitarianism is often incompatible with justice in a strict sense. However, even if it did seem sufficient and an ethical justification could be found, the legal context might prohibit even this compromise solution unless wider-ranging legal changes than those envisaged by the Swisstransplant expert group were made, as we shall see in Chapter Four. On the most basic level, even conferring orphaned recipients a small advantage over others on the waiting list amounts to a small degree of discrimination - but discrimination nonetheless. Ultimately, the injustice done to orphaned recipients is less than is suggested in the expert group's proposal, and the potential injustice done to others on the waiting list is much greater than suggested.

One last point should be addressed before moving on to the next chapter. What if the orphaned recipient is neither resident in Switzerland, nor meets any of the other criteria under Article 17 of the Transplantation Act, meaning that he or she does not have equal rights with respect to allocation? As we have seen, prioritisation is likely to be unethical in any case so this is something of a moot point. In this case, given that the orphaned recipient in this situation does not qualify to join the waiting list, it would clearly be unethical to grant priority over almost everyone else on that list. In such circumstances, it might seem ethical to place the person on the Swiss waiting list like anyone else in need of an organ (because an organ has been donated and possibly removed someone from the waiting list), but not to grant priority. This would not discriminate against other people already on the waiting list, but would give some compensation to the orphaned recipient, who would not normally qualify to be added to the list. However, this would possibly grant the orphaned recipient an advantage over other people not resident in Switzerland who are in need of an organ, and possibly also result in Swiss residents who are added to the list waiting longer for an organ; thus the discrimination objection would also prevent any exceptions being made for orphaned recipients. (In any case, someone in such a position might well be placed on a waiting list in his or her own country, and the law prevents such people being added to the Swiss waiting list.)



Chapter 3 – Prioritisation of Former Donors with Renal Insufficiency

We have already seen that it would be unethical and unjust to accord orphaned recipients priority over other patients on the waiting list. The main reason for this is that it would be discriminatory in terms of social justice to grant someone priority simply because he or she was lucky enough to have a family member willing to donate an organ. On the face of it, it might seem that former kidney donors who go on to develop renal insufficiency represent an entirely different type of case. The Swiss Academy of Medical Sciences guidelines on living donation state that former donors who go on to develop renal insufficiency should be given priority for an organ, but no argumentation is provided for this recommendation.¹⁴

Here we have someone who freely chose to donate a kidney to a family member or friend or, in the case of non-directed donation, to a complete stranger. Intuitively, someone who has him- or herself made the sacrifice of donating a kidney deserves some type of compensation if it later turns out that he or she now needs a new kidney. But we should not forget that intuitively it seems to many that orphaned recipients should be prioritised to urgency; if the conclusions of the previous chapter are correct, then this is a mistaken intuition. Could the same apply to our intuitions in the case of the former donor with renal failure?

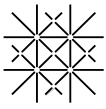
In fact, much of the same logic applies to both the orphaned recipient and the renal insufficiency patient. In both cases, a decision was made after full information was provided about the prospective benefits and potential risks. In both cases, one of those risks has actualised, meaning that someone still needs a kidney. And in both cases, prioritisation resulting in the accordance of “urgent” status would place patients in greater medical need at a disadvantage. Let us look at these points in more detail.

First, anyone considering donating a kidney receives extensive counselling about the potential risks of doing so. One of those risks is the possibility of the donor going on to develop renal insufficiency. People who choose to go ahead with donation know well the risks of what they are doing, and they are also told that they will receive no special treatment if one of those risks occurs. It can of course be argued that they should receive special treatment because of the sacrifice made, but the point is that, as in the case of orphaned recipients, the donor here is not treated unjustly simply in virtue of the fact that something bad happened that was a known possibility.

Second, from the perspective of those on the waiting list, the fact that someone once donated a kidney does not change the fact that that person is in less medical need than those that he is leapfrogging. Once again, while the donor’s kidney may have reduced the waiting list by one (though not in all cases, as it may have been donated to someone who was not yet on the list, or gone to a foreign participant in the programme), it might have gone to someone lower down the waiting list, while those close to the top are leapfrogged by the former living donor. To take a specific example, some people on the waiting list will have had kidney problems for many years, and were never in a position to be able to donate a kidney. Why should such patients have to wait longer for a kidney because someone made the (brave) decision to donate one? Once again, this is a case of those who were originally better off (the person who donated a kidney) gaining advantage over those who were originally worse off (those who could never donate a kidney because of kidney or other medical issues). This is just a specific example, but all of the criticisms in Chapter 2 regarding the injustice of someone in less medical need leapfrogging those in greater need apply here too.

The only sense in which there is ethical distinction from the case of the orphaned recipient is that a former donor with renal insufficiency himself (or herself) donated a kidney. However, even here it is not clear that

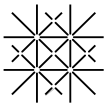
¹⁴ Swiss Academy of Medical Sciences. Don d’organes solides par des personnes vivantes: Directives médico-éthiques et recommandations. 2007.



this distinction does the intended work. At first glance it might appear that giving a kidney generates at least a weak expectation that one might be provided in return if needed later in life. The donor is running a medical risk to help someone else, and if something goes wrong it might seem fair that a kidney be given in return.

However, the orphaned recipient chose to enter into an agreement; something went wrong and the expected kidney was not delivered, through no fault of the orphaned recipient or his/her donor. But the person who donated a kidney before going on to develop renal insufficiency made a choice to donate. It is an obvious risk of doing so that one might in future need an organ (just as the orphaned recipient knew the risk of KPD going wrong). Why, patients being leapfrogged on the waiting list might ask, should this person get priority over me because he or she made a risky choice that turned out to be a bad one? If the response is “because it contributed a kidney” that may not be sufficient, because (as stated above) not everyone is in a position to do that in the first place, and the kidney may not have gone to someone on the waiting list in any case (see above). It is actually rather ironic that someone who made a sacrifice to help someone else who was in medical need might end up disadvantaging those in greater medical need by being prioritised over them for an organ. People who develop renal insufficiency after donating have chosen to put themselves in that unfortunate situation. The fact that they helped someone by doing so is neither here nor there; they should not be given urgent priority over people who are in greater medical need, as that would be discriminatory. As in the case of the orphaned recipient, prioritisation within a tiered system might seem less unjust, but it would still be discriminatory to some extent. In both the case of the orphaned recipient and the former donor, a social fact (a paired donor donated an organ, or the former donor did) would be used to justify giving priority (even within a tier) over other people in greater medical need, and who have been waiting longer.

Finally, what about a situation where the donor’s organ was given to someone outside Switzerland, meaning that the Swiss waiting list does not benefit from it? As already stated, it seems that prioritisation is unethical in any case. But if prioritisation were to take place, and the rationale for that is the ‘spare’ organ being provided to the waiting list in Switzerland, then that rationale would not apply in cases where the donated organ went to someone outside Switzerland. However, the situation could occur where someone living outside Switzerland donated a kidney to someone resident in Switzerland, before going on to develop renal insufficiency. As argued above, this person should not be given priority for an organ from the Swiss pool, but we should consider whether such a person could simply be added to the Swiss waiting list despite not living in Switzerland. Once again, however, the same objections come into play; why should someone who chose to donate a kidney be placed on a waiting list in a country where he or she is not resident, thus conferring substantial advantage over others in need of an organ in his or her own country, and potentially disadvantaging or at least competing with residents of Switzerland on the list? Finally, the person to whom the organ was donated may not have been on the waiting list in any case. This would be another case of potentially gaining an unfair advantage over those who may be in greater medical need, and in most countries this person would qualify for the local national waiting list without involving the Swiss one (and again, those added to a list in another country cannot normally join the Swiss list).



Chapter 4 – Legal analysis

4.1 Introduction

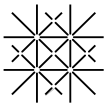
The ethical issues associated with prioritising orphaned recipients and former donors with renal failure are closely linked with the legislative context in Switzerland. There are two main features of the Swiss legislation: an emphasis on the importance of non-discrimination (ie justice), and clear setting of definitions and criteria for urgency. The Swisstransplant expert group's proposal is to change only the Allocation Ordinance, but the Transplantation Act and even the Swiss Constitution are also relevant to the issues under discussion. In this chapter the proposal is analysed in light of key passages from these pieces of legislation. If the foregoing ethical analysis is accepted, then it is to be expected that the law's emphasis on non-discrimination will generally be in opposition to prioritisation, but other aspects are also highly relevant. (The legal points made in this section also apply to prioritisation to receiving an organ from the next altruistic donor.)

It should be noted that the law reflects the moral and political views of citizens as expressed via legislators, and as such is itself an ethical instrument. Regardless of what appears ethically right, it is prima facie unethical to introduce a regulation that contradicts the underlying ethical concept of the law. The Swisstransplant expert group proposes a change in the law, which the preceding chapters suggest would be unethical. This chapter thus describes the relevant legislation, comments on the ethical issues raised by the legislation, and comments on how these legal instruments reflect on the proposal by the Swisstransplant expert group.

4.2 Clarification regarding the 'Starting Position'

Before examining the Allocation Ordinance, an important clarification is necessary. The request for this report states that Articles 16-23 of the Transplantation Act do not apply to crossover donation, as it is a form of directed donation and those articles only apply to non-directed donation. It is therefore suggested that these articles are not relevant to the proposal under consideration. However, the proposal concerns whether organs from the deceased donor waiting list pool should be permitted to be prioritised towards the orphaned recipient in situations where crossover donation has gone wrong; therefore, Articles 16-23 are relevant, and should be considered. Article 16 itself states "This section concerns the allocation of organs which the donor has not donated for a specific person" – in the context of the orphaned recipient and failed paired donation, the proposal is to allocate a deceased organ that was not donated for anyone in particular. Because the proposal concerns prioritisation of a non-directed organ, these articles clearly apply, and indeed are highly relevant as they lay down important ethical principles for the allocation of organs. As such, consideration of Articles 16-23 is essential for consideration of the Transplantation Act, as shall be seen.

(The aforementioned Dutch report makes a similar point, stating that: "Living kidney donation does not come under the public distribution of scarce resources. Rather, it entails a private agreement concluded within a relationship or, where crossover donation is concerned, within a closed circle of people brought together for their mutual advantage. LDLE, on the other hand, involves advantage derived from a private transaction being transferred to the public system for distributing organs. It is this transference that introduces the issue of formal justice.")



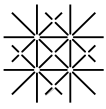
4.3 Allocation ordinance

The allocation ordinance has different sections for different organs; Article 13 concerns kidneys. As described in the introduction, the Swisstransplant expert group's proposal is to alter Article 13 of the allocation ordinance to also include orphaned recipients and former donors experiencing renal failure. Currently, this Article is entitled "medical urgency", but the Swisstransplant expert group's proposal would also drop "medical" from the title, changing it to "urgency". The reason for this is not explained in the proposal, but it is a major change as the two new types of urgency are not medical. This change encapsulates the ethical challenges in the proposal; orphaned recipients and former donors with renal failure would be placed in the same category as those who are in urgent medical need of a kidney, despite not being in urgent medical need of a kidney. Regardless of whether there are really sound reasons of justice for prioritising them, this does seem like unfair discrimination: how can it be fair to award urgency, which previously only applied in a medical sense, to people not because of medical need, but because of some other feature? In the case of the orphaned recipient, the feature is that he or she has a family member who was willing to and donated an organ. That feature itself is one that not everyone has access to, making prioritisation seem unjust. In the case of the donor with renal failure, the feature is that he or she needs a kidney because he or she once donated one. While the orphaned recipient enjoys a social advantage denied to some others, the former donor has put him or herself at a disadvantage by donating a kidney – a selfless act that might be seen as deserving reward, or at least compensation. However, most other people on the waiting list are at this disadvantage even though they have two kidneys – they may never have been in a position to donate one in the first place. As such, the former donor did enjoy an initial (health-related) advantage over others with renal failure. In any case, while a former donor should certainly be placed on the waiting list, it remains unclear why the fact that he or she was once healthy enough to donate a kidney means that he or she should be accorded priority over those who are in greater medical need and may never have been in a position to donate one. The introduction of non-medical types of urgency may also raise problems when we go on to consider the Transplantation Act itself.

4.4 Transplantation Act

The Transplantation Act makes several statements concerning the importance of non-discrimination, and also sets "decisive criteria" for the allocation of organs. Article 6.1 states "It is prohibited to grant or derive financial gain or any other advantage from a donation of human organs, tissues or cells." However, Article 6.2 states "The following are not regarded as financial gain or other advantage... (d) crossover donation." Again, it is important to bear in mind that the proposal concerns prioritisation that arises from a situation where a crossover donation has gone wrong, but is not itself crossover donation. In crossover donation, one pair donates an organ and the other receives an organ – no-one is disadvantaged. In prioritisation of orphaned recipients, however, others on the waiting list would be disadvantaged, meaning that the orphaned recipient would be obtaining an "advantage" obtained by their donor's donation of human organs, which would thus arguably be prohibited by Article 6.2 despite the crossover donation exception. In other words, crossover donation itself is not prohibited by article 6.2, but prioritising the orphaned recipient would be – because an advantage over others on the waiting list would be obtained because an organ was donated by someone else. While article 6.2 may be aimed at combating organ trafficking, its exception for crossover donation does not seem extendable to compensating the orphaned recipient if doing so disadvantages others on the waiting list.

Let us now turn to the allocation criteria set out in the Act. As set out above, Articles 16-23 do clearly apply to the proposal to take an organ that was donated by a deceased donor to the pool and prioritise its allocation to an orphaned recipient or donor with renal failure. These articles set the ethical principles for the allocation



of organs. Once again, Article 16 states “this section concerns the allocation of organs which the donor has not donated for a specific person”, which applies to organs from the deceased donor pool, including those that could be given to an orphaned recipient or donor with renal failure if the prioritisation proposal were to be implemented. Article 17.1 states “No-one may be discriminated against with respect to the allocation of organs;” 17.2 states “persons must be treated equally with respect to allocation.” Article 17.4 further states that “There is no fundamental right to allocation of an organ”, which is particularly relevant in light of the perceived right to an organ of the orphaned recipient. Article 18 states the “decisive criteria” for allocation:

The following criteria in particular shall be observed when allocating organs:

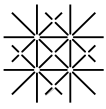
- a. the medical urgency of a transplantation;
- b. the medical benefit of a transplantation;
- c. the waiting time.

These criteria reflect the typical ethical principles used in allocation of organs or other scarce medical resources: medical urgency, medical benefit, and time spent waiting are criteria that can normally be used without fear of discrimination. But none of these criteria would apply if an orphaned recipient was prioritised for allocation of an organ; the urgency is not medical, the benefit will be less than it would be if the organ went to someone for whom the medical urgency criterion did apply, and the waiting time is irrelevant for someone who is leapfrogging the list. It would be convenient for the Swiss transplant expert group’s proposal if these criteria did not apply to it, but they clearly do, as a matter of law, and should, as a matter of ethics.

It might be argued in response that these three criteria “in particular” are to be observed, which suggests that other unspecified criteria can be used. This is true, but the last part of Article 18 adds that “The Federal Council shall specify the order in which the criteria are to be applied, or shall give them a weighting”, which strongly implies that only these criteria are to be used; and as stated in the following paragraph, Article 69.1(g) states that the decisive criteria must be used as a matter of both ethics and law. Even if this were not the case, the claim has little argumentative power. As stated above, the criterion used if the proposal was adopted would be something like “had family member or friend willing to donate but was left without an organ in a crossover donation” or “once donated a kidney”. As argued in the previous chapters, this would be discriminatory and thus contrary to Article 17.1; but it would also involve entirely ignoring those criteria that are particularly meant to be observed. In fact, it is worse than that; it would not simply be ignoring, but inverting the decisive criteria for allocation, because the person receiving the organ would in most cases need the organ less and would benefit less than the patient who would otherwise receive it, and might not even be on the waiting list for an organ yet. The fact that the proposal would invert the criteria set down in law that are supposed to govern allocation of organs is yet another indicator that it would be discriminatory to implement it.

Finally, Article 21 of the Transplantation Act also makes it clear that medical necessity is the key ethical principle underlying the legislation, stating that “The transplant centres shall decide whom to place on or remove from the waiting list. They may take only medical reasons into account. Article 17 paragraph 1 applies *mutatis mutandis*.” Again, 17.1 states that “No-one may be discriminated against with respect to the allocation of organs.” If an orphaned recipient is placed on the waiting list in order to be prioritised for an organ, this would be contrary to Article 21 and the ethical spirit of the legislation in general.

(It is also worth noting that anyone who “discriminates against persons with respect to inclusion in the waiting list or the allocation of organs (Art. 17 and 21 para. 2) or fails to allocate organs in accordance with the decisive criteria” is guilty of a criminal offence.” Art. 69 para. 1 litera g “TxG” As argued in the previous chapters, it does indeed seem that it would be discriminatory to fail to apply the decisive criteria.)



Of course, one solution to the problem posed for the proposal by the decisive criteria would be to change the Transplantation Act itself, either to add the new proposed categories of urgency to Article 18 of the Act as well as the Ordinance or to alter Article 16 to exclude compensation for orphaned recipients and donors with renal failure from the rules in that section. However, even if that were done, other Swiss laws might also need to be changed: potentially, even the Swiss Constitution itself.

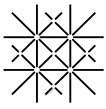
4.5 The Swiss Constitution

Finally, the Swiss Constitution is relevant to the expert group's proposal – at least on an ethical level, as it sets the parameters for all Swiss legislation. Article 8 of the Swiss Constitution is entitled “Equality before the law”, and it states: “Every person is equal before the law.”¹⁵ It continues: “No person may be discriminated against, in particular on grounds of origin, race, gender, age, language, social position, way of life, religious, ideological, or political convictions, or because of a physical, mental or psychological disability.” (8.2) If the foregoing analysis is correct, prioritising orphaned recipients or those who have donated an organ would be a type of discrimination.

4.6 Swiss law and the ‘compromise solution’

As stated in Chapter 3, while the Swisstransplant expert group's proposal as it stands is unjust, it is possible that a compromise solution of giving slightly increased priority might not be seen as unjustified discrimination, given the contribution made by the orphaned recipient's donor or indeed by the living donor who has gone on to need a new kidney. Would such a solution be legally acceptable? To a large extent, the legal acceptability of this solution depends on the ethical acceptability of it. If the solution seems ethical and just, it is unlikely to be discriminatory, and if it is not discriminatory, it would not be against the law. However, as suggested earlier, in order to avoid the charge of discrimination within a tier, the advantage gained by prioritising the orphaned recipient would have to be relatively small – so small, perhaps, that it is not worth doing in the first place. This prioritisation paradox is a challenging one. Only if a convincing case could be made that the contribution of a kidney made by the orphaned recipient's donor or by the donor who now has renal failure is such a substantial one that it justifies prioritisation over those who may be in greater medical need within the same tier, or with the same points, could the law's emphasis on non-discrimination be respected. On balance, the proposal of the Swisstransplant expert group amounts to compensating the orphaned recipient for what seems to be an unfair disadvantage (but is not really) by unfairly disadvantaging those who are in greater need, or have at least been waiting longer. As such, even within tiers, compensating orphaned recipients for their ‘loss’ would be discriminatory on the level of justice and ethics – and thus, presumably, law.

¹⁵ Federal Constitution of the Swiss Confederation. 1999. <https://www.admin.ch/opc/en/classified-compilation/19995395/index.html>



Chapter 5 – Conclusion and Recommendations

The Swisstransplant expert group's proposal is based on a claim about justice, but unfortunately, the argument in favour of prioritising orphaned recipients and donors with renal failure relies on a narrow conception of justice that ignores the substantial injustices that would be done to others on the waiting list via discrimination. When crossover donation is successful, it disadvantages no-one on the waiting list, and indeed may remove people from that list. When a recipient is orphaned, and the 'spare' organ goes to someone on the waiting list, those on the list can benefit. But prioritising the orphaned recipient over others on the waiting list would be discriminatory, even if someone on the list benefits from the spare organ. The former donor who now has renal insufficiency may appear more deserving of prioritisation, but here too discrimination against those on the waiting list would be the result.

Furthermore, the legal implications of the Swisstransplant expert group's proposals are further reaching than was perhaps anticipated. They would involve not only adding two new categories of non-medical urgency to the ordinance, but also dropping "medical" from the title of that Article of the ordinance and altering the decisive criteria in the Transplantation Act. The proposal would seem easily implemented only if Articles 16-23 of the Transplantation Act did not apply, but they clearly do apply, enshrining as they do important ethical principles in law. Because crossover donation concerns direction of organs donated by living donors, which is not covered by these articles, it is easy to assume that compensating orphaned donors is also not covered, but Article 16 makes clear that all organs from deceased donors are covered. These articles make it even clearer, if it were necessary, that it would be discriminatory to prioritise these two groups. The Swiss Constitution also suggests that prioritisation would be discriminatory.

Given these legal constraints, which also apply to prioritising an organ from the next altruistic donor, the only viable solution would be to prioritise only within tiers, or to accord more points to orphaned recipients or former donors who develop renal insufficiency. As already stated, however, this compromise would still be at least slightly discriminatory, while also not seeming sufficient to combat the (mis)perceived injustice affecting these two groups. Ultimately, despite impressions to the contrary, the status quo of the current system may be the most just way to treat orphaned recipients, their donors, and those on the waiting list.