Living Organ Donation and Minors: A Major Dilemma

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Abstract
In this article, the case of living organ donation by minors is discussed. A distinction can be made between minors who are in fact already competent and those who are not. Minors who are in fact competent, should be able to decide on organ donation under the same conditions as competent adults. Incompetent minors could be allowed to act as living organ donors under exceptional circumstances on the basis of a best interest test. Decisions on living organ donation by incompetent minors should be embedded into a procedural framework in which parental consent, the approval of an independent body of health professionals, and the minor’s wishes play a substantial role.

Keywords
minors; solid organ donation; competence; surrogate decision-making

Introduction
Organ transplantation is often the treatment of choice for organ failure. However, this is not always an available treatment option due to the significant shortage of transplantable human organs. This well-known problem has resulted in ever-increasing waiting lists. It is clear that solely relying on deceased organ donors will no longer suffice to cover the need which exists. It is generally stated that a partial solution to the organ shortage is to use living donors as a complementary organ source. In the USA, the UK and the Netherlands, living donors already make up a considerable part of the total amount of donors.¹ But how far can we walk down the path of living organ donation? One of the questions that arises is whether minors may also act as living organ donors. Although medically speaking the organs of a minor (e.g. single kidney or liver lobe) could be used to save a patient’s life or at least greatly improve a patient’s quality of life, organ donation appears to have no therapeutic benefit for the minor donor. Moreover, minors are, in principle, legally incompetent. Should living organ donation by minors

therefore be prohibited at all times, knowing that this will have detrimental consequences for the life of potential recipients? Or are there conditions under which this kind of donation could be justified, even though this means invading the vulnerable minor’s body outside the context of his own medical treatment?

This article will focus on the dilemma of living donation by minors in relation to solid organs and will attempt to provide a general framework for making this complex choice. In part 1, the level of autonomy that can be given to minors in deciding on organ donation will be discussed. It will be argued that some minors could be as competent as adults and thus deserve just as much autonomy. In part 2, the situation of minors who are in fact not competent, will be studied. This section will examine how it should be decided whether living organ donation by a factually incompetent minor is justified. In part 3, the procedural framework for determining a minor’s competence and verifying whether organ donation is justified in a particular case will be discussed. The findings of this paper will be summarized in part 4. The conclusions of this paper are based on a comparative study. The countries whose law has been examined are France, Belgium, the Netherlands, England and the United States. This selection represents both continental law systems (France, Belgium and the Netherlands) and common law systems (USA and England).

1. Minor Donors and Autonomous Decision-Making

1.1. Adults and Minors: A Comparison

For living donation by competent adults, the adult’s voluntary informed consent is generally the main requirement. In addition, some safeguards are usually

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added, such as screening by a (non-judicial) supervisory body or a committee of experts,\(^3\) the need for a written consent document\(^4\) or the requirement of imminent danger to the recipient’s life and the absence of equally adequate alternatives to avert this threat if considerable consequences or risks are to be expected for the donor (last resort-criterion).\(^5\) The French law appears somewhat more restrictive than the others, by requiring judicial involvement and by limiting genetically and emotionally unrelated donations to exceptional cases of cross-over donation.\(^6\) The law in the other countries does not legally require a genetic or emotional relationship, although in practice, consent for donation purposes will usually be given because of an emotional attachment to the recipient. It can be said that donation of a single kidney, a partial liver or even a lung lobe is generally a real possibility for adult donors in the examined countries.

When compared to adults, minors are treated quite differently in the area of organ donation. The French law is by far the most restrictive as it completely prohibits solid organ donation by minors.\(^7\) In other countries, minors can only act as donors under rather strict conditions, such as minimal risk, no permanent consequences, only regenerative organs to be donated, urgent recipient needs, lack of alternatives and only genetically related recipients.\(^8\) And even when these conditions are met, parental consent and/or court approval are usually an additional requirement.\(^9\) In general, a minor’s legal capacity to decide on donating organs is thus severely restricted.


\(^4\) Art. 8, § 2 Belgian Organ Removal and Transplantation Act; Art. 6 Dutch Organ Donation Act; para. 74 Human Tissue Authority Code of practice 2 (2009).


\(^6\) Art. L.1231-1, al. 1-3 French Public Health Code: only a parent of the recipient or, after authorization by a multidisciplinary expert committee, the recipient’s spouse, sibling, (adult) child, grandparent, uncle/aunt, cousin, parent’s spouse or anyone who can approve that he/she lives together or has a stable and close relationship with the recipient for at least two years, can act as a donor. When none of the aforementioned persons are compatible with the recipient, the French law permits a cross-over donation (no genetic or emotional relationship).

\(^7\) Art. L.1231-2 French Public Health Code. This prohibition also exists for tissues and cells (art. L.1241-2). However, a narrow exception exists for hematopoietic cells, derived from bone marrow or peripheral blood (art. L.1241-3).

\(^8\) These conditions will be discussed in part 2.

\(^9\) These conditions will be discussed in part 2.
1.2. The Importance of Competence

To determine whether the legal disparity between adult donors and minor donors is appropriate, its underlying reasons need to be examined. It is generally recognized that adults have a right to privacy or physical integrity, which can be used to ward off physical invasions or to pursue self-determination. It has been acknowledged that they can even use this right in a non-therapeutic way, e.g. refusing life-saving treatment in some cases. Thus, a non-therapeutic procedure such as organ donation is evidently governed by the right to physical integrity as well. Adults are generally presumed to possess sufficient understanding and mental capacity to assess their own interests. Therefore, the law accordingly gives them a rather broad decisional margin by considering them legally competent to exercise their rights, including those with regard to organ donation. Indeed, the starting premise should be that the adult donor — and not society — is the most suitable person to decide what is best for that adult concerning donation of organs.

Unlike the organ donation position for adults, the law assumes that minors lack the understanding and mental capacity needed to assess their interests in a well-balanced manner. Therefore, their actions, such as consenting to medical treatment, are generally not granted legal validity. The minority status implies

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legal incompetence. However, it is recognized that incompetents do have a right to privacy and bodily integrity to some extent. As is the case for adults, this right also applies to organ donation. It would obviously be detrimental to the minor if the minor's rights and interests would remain undefended until he reaches the age of majority. Therefore, the law — having a compelling interest in protecting society's vulnerable persons — must provide for a regime of surrogate decision-making in exercising the minor's rights, such as those regarding organ donation. The state can further regulate the decisional margin of the surrogate decision-makers.

Legally restricting a minor's autonomy can indeed be justified because of a minor's limited understanding and reasoning skills. Restricting a minor's decisional capacity with regard to living organ donation would thus pose no fundamental problem if imposing the status of minority would indeed be based on such factual incompetence. However, this is not the case. Minority, and thus legal incompetence, is automatically imposed upon persons who have not yet reached a fixed legal age, generally 18 years old. It cannot be denied that normal psychological development is proportional to the growth of the minor in time. However, many other factors, such as education, intelligence or life experiences, also play an important role in indicating a person's true level of understanding and decision-making capacity with regard to a specific medical procedure. These factors obviously differ from person to person. Solely taking into account a person's age is therefore nothing more than an assumption, an abstraction of reality. It can be argued that some persons below the age of majority in fact already possess sufficient mental capacity to adequately assess their interests in matters regarding physical integrity, such as organ donation. It would be unrealistic and too

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16) Moreover, the minor could also have ownership interests regarding a removed organ: S. Panis, “The curious case of umbilical cord blood: minors and donation”, 30 Med. & Law. 383 (2011) 386.

17) Morley, supra note 10, 1230-1232; Shartle, supra note 14, 440-441; Dufault, supra note 15, 215-217. See also part 3 infra.

18) See part 3 infra.


20) W.N. Keyes, Bioethical and evolutionary approaches to medicine and the law, (Chicago Ill.: American Bar Association, 2007) p. 637; B. Sluyters, “Juridische aspecten” in: J.M. Greep (ed.), Organtransplantatie, (Leiden: Stafleu, 1970) p. 386. Contrary to Baron et al., supra note 13, 177-178, who believed donation considerations to be too complex and abstract for children below the age of 18. See also: In Re W (A Minor) (Medical Treatment: Court's jurisdiction) [1993] Fam. 64, where it was believed to be highly improbable that a minor would be sufficiently capable of deciding on so serious a procedure.
dogmatic to act as if a minor obtains his adult intelligence and understanding overnight upon turning 18 years old. When privacy and physical integrity are involved, it is more important than ever to closely align the law with reality. In other words, when a minor is in fact sufficiently competent, the minor should be granted the same level of autonomy as a competent adult. He should be allowed to legally express his voluntary and informed consent on organ donation under the same conditions as a competent adult, without someone else’s consent or approval being a legal requirement. Consent of a surrogate decision-maker should not be required, because there is simply no longer any need for such paternalism.

Based on the above, it can already be argued that a total prohibition on solid organ donation by minors, as found in the French law, is too abstract (as far as competent minors are concerned). Other countries do recognize the fact that some persons below the age of 18 can be factually competent to decide on organ donation, although the decisional margin of minors is often still less broad than that of adults. Unless a compelling justification (e.g. difference in physical

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25) Contrary to Dufault, supra note 15, 242-244, who pleas for a substituted judgment for all minors between five and eighteen in order to avoid a too paternalistic approach.

26) Art. L.1231-2 French Public Health Code. The French law is apparently based on the Council of Europe’s Additional protocol to the convention on human rights and biomedicine concerning transplantation of organs and tissues of human origin (2002 — ETS no. 186) (www.conventions.coe.int). However, Art. 14, sec. 1 of this additional protocol does not prohibit organ donation by minors (age-criterion), but rather by persons who do not have the capacity to free, informed consent.

27) Art. 7 Belgian Organ Removal and Transplantation Act, which accepts that minors between 12 and 18 could be competent, but which always prohibits kidney donation by competent minors (no non-regenerative organs), while this is not always the case for adult donors; Art. 5, sec. 1 Dutch Organ Donation Act, which accepts that minors between 12 and 18 could be competent, but which also prohibits kidney donation by minors and furthermore requires parental consent and court approval for donation of regenerating organs, while these aren’t requirements for adult donors; Hurdle v. Carrier, [1977] WL 191146 (Va.Cir.Ct.), where parental consent was still required for a kidney donation by a 16 year old,
constitution) can be found to always treat factually competent minors as less free than competent adults — which doesn’t seem to be the case — such an intermediate approach is also still too restrictive in light of the minor’s right to privacy and physical integrity. Let it be clear that treating competent minors the same as competent adults does not leave the minor unprotected. The suggested equal treatment implies that the necessary safeguards, which exist for adults, should also be applied to mature minors.

1.3. Assessing a Minor’s Competence

It has been argued that a rebuttal of the legal assumption of incompetence towards persons below the age of 18 (minors), in the context of organ donation, should be allowed, i.e. when the minor is in fact sufficiently competent. This leaves us with the question of how this factual competence can legally be determined. Two approaches will be discussed. One way is to combine a case-by-case assessment of competence with a fixed age limit, although one that is lower than the age of majority. Another way is to abandon the fixed age approach entirely and always conduct a case-by-case assessment.

As mentioned previously, determining one’s mental capacity requires a psychological assessment which takes into account several factors (e.g. intelligence, experience and education). Since these factors vary from person to person, their use requires a specific case-by-case assessment (e.g. interview with the donor). Nevertheless, it can generally be agreed that very young children will never be sufficiently competent. Research indeed suggests that children younger than 12 or 13 years old do not yet possess the cognitive skills necessary to make a balanced decision. It could thus be argued that it is appropriate to irrefutably presume that children below a fixed minimum age of, for example, 12 years are never competent to make an autonomous decision. This could especially be true for a complex dilemma such as living organ donation. Below the minimum age, the question of whether a minor can act as an organ donor becomes, at best, a matter of surrogate decision-making. By combining a fixed age limit with a case-by-case...
assessment, the law would still wield a legal assumption, but one that is more closely aligned with reality, given that the fixed age is low enough. The chance that this age limit is still too high in exceptional cases appears very small and seems compensated by its clear, easy-to-verify nature.

Nevertheless, a fixed minimum age would remain artificial to some extent, since competence is not grown overnight. A case-by-case assessment without being bound to a fixed age limit, would principally allow a more accurate representation of the minor’s autonomy. It could be feared that this creates the risk of attributing young minors a competence they actually do not yet possess, e.g. in order to circumvent a surrogate decision-maker’s veto and to acquire a transplantable organ. However, such manipulation might also be possible for minors who have already reached the minimum age, as the age limit would not protect this category of minors from the dangers of unlimited case-by-case assessment. In turn, raising the suggested age limit of 12 years would not be an appropriate option, since the law would again drift further away from possible realities. It becomes clear that the focus should not be on finding the appropriate age limit, but rather on providing the case-by-case assessment with sufficient safeguards in general. An important safeguard seems to be that competence with regard to organ donation must be established with clear evidence, based on up-to-date medical and psychological knowledge. The procedural framework can be adjusted to embed this rule and other potential safeguards.33 The conclusion is thus that a low fixed minimum age is largely justifiable, but not really necessary for protecting incompetent minors and should therefore be avoided in order to respect the minor’s potential autonomy and his right to self-determination as much as possible.34

2. Minor Donors and Surrogate Decision-Making

2.1. The Decisional Standard: Best Interest v. Substituted Judgment

When a minor is in fact not competent to make a balanced decision on organ donation, a decision would obviously have to be made by a surrogate decision-maker. This raises the question under which conditions, if any, another person can decide to allow an incompetent minor to undergo an organ removal for the therapeutic benefit of someone other than the minor. In extremis, two decisional


standards are available: the best interest standard and the substituted judgment standard. The general idea behind the best interest standard is that a surrogate decision-maker could only consent to a medical procedure when it can objectively be argued that the benefits of the procedure outweigh the costs, regardless of what the incompetent’s actual wishes might have been. On the other hand, the substituted judgment standard essentially means that the surrogate decision-maker decides in the same way as the donor would have, if he were competent to do so. The surrogate decision-maker should thus base his consent or refusal on any clear evidence that indicates what the wishes of the incompetent would have been, if he were competent now (e.g. previous decisions, known values). Contrary to the best interest approach, this is to be understood as a subjective standard.

The strongest argument in favour of the substituted judgment standard is that this subjective approach respects an incompetent’s personal right to privacy and self-determination as much as possible. However, it has been stated that this decisional standard is not applicable to persons who have never been competent before, such as (young) minors. They might have never been able to make a well-balanced decision or even express any wishes, so it would probably come down to a decision according to the personal wishes of the surrogate decision-maker. Therefore, the best interest standard can generally be deemed a more appropriate option for minors with regard to living organ donation. It should be noted that even the courts who claim to apply the substituted judgment doctrine on the

37) Schenberg, supra note 14, 328-330; Nygren, supra note 35, 480-481.
38) Schenberg, ibid., 332; Nygren, ibid., 482, who also mentions ‘closure for relatives and friends’ as a positive aspect of the substituted judgment doctrine; Robbennolt et al., supra note 23, 223; Veatch, supra note 11, 440.
40) In Re Richardson [1973] 284 So.2d 185 (prohibition of kidney donation by an incompetent, 17 year old minor with the mental age of a 3 year old); In re Guardianship of Pescinski [1975] 67 Wis. 2d 4 (prohibition of kidney donation by mentally incompetent adult with the mental age of a 12 year old); Little v. Little [1979] 576 S.W.2d 493 (kidney donation by a mentally incompetent, 14 year old minor); In re Doe, 104 A.D.2d 200 (bone marrow donation by an incompetent adult with the mental age of a 2 year old); Curran v. Bosse [1990] 141 Ill.2d 473 (bone marrow donation by a 3 ½ year old minor);
matter still base their *dictum* on factual considerations quite identical to those manifested in opinions based upon the best interest doctrine.41 The focus of the best interest standard is placed clearly on protecting the needs and welfare of the incompetent donor, which also pleas in its favour.42 However, a major criticism to the best interest approach is that it contains no real model for determining what constitutes a benefit, thus opening the door for arbitrary (and even utilitarian) decision-making.43 Indeed, the term ‘best interest’ is by itself too vague. Obviously, the benefits and costs will have to be materialized in light of the concrete elements of a transplant context. After these factors have been identified, they have to be weighed against each other.

2.2. Best Interest of the Minor: Benefits and Costs

2.2.1. Benefits
Living organ donation normally has no physical, therapeutic benefits for the donor, whether this concerns an adult or a minor.44 In theory, it could be possible that the minor would receive a benefit from material advantages, such as payment.45 However, this touches the delicate issue of commercial organ trade. Donating organs for money is generally forbidden,46 so this study will not go into this matter in any depth. Besides monetary remuneration, it can be imagined that the recipient (e.g. a sole parent of the minor donor) stays alive and thus is able to continue providing financial support and guidance to the minor.47 However, it is

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42) Sankoorikal, *ibid.*, 612; Schenberg, *supra* note 14, 342 and 615.
44) Only in the case of a domino transplantation, the minor can donate a healthy, solid organ and profit medically at the same time (e.g. T.L. Astor et al., “Domino Heart Transplantation involving infants”, *American Journal of Transplantation* 7 (2007) 2626-2629). However, even then, the physical benefit is not really founded on donating (i.e. giving an organ to another person), but rather on receiving an organ from another person after removal of one’s own organs.
47) Griner, *supra* note 15, 611. See also: *In Re Richardson*, [1973] 284 So.2d 185, where permission for kidney donation was denied, because it was found highly unlikely that the recipient (sister of the donor) would take care of the mentally incompetent minor donor after the deaths of their parents, if she received the transplant and thus survived.
unclear whether this could really be seen as a material benefit, as the law generally provides systems to sustain the minor orphan (e.g. estate, legal guardian, social services).

Due to the lack of physical or material benefits, allowing living organ donation by minors will thus depend on the existence of another type of benefits. In this respect, psychological, emotional and social benefits for the donor have already been recognized in cases where a close, active relationship exists between siblings. When an intimate attachment between the minor donor and the recipient exists, it can indeed be accepted that the donor benefits psychologically if the recipient’s life is saved or if the health of the recipient is significantly improved. The benefit thus lies mainly in the prevention of emotional pain. Some countries legally restrict living organ donation by minors to a number of genetically related recipients. However, blood ties are not determinative to receive an emotional benefit. The foundation for emotional benefits is formed by an intimate attachment, which does not always go hand-in-hand with a genetic relationship. The psychological benefits should thus be examined on a case-by-case basis, without excluding certain recipients in advance (e.g. parents, adopted or half siblings, other relatives or even close friends).

Apart from a relationship with the recipient, the joy of having a complete, happy family might also be very beneficial. Other psychological benefits, such as heightened self-esteem, are possible as well. However, it appears that not every minor will be able to experience such psychological benefits. The necessary psychological awareness will only surface at a certain stage of cognitive development. Without referring to a fixed age, it can be argued that very young children

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49) Ross, supra note 24, 253: “[…] by promoting the well-being of a family member, he [the donor; N.B.] is also serving his own interests (ends).”; S. Month, “Preventing children from donating may not be in their best interests”, BMJ 312 (1996) 240; A. Spital, “Donor benefit is the key to justified living organ donation”, Camb. Q. Healthc. Ethics 13 (2004) 107; Jansen, supra note 43, 138.


51) Art. 7, § 1 Belgian Organ Removal and Transplantation Act (only siblings); Art. L.1241-3, al. 1 and 2 French Public Health Code (hemopoietic cells for siblings, cousins, aunts and uncles); Art. 5, sec. 1 and 2 Dutch Organ Donation Act (parents, grandparents, children and grandchildren).


53) Schenberg, supra note 14, 358; Shartle, supra note 14, 468; Jansen, supra note 43, 138-139. Contrary to: Ross, supra note 24, 255.

54) J. Savulescu, “Substantial harm but substantial benefit”, BMJ 312 (1996) 241; In Re Y. (Mental patient: Bone Marrow Donation) [1997] Fam. 110. However, the court in Re Y expressed doubts whether the closeness of the particular family in this case would also suffice to allow donation procedures which require more intrusive surgery than bone marrow harvesting.


56) Baron et al., supra note 13, 181.
will have no clear benefit due to a lack of awareness and established emotional bonds, which makes donation hard to justify in those cases.57

The best interest standard has been criticized in relation to incompetent donors because it allegedly “strips them of their humanity” by not taking into account the fact that “especially when family members are in need, people are often motivated by altruism and empathy” instead of direct personal gain.58 The suggested altruism is apparently to be understood as indirect personal gain due to intimate family relationships. By incorporating the possibility of emotional, relationship-based benefits into the best interest test, the criticism that this standard is too self-regarding can be countered.59

2.2.2. Costs

Although organ donation does not entail physical benefits, it does present physical risks for the donor. These risks vary by organ. The peri-operative risks for kidney removal from a healthy person are considered to be small.60 There is generally a 0.02 % chance of mortality and a less than 5% chance of serious morbidity (e.g. infections).61 The long term risks (e.g. less chance of coping with kidney disease with only one remaining kidney) are still not entirely certain due to insufficient data on child donors (who have a longer risk period), but donation does not really appear to present an increased risk.62 Removal of a liver lobe bears noticeably greater risks than kidney removal. For partial liver donation, the mortality risk is 0.2% and significant morbidity varies strongly (0%-69%).63 The actual long-term risks of a partial liver donation by children are largely unknown, although this appears to be limited due to the regenerative nature of the liver.64 Data on other organs are very limited. Lung donation already proves to have severe consequences (e.g. loss of lung capacity, which prevents practicing sports).65 Donation of a part of the small intestine has been considered to be experimental.66

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57) L. Delany, “Protecting children from forced altruism: the legal approach”, BMJ 312 (1996), 240. However, bone marrow donation by an incompetent adult donor, who did not even understand what was being said to her, has already been allowed, because of a close and strong relationship with her mother, who was also the mother of the recipient: In Re Y. (Mental patient: Bone Marrow Donation) [1997] Fam. 110.

58) Morley, supra note 10, 1241-1242; Dufault, supra note 15, 237.

59) Jansen, supra note 43, 134 and 139-140.


62) Ross et al., ibid., 455-456; Morley, supra note 10, 1222.

63) Ross et al., ibid., 459; Ross et al., ibid., 455.

64) Ibid., 456.


66) Ibid., 179.
Donation of a partial pancreas is very complex. Moreover, all donors experience pain. The geographical and economical context in which organ removal takes place also has a significant impact on the risks. The above mentioned figures are based on results of organ removal from healthy persons in countries with a rather high level of healthcare.

In Belgium and the Netherlands, a legal distinction is made between regenerative (e.g. partial liver) and non-regenerative (e.g. kidney) organs. The law in these countries prohibits the removal of the latter for donation purposes. It is apparently deemed that the consequences of removing a non-regenerative organ are always too severe. However, as shown above, the removal of a kidney, which does not regenerate, generally entails low perioperative and long-term risks for the minor donor. Therefore, it doesn’t appear appropriate to reject the possibility of donating an organ in advance, solely based on the cost of non-regeneration. The Dutch law makes a further distinction between organ removals that entail ‘lasting consequences’ for the donor’s health and those which do not. As is the case for the regeneration-criterion, prohibiting organ donations that will have permanent health consequences might prevent a correct cost-benefit assessment, as it does not seem to take the gravity of the consequences into account. If the benefit is strong enough, it could still possibly outweigh permanent, but minimal health consequences. A more flexible, case-by-case assessment of the actual risk would be more accurate.

The costs of organ donation are not always limited to a physical level. Although donating to an emotionally-related recipient can provide great psychological benefits, the donor could also suffer adverse psychological consequences. In this respect, it must be noted that some courts consider the success rate of transplantation when examining whether a certain minor should be allowed to act as a living organ donor. This is not surprising, since the outcome for the recipient has an influence on the psychological effects on the donor. As said previously, the donor could benefit psychologically because the recipient’s health is greatly improved. If the transplant fails, the donor might feel guilty or might regret the donation. So, without a good chance of success, the donor might suffer a psychological (in addition to a physical) cost. Therefore, the donor-recipient compatibility must be

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67) Ibid., 181.
68) Ross et al., supra note 55, 455.
70) Art. 7, § 1 Belgian Organ Removal and Transplantation Act; Art. 5, sec. 1 and 2 Dutch Organ Donation Act.
71) Art. 5, sec. 1 and 2 Dutch Organ Donation Act.
73) Cheyette, supra note 39, 474 et seq.; Morley, supra note 10, 1223; Spital, supra note 49, 106.
74) Ross et al., supra note 55, 455.
high enough to ensure a reasonable chance of success. However, a lower success rate does not necessarily lead to higher psychological risks. The guilt and regret might only be a minor component of the devastating loss of the family member. And even if the transplant fails, the donor might still find solace in the fact that all that was possible was done to save the recipient. On the other hand, a high success rate does not necessarily ensure psychological benefits. Even if the transplant is successful, psychological risks for the donor are still possible (e.g. lack of understanding, sense of neglect and lack of appreciation), although the data on children are limited. This is why it is rightly stated that, apart from a good success rate, there should also be adequate emotional guidance and support for the minor donor before and after the procedure, especially by parents, in order to prevent psychological risks to the donor (e.g. sense of neglect, fear, guilt, lack of understanding).

2.2.3. Balancing the Benefits and the Costs
According to the best interest test, living organ donation by an incompetent minor can only be permitted if the benefits outweigh the costs. It appears that living organ donation always presents a physical cost, but not always benefits for the minor. However, when no benefits for the minor can be found in a particular case, the organ donation would still be beneficial to the recipient, and the transplant from a living donor might also reduce the waiting list and healthcare costs. The question arises whether these benefits for others (i.e. the recipient and society as a whole) could in themselves serve as sufficient justification for infringing the minor’s bodily integrity. In theory, the fundamental rights of an individual are not absolute and can be limited in a proportionate manner to satisfy the need of protecting other interests and rights. However, it is generally acknowledged that competent adults cannot be compelled to donate without consent, whatever the counterweighing interest might be. The minor’s right to bodily integrity can be

76) Month, supra note 49, 241.
77) Ross et al., supra note 55, 455; Korins, supra note 75, 502.
78) Ross et al., ibid.; Cheyette, supra note 39, 478 and 505.
79) Curran v. Bosze [1990] 141 Ill.2d 473; Schenberg, supra note 14, 357; Shartle, supra note 14, 468; Month, supra note 49, 240-241; L.F. Ross et al., supra note 55, 457.
considered just as fundamental.\textsuperscript{83} It is crucial that the well-balanced protection of the incompetent minor remains the focus of attention, which is hard to guarantee if a utilitarian approach is followed.\textsuperscript{84} Therefore, the starting point should be that only the benefits and costs for the minor donor are weighed.\textsuperscript{85} Nevertheless, this does not prevent that the interests of the recipient and society are included in the cost-benefit analysis, namely when they influence and coincide with the interests of the donor.\textsuperscript{86}

It has become clear that the actual existence of benefits for the minor, as well as the exact extent of the potential costs, depend on variable facts (e.g. intimate attachment, pre-existing medical and psychological condition, available guidance). It has been emphasized that especially the extent of psychological benefits is difficult to predict or to verify.\textsuperscript{87} Although these may indeed be difficult to assess, the existence of psychological benefits is nevertheless possible and cannot simply be ignored. As it is practically impossible to quantify all benefits and costs, it is equally impossible to determine the benefit-cost ratio with 100% accuracy. However, this difficulty should not be seen as a reason to prohibit donation by incompetent minors entirely.\textsuperscript{88} In determining the minor’s best interest, one should rather be aware of this difficulty and only decide in favour of donation when it is clear to a reasonable person that the benefits outweigh the costs.\textsuperscript{89} A reasonableness standard may lack some clarity, but pervades many areas in law (e.g. tort law).\textsuperscript{90} It has been said that a psychological (emotional, social) benefit may prove as valuable to one’s mental health as therapeutic benefits to one’s physical health.\textsuperscript{91} It has further been noted that emotions generally play a very prominent role in health decisions.\textsuperscript{92} It can safely be assumed that a competent person would be willing to take some risk in order to obtain the benefit of saving or substantially aiding someone very close to him.\textsuperscript{93} The lower the risk
the greater the benefit, the stronger the argument for allowing a living organ donation.

Obviously, the minor’s interest would be best served if he could obtain the benefits without having any costs. In other words, when donation is in fact unnecessary for the minor to achieve a psychological benefit, then donating is not in the minor’s best interest. That is why it is reasonable to only allow organ donation by an incompetent minor when there are no equally or more adequate alternatives available (e.g. deceased donor, competent living donor, other treatment options such as kidney dialysis).94 Based on medical research, it cannot be said in advance that if other donors or treatment alternatives are available, they automatically are a better option than living donation by a minor.95 Again, an individual assessment of each case is needed.96

Not only the availability of alternatives, but also the urgency of their need has been taken into account by courts.97 The opinion exists that living organ donation by minors should only be allowed when the recipient’s life is in imminent danger.98 Because of kidney dialysis, a potential kidney recipient can sometimes be kept alive for a while, in which case the recipient’s life is not in immediate danger. Nevertheless, as suggested before, the psychological benefit for the donor can either flow from saving the recipient’s life or greatly improving the recipient’s quality of life. Dialysis can put a strain on the family.99 Minors could experience a lack of care by their parents when a sibling is on dialysis.100 Although sacrificing case-by-case flexibility by prohibiting kidney donation unless the recipient’s life is


96) Price and Akveld, supra note 13, 23-25.


98) Art. 5, sec. 1 and 2 Dutch Organ Donation Act; Tilden, supra note 87, 93; Steinberg, supra note 80, 237; Dissenting opinion in In re Guardianship of Pescinski, [1975] 67 Wis. 2d 4.


threatened might protect vulnerable persons such as incompetent minors,\textsuperscript{101} it is possible that on rare occasions this would be contrary to the minor’s best interest. A rule which always requires that the recipient’s life is in imminent danger therefore appears too strict.

In conclusion, the possibility of a net benefit for a minor with regard to living organ donation appears real.\textsuperscript{102} Always prohibiting organ donation by incompetent minors would therefore not be appropriate, as it might be contrary to the minor’s well-being and deny the existence of any altruistic sentiment of the donor.\textsuperscript{103} To determine in which cases organ donation by a minor can be permitted, some clear legal rules have been discussed (e.g. only genetically-related siblings, only regenerative organs, only recipients whose life is in imminent danger). However, it has been found that a best interest surrogate-decision on living organ donation is hard to contain within such clear, strict criteria. The complex, variable nature of this decision requires a flexible approach altogether. As will be discussed in the next part of this essay, the risk of arbitrary decision-making can be countered by embedding the flexible approach within an adequate procedural framework. A case-by-case examination, which takes into account the totality of specific, relevant circumstances, is therefore preferable.\textsuperscript{104}

\textbf{3. Procedural Framework}

A difference has been made between mature minors, and minors who are not yet fully competent to consent to an organ removal for donation purposes. As already stated, this approach needs to be applied within a procedural framework, which provides the necessary safeguards. In this part, that framework will be discussed. It will be examined who should eventually assess whether the minor is competent and, if not, who should act as a surrogate decision-maker. It seems only logical that the person who may assess a minor’s competence, should be the one who can best apply the competence criteria. Similarly, the person who may decide to allow donation by an incompetent minor should be the one who can best apply the decisional standard. Four parties come to mind: the minor donor, the parents, courts and health professionals.

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\textsuperscript{101} Steinberg, supra note 80, 237.
\textsuperscript{102} This possibility especially exists with regard to kidney donation between emotionally and genetically related siblings: Belgian Advisory Committee on Bioethics, opinion nr. 50 of 9 May 2011, www.health.fgov.be/bioeth, p. 81.
\textsuperscript{103} Schenberg, supra note 14, 357; Nygren, supra note 35, 497; Morley, supra note 10, 1242; Belgian Advisory Committee on Bioethics, opinion nr. 50 of 9 May 2011, www.health.fgov.be/bioeth, p. 93.
\textsuperscript{104} Bonk, supra note 19, 46 en 50; Schenberg, supra note 14, 355; Robertson, supra note 43, 70. A statutory, illustrative checklist-approach could prove useful: L. Delany, supra note 57, 240; sec. 4 English Mental Capacity Act 2005.
\end{flushleft}
3.1. The Minor Donor

Obviously, the minor donor should not be the one who assesses his own competence. An assessment by someone other than the minor is therefore always needed. If the minor is found competent, his consent should be a main requirement. Thus, in a way, the minor can assess his own best interest. If the minor is found incompetent, his consent should obviously not be a requirement. However, some courts have emphasized the willingness of a minor to donate, without regarding this as true informed consent.105 Children who are able to experience a psychological benefit are normally capable of understanding organ donation to some extent and are able to express some opinion about it.106 The legal value of this assent is difficult to define. As mentioned, this is not yet the well-balanced decision-making which can constitute legally valid consent.107 Moreover, the risk of parental coercion seems to be more likely.108 Nevertheless, it can be argued that the expressed willingness of the minor can indicate whether or not the donation would provide a psychological benefit to the minor, as it might inter alia suggest the existence of an intimate attachment.109 The respect for the minor’s emerging autonomy, therefore, requires that the minor’s assent should be given substantial, but not automatically decisive, weight in determining the minor’s best interest.110 Likewise, resistance111 or refusal by the minor should also be given significant weight,112 as this would indicate psychological costs (e.g. trauma of unwanted

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106) Zinner, supra note 29, 126.

107) Korins, supra note 75, 507. Although, it has been argued that in practice even adults do not necessarily make a rational cost-benefit analysis to decide on medical issues, but rather are motivated by emotional incentives stemming from affectionate ties: Kallich et al., supra note 92, 146; Robbennolt et al., supra note 23, 227.


109) Jansen, supra note 43, 140; Baron et al., supra note 13, 179; Robbennolt et al., supra note 23, 244. Compare to Cheyette, supra note 39, 514, who concluded that psychological benefits are impossible to predict when the donor is compelled to donate; S.E. Mumford, “Bone marrow donation — the law in context”, 10 Child & Fam. L. Q. 135 (1998) 142; Schenberg, supra note 14, 355.


111) See in particular Lemmens, supra note 21, 487.

112) Tilden, supra note 87, 94; Shartle, supra note 14, 460; Mumford, supra note 109, 145; Robbennolt et al., supra note 23, 243; Korins, supra note 75, 535, who demands respect for the minor’s refusal “because it is more objectionable to force transplants on unwilling donors than it is to withhold treatment from willing patients”. In the same vein, it can be considered more certain that preventing organ removal is beneficial to the donor because of the clear physical benefits (i.e. avoiding medical risks), whereas donation requires psychological benefits, which become questionable in case of the refusal; Ross, supra note 24, 254-255, with some nuance that the minor’s dissent should be respected in case
bodily invasion). The foregoing requires that the minor should always be informed about the procedure and involved in the decision process according to his level of understanding.\textsuperscript{113} The relationship between assent and psychological benefits or costs, provides another strong argument to keep very young children outside the scope of living organ donation.\textsuperscript{114} It would not be possible to involve them in the decision process, in which case organ removal could give them adverse feelings about the infringement of their physical integrity later in life.\textsuperscript{115} By not holding on to a strictly objective test, but also giving weight to the minor’s preferences, the criticism that the best interest standard ignores a minor’s right to self-determination and is paternalistic, can be countered.\textsuperscript{116}

3.2. Parents of the Minor Donor

Parents are traditionally bestowed with decision-making authority for their minor children, because they are presumed to generally act according to the child’s best interest.\textsuperscript{117} It must be noted that this authority is purpose-bound: it is granted to protect the welfare of the minor.\textsuperscript{118} Therefore, the state can limit the parents’ power, if they are no longer suited to protect the minor’s best interest.\textsuperscript{119} With regard to the transplant context, and especially when the recipient is a sibling or a parent, a conflict of interest might arise for the parents.\textsuperscript{120} Moreover, determining of donations of significant risk, but not in case of minimal risk, although the dissent might still alert the need for further discussion. However, one could wonder why minimal risk requires such a further restriction of the minor’s autonomy. See also: Art. L.1241-3, al. 4 French Public Health Code (hematopoietic cells).

\textsuperscript{115} Art. 5, sec. 3 Dutch Organ Donation Act; Art. 9, al. 2 Belgian Organ Removal and Transplantation Act. Compare to Art. 12, §2 Belgian Patients’ Rights Act.

\textsuperscript{116} Korins, supra note 75, 513 and 536; A.G., [Commentary on Re Y], 2 Med. L. Rev. 205 (1996) 207. See also supra note 57.


\textsuperscript{118} Shartle, supra note 14, 449; Nygren, supra note 35, 492; Robbenolt et al., supra note 23, 226-228, 230, 242 and 244-245; Dufault, supra note 15, 243-245.

\textsuperscript{119} Parham v. J.R. [1979] 442 U.S. 584; Baron et al., supra note 13, 165; Zinner, supra note 29, 130; Morley, supra note 10, 1236-1237; Sankoorikal, supra note 39, 602. See also: Bonner v. Moran [1941] 126 F.2d 121 (parental consent was required for a skin donation by a 15-year-old boy, as the procedure did not benefit the minor).

\textsuperscript{120} C. Baron et al., supra note 13, 167; Griner, supra note 15, 601-602; article 15, § 2 Belgian Patients’ Rights Act; Art. 7:450, sec. 2 juncto Art. 7:465, sec. 4 Dutch Civil Code; Art. L.1111-4, al. 6 French Public Health Code.
a child’s competence or assessing whether the decision would be in the minor’s best interest, is only possible if the decision-maker possesses sufficient medical and psychological knowledge, which will not always be the case with parents.\(^{121}\) Parents might fail to appreciate the psychological benefits, e.g. when the recipient has no close relationship with the parents, but only with the child. Moreover, they will most likely rely strongly on the advice of their physicians, who in turn may be biased and may not consider all benefits and costs.\(^{122}\) For these reasons, the assumption that parents will act according to the child’s best interest, seems to falter.

On the other hand, it has been found that the best interest of a minor with regard to organ donation is hard to determine. Parents might possess useful insight into what would be in the child’s best interest, especially because it might be emotionally connected with that of the family.\(^{123}\) Moreover, it would be contradictory if the parents, who still retain authority in view of the child’s guidance in other matters, would be excluded from such a far-reaching and significant decision, while their emotional support before and after the procedure is so important for the minor donor.\(^{124}\) Parental refusal will therefore make a donation very hard to justify and should thus be respected.\(^{125}\) Informed parental consent to organ donation by an incompetent minor can be deemed necessary, but would however, not suffice on its own, given the above mentioned concerns.\(^{126}\) Some less drastic form of state intervention, other than completely relieving the parents of their decisional authority, is needed. An independent best-interest review of the parents’ assessment is required.\(^{127}\)

3.3. **Courts**

In several countries, it is deemed necessary that cases involving organ donation by minors should first be presented to a court for obtaining approval after a judicial review.\(^{128}\) The benefit of such an approach is that the court can be considered to

\(^{121}\) Dufault, *supra* note 15, 235.

\(^{122}\) Korins, *supra* note 75, 532-533.

\(^{123}\) Korins, *ibid.*, 75, 532; Savulescu, *supra* note 54, 241.

\(^{124}\) *Supra* note 79.

\(^{125}\) Shartle, *supra* note 14, 460-461.

\(^{126}\) Art. 5, sec. 1 and 2 Dutch Organ Donation Act; Griner, *supra* note 15, 609. See also: Savulescu, *supra* note 54, 242, where it has been argued that if decisions about donation are not substantially different from the normal distribution of benefits and burdens within a family, then parents alone should also be able to distribute within the family in regard to donation. However, there is a substantial difference: deciding on one’s bodily integrity without a clear therapeutic benefit strongly differs from e.g. deciding which child gets which toy and which one can go to college.


be an independent body, thus seemingly eliminating the problem of a conflict of interests of the parents.\textsuperscript{129}

However, most judges lack the specific knowledge needed to adequately assess the medical, emotional and psychological aspects.\textsuperscript{130} Invoking the expertise of physicians and psychologists and the testimony of parents remains necessary.\textsuperscript{131} Even then, it has been argued on the basis of past cases that courts fail to appreciate the complex interaction between psychological costs and benefits.\textsuperscript{132} Furthermore, making use of the judicial system might create a formal, tense atmosphere at an emotionally stressful time, especially to the donor child involved.\textsuperscript{133} Such confrontation between recipient, parents and donor child might adversely affect the ability of the parents to assist the child during the process.\textsuperscript{134} Thus, an obligatory judicial review does not seem to be an ideal solution.

3.4. Health Professionals

Because of the great importance of medical and psychological knowledge and the difficulty of assessing these aspects, a body of multiple health professionals (e.g. transplant surgeons, paediatricians, psychiatrists and psychologists) would be well suited to assess the minor’s competence and to review the parents’ consent in light of the minor’s best interests.\textsuperscript{135} In order to prevent conflicts of interest, the independence of the professional body should be safeguarded, *inter alia* by excluding the recipient’s or even the donor’s physicians.\textsuperscript{136}

\begin{itemize}
  \item \textsuperscript{129} Nygren, *supra* note 35, 499; Sankoorikal, *supra* note 39, 614; Dufault, *supra* note 15, 236.
  \item \textsuperscript{130} Sankoorikal, *supra* note 39, 602; J.E.M. Akveld, “Het Voorstel van wet op de orgaandonatie gewogen”, *Tijdschrift voor Gezondheidsrecht* (1992) 69; *Parham v. J.R.* [1979] 442 U.S. 584: “we do not accept the notion that the shortcomings of specialists can always be avoided by shifting the decision from a trained specialist using the traditional tools of medical science to an untrained judge or administrative hearing officer after a judicial-type hearing”.
  \item \textsuperscript{132} Cheyette, *supra* note 39, 504.
  \item \textsuperscript{133} Korins, *supra* note 75, 520 and 530; C.H. Baron et al., *supra* note 13, 162. Although, it can be agreed upon that some emotional burden due to the review process cannot be avoided in order to protect the fundamental interests of the minor: C.H. Baron et al., *supra* note 13, 186.
  \item \textsuperscript{134} *Parham v. J.R.* [1979] 442 U.S. 584 (1979).
  \item \textsuperscript{135} *Ibid.*: “What is best for a child is an individual medical decision that must be left to the judgment of physicians in each case”; Akveld, *supra* note 130, 69; Nygren, *supra* note 35, 500 and 501; Zinner, *supra* note 29, 131; Shartle, *supra* note 14, 461; Lebit, *supra* note 39, 129; Belgian Advisory Committee on Bioethics, opinion nr. 50 of 9 May 2011, www.health.fgov.be/bioeth, p. 82 (referring to a donor advocacy team). Elements of this type of approach can already be found in some countries to some extent: paras. 58-70 Human Tissue Authority Code of practice 2 (2009); Art. 8bis Belgian Organ Removal and Transplantation Act; Art. L.1231-3 French Public Health Code.
  \item \textsuperscript{136} Tilden, *supra* note 87, 113 and 116; Shartle, *supra* note 14, 462; Kallich et al., *supra* note 92, 151; Caplan, *supra* note 75, 1199; Baron et al., *supra* note 13, 167. They can still be summoned to testify about the specific aspects of the case.
\end{itemize}
Negligent decisions by the body of health professionals could give rise to professional liability.\(^{137}\) After the body has made its decision, anyone who has an interest (e.g. the minor, a parent), would still have the right to address a court. However, making the judicial review obligatory does not seem to add any value. To allow control later on, the decisional process should be well documented. Rather than simply stating that the benefits outweigh the risks, the committee should base its report on the foundation of specific facts. Combining a flexible decisional standard with the safeguards of an independent review by a body of health professionals appears to be the best compromise for protecting the minor donor against both unjust intrusion and unjust restriction of his privacy and bodily integrity in the face of constantly evolving medical science.

4. Conclusion

Living organ donation by minors provides a complex dilemma. No easy, clear-cut solutions have been found appropriate. Simply prohibiting donation by all minors or only by factually incompetent minors will not always be in the minor’s best interest. Permitting donation by minors under clear, strict legal rules has also appeared to pose a similar problem. Therefore, the law should keep an open mind and adopt a flexible approach combined with procedural safeguards. An independent body of health professionals should first assess whether the minor is in fact competent to decide autonomously on donating an organ. The body should be able to take into account not only the age, but all other relevant factors as well. If the minor is found sufficiently competent, then he should be treated no differently from a competent adult donor. When the minor is not found competent, the body has the authority to approve or disapprove the procedure after a best interest review. The suggested best interest standard is a flexible one. All relevant benefits and costs, both physical and psychological, should be analyzed in light of a particular case. The benefits should reasonably outweigh the costs. It can be expected that this will sometimes be the case, e.g. when an older child is presented as a kidney donor for an emotionally related recipient. It has been found that the assent or refusal of the minor should be incorporated in the best interest review as an important factor. Furthermore, the supporting role of the parents with regard to their incompetent children should also be recognized. Their consent should thus be an additional requirement.

\(^{137}\) Veatch, supra note 11, 457.