The conversation this week focuses on the rights of individuals through the shared experience of conjoined twins. Concepts like identity, medical ethics, and the doctrine of double effect only begin to describe the places this important work poses. Fasten your seatbelt for a tour de force philosophical enquiry.*

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Conjoined Twins: Philosophical Problems and Ethical Challenges

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We examine the philosophical and ethical issues associated with conjoined twins and their surgical separation. In cases in which there is an extensive sharing of organs, but nevertheless two distinguishable functioning brains, there are a number of philosophical and ethical challenges. This is because such conjoined twins:

1. give rise to puzzles concerning our identity, about whether we are identical to something psychological or biological;
2. force us to decide whether what matters from an ethical point of view is the biological life of our organisms or the existence of our consciousness or mind;
raise questions concerning when, if ever, it is morally acceptable to sacrifice one of us to save another;

4. force us to reflect on the conditions for ownership of organs and the justification of removal of organs for transplantation which causes the death of the donor;

5. raise questions about who should take decisions about liferisking treatments when this cannot be decided by patients themselves.

We examine and suggest answers to these questions.

Keywords: conjoined twins, doctrine of the double effect, organ transplantation, personal identity, value of life

I. INTRODUCTION

Angela Formasa was happily pregnant with twins. However, pregnancy scans in the second trimester revealed that they were conjoined but could not show exactly where until the birth was induced at 34 weeks. They were conjoined at the abdomen at the level of the umbilicus, sharing an intestine. One day after birth, they underwent surgery. Twelve weeks later, Rosie and Ruby Formasa were described as two “normal, smiling bubbly babies.” Angela Formasa said, “What they have done for my two girls is amazing. When I was pregnant they were saying that the survival chances were quite low” (BBC, 2012b).

Surgery to separate conjoined twins has advanced to a stage where many twins who historically had to remain connected or die can now be successfully separated. However, this is not universally the case, and conjoined twins raise fascinating philosophical and ethical issues (Savulescu, 2012). They can be joined anywhere—head, chest, abdomen, hips, and so on. More importantly, there is a whole spectrum of cases with different degrees of bodily overlapping. They can be joined by a thin sliver of skin or they can be extensively fused—in fact, the “fusion” can be so extensive that in some cases, it is no longer correct to talk about “twins” because there is only one individual with some extra organs. When the organic overlap is insignificant, they can be easily surgically separated, which is indicated by the fact that the first recorded separation of conjoined twins in which both of them survived occurred as early as 1689. In other cases, separation is medically impossible because they share too many vital organs.

Conjoined twins arise because of an anomaly of human development. Sometimes, a single embryo is formed by a sperm and egg but splits early in the development to form genetically identical clones: identical twins. These share the same set of genes. Thus, they look identical and have similar behavioral traits. Sometimes, the embryo does not completely split into two clones—the split occurs later and the two twins share some body parts. Sometimes, one identical twin is incorporated into the body of the other.1

It is the cases in which there is an extensive sharing of organs, but nevertheless two distinguishable functioning brains, that are philosophically and ethically challenging. This is because they:
1. give rise to puzzles concerning our identity, about whether we are identical to something psychological or biological;
2. force us to decide whether what matters from an ethical point of view is the biological life of our organisms or the existence of our consciousness or mind;
3. raise questions concerning when, if ever, it is morally acceptable to sacrifice one of us to save another;
4. force us to reflect on the conditions for ownership of organs and the justification of removal of organs for transplantation which causes the death of the donor;
5. raise questions about who should make decisions about life-risking treatments when this cannot be decided by the patients themselves.

II. OUR NATURE AND IDENTITY

In the past, there was discrimination against conjoined twins. The following is a quote from the *Lancet*, as respected a medical journal then as it is today: “The monster here described was born at full term and survived four and a half days; its two components behaved as two separate individuals and died within a few minutes of each other” (Vincent Patrick, 1928, 282). While most people today do not have such primitive prejudices towards conjoined twins, some of these cases nevertheless raise philosophical questions about our nature and identity. These are the cases in which there is such an extensive sharing of vital organs—heart, lungs, liver, kidneys, gastrointestinal organs—that it is doubtful whether there are two distinct human organisms, while there are nonetheless two distinct functioning brains, each supporting a consciousness and mind of its own. There is a philosophical problem here because there are two leading types of theory of our nature and identity, both traceable back to John Locke’s ([1689] 1979, II.27) discussion in *An Essay concerning Human Understanding*. According to the first, psychological type of theory, we—that is, the referents of our uses of personal pronouns like “I,” “you,” etc.—are identical to our consciousness or mind and those areas of our brains which are the seat of our consciousness or mind. According to the other, biological type of theory, we are identical to our entire human organism or body. There are several variants of each of these types, but there is no need to specify them for the purposes of this paper.

To see how these two types of theory differ in general, imagine taking out those areas of your brain which sustain your mind and transplanting them into another human organism or body in which those brain parts are missing. We can imagine this organism to be as similar to yours as an identical twin would be. Imagine also that the operation is successful, and that after it there is someone with your mind in the latter body, that is, there is someone with your memories, interests, personality traits, and so on, in a different, but similar body. Then, on psychological theories, the person in this body will be you; you will have followed the mind-supporting areas of your brain and will have received a new body. This will be an extreme case of organ donation: you will have received not merely a new heart, new kidneys, etc.,
but a whole new body, apart from those areas of a brain which are the seat of your psychology.

According to biological theories, this will not be so, because on these theories, you are identical to your human body or organism, and this body or organism is the one which is now bereft of its mind-supporting brain parts. This may seem implausible, since many of us have a strong intuition that we go with our brains in such brain transplant cases. Yet, we also have intuitions that tell in favor of biological theories, as the following example indicates.

Suppose that when the mind-supporting segments of your brain are taken out, what is left behind is a human organism which is still biologically alive, that is, an organism which breathes, digests food, whose heart beats, etc. This is possible because the areas of your brain that regulate these functions are different from the mind-supporting ones and could remain in your (original) body when the latter are removed. The result would be a human organism in a persistent vegetative state (PVS). If we encounter this body without realizing that the mind-supporting brain parts have been kept alive and transplanted, it is plausible to say, as biological theories of our identity imply, that you are in PVS. For instance, we say of cases such as that of Terri Schiavo that it is Terri Schiavo, a woman who was once conscious, who is now in PVS, and remained so for 15 years. And imagining that we ourselves were to end up in similar unfortunate circumstances, we could say things like “I don’t want to be kept alive if I were to enter into PVS.” Such claims would be false on psychological theories. On such theories, you would have already ceased to exist when your organism is in PVS.

However, we cannot have it both ways: we cannot claim both that you are now an organism in PVS and that you are the person in the body which has received your mind-supporting brain parts. So, we face a dilemma. The existence of this dilemma shows that there is a philosophical problem about what precisely of our mind-endowed human organisms we are identical to. Obviously, we are not identical to our mind-endowed organisms in their entirety; if that were the case, we could not lose, say, a hand, or some memories without ceasing to exist. But precisely how much could we lose of our psychological characteristics and bodily parts and still be around? Psychological theories say that we could lose almost all of our bodies, except the parts of our brains which are responsible for our psychology, while biological theories say that we could lose all of our psychology. Clearly, both cannot be right, since then we would still be around, though nothing is left of our formerly mind-endowed human organisms!

We shall not here attempt to solve this philosophical problem of our identity. We simply want to point out that in cases of conjoined twins in which there are two independent minds, but only one viable human organism, psychological and biological theories of our identity will disagree about whether there is one or two human beings in existence. This is so in one of the more common forms of conjoined twins, thoracopagus, in which most of the torso of the twins is fused, and they share many vital organs, including the heart. According to psychological theories, there are unquestionably two of us here sharing organs and most of a human body. On biological theories, there is only one of us with two minds. In some cases, for example, cephalopagus—in which there are two faces on opposite sides of a single, conjoined head, and the upper portion of the body is fused while
the bottom portions are separate—the fusion of crucial organs, in particular the brain, is so extensive, that on any reasonable theory of our nature and identity there are not twins, but only one of us, with some extra organs. When twins share significant amounts of brain tissue, like Tatjana and Krista Hogan (Ryan, 2012) who can see through each other’s eyes and feel each others’ pin pricks, it may be unclear whether there is one partially split mind or two separate minds and, thus, one or two of us, according to psychological theories. On biological theories, however, in some of these cases, there is definitely only one of us with a more or less split mind.

III. WHAT MATTERS IS THE EXISTENCE OF CONSCIOUSNESS, NOT BIOLOGICAL LIFE

Fortunately, we can side-step this problem of our identity if our interest in conjoined twins cases is in ethical or evaluative issues. Suppose that the mind-supporting areas of your brain have been transplanted to a new organism, but your old organism is left behind, biologically alive but in PVS. Irrespective of whether you are identical to the mind in the new body or the organism in PVS, we can ask: what is most important for you, what matters most for you, that your mind goes on functioning and is conscious in the new organism, or that your old organism continues to be (biologically) alive? For most of us, this question of what matters or is of value to us is quite easy to answer: it is much more important that our minds continue to be conscious than that our organism continues to be alive. Just as most of us would be ready to receive a new heart if this was necessary to stay alive, many of us (the authors included) would be ready to receive a whole new body if this was necessary to keep our minds functioning. What is most important to us, we may say, is our conscious existence, that our minds continue to have experiences rather than that the biological life of our organisms goes on.3

Of course, it matters to us what kinds of experiences we have: it is good for us to have pleasant or stimulating experiences, and bad for us to have painful or boring experiences. Some experiences are neither good nor bad, but indifferent, for instance, thinking of series of random letters or numbers (if this does not go on for too long, in which case it becomes boring). So, what is important to us is, roughly, that our minds go on having predominantly pleasant, stimulating, or otherwise worthwhile experiences. Let us say that our life-prospect is good if this is the case for a significant period of time, while it is poor if our future contains predominantly bad or worthless experiences, or our future is very short.

IV. CONJOINED TWINS WITH GOOD LIFE-PROSPECTS FOR BOTH TWINS

The cases which raise hard moral problems are a subset of those which raise problems of identity, namely, cases in which there is an extensive organic overlap, but still two separate functioning brains. These cases raise hard moral problems about whether to attempt surgical separation when the extensive organic overlap both makes (a) the life-prospects of the unseparated twins poor but (b) the surgical separation of them is medically difficult and risks making the life-prospect worse
for at least one of the twins. By contrast, when the overlap is relatively slight, this is likely to impoverish the life-prospects of the twins to a comparatively smaller extent, and surgical separation of them is probably easy. If the requisite surgery is easily accomplished and risk-free, there is a strong moral reason for performing it, since this will probably enhance the life-prospects of the twins still further, because being conjoined in all forms brings along some disadvantages, such as reduced privacy and exposure to public curiosity. We may call such cases win–win cases because the life-prospects of both twins are improved by separation.

The case of Rosie and Ruby mentioned at the beginning is of this type. So was presumably the case of the perhaps most famous conjoined twins, Chang and Eng Bunker, from which the term “Siamese twins” is derived, since they were born in Siam, that is, what is called Thailand today. They lived into their 60s and together fathered more than 20 children. So, their life-prospects cannot be said to have been poor. Nevertheless, there are obvious drawbacks of not separating which these twins illustrate. If one twin dies, the other might die shortly after, as happened in the case of Chang and Eng Bunker. Moreover, they had to put up with being displayed as “freaks” at a circus. While such exploitation is unlikely today in most societies, being conjoined draws obvious public attention, and it is likely that if they had been born today, they would have been separated.

It is, then, to cases in which there are two brains and minds, but otherwise extensive organic fusion that we must turn to find the hardest moral problems about whether to separate the twins. However, not all such cases are problematic. In some of them, the organic fusion does not make the life-prospects of the twins poor, though it makes surgical separation medically difficult and risky for them. Lori and George (born Dori, but now identifying as male) Schappell is a case in point. They are craniopagus twins, joined at the forehead. They were born in 1961, so are now in their early 50s. Although George also suffers from spina bifida which has reduced his growth, he has pursued a career as a Country and Western singer. His sister helps him to move around and works in a laundry. The separation of craniopagus twins is difficult, and there have been very few successful attempts, so it would be unjustified in the case of twins like Lori and George (Brown and Whitley, 2006).

One Indian set, Saba and Farah, are also connected at the skull. They and their parents refuse surgery because it is “too risky.” They are now 15 years old and want to remain together (BBC, 2012a). What these twins are looking for is not surgery, but social support because they live in poverty. What they are claiming, in effect, is that providing better social support would make them happiest.

Abby and Brittany Hensel (Daily Mail, 2012) also belong to the kind of conjoined twins who have had good lives in spite of an extensive organic overlap which would make separation very hard, if not impossible. They are now in their 20s and lead reasonably normal lives. They go to university, drive, cycle, etc. Abby and Brittany are omphalopagus twins who share a torso with a single liver and gastrointestinal tract, but they have a healthy heart each. There is no justification for attempting to separate them because it would put the lives of both twins at risk, and it is likely to make the existence of both twins worse—for instance, by leaving each twin with one leg each. It would take considerable re-constructive surgery to remedy such disadvantages.
V. CONJOINED TWINS WITH A POOR LIFE-PROSPECT FOR AT LEAST ONE TWIN

The presence of two healthy hearts is a necessary condition for the good life-prospects of the Hensel twins, but such duplication is a rarity. Only four known instances of this type of conjoined twins have ever survived into adulthood. Most have congenital heart defects or other organ anomalies which make the life-prospects of the twins poor in the absence of surgical separation. Then the other condition, (b), that the surgical separation of them is medically difficult and risks making life-prospects worse for at least one of the twins, kicks in and creates a moral problem of whether to separate them.

This is so in a more recent case, when a 23-year old woman gave birth to conjoined twins in Brazil (AFP, 2011). The two boys had separate brains and spinal columns but shared other major organs, including heart, lungs, and liver. A crucial difference between these twins and Abby and Brittany Hensel is, then, that they share the same heart which greatly reduces their chance of surviving. The twins, who have *diencephalic parapagus*, an extremely rare disorder, were initially in a stable condition, and Dr. Neila Dahas of Santa Casa de Misericordia Hospital ruled out separation for both “medical and moral reasons.” A recent documentary reported that they died aged 6 months.4

Contrast this case with what happened to Amy and Angela Lakeberg who shared a complex six-chambered heart and one liver but had separate lungs, kidneys, and gastrointestinal tracts. These twins who were born in Chicago in 1993 were subjected to separation at the request of the parents.5 This was so, though the medical expertise regarded separation as futile, since it would certainly kill the weaker twin, Amy, and there was only the slimmest chance that Angela would survive for long and, certainly, would always be dependent on ventilation. Nonetheless, the costly separation was executed, killing Amy as she was cut off from the heart, and leaving Angela in such a poor state that she died before her first birthday.

Clearly, this separation should not have been performed—the possible benefit to Angela was too small to justify it. But there is a question of greater theoretical interest—in cases in which the life-prospects for both twins are very poor if they are not separated, could an improved life-prospect for one twin be so great that it justifies surgical separation, though this will certainly kill the other twin?

A case in which this is arguably so is the much publicized case of the twins Jodie (real name Grace) and Mary (Rose), born to the Maltese couple Michaelangelo and Rina Attard. These twins were joined at the lower abdomen, but they each had their own hearts and lungs. The family travelled to the UK for treatment. If separation was not performed, it was expected that the twins would die within three to six months. But even though there was a chance that a separation of the twins would give Jodie a good life-prospect, the parents opposed it on religious grounds because it would certainly kill Mary. However, the decision was taken out of their hands and placed in the Court of Appeal which authorized separation.

In support of this decision, Lord Justice Ward claimed:

The best interests of the twins is to give the chance of life to the child whose actual bodily condition is capable of accepting the chance to her advantage even if that has to be at the
cost of the sacrifice of the life which is so unnaturally supported. I am wholly satisfied that
the least detrimental choice, balancing the interests of Mary against Jodie and Jodie against
Mary, is to permit the operation to be performed. (Re A, 2001)

This seems to us to be along the right track. If you weigh the loss in respective life-
prospects for Mary—a few months of life—against the gain for Jodie—decades of
good life—the latter outweighs the former by far.

However, considerations of just or fair equality oppose this utilitarian reason of
maximizing the life-prospects of the twins taken together. It might be said that it is
not just or fair to make one twin so much better off at the expense of the other.
Certainly, Jodie, being the stronger twin, is naturally in a better position to be
helped than Mary, but this is just a matter of luck, without there being anything to
justify morally her better position. An operation which takes advantage of the
natural inequality between the twins to further enhance Jodie’s life-prospect
amplifies an initial natural inequality which appears unfair. Still, even though this
concern for just equality has considerable weight, it is reasonable to think that it is
outweighed if one party wins a lot by there being unfair inequality, and the other
party loses comparatively little, as is the situation with respect to Jodie and Mary. It
should be conceded, though, that such weighings of gains in respect of
life-prospects overall against losses in respect of equality have to be done in an
intuitive fashion and cannot be shown to be objectively right or wrong.

However, the decision is made more morally complicated by the fact that there
are further moral considerations that could be brought into play. The parents
opposed the surgical separation because they thought it wrong to kill one infant to
save the other. That this is wrong is an implication of the act-omission doctrine, the
doctrine that it is more difficult morally to justify actions of causing harm, for
example killing one of us, than omissions to benefit, for example letting one of us
die by omitting to make efforts to save life. By omitting to perform surgery here, we
would be letting both of these twins die in the near future instead of doing what
would ensure a better life-prospect for one at the price of killing the other.

It is, however, customary to qualify the act-omission doctrine with the doctrine of
the double effect which declares it morally permissible to kill—or harm—some of us in
the process of saving—or benefiting—a greater number of us, provided the killing
is merely a foreseen side-effect and not intended as a means to the saving. Thus, the
doctrine of the double effect claims that there is an important moral difference
between (harmful) effects which are intended by the agent as means (or ends) and
ones that are merely foreseen but unintended. This doctrine is problematic for
several reasons, but for present purposes, it is enough to note that if it is taken as a
guide in the case of Jodie and Mary, to defend their surgical separation, it is hard to
see why it should not also be taken as a guide in some cases in which its advocates
would not want to defend surgery, such as lethal organ harvesting, as we shall now
discuss.

The separation of Jodie and Mary meant severing the common artery which
enabled oxygenated blood circulated by the stronger heart on Jodie’s side to pass
through Mary’s body as well. If Mary’s death counts as a “merely foreseen side-
effect” of this piece of surgery, it is unclear why the death of a “donor twin” would
not count as a mere side-effect if her heart were removed with the intended end of
transplanting it to a “recipient twin.” What we have in mind is something like this.
Suppose that Jodie and Mary instead of being conjoined had been separate monozygotic twins. Suppose further that Mary had possessed a healthy heart, but had other medical conditions which made her death imminent (e.g., complete absence of the kidneys). By contrast, Jodie has inoperable congenital abnormalities of her heart causing progressive, lethal heart failure, but her other vital organs are perfectly healthy. Now, what if Mary’s heart were taken out and transplanted into Jodie’s body? Typically, advocates of the doctrine of the double effect would hold this transplantation to be morally impermissible. They would say that Mary’s death here is an intended means to save Jodie rather than merely a foreseen side-effect of this saving. But if Mary’s death is an intended means of the surgery in this case where Mary and Jodie are separate, why isn’t it also an intended means in the actual case when they are conjoined? In both cases, Mary’s death is a certain effect of the relevant surgery. In both cases, it could be said with equal plausibility that, if Mary miraculously had survived, so much the better. Her death is strictly speaking not causally necessary in either case for the surgery being successful in achieving its intended end of ensuring a better life-prospect for Jodie.

To be sure, these cases are dissimilar in an obvious way: in the case of conjoined twins, there is a single act of surgery—the separation of the twins—with the intended end of ensuring that Jodie gets an adequate heart, whereas in the case of the monozygotic twins, there are two acts of surgery, namely, removing the heart from Mary and transplanting it to Jodie. But the question which is relevant to the applicability of the doctrine of the double effect is the following: if the separation can be performed simply with the intended end of ensuring that Jodie gets an adequate heart—though Mary’s death is foreseen with certainty—why can’t the removal of Mary’s heart when it is intended to be followed by a transplantation of the heart to Jodie be performed simply with the same intended end, while Mary’s death is merely foreseen with certainty?

On the basis of such considerations, it seems to us that the High Court was inconsistent when it authorized the separation of Jodie and Mary, since it would not approve of transplantation in case they were separated twins. Lord Justice Ward was aware that the separation of Mary would seem to involve intentionally or consciously killing her and tried to avoid the implication that this therefore amounted to unlawful killing by appealing to the right of self-defense, that is, in this case, the right of one conjoined twin to defend herself against the threat to her life that the other twin poses. Thus, he writes that Mary “sucks the lifeblood of Jodie… Mary’s parasitic living will be the cause of Jodie’s ceasing to live. If Jodie could speak, she would surely protest, ‘Stop it, Mary, you’re killing me’. Mary would have no answer to that” (Boseley, 2002).

According to common sense morality, we do have a right to defend ourselves to threats to our lives, by intentionally killing the aggressors, not only if they are responsible for the assault on our life, but even if they are innocent agents who threaten our lives without being responsible for doing so. But, first, it is controversial whether, if the threats are innocent, third parties have a right to interfere on behalf of the victims and kill the threats. It is arguable that only the victims themselves have this right; third parties should remain passive and let the parties “fight it out” between themselves. If this is correct, doctors would not have the right to interfere on Jodie’s behalf even if Mary could properly be described as a
threat or parasite who is in the process of (innocently) killing Jodie. That is, while Jodie may have had a right of self-defense against Mary, doctors should not have taken sides and enforced this right.

Secondly, and more importantly, it is tendentious and inaccurate to describe Mary’s living as “parasitic” on Jodie’s living, or Mary as using Jodie’s body as a “life-support machine,” as neonatal surgeon Adrian Bianchi reportedly said (Boseley, 2002). There is no justification for holding that Jodie has more of a right to the healthier organs in the organism that the twins share. Jodie is not more of an “owner” of the stronger heart than Mary is. Neither has a stronger right to the shared organs which are insufficient to sustain the life of the brains and minds of both of them. These twins are like two drowning individuals who are both clinging to a plank which is incapable of supporting both of them. Neither of these individuals is in the process of killing the other, and it is no more morally permissible for the strong one to push the weaker one off this plank than it would be for the stronger one to rob the weaker one of a plank that she has acquired in order to save her own life. Still less is it permissible for others to help the stronger one to act in these ways.⁸

So, we can’t see any reason why the separation case and the transplant case described are not morally on a par: either both operations are morally permissible, or neither is permissible. If we believe that we have absolute rights to our bodily parts which make it wrong to take them, unless we give our consent, whatever the consequences may be, then neither operation would be permissible. But if we believe that these rights are not absolute, but could plausibly be set aside without our consent if the consequences are good enough, then both operations could be permissible. The consequences of depriving Mary of the use of the healthier heart—to which she has a shared right when she is a conjoined twin and a sole right when she is a separate twin—are overall reasonably good enough, since it does little to reduce her life-prospect, but a great deal to enhance Jodie’s life-prospect.

A different kind of transplant example may help to bring home the point. Imagine that Jodie and Mary are separate identical twins with separate umbilical cords and that stem cells have been retained from each of their umbilical cords, but that the stem cells retained from Jodie’s umbilical cord have been lost. Both twins later are affected by radiation and suffer bone marrow failure. However, Mary is much worse affected, so even if she is treated with all of the stem cells, she will only survive for a few months. In contrast, Jodie can be restored to full health by this treatment. If the stem cells are divided equally between the twins, the effect will be pretty much the same as if they were not treated at all: they would both die within a month. In this case, it seems reasonable to claim that good consequences in the shape of improved life-prospects would overrule ownership rights, that is, Mary’s right to the stem cells because they happen to be collected from “her” umbilical cord. Similarly, as we have remarked earlier, they outweigh considerations of just or fair equality, since the life-prospects for both of dividing the stem cells equally between them, or giving none to either, would be poor.

Many possible variations of this example are worth discussing. What if Mary stood the same chance of being restored to full health as Jodie, should we then use her right to the stem cells as a tie-breaker, or should we toss a coin? Suppose we go for using the right as a tie-breaker here, what if Jodie’s chance of being restored
were twice as big as Mary’s, 66% as opposed to 33%? Should the right still settle the matter in Mary’s favor? Our inclination is to avoid any appeal to rights and settle the matter by lottery, a weighted lottery in Jodie’s favor in the latter case. But in the present context, we would only like to claim that rights are not absolute but can be overruled if the consequences for life-prospects are good enough.

Such an argument might have far-reaching implications for organ retrieval and transplantation, both in children and adults. It implies that healthy organs should be taken from dying people (children or adults) to save the lives of other people requiring organ transplantation. At present, such organ transfers require both that the donor be brain dead (or that the heart has stopped for some period—nonheart beating donors) and that the family consents. But from an ethical (as opposed to a legal) perspective, this may be too restrictive a standard. Perhaps organ transfers should be encouraged even when the child or adult is not brain dead but has such dim life-prospects that euthanasia becomes a reasonable option. In the Netherlands, such organ retrieval euthanasia might be legally possible. One of us has previously argued that such “organ retrieval euthanasia” could be justified in adults who have given advanced consent to organ retrieval in the face of imminent and certain death (Wilkinson and Savulescu, 2012).

VI. WHO SHOULD DECIDE ABOUT SEPARATION?

We have been discussing the morality of surgical separation of conjoined twins who are not competent to give informed consent. In such cases, we could be guided by the model of hypothetical consent: we could ask ourselves whether a competent person who was in the position of, say, Mary, could reasonably consent to a treatment that would kill her. It does seem that a person could reasonably consent to this treatment, since her death is imminent in any case. But although this model could provide a guide to sensible moral judgments, it could hardly be what justifies them. What justifies the moral judgments is rather the same as what justifies our judgment that consent would be reasonable, namely, that one party would lose very little by the treatment and another would gain a lot.

It might be suggested that, wherever possible, decisions about surgical separation should be postponed until the conjoined twins have become competent to give informed consent. But, as we have seen, this is hardly ever feasible, since separation is a live option only in cases in which life-prospects are poor due to extensive organic fusion. So, delaying means inviting death. In practice, then, someone else must always make the decision on behalf of the conjoined twins.

It is natural to think that it is the parents who should make these decisions, firmly guided by medical expertise. Thus, the parents should not be granted separation even when they request it in situations in which medical expertise regards this as a waste of resources (as in the Lakeberg case). However, we have come across one case in which this decision was taken from the parents and placed in the hands of legal courts, the case of Jodie and Mary.

Given the state of the law, this created a bizarre situation. For the law in effect forbade the parents to let their conjoined twins die but, as has transpired, if they had instead been nonconjoined twins as previously described (one with a failing
heart, the other with other lethal medical conditions), it would have constrained them to let the twins die, rather than having organs transplanted from one to save the other!

In our opinion, the law should be changed so that transplantation in the latter case becomes permissible as separation in the conjoined case. Perhaps, the law should also be changed to allow more liberal organ retrieval from people, children as well as adults, who will certainly die, but whose organs could save the lives of many others. This would require revision of the “dead donor” rule which states that people must be dead before organs are removed to a rule that allows taking organs from people who will imminently die—provided that, if competent, these people give their consent.

However, if the law is changed in this way, the decision must be left with parents or family in the case of individuals who are not capable of informed consent. If it were up to the courts to decide about the separation of conjoined twins, it is hard to see why it should not also be up to them to decide about transplantation in the case of separate twins or in other cases of pediatric organ transfer. But this is surely hard to swallow. Moreover, if we could not be entrusted with the power to decide on behalf of our children, it might be asked whether we could be entrusted with the power to make such decisions with respect to ourselves.

What this would amount to is giving parents and persons themselves the power to retrieve organs while their child or they themselves were alive, but in such a grave medical condition that they would imminently die, a practice which has been called “organ retrieval euthanasia.”

We have considered conditions under which it may be permissible surgically to separate conjoined twins. But it should be stressed that many unseparated conjoined twins have gone on to live good lives. There is an ever-present risk that separations are not performed in the interests of the twins but to make them conform to stereotypes of human existence, or out of disgust or superstition. We should bear in mind that conjoined twins who have become old enough to evaluate their own situation usually do not wish separation.

NOTES

1. This happened to Julian Savulescu’s father.
2. It should be noted that, according to some biological theories, like that of Eric Olson (1997), there are two human organisms even in this case. Thus, the difference between biological and psychological theories can be made smaller than one may initially think—though it cannot shrink to nothing. However, on a more commonsensical understanding of the concept of an organism, according to which an organism is something which is independently viable, there is clearly only a single organism in this type of case. Nevertheless, as will become apparent, there is a clear tendency to talk as though there were two of us in such cases. This indicates that the persistence of our whole organism is not necessary for our identity, but more organic identity than there is in brain transplant cases may still be necessary.
3. For a well-known defense of the psychological view and a seminal discussion of what matters with respect to our identity, see Parfit (1984, pt. III).
5. For a detailed description of the Lakeberg case, see Thomasma et al. (1996).
6. For a fuller discussion of the problems of both the act-omission doctrine and the doctrine of the double effect, see Persson (2013, chapters 4 and 6).
8. For a—harsh—criticism of the High Court, see Harris (2001).
REFERENCES


Re A. (Children) (Conjoined Twins: Surgical Separation) [2001] Fam. 147, 197.


