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## **Neither Property Right Nor Heroic Gift, Neither Sacrifice Nor Aporia— The Benefit of the Theoretical Lens of Sharing in Donation Ethics**

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### **Abstract**

Two ethical frameworks have dominated the discussion of organ donation for long: that of property rights and that of gift-giving. However, recent years have seen a drastic rise in the number of philosophical analyses of the meaning of giving and generosity, which has been mirrored in ethical debates on organ donation and in critical sociological, anthropological and ethnological work on the gift metaphor in this context. In order to capture the flourishing of this field, this article distinguishes between four frameworks for thinking about bodily exchanges in medicine: those of property rights, heroic gift-giving, sacrifice, and gift-giving as aporia. These frameworks represent four different ways of making sense of donation of organs as well as tissue, gametes and blood, draw on different conceptions of the relations between the self and the other, and bring out different ethical issues as core ones. The article presents these frameworks, argues that all of them run into difficulties when trying to make sense of reciprocity and relational interdependence in donation, and shows how the three gift-giving frameworks (of heroism, sacrifice and aporia) hang together in a critical discussion about what is at stake in organ donation. It also presents and argues in favour of an alternative intercorporeal framework of giving-through-sharing that more thoroughly explicates the gift metaphor in the context of donation, and offers tools for making sense of relational dimensions of live and post mortem donations.

**Keywords:** aporia, blood donation, gift-giving, intercorporeality, organ donation, phenomenology of the body, property right, relationality, sacrifice, sharing, tissue donation.

## **Neither Property Right Nor Heroic Gift, Neither Sacrifice Nor Aporia – The Benefit of the Theoretical Lens of Sharing in Donation Ethics**

### **Introduction**

In 1995, Donald Joralemon identified two cultural scripts that ethical discussion of organ donation in the sphere of medicine, of media, and in the organ donation campaigns in the USA had typically followed: that of property rights and gift-giving. Both scripts made use of the culturally familiar in order to legitimize a profound transformation of the way in which we act towards and think about the human body and bodily exchanges in medicine. Both also started in a shared cultural baseline where medical science was seen as challenging death, transplantation as an unquestioned good, and the shortage of organs as particularly tragic because it resulted in the death of thousands of individuals who died unnecessarily since “enough” people died every year in ways that would have had made them possible organ donors *if* they and their family members agreed to donation. After this shared starting-point, the scripts parted from each other.

The script of property rights introduced an ownership conception of the body and sought to connect to discourses of ownership and individuals’ ownership rights in other areas. Emphasis was put on individual’s right to possess, use, transfer, sell or buy body-parts. In Joralemon’s analysis, this script also expressed faith in the market system to offer incentives that would balance demand and supply within the area of bodily exchanges. In contrast, the script of gift-giving sought to connect organ donation to other forms of caring responses to others, such as caring responses to unknown others who need our help after natural disasters. Emphasis was put on the generosity of donors who donated without any financial benefit.

These scripts still prevail in discussion of organ donation. However, recent years have also seen a drastic rise particularly in the philosophical and theological interest in the meaning of giving and generosity (see Hénaff, 2010; Wyschogrod, Goux and Boynton, 2002; Milbank, 2001; Schrift, 1997; Derrida, 1997), which has been mirrored in ethical debates on organ donation and in critical sociological, anthropological and ethnological work on the gift metaphor in this context (see Shaw, 2010; Sque et al, 2007; Scheper-Hughes, 2007, Fox and Swazey, 2001).

In order to capture the flourishing of this field, this article distinguishes between four frameworks for thinking about bodily exchanges in medicine: those of property rights, heroic gift-giving, sacrifice, and gift-giving as aporia. These frameworks represent four different ways of making sense of donation, draw on different conceptions of the relations between the self and the other, and bring out different ethical issues as core ones. The article presents the frameworks, shows how the three gift-giving frameworks (of heroism, sacrifice and aporia) hang together in a discussion about what is at stake in organ donation, and argues that all four

frameworks run into difficulties when trying to make sense of reciprocity and relational interdependence in donation. The critical discussion of the four frameworks starts from the idea that an ethical framework of organ donation preferably should be able to do two things: both capture the phenomenon at stake in a nuanced manner and be normatively adequate in the sense being able to shed light and guidance on ethical concerns when a body-part, tissue or blood is donated. My main focus, however, will be on organ donation.

Finally, the article argues for the benefit of an alternative framework that more thoroughly explicates the gift metaphor in this context (compare Svenaeus 2010) and that offers tools for making sense of the relational dimensions of these donations: an *intercorporeal framework of giving-through-sharing*. When so doing, the article draws on the philosophical perspective of phenomenology of the body. This framework offers philosophical support for the conclusion by the United Kingdom's Organ Donation Taskforce report: donations may preferably be understood as usual and normal rather than unusual and exceptional. The implications of the intercorporeal framework of giving-through-sharing, however, are more far-reaching. This framework calls for a rethinking of the relation between self and other, where focus is less on the individual's boundaries and more on that which takes place between the self and the other, and a continuous examination of the role of embodiment for how we act and interact with others.

#### **Four frameworks of organ donation**

What will be labelled the *property rights framework* of organ donation weaves together two ideas – the body as property-like in decisive aspects and the conviction that each individual owns her or his body, alone – and concludes that because I own my body, I have decision-making authority over it and have a right to alienate all or some parts of it to my own liking.<sup>1</sup> This framework is typically underpinned by one of two schools of thought: the natural rights theory in political philosophy, commonly exemplified with John Locke's (1956) discussion of how human labour adds value to that which was first given (through labour we become legitimate owners of that which we have worked upon), or the "social construction theory of property" where ownership is conceived as a bundle of rights that is the result of a wider span of social choices (Björkman and Hanson, 2006:209).

Debates have centred on what components constitute ownership and what criteria have to be fulfilled in order for something to be owned (Campbell, 2012; Wall, 2011; Becker, 1980;

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<sup>1</sup> Many others have also noted how these features recur in property rights discussions, though not everyone labels this as a property rights framework. As examples, see Campbell (2012), Leder (1999), Joralemon (1995). As a tangent: one may also adhere to the body-as-property conception but see the owner or the property as the state rather than the individual.

Honoré, 1961). In his seminal work “Ownership,” Honoré identifies eleven instances of ownership that all are constitutive of but not necessary to ownership, such as the right to possess, to use, to manage, to transfer ownership to others, and to income. Discussions as regard organ donation have focused on whether property rights can be applied to one’s own body and on whether property rights over one’s body always include income rights. In the latter regard, some argue that an individual’s right to sell an object is “the *core feature of ownership* of that entity” since we typically are considered to own that which we are entitled to sell and only rarely are we considered to own something without being entitled to sell it (Björkman and Hanson, 2006: 211). Others, however, follow John Christman’s suggestion that we should distinguish between different property rights (or bundles of ownership) due to their different functions. We may, for example, distinguish between control rights and income rights. Because I have control rights over my body, this does not entail that I also have income rights, since the latter in contrast to the former are conditional on “the contingencies of the market sector” (Christman, 1994:232).

As I characterise the property right framework, the decisive issue is not whether ownership implies the right to sell a body-part. Important instead are the views that one’s body is property-like and that it is something that the individual owns, alone. The view that “if we can be said to own anything, certainly we own our bodies” (Trough, 2005:14) exemplify this position. Again, however, there are different possible approaches. The property rights framework of organ donation outlined here could include a position where one’s body is seen as property-like in the sense that I alone own it and yet all parts are not equally interchangeable with other items or money. Such a position could draw on Margaret Radin’s (1996) distinction between personal property that is constitutive of the self and connected to the self in a morally justifiable way and fungible property that are not bound up with the self in this way and thus can be alienated.<sup>2</sup>

The property rights framework is far from homogeneous. As a consequence, even if scholars start their ethical analysis of organ donation with a discussion of ownership and property rights they may come to very different conclusions as regards how to make sense of the donation and remedy organ shortage. This is particularly the case when it comes to organ sale. In this regard, the script identified by Joralemon (1995) still holds for some property rights discussions, but not for all. Property rights proponents who state that organ shortage will “not be curtailed until an expansion of property rights in the human body is recognized” and certain organ sale prohibitions are removed (Dunham IV, 2008:49) still exemplify Joralemon’s script. The basic idea seems to be that I as an individual own my body, that I therefore am entitled to

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<sup>2</sup> For a discussion of which parts of the body can qualify as property-like, see the seminal work of Radin (1996).

give away or sell part of it, and that this opens the door to the market economy as a route to balance organ needs against organ supply. Others, however, who also adhere to the views that the body is property-like in decisive aspects and that each individual owns her or his body, alone, argue that there may be other good reasons why we shouldn't be allowed to sell body-parts. Such a position would fit less well with the script identified by Joralemon, but qualify as an example of the property rights framework as characterized here.

To add to the heterogeneity of bodily ownership discussions, some may adhere to the view that each individual owns her or his body because it is, as a whole, constitutive of her or his selfhood *and* want to avoid the language of property rights over one's body. Such an approach would fall outside the property rights framework as both I and Joralemon outline it. Finally, the idea that we own our bodies of course is compatible with the idea that we value it also for a variety of other reasons than that of it being our property.

I see two major reasons why the property rights framework as characterised above is insufficient, irrespective of the stance one may take on the issue of organ sale. My first concern is that it seems inadequate to make sense of the complexity of human embodiment, i.e. of the fact that my body is not easily separated from my identity as a self that engages with others and the world. This is a critique that isn't directed towards property rights discussions such as Margaret Radin's and but more so towards property rights discussions that are based on a one-sided emphasis on the body as *that which I have*, just as I have (other) property. My concern is that this position only is able to acknowledge some experiences of embodiment.

In contrast, the philosophical perspective of phenomenology of the body is particularly apt for making sense of the complex phenomenon of embodiment. While I may experience my body as that which I have rather than am when I am ill and while pain can make me unable to attend to anything but the hurting body-part and make that body-part appear as an object, an "it," to me, this is far from the whole story of embodiment (Leder, 1990). More commonly in everyday situations when we are healthy, the body does not appear as an object but functions as the taken-for-granted centre of my existence through which I engage with others and the world. If we draw only on certain experiences of illness, we may assume that the self is separated from the body and that the body can be reduced to what I have – but this omits much. It omits the phenomenon of bodily ambiguity, i.e. the ways my body can be experienced as both subject and object, both what I am and what I have.

This bodily ambiguity recurs in organ recipients' stories where the organ is both experienced as hers or his and as *other than* her or him (Haddow, 2005; Waldby, 2002; Lock, 2002; Varela, 2001). In the philosopher and heart transplant recipient Jean-Luc Nancy's (2002:10) words, "in me there is the *intrus* [the new heart], and I become foreign to myself. If the rejection is very strong, I must receive treatment that will make me resist the human defense system mechanisms that produce it ... I feel it distinctly; it is much stronger than a sensation:

never has the strangeness of my own identity, which I've nonetheless always found so striking, touched me with such acuity.”

Unfortunately, much of the property rights discussions of organ donation fails to make sense of embodiment and of what it can mean for donors and recipients to engage in this bodily exchange.

However, please also note a contra-argument against this critique of mine (and others): the property rights framework does not intend to capture the complexity of embodiment but to make a claim about rights, so why see this as a problem? I agree that the property rights framework may not intend to capture this complexity, but see a framework that manages both to capture the complexity in the phenomenon discussed and that offers normative guidance as preferable to one that only performs the latter task. It is theoretically more nuanced and can better make us understand what is at stake.

My second concern is that the property rights framework of organ donation is insufficient in its focus on the individual self and her or his rights at the expense of how we, as bodily selves, are interdependent and interconnected with others in organ donation. This criticism also needs to be qualified: the property rights framework needs surely not imply moral blindness to others. Those who adhere to the property rights framework may well emphasise that one individual's proprietary rights need to be balanced against those rights in others and against other competing moral obligations. Furthermore, it may be possible to combine a focus on property rights with a focus on the individual as dependent upon others. Still, however, the focus on the individual *has* gained much traction in property rights discussions, and this is unfortunate. It is unfortunate since post mortem organ donation evokes ardent questions about how to understand relational aspects of the decision-making process where relatives in bereavement and shock need to make decisions about donation (Lauritzen, et al 2001; see also Mongoven, 2003). Relational aspects lie also at the heart of live organ donation between family-members or friends where donation can be a response to the long-term suffering of a close one *and* evoke concerns about social pressure to donate. A narrow focus on the individual fails to make sense of such aspects, and in this way is also normatively unfortunate in the sense that it fails to help us discuss crucial ethical questions in donation debates. But are any of the gift-giving frameworks more promising in this regard?

First, much pro-donation activism and many campaigns have drawn on a gift of life discourse that sets the gift of the organ apart from other gifts as *the* invaluable gift of life (see Siminoff & Chillag, 1999; Sque et al, 2008; Shaw, 2010). This is a main feature of what here is labelled the *heroic gift-giving* framework, and other defining features are the generosity of donors who donate without any financial benefits and the heroism within this caring act that saves lives without requiring anything in return.

The German organ donation campaign from 2009 exemplifies this: large screens in Berlin

and other cities showed a vigilant Superman flying over a city at night and, alluding to the way Superman saves lives in a heroic and generous way for the good of his fellow-beings, the text next to Superman read: *Du kannst Du auch! Organspenden heisst Lebensretten*. The campaign mixed humour with an appeal to take action for the good of others: organ donation can save the lives of fellow beings and it is heroic. Features of the heroic gift-giving framework also recur in empirical studies of donors', recipients' and health care professionals' views on organ donation, as when transplant co-ordinators state that the notion of the gift is the best one available because it highlights the beauty of giving to others without any "strings attached" (Shaw, 2010: 613, see also Sque et al, 2007), or when donors are described, indeed, as heroes (Chen et al, 2006).

Some words are needed about the notion of heroism here. I label this framework heroic gift-giving, but at stake is a special kind of heroism. In the German organ donation campaign Superman is alluded to, and while being a hero, Superman seems not to put himself at risk since he after all has superpowers. This also results in a contrast to the notion of heroism in everyday language – at least when it is used to refer to acts that one not only performs unselfishly for the benefit of others, but that also implies some risks to oneself. While references are made to Superman in the particular campaign in Germany, the notion of everyday heroism may be more apt to capture the phenomenon of organ donation as being presented in organ donation campaigns: organ donation as a generous and unselfish act for the benefit of others which is primarily positive for others (rather than dangerous for the donor).

The focus on generous gift-giving can be seen in the light of larger cultural settings that emphasise the value of human solidarity. Organ donation scholars have drawn on Richard Titmuss's (1970) conception in *The Gift Relationship: From Human Blood to Social Policy* where the giving of blood to unknown others is understood as the basis for reconciling individual existence with communal life, via acts of altruism towards and in solidarity with unknown others, and on Marcel Mauss's study (1966) study on how gift exchange practices formed the building-blocks for social bonds between groups of people in traditional societies world-wide. However, it is noteworthy that the heroic gift-giving framework differs from the conceptualizations of the act of giving in these works. Titmuss points to the phenomenon of delayed reciprocity in communal life: I act in solidarity with others by giving blood and if I later need blood myself, I hope that I will receive it from others. Solidarity *combined with* delayed reciprocity does not characterize the heroic gift-giving: the focus is instead on the beauty of the gift without strings and solidarity *without* emphasis on reciprocity. Also Mauss's conception of gift-giving differs from the heroic gift-giving. Marcel Hénaff (2010:114-115) suggests that Mauss's gift-giving might best be labelled sumptuary offering since what matters is not "giving per se but the launching and continuing of a procedure of reciprocal recognition (in the sense of *recognizing one another*) expressed through precious goods and services." Even if a gift is given to a specific individual, it is not she or he that matters but what she or he represents, and

Hénaff holds that this “has nothing to do with a generous act that implies an attitude of moral renouncement on the part of the giver” (ibid.). Now, while the heroic gift-giving framework typically is applied to post mortem organ donation where, in contrast to most forms of live organ donation, it is not a specific individual as such that matters, the focus is on generous giving to others who do *not* form part of continuous mutual recognition processes.

Having said this, Mauss’s (1966) analysis of how acts of giving typically involve an obligation to give, an obligation to receive and an obligation to repay have illuminatively been used in order to highlight features of another kind of gift-giving framework of the organ donation debate: that of gift-giving as *sacrifice* (Fox and Swazey, 2001). Within this framework, organ donation is seen as a personal offering for the good of others at great expense for the sacrificer (who can be a donor or a relative), and who are seen as deeply affected by the role she or he plays in the sacrificial giving. The focus is on the darker sides of organ donation. The act of donation is seen as potentially painful and emotionally complex: it can be the result of social pressures and power dynamics, and because the act of giving carries with it an expectation of reciprocity that can be most difficult or even indeed impossible to fulfil, there can be a “tyranny” of the gift (Fox, 1996; Scheper-Hughes, 2007).

Ann Mongoven’s (2003) analysis of two dimensions of the sacrifice, that of motivation and that of cult, that she sees as prevailing in post mortem organ donation practice illuminatively exemplifies this. For Mongoven, the motivational dimension is the donor’s intention to give of her body, whereas the cultic dimension is expressed in the standardized means of the donation process: the declaration of death by use of brain-death criteria, ventilator support for the dead body and the surgical removal of the organs. Furthermore, she underlines the emotionally complex and painful dimensions of “letting go” of a loved-one and states that transplantation can imply a “hard-wrought, difficult-to-relinquish” gift that is nonetheless “offered” to others in need (Mongoven, 2003:90). As another example, on the live organ donation side, empirical studies have shown that emotional bonds can turn into bondages: there may be social pressures within families that make some individuals feel called to “self-sacrifice” in terms of organ donation even though many live organ donation practices are designed in ways that seek to minimize donation based on such pressures (Scheper-Hughes, 2007:507. See also Sque et al, 2007; Fox and Swazey, 2001; Simingoff and Chillag, 1999). These are critiques of the heroic gift-giving framework on descriptive grounds: it fails to capture that which is at stake in these bodily exchanges in a sufficiently nuanced manner.

Now, if the organ is perceived as a sacrifice that comes at a high price to the donor, the recipient may experience the need to repay the gift in one way or the other. This leads to the major concern within the last of the four frameworks: the *gift as aporia* framework of organ donation where concerns about repayment are understood as dissolving the act of gift-giving. No philosopher has taken this reasoning further than Jacques Derrida, who argues that the gift

must not return to the giver, in any sense, for it to qualify as a gift. In his words:

There must be no reciprocity, return, exchange, counter-gift, or debt. If the other *gives* me back or *owes* me or has to give me back what I give him or her, there will not have been a gift, whether this restitution is immediate or whether it is programmed by a complex calculation of a long-term deferral or *différance*. (Derrida, 1997:12)

For Derrida, a concern with reciprocity reduces gift-giving to gift exchange and to a matter of the human propensity to give-and-reciprocate in circles of gift-debt-counter-gift. Such exchanges cannot qualify as gift-giving; gift-giving for him implies that the giver must neither “see” nor “know” that he engages in this activity, “otherwise he begins, at the threshold, as soon as he intends to give, to pay himself with a symbolic recognition, to praise himself, to approve of himself ... to give back to himself symbolically the value of what he thinks he has given or what he is prepared to give” (Derrida, 1997: 14).

Derrida defines the gift as an *aporia*, i.e. a problem that cannot be solved because it simply does not fit into our usual frameworks. This is an apt categorization of the gift as he outlines it. In order to give, we must have no expectations of return nor delight in the act of giving, and yet as soon as I give to others, and others recognize the gift as gift, it bestows these others with a debt which is annulled only through some kind of return. As put by Robyn Horner (2001:9), as soon as the gift “appears *as* gift, its gift-aspect disappears ... those conditions that make the gift what it is are also the very conditions that annul it.” At the same time, Derrida declares that his point is not to annul the possibility of gifts but examine unconditional hospitality where we give to the other without any concerns for reciprocity and even without being aware that we do so as *the* ethical gesture: ethics, he states, must do that which appears as impossible (Derrida, 1999:50).

Aporetic gift-giving in organ donation would require that we do not give with expectance of return and that the other does not recognize the gift as gift. Ideally, we should not even know that we give. This seems to rule out at least most cases of live organ donation. At the same time, scholars have engaged with Derrida in order to rethink post mortem organ donation from within the perspectives of organ recipients. When Margrit Shildrick (2008:42) does so, she underlines the ambiguity of the “unpredictable opening to the other” that heart transplantation implies for the recipient, in terms of being given an organ by someone else, which the recipient neither can claim a right to nor can expect to integrate comfortably into her own body. Shildrick (2008:42) suggests that the core feature of Derrida’s understanding of the gift is that the gift is marked by uncertainty and openness. This is very useful when it comes to making sense of the case of heart transplantation where the organ receiver must “not set limits on what crosses the threshold of the body but must offer an unconditional welcome” and where this “hospitality” exposes the

recipient to risks of the unknown. This highlights that any presumed strict boundaries between the self and the other need to be re-thought in terms of openness to the other, and what is given to the other – the new organ – will remain other within the same (hence the need for immunosuppressive drugs).

At this stage, we may also return to the issue whether the giving of gifts somehow presupposes that that which I give is mine, i.e. that I own it. Irrespective of whether I give attention, food or a body-part to another, and hence irrespective of whether that which I give is detachable or not, to give seems to require that I first “have” it. Indeed, it seems both less heroic and less sacrificial to give to others what is not (at least partly) mine. However, Derrida seems to make another point. Since neither the givers nor the receivers preferably should attend to the fact that they give and receive, and hence not to what they have or have not, and in line with the call for re-thinking the relation between the self and the other in terms of openness rather than a strict boundary, the issue of individual bodily ownership seems peripheral to Derrida. Giving, for him, may instead best be characterized in terms of a far-reaching hospitality where we let the other in to ourselves, where the other is welcome to share time, food, bodies without any strings attached. Such giving and such hospitality are dangerous, impossible – and it is ethics (Derrida, 2001; Still, 2010).

The three gift-giving frameworks (of heroism, sacrifice and aporia) hang together in a critical discussion about what is at stake in organ donation. While the sacrifice framework can be seen as a critical response to the focus on beautiful and positive aspects of organ donation within the heroic gift-giving framework and to the way this framework implicitly downplays painful aspects of organ donation that need to be acknowledged in order to enable a thought-through informed choice to donate, the gift as aporia framework can be seen as a critical response to the sacrifice framework. The emphasis on the gift as sacrifice may be emotionally difficult to handle for recipients who feel the need to repay for the hardships of the sacrificial giving (even more so than for the heroic act of gift-giving); the gift as aporia makes a point about the reduction of gifts to gift exchanges.

However, I see difficulties with each of them for scholars who want to elaborate a framework that makes sense of both communal aspects of post mortem organ and tissue donation, blood donation and familial aspects of live organ and tissue donation within one and the same framework. While the sacrifice model brings out the emotionally complex decisions involved in some cases of organ donation and by so doing indicates the insufficiency of the heroic gift-giving framework, it seems less promising when it comes to doing justice to parents’ experiences of live kidney donation, where parents state that it is “natural” and “self-evident” for them to give – and where their worst fear is not to be accepted as a donor for medical reasons (Zeiler et al 2010). I see it as likewise problematic to define gift-giving in a way that precludes the very possibility of a giving that is appreciated by giver and receiver if we want to

make sense of organ donation. Whereas organ donation can result in feelings of indebtedness to the detriment of recipients, this is arguably not resolved by a definition of gift-giving that causes *any* appreciation and enjoyment of the good act to be seen as a dissolving the act of giving.

Furthermore, and perhaps surprisingly, the frameworks of property rights, heroic gift-giving and gift-giving as *aporia* share a feature: they all downplay reciprocal interdependence between the self and the other as concrete individuals. In order to explicate this point, I will turn to Mauss's (1966) work. Whereas Mauss is commonly interpreted as showing that there is no such thing as a gift without exchange, some – such as Jonathan Parry (1986) – suggest that Mauss can be read as asking *how we have come to develop the idea* that there is no gift without exchange. After all, Mauss does suggest that “we,” his contemporaries in the West, make a distinction between on the one hand exchanges as obligatory prestations performed with self-interest, and on the other hand gifts that are given without self-interest – and he asks rhetorically whether this distinction is “not of relatively recent appearance in the codes of the great civilizations?” (Mauss, 1966:46 quoted in Parry, 1986: 458).

Parry (*ibid.*) takes this one step further in stating that exchanges within an economic framework, which are typically seen as performed out of self-interest, and gifts-that-have-nothing-to-do-with-exchanges in fact emerge in present-day societies as “two sides of the same coin” but yet have been conceptualized as opposites. Simon Jarvis (2001:73) adds: both the gift-that-has-nothing-to-do-with-exchange and the exchange-of-commodities “deny relation ... they refuse any relation between donee and donor, between buyer and seller.” After all, when “I pay you for the loaf of bread, there is no need for us ever to meet again. Any ideally non-returnable gift would bring about the same result” (*ibid.*).

What happens if this reasoning is applied to the frameworks of organ donation? It may seem strong to talk about a “refused” relation in cases of exchanges of body-parts-as-commodities since there can of course be a relation over time between a buyer and a seller where the buyer returns and buys more from the seller (as could be the case in paid egg, sperm or blood donation but not in kidney donation). The point, however, as I read Parry and Jarvis, is that economic exchange and many gift-giving theories downplay reciprocal dependence between the self and the other as concrete, specific individuals.

Now, the property rights framework focuses on the individual rather than relationality or reciprocity, the heroic gift-giving framework emphasises the beauty of the act without any concern for reciprocity attached and thus downplays reciprocity, and the gift as *aporia* dismisses any concern for reciprocity or delight in the act of giving to another human being on the basis that they dissolve the very act of gift-giving. This makes these frameworks unfortunate as starting-points if one wants to elaborate a relational approach to ethics that takes seriously the way the self is formed in interactions with others, and that acknowledges the reciprocal dependence and other relational dimensions of organ donations. And, as said earlier, the

sacrifice framework is suitable when it comes to making sense of the more complicated, darker relational aspects but less so the desire to give, particularly in the case of parental live organ donation. What is needed, instead, is a framework that acknowledges the positive aspects of gift-giving, that offers conceptual tools for making sense of the connectedness between the self and the other that make organ, tissue and blood donation possible, the self-evidence of some forms of live organ donation (as described by some parents in parental live kidney donation, see for example Zeiler et al 2010), *and* the relational complexities and darker sides of particularly organ and tissue donations.

Finally, the choice of frameworks for thinking about organ donation is not an ethically neutral matter. These frameworks do things: they bring to light certain ethical questions, downplay others and cause some answers to low organ donation rates to appear as more ethically acceptable than others. Within the property rights framework it becomes crucial to discuss what specific rights I have over my body, for which there is a lot of discussion about the right to sell or buy one's body-parts. Furthermore, whereas not all proponents for the property rights framework see the answer to the low donation rates in a market that eventually will balance supply and demand, this is still a common answer. Within the gift-as-sacrifice framework, as another example, it becomes crucial to examine social pressures that may mark some cases of organ donation. The answer to the low organ donation rates is to keep to the gift-giving framework but make explicit that this gift-giving is not easy: it is a sacrifice. It does matter, in other words, which framework one starts with when it comes to what ethical issues become crucial. And I will now argue that a better alternative than the ones discussed above can be elaborated from the perspective of phenomenology of the body.

### **The phenomenological turn**

As indicated earlier, the perspective of phenomenology, and particularly phenomenology of the body, is apt for making sense of the bodily ambiguity that some organ recipients describe: the way my body can appear as mine and other than me in post-transplant experiences (Shildrick, 2008; Haddow, 2005; Nancy, 2001; Varela, 2001). It has also proved useful for differentiating, phenomenologically, between post-transplantation experiences of the organ as other than me in cases of heart, hand and kidneys (Svenaesus, 2012). In contrast to dualistic understandings of mind and body, Maurice Merleau-Ponty (2006) uses the notion of the lived body in order to emphasize that I exist neither only as an object nor only as consciousness: the lived body is a mind-body unity, acting and experiencing in a specific situation. It is our lived relationship, as embodied beings, to a world immersed in meaning, and this world of people, objects, and landscapes is opened up to me through my bodily senses and made meaningful in interactions with others that familiarize me to it during my early years and continuously. And while my body in everyday situations, as long as I am healthy, typically functions as my taken-for-granted

centre of existence, I can also experience my hurting body-part as other-than-me, as an object that I cannot but attend to; and this may have a strong effect on my mode of being-in-the world, on what I can be and do.

Furthermore, this perspective offers an explication of the phenomenon of gift-giving via an analysis of bodily existence and co-existence. In the perspective of phenomenology of the body, gift-giving does not take place at specific moments in time, on special occasions, even though it can be accentuated on such occasions. Rather, as bodily subjects we are given our bodily existence by others and others give the world to us as meaningful, in close interaction when we are small children and continuously. In this sense, giving and being-given are basic features of human existence and co-existence. This has also been taken as a starting-point for an ethics of organ donation. In one of the few efforts to outline such an ethics on phenomenological grounds, Drew Leder (1999) suggests that an acknowledgement of the connectedness and continuity in human existence can enable us to understand organ donation as a positive confirmation of the way of things, i.e. of us all being interconnected. More recently, Fredrik Svenaeus (2010:171) suggests that perhaps at least post mortem organ donation may best be understood as a matter of “giving back.”

Formulations such as these call for a detailed discussion of the notion of giving, the ways in which we may give, and the ethically relevant differences depending on how we give and what we give. We may give when putting something into the possession or keeping of another, when offering something, when causing something to pass from one to another or when designating something as a share or portion that one accords to and shares with another, and we may give in different affective modes. Furthermore, while phenomenology of the body reminds us of a basic mode of giving and being-given that characterizes human existence (where our bodily being-in-the-world is given to us as familiar and meaningful, in our early years and continuously, and how we may give the world to others), the giving of body-parts and blood is different in distinct ways.

First, the notion of intercorporeality, introduced in the posthumous work of Merleau-Ponty (1964/1968), is useful for explicating the gift metaphor via an analysis of bodily existence and co-existence. This notion has been used to denote the basic openness and non-discreteness of bodies, bring out the modes of connectedness and continuity in human existence and co-existence, and highlight how bodily selves develop and come to be in relation to each other (Merleau-Ponty, 1964/1968; Käll, 2013; Weiss, 1999; Crossley, 1999; Joas, 1985). This has made it useful in examination of how the self in interaction with others may repeatedly mimic others' bodily habits, gestures, postures and skills and (sometimes without being reflectively aware that, or how, this happens) come to incorporate others' patterns of behaviour into her or his own body and vice versa – via intercorporeal exchanges – as well as in the examination of how the self and the other can attune to each other's behaviour in ways that enable joint

activities. Studies of child development exemplify this, as do studies of interaction in dementia care (Gallagher and Meltzoff, 1996; Zeiler 2013a). As yet another example, Gail Weiss (1999:2) shows how body images (or imaginary anatomy as she also labels it) are “construed through a series of corporeal exchanges that take place both within and outside of specific bodies” in engagement with others. This can explain how we are given the world, ourselves and others as familiar in relations with others: it shows how the self is formed in relations with others, also on a bodily level, without implying any determinism.

The continuous intercorporeal giving and sharing exemplified above, or *giving-through-sharing* as I will label it, does not require reflective awareness of the fact that, or how, we may exchange body images or bodily habits. This makes these forms of giving *different* from that of organ donation. Furthermore, while there may be no difference between “learning a skill or inheriting someone else’s kidney” (Diprose, 2002:54) in the sense that I am given new possibilities deriving from the other’s bodily existence, there are other differences that need to be acknowledged. Whereas there may be good ethical reasons for giving of one’s body even when this giving involves serious risks to the health of the giver, such risks differ both in volume and quality from those involved in most everyday intercorporeal exchanges of bodily habits or skills.

At the same time, intercorporeal giving-through-sharing of on the one hand bodily ways of being and on the other hand body-parts, also *share* important features. In both cases, the notion of intercorporeality performs the analytic work of highlighting how the basic openness to others combined with the mode of connectedness and continuity, i.e. the sharing of features of embodiment, make possible a continuous giving. And in both cases, the intercorporeal giving-through-sharing opens the door to the unknowable. We cannot know beforehand how we will experience the world differently, how our transformed lived body will open up the world to us after this gifting. Finally, the receiving of none of these gifts is a quick endeavor: because of its bodily dimension, the bodily exchange requires habituation over time either through repeated mimicking (in incorporation) or a regime of immunosuppressive drugs and rehabilitation (in transplantation).

Now, an ethics of intercorporeal giving-through-sharing could acknowledge the continuity and connectedness of the self and the other along the lines suggested by Leder (1999). It allows for a reasoning where organ donation is seen as *one more version of a basic mode of giving-through-sharing*, where we give to others by sharing our bodily existence in different ways. Such an ethics offers an explication of post mortem organ donation as a way to acknowledge a basic connectedness also with those we do not know. Furthermore, as argued elsewhere, the emphasis on shared bodily existence can prove useful to help us understand parental live kidney donation as a response to the child’s pain, in situations where parents have lived with and shared the pain of the child over a long period (Zeiler 2013b).

This, however, is not enough. An intercorporeal ethics of giving-through-sharing must also offer tools for critically examining the conditions for this giving. Otherwise, this ethics risks running into the same problem as the heroic gift-giving framework: little room is given for the articulation and critical examination of potentially darker side of organ donation – like those indicated within the sacrifice framework – or indeed of gender- and ethnicity-based asymmetries in terms of who gives and who receives organs or body parts. For this reason, an ethics of giving-through-sharing needs to be combined with insights from recent phenomenologists who hold on to the conception of the body as a mode of intentionality *and* examine how cultural, historical and individual differences can matter for the subject’s bodily being-in-the-world together with others (Diprose, 2002; Weiss, 1999). Because the notion of intercorporeality invites a focus on that which takes place *between* the self and the other, it can also open the door to this critical examination of how cultural, historical and individual differences can matter for the bodily exchange between individuals.

I will make a short detour to Rosalyn Diprose’s work on corporeal generosity in order to conceptualize this concern in phenomenological terms. Diprose uses the term generosity in a very different way than in most ethical discussions. Corporeal generosity is not understood as a moral virtue, but described as an “openness to others” and the “dispossession of oneself, the being-given to others that undercuts any self-contained ego” (Diprose 2002, 4). The term is designed to highlight that we are continuously being-given to each other. In line with this, she investigates how we continuously “give” bodily habits, orientations, ways of thinking, acting and feeling to others, sometimes without even noticing that we do so, and yet this matters for self-formation and sociality. In the next step, she offers a genealogy of the relation between corporeal generosity and power, and examines how power relations can regulate who gives, is allowed to give, and is remembered as giving.

For Diprose, the self is given by others and giving of itself to others, and problems such as social inequalities and injustice arise if this gift-giving is not acknowledged or if it involves a systematic asymmetrical forgetting of the gift. In this regard, cultural beliefs and norms about bodies matter when it comes to which bodies are remembered as generous and which bodies are considered worthy of gifts; this discrimination both operates through bodies and impacts on them. In this way, the selective forgetting of the gift is unjust because it unfairly makes some gifts – given by some persons – invisible. Furthermore, forcing the gift is unjust, not because that which is given is proper to the particular subject’s body but because it denies the generosity, the basic mode of giving, at stake in human interactions.<sup>3</sup> Finally, Diprose suggests

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<sup>3</sup> While the term generosity, for her, does not denote a moral renouncement or, indeed, an intention to give, and for this reason is less apt in tissue and organ donation debates, her concern with forgetting of gifts have more aptness.

that trying to keep one's body only to oneself compromises one's own freedom. This is the case since freedom is understood as the ability to be open to the other, to give and receive bodily modes of being. Indeed, if there is an ethical limit to bodily giving, it is set by the subject's own bodily way of being in the world. Our "freedom to give" is limited by our bodily styles of being, i.e. by the habits and previous experiences that have formed our bodily existence and made some actions most unlikely and others easy for us. Diprose states, in a discussion of some concrete forms of bodily giving:

So the ethics of giving blood, gametes, sexual pleasure, or children to another is not decided on the basis of whether these gifts are alienable, unconditionally and universally, and therefore whether giving them put's one's freedom at risk. Rather, our freedom to give in any of these ways is limited by the habits and capacities we have developed as well as those of the bodies with whom we dwell, limits guided by the social signification of the corporeality in question. (Diprose, 2002:55)

A longer discussion would be needed in order to present this reasoning in all its nuances, but it does highlight the need to examine asymmetrical bodily giving. The forgetting of gifts can be phenomenologically explained in terms of disappearance: once incorporated into my lived body, once that which is given enables my engagement with others and the world, I need no longer attend to the gift *as* gift; that which is given instead opens up the world to me and I attend to others through or thanks to the "archiving" of corporeal gifts, to use Cadwallader's formulation (2010:121). While phenomenologically understandable, this forgetting of the gift becomes far from innocent against the background of the non-medically explained gender imbalances in the field of kidney donation in some countries (Schicktanz et al 2006). For this reason, it is not enough to claim that we all belong together, that my body is not fully mine and that we therefore should be organ donors. Keeping in mind the possible asymmetry in who gives and who receives, we need to examine "how and why subjects are embodied through the *archival* engagement with the generosity of others" (Cadwallader, 2010:122), how we come to develop bodily styles of being that allow for intercorporeal giving of one's body in blood, tissue or organ donation, and whether such bodily styles are distributed unequally among populations in ways that should evoke an ethical concern.

This, however, can be done from within the framework of giving-through-sharing via analyses of the conditions for this exchange and how cultural, historical and individual differences can form the subject's bodily being-in-the-world together with others.

### **The benefit of an ethics of giving-through-sharing**

Critics of the heroic gift-giving script state that the gift-of-life rhetoric can create and/or strengthen an already existing feeling of indebtedness on the part of organ recipients. Such criticism can be given new strength in the light of recent psychological studies indicating that the more someone is *told to feel gratitude* for having been given something, the more this person is prone *to feel indebted* (Watson et al, 2009). This leaves proponents of the heroic gift-giving framework in organ donation with a paradox. The more the emphasis is put on the extraordinary event of being given an organ as something to be grateful for, the more the recipient is likely to experience indebtedness with the possible detrimental effects on the self that this may have. Unfortunately, this can also be the effect of the sacrifice framework. If organ donation is a sacrifice, recipients may feel even more strongly that they are indebted to donors who have suffered for them.

The alternative, however, need neither be the property rights approach nor a gift as aporia framework. The intercorporeal framework of giving-through-sharing takes seriously the relational dimensions of human existence and co-existence and the interconnectedness with others. Furthermore, the framework of giving-through-sharing may not only make recipients feel less indebted, but also explain – philosophically – why recipients should not feel indebted. Whereas gifts call for counter-gifts in the logic investigated by Mauss and others, the appropriate response to sharing may rather be gratitude for shared existence than the giving-back of what was first given or its equivalent.

I will end by turning to the theologian John Milbank's (1999; 2001) discussion of Derrida's vision of the ethical as unconditional hospitality where neither giver nor receiver notes that any gift has been given. Milbank (1999:4) offers the image of a feast where the self and the others share a meal and enjoy "living convivially through generosity to the other and through receiving" from the other, where the supreme good is "living life as departing from oneself while in this very departing receiving oneself back again" from others. For Milbank, it is not giving back *as such* that is problematic but *how* one gives and gives back: there is a difference between returns of gifts that are carefully measured against that which was first given and giving-and-a-new-giving that is delayed and different and that does *not* merely come back as the same as was first given. The former can be seen as insults rather than gifts, where the latter, Milbank suggests, do qualify as gifts.

Milbank's image can be useful for bringing out the shared dimension of human existence that I want to highlight with the notion of giving-through-sharing. Organ donation as giving-through-sharing can give us tools for thinking about this bodily exchange in ways that make organ recipients somewhat less prone to feel indebtedness – *if* combined with the insight that we always give in this way to each other: that being given is part of human existence and co-existence though being-given an organ still is, of course, very special. This conceptualization

shifts the focus from gift-giving-without-exchanges to an on-going sharing of one's bodily existence on discursive and corporeal levels where relational dependence and the giving-through-sharing is seen as positive at the same time as the potentially darker sides of organ donations are continuously examined.

Put somewhat differently, the intercorporeal framework of giving-through-sharing offers philosophical support for what may be called a normalization of bodily exchanges in medicine – with the crucial amendments that even though these bodily exchanges may alleviate others' suffering and prolong life, they may also be painful to donors and/or relatives, and that a continuous analysis of these practices is needed. In this way, the framework supports the conclusion by the United Kingdom's Organ Donation Taskforce report: donations may preferably be understood as usual and normal rather than unusual and exceptional. The implications of the intercorporeal framework of giving-through-sharing, however, are more far-reaching than such a formulation suggests. This framework implies a rethinking of the relation between self and other, where focus is less on the individual's boundaries and more on that which takes place between self and other, and where we start to examine the role of embodiment for how we act and interact with others. The framework, and the arguments given for it, also has concrete implication for the way in which organ donation preferably should be conducted: less in the spirit of heroism and more in that of one more important way in which we may share that which makes possible human existence. Finally, it has implications for the way post mortem organ donation campaigns preferably should be conceptualised: not in terms of giving of *the* gift of life but rather in terms of sharing life.

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