

# The Utterable and Unutterable Anthropological Meaning of the Body in the Context of Organ Transplantation\*

Silke Schicktanz

Sabine Wöhlke

University Medical Center Göttingen

Department of Medical Ethics and History of  
Medicine (Germany)

[silke.schicktanz@medizin.uni-goettingen.de](mailto:silke.schicktanz@medizin.uni-goettingen.de)

## Significados pronunciables e inefables del cuerpo en el contexto del trasplante de órganos

**ABSTRACT:** In the following, we present four interpretative approaches providing a theoretical framework of an extended body anthropology of organ transplantation, which aims to accommodate empirical phenomena in the context of organ donation.<sup>1</sup> These approaches are concerned with the specific relation between body ascription and identity ascription in organ donation. Regarding this relation, we distinguish between thingification, personalisation, identification and tabooing. Finally, we discuss to which extent these four approaches can influence moral attitudes towards organ donation and which socio-cultural and politico-ethical implications they may entail.

**RESUMEN:** En lo que sigue, presentamos cuatro líneas interpretativas que sirven de marco teórico para una antropología del cuerpo en los trasplantes de órganos. Con este marco se pretende dar cuenta de una serie de fenómenos empíricos en el contexto de la donación de órganos.<sup>2</sup> Esas líneas de interpretación tienen que ver con la relación específica entre el cuerpo y la adscripción de identidad en la donación de órganos. Con respecto a esta relación, distinguimos entre la cosificación, la personalización, la identificación y el tabú. Por último, discutimos en qué medida estas cuatro aproximaciones pueden influir en las actitudes morales que se tienen con respecto a la donación de órganos, así como sus implicaciones socioculturales, y éticopolíticas.

**KEYWORDS:** organ donation, body ascription, identity, anthropology, exchange of body parts

**PALABRAS CLAVE:** donación de órganos, adscripción del cuerpo, identidad, antropología, intercambio de partes del cuerpo

### 1. Introduction

In Spanish movie *'Todo sobre mi madre'* (in English: *All About My Mother*, 1999) the director Pedro Almodovar takes the idea of transmortality (or should we say 'transvitality'?<sup>3</sup>) to extremes by addressing the subject of living on after an organ transplantation. Manuela is portrayed as the main character, a nurse working at a hospital in Madrid, about whom we get to know 'everything'. At the beginning of the film, her son Esteban is hit by a car. Manuela, who professionally oversees donor organ transplants, asks herself whether she should agree to the donation of her brain-dead son's organs. She eventually gives permission but also illegally searches the hospital records and determines recipients of the organs. The heart transplant surgery takes place in the Northern Spanish city of La Coruña, where Manuela travels to and sees the recipient leaving the hospital with her son's heart. The camera's focus on the recipient's chest, and hence his new heart, can be understood as a symbol of transmortality: Esteban is dead but a part of him – his most important organ – lives on in

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other persons' bodies. The viewer then accompanies Manuela in her search for her dead son's father and thus receives a reconstruction of Manuela's own biography which her son had asked her for just before he died. The viewer is confronted with tragicomical stories of several people whose lives are pervaded by transgressions, e.g. between men and women, natural and artificial. However, Almodovar's film does not give any concrete representation of a spiritual indication that Esteban *lives on* within the recipient of the organ.

In line with the typical themes of genealogy and social transgressions in Almodovar's work, the film addresses medical interventions of organ transplantation, sex transformation, and cosmetic surgeries. These interventions do not only modify or cure the body, they also make changes of identities possible without generally questioning the continuity of identity (understood as the possibility of a consistent biographical narration). The film elucidates that transplantation medicine leads to transgressions of various kinds, which can be scrutinised and interpreted on a biotechnical, ethical-moral, or socio-cultural level.

We here focus on the shifts of boundaries in the conceptions of the body from the perspective of both affected people and potential donors. Our particular focus lies on the motifs of continuity and discontinuity in the context of organ donation. We aim to clarify the relevant conceptions of body and identity within the complex interplay of organ donation. Our approach is based on our own socio-empirical and ethical studies<sup>4</sup> but also takes into account the current state of research.

Our following considerations mainly serve the purpose of enriching the theorisation of the body.<sup>5</sup> That is, they entail how different phenomena such as bodies (or body parts) and identity interrelate or to which extent particular notions of the body are accessible forms of knowledge. In discussing these issues we draw on our own qualitative and quantitative research.<sup>6</sup>

We assume that these views are mostly held implicitly, i.e. they exist in the form of concealed individual convictions mixed with hidden cultural interpretive schemes. The public discourse on organ donation, however, is widely dominated by explicitly invoked moral concepts of social responsibility and altruism. We claim that these moral narratives obliterate further motifs of those affected and their associations with organ donation.

The discoursivation of what counts as utterable or unutterable is not only epistemically but also ethically relevant (Schicktanz, 2015). If certain perspectives are taken to be unutterable, 'hermeneutic injustice' can occur. This idea is put forward by the philosopher Miranda Fricker (2009), according to whom, access to public, political, and legal discourses is of utmost normative relevance. However, not only formal procedural principles of just participation but also practices of ascribing competences and knowledge need to be considered. If certain forms of access to knowledge are denied or if certain people are considered generally incompetent and their 'knowledge', in turn, is devaluated, it is possible that such discourses instantiate cases of epistemic injustice.

## 2. Approximating the unutterable?

Many empirical and theoretical analyses concerning medicine centre on the 'discourse', i.e. on the utterable and uttered. However, for lay and affected people, the highly technical and hierarchal fields of biomedicine generate an "irregular discourse" (Voß, 1996). This means that those affected do not lack arguments, but instead of expressing their issues with receiving an organ primarily in the form of talking, they rather express them by being silent about them and withholding them. Consequently, the anonymity and undirectedness of post-mortem organ donation, as it is common in many countries, thwarts a directly personal, morally relevant connection between the donor, or his or her family, and a concrete, identifiable recipient. Despite this anonymity, public discourses attempt to counteract this lack of knowledge by at least addressing the symbolic and emotional aspects connected with it. The public discourses try to render one of the two perspectives visible. For instance, many poster campaigns show potential post-mortal organ donors as exemplary people, in some cases even as heroes (Morgan; Stephenson; Harrison; Afifi; Long, 2008). Alternatively, potential recipients are presented as specific people with faces, especially children and teenagers who are in urgent need of an organ donation (Wöhlke; Schicktanz, 2014).

These public presentations instantiate a powerful conjunction of two characteristic notions accompanying transplantation medicine since its beginnings: scientific

technological progress and morally highly charged pleas (Hansen; Eisner; Pfaller; Schicktanz, under review).

Already in the late 1960s, the talk of morally desirable altruism had a stabilising effect on cultural values and social norms, for transplantation medicine itself blurs the boundaries between life and death, redefines them, and thus destabilised traditional values and ideas (Hogle, 1996; Schlich, 2010). On the individual level, these uncommon boundaries are associated with great uncertainty. Patients have to cope with the process of transplant rejection, i.e. they have to dissociate themselves from the exterior and integrate the foreign by means of immunosuppression and organ fantasies (Decker, 2014). Transplantation medicine thus creates its own concepts of the availability of bodies that do not correspond to everyday practice. The body seems to be modifiable by means of medical techniques, but not all boundaries between body and technology, life and death, natural and artificial, own and foreign disappear completely. Rather, boundary shifts occur whereby the boundaries obtain a new meaning (Schneider, 2005, 213). Those affected by organ donation know that *artificially* shifting mortality is one of its effects (Wagner, 2013).

Although concepts such as brain death or organ donor cards have been now integrated into the cultural self-understanding, uncertainties persist (Crouch; Elliott, 1999, 286). These concepts conflict with individual notions of the body, especially if a dualistic concept of the body does not exist that sharply distinguishes between self (or mind) and body. The US medical anthropologist Hogle already in the 1990s noted that people consider it very important to know from whom an organ comes from and that there are regulations which secure the utility of organs (among other things, by excluding deficient organs). In Germany, according to Hogle's study, by viewing human material as a 'natural product', the efficacy of transplanted organs is propagated. This view is significantly more common in the German context than it is in the US where preserving a certain physical image of the dead prevails (Hogle, 1996, 680).

### 3. Different body-related interpretations of the unutterable<sup>7</sup>

The considerations presented here focus on arguments and descriptions relating to attitudes towards and evaluations of organ transplantation (post-mortal and living) – from the experience of affected lay people and patients.

Such a phenomenological perspective draws a rather different picture of the moral dimension of organ transplantation from the genuinely ethical-legal discourse (BÄK, 2011; Fateh-Moghadam; Schroth; Gross; Gutmann, 2006). Affected and lay people describe the process of organ transplantation as a social process of reciprocity and mutuality that entails various assumptions about solidarity, concessions, and recognition (Schweda; Schicktanz, 2009b; Hoeyer; Schicktanz; Deleuran, 2013). This differs from the two dominant ethical-legal conceptions of either a purely altruistic, morally supererogatory act of donation or an absolute obligation of the individual towards the sick or towards society.

Contrary to the postmodern and medical-scientific tendency of increasingly introducing intermediate stages or advocating ambivalence as a positive account (see also Hazan, 2015), lay and affected people seem to heavily rely on structured dualities (such as technological vs natural, living vs dead, visible vs invisible, or healthy vs ill) for the purpose of orientation. In particular, distinguishing the dead from the living body plays a crucial role in the context of legitimising organ harvesting. The anthropological uncertainty whether brain death is the definitive criterion for death (Lock, 2000) also gives rise to a moral uncertainty regarding the consent to a post-mortal organ donation. The moral uncertainty can, in practice, lead to systematically favouring living organ donation. In contrast to the US where post-mortal organ donation is widely socially accepted, organ harvesting from brain-dead patients is legally possible in Japan, however, the practice is not socially accepted and brain death as such is not socially recognised as death. To balance this, post-mortal organ donation requires, by Japanese law, not only the donor's written consent, but also his or her family's consent (Lock, 2000).

The structural distinction between dead and living, however, seems to contradict the equally common idea of continuity between donor and recipient. This idea manifests itself as a new form of a perceived *relationship* between the deceased donor and the living recipient. Such a relationship is not only imagined post-operatively by the recipient, it also prospectively provides both, potential living organ donors and relatives of deceased donors, with a motivation to consent to a donation. What at first sight may appear to be an obvious contradiction between the structural discrepancy of living vs. dead and the conception of continuity can be theoretically resolved by looking more closely at *how* continuity is exactly conceived. For those affected, as we will argue, it is hardly possible to live with the explicit contradiction.

Individual and cultural exploratory movements can be understood as a reaction to this ambivalence. They aim to find a way to respond to the epistemic and the moral uncertainty. Living with these uncertainties in practice is less attractive for the affected people.

Searching for a solution does not necessarily have to rest upon a traditional binary logic (living vs dead, human vs machine). Implicit strategies to resolve these contradictions by adopting a pre-theoretical perspective of sorts can also be regarded as strategies with the aim of achieving consistency or reducing dissonance. Since fundamental conceptions of the human body and its identity are at stake in this context, one could speak of basic patterns of the anthropology of the body.

It is important to note that these basic patterns can take plural forms. This plurality fits more neatly into the late-modern, highly industrialised society which conceives itself as being putatively ideologically impartial or at least tolerant towards a diversity of religious frameworks and notions of what it means to be human.

We postulate that there are at least four of these basic patterns in the socio-cultural sphere regarding the practice of organ donation including *thingification*, *personalisation*, *identification*, and *tabooing*. These patterns will be explained in further detail in the following.

### **3.1. Thingification<sup>8</sup>**

Social reality is primarily constituted within and through discursive practices. These give sense and meaning to what we perceive. Thus, what is decisive is not 'the human' or 'being human' but a discursively produced boundary which validated and entails symbolically communicated practices of drawing boundaries. According to Schneider (2005), organ transplants should be labelled as 'prostheses' to which the body reacts differently – in a tolerant, indulgent, or repellent manner. In every case of organ transplantation the question arises whether the body will accept the 'foreign' tissue. By contrast, the essentially different, completely alien, the anorganic, does not seem to pose such a challenge for the body. The body becomes an object of material adjustment and representation (Laederach-Hofmann; Begré; Bunzel, 2002; Waldby, 2002) and also an individually lived body is perceived as the locus of identity. The organ (the prosthesis) as a 'material artefact', can be regarded as a

specific technique and the related process would be referred to as 'technification'. In the social process, the 'normative programme' which is located behind the artefact manifests itself.

By interpreting the transformation process in terms of 'completeness and incompleteness' of the body, the relation between subject and body also undergoes a shift (Schneider, 2005). In this course, distinctions emerge concerning what defines human beings: what designates one thing to be (more or less) human or another thing to be (more or less) non-human, and what should perhaps be viewed as living and non-living at the same time.

We use the concept of thingification to describe the process by which, in the context of organ harvesting, the human organ is transformed from a part of a living whole into a 'material thing' (cf. Lindemann, 2010). This also includes the process of de-personalisation and de-identification: it is just a heart like all the others; the organ has nothing to do with the donor's personality. In addition, it is often conceived as non-living. In principle it is more difficult to separate vitality from notions of consciousness (Lindemann, 2010). Thus thingification takes place in the context of technification or mechanisation of the body to the effect that the heart remains to be just a pump and the kidney just a filtration device.

Being capable of clearly distinguishing the state of being dead from that of being alive is decisive here (Lindemann, 2011). Especially patients who are waiting for an organ or have already received one accept the brain death criterion as a sufficient criterion for death. They often only consider living organ donation a solution in an emergency situation. This can be seen as a strategy to avoid moral obligations to the family donor (Mossialos; Costa-Font; Rudisill, 2008). Furthermore, on the basis of accepting the brain death criterion, the (psychological) integration of an organ can succeed more easily since the organ comes from a dead person. The recipient's identity would, therefore, not be jeopardised by some foreign vitality. The acceptance of brain death as a sufficient criterion to define death is linked to the idea that a human being's personality is dependent on the brain. This corresponds to the common scientific opinion of brain death which is also widely spread over the public discourse and social practice. According to this opinion, it is wholly unproblematic and virtually consistent to transplant organs such as hearts and kidneys. Transplanting a brain or crucial parts of brain tissue, however, would

be considered precarious because the missing de-personalisation did not allow for a thingification. Medical students, who only hypothetically decide over harvesting an organ, tend to decide differently than affected people. They often prefer the option of living organ donation among close relatives than post-mortal donation (Wöhlke; Inthorn, Schicktanz, 2015).

As a gateway to thingification such a form of mechanisation can collide with the lived body experience of patients who often criticise the reductionist conception of the body in medicine. Correspondingly, some organ recipients criticise that the medical system withdraws care as soon as the new organ *functions* (Wöhlke, 2015).

Another gateway to thingification is the assessment in terms of means, cycles, and chains of production. The logic of late modernity prescribes conceptualising things as being part of a perpetual process of production, utilisation, disposal, and recycling (Walby; Mitchell, 2006). Thingification does not necessarily imply a fixed or merely mechanical understanding of objects. The understanding can very well be processual and dynamic in that it can conceive of a brain-dead patient's organs as *valuable waste*. Dying and being buried without re-using these valuable resources is often considered careless or even profligate and unsustainable by affected people.

Thingification is a compelling strategy especially when organs are seen as distinct functional units. For then harvesting particular organs does not destroy the body and its wholeness. On this view, transplanting inner organs is acceptable for many lay and affected people, whereas harvesting visible organs such as eyes, extremities, or large parts of skin causes irritations or disapproval. Many lay and affected people regard the notion of a *complete* utilisation of all parts of the body (incl. eyes, skin, bones, and extremities) as unacceptable (Weeks; Harris; Kinzey, 1995; Nelkin; Andrews, 1998). Because of its radicality the complete utilisation as the consistently thought-through thingification stretches the limits of the acceptable in our everyday world.

Thingification is not only effective in post-mortal organ donation but also in living organ donation. Thingification concerns sick organs that are referred to as 'things' which 'have to be removed immediately'. In addition, implanted kidneys are described as 'foreign bodies', as foreign 'things'. The implanted organ has to be vitalised retrospectively (Wöhlke, 2015). This occurs by means of the idea that the new organ has to be newly innervated and is *connected* to the body's own vessels

step by step. This example makes clear that one basic anthropological pattern about the body can supersede another of these basic patterns (here: thingification). The basic patterns can thus be practical and suitable for describing the complex and protracted process of organ transplantation. The phenomenon of re-vitalisation presupposes thingification and can be understood as an intermediary stage between thingification and the basic patterns of personalisation and identification.

### 3.2. Personalisation

Personalisation can be understood as a counter position to thingification. Giving an organ a personal or pet name indicates that the organ has a life on its own and that the body as a *collective entity of its parts* is demanded to integrate the *new*. Personalisation is often accompanied by the conception that certain features are in one way or another transferred from the donor to the recipient. Alternatively, the organ as an autonomous third generates new, individual features.

Medical professionals as well as organ recipients and the relatives of donors can be ambivalent towards the idea of the human body as a *material thing*, which is also referred to as the *other*. While brain-dead bodies or dying humans are categorised as either dead or at least as non-persons (Scheper-Hughes, 1994), the concept of *organ transfer* conveys that a part of the individual lives on in a different form (in the other), even though the rest of the body inevitably dies (Sharp, 1995, 364). Despite the efforts of psychiatrists and surgeons to put forward a merely mechanistic understanding of the parts of the body involved in organ transplantation, many recipients believe that a connection is made between their *selves* and the *other* in their bodies. Thus, transplanted body parts are more than just material things (Lock, 1995, 392). Yet medicine rarely discusses the status of chimeras<sup>9</sup>. It focuses instead on unsolved problem such as immunosuppression. However, some recipients as well as the families of some donors have a strong wish for the continuity of a person by means of the donated organs. Psychiatric and medical views pathologise this wish (ibid. 393).

The strategy of personalising a donated organ goes hand in hand with the recipient's attachment and obligation towards the donor. The recipient has to take care of the new organ and its health. It is doubtful whether sheer gratitude is sufficient for explaining the often reported feeling of an obligation, sometimes leading to strong feelings of guilt (Wöhlke, 2013).

In the moral setting of giving, personalisation produces a value in its own right (Wöhlke, 2015). The obligation consists of, *inter alia*, having to treat the precious gift in a particularly careful and responsible manner.

The most explicit form of personalisation can be found where directly affected living donors and recipients are reflecting about personal characteristics of the donor getting transferred to the recipient via an organ. In this picture, a person may undergo psychosomatic changes. Similarly, studies on xenotransplantation clearly demonstrate that uncertainties and worries concerning animal organ transplantations are expressions of a supposed threat of one's own identity. In their cultural context, such ideas do not only concern the anatomical mixture but also the alteration of essential character traits and one's self-image (Schicktanz, 2006).

Living donors of kidneys often comment humorously on reflections about psychosomatic changes. This indicates that the explication of such strategies of personalisation counts as unutterable. The alleged potentially transferrable attributions are specific character traits, preferences and aversions, talents and hobbies. Some organ recipients understand their rejection of thoughts on personalisation in a self-critical manner as some coping strategy to avoid emotional distress. This distress could be caused by thinking of *the* donor. Avoiding such thoughts is supposed to serve one's own safety since it is feared that one could be 'carried away' by them, as one organ recipient puts it (Schweda; Schicktanz, 2009b).

These kinds of perspective are often ignored in the hegemonic, public discourse. They are seen as problematic where the emphasis lies on medical urgency, organ shortage, and successful life-saving. Such normalisations of discourse render certain aspects unutterable. Another indication of the unutterable is that lay people strictly reject or dismiss those kinds of perspective as irrational when considering hypothetical scenarios and the question of whether character traits are transferred via organ transplantation. For many of them, the brain is, at best, the locus of personal identity: a survey shows that only 20 percent of the people queried said that they would accept a brain transplant, almost a third was undecided (Wöhlke; Inthorn; Schicktanz, 2015).

Especially in cases of living organ donation, personalisation in the social communication between donor and recipient is a common phenomenon. Accordingly,

one organ recipient reported in an interview that she gave the donor organ a name and collected all sonography images in an album. She also gave her father, the donor, a mug which had one of those images printed on it as a Christmas present. Other donor recipient pairs have established linguistic or tactile rituals to signify their connection. They created neologisms such as 'your-my kidney' (Wöhlke, 2015) or, in order to make a bodily connection, they regularly touched the spot on the recipient's body where they believed the kidney transplant was.

### **3.3. Identification**

Identification is a further basic anthropological assumption about the body that conceptualises the new, transplanted organ in terms of the donor's continuity. However, unlike personalisation, identification does not conceive of the organ as an independent link within a 'ménage a trois'. Rather, the organ connotes the idea that the donor and her individuality live on – at least partially.

Leslie Sharp (1995) criticises the common rhetoric about organ transplantation that lays stress on the social act of giving. That rhetoric would make it hard for organ recipients to re-define their identity after transplantation. According to Sharp, psychiatric and psychological professionals play a decisive role in determining the parameter of normative behaviour after transplantation. As a result, it is regarded as psychopathological when recipients identify themselves with their donors. The recipients, however, draw a picture of the anonymous donors in their minds and integrate it into their self. They know about medicine's critical attitude towards such identity constructions and, therefore, do not talk to medical professionals about these constructions (Sharp, 1995, 371). The imaginative construction of an anonymous donor could be developed further, thereby influencing the recipient's identity and body image (ibid.). Sharp thinks that the Cartesian dualism, which is characteristic of the biomedical paradigm, cuts across the cultural presuppositions that present body and mind/soul as inextricably intertwined.

Especially in view of the recurrent and blazing debates about possible brain transplantation demonstrates the necessity to resolve issues about identity. Many lay people and experts argue from an empirical standpoint that, as long as brains cannot be transplanted, we can only speculate over questions about identity transfer (Schweda; Schicktanz, 2009b).

Although this argument allows for alternative perspectives, including that also other organs directly affect the recipient's identity, it can be illustrated with this line of argumentation that the possibility is not entirely excluded of a physical-living organ transferring a person's identity or even developing its own subject status.<sup>10</sup>

The underlying neurocentric perspective is supported not only by the acceptance of brain death as the criterion to define death. It gets further support by the view shared within the group of queried students, namely, that transplanting the brain would be unimaginable or unacceptable, respectively.

Fantasies about head or brain transplantations as transgressive medical techniques are often publicly called into question (Mims, 2013; Berres; Merlot, 2015) by culturally addressing these techniques in film, literature or art. They look at this topic from the perspective of identity and personality changes and once again undermine the scientific assumptions of thingification, fragmentation and depersonalisation of the body, on which the techniques at hand are based (Schicktanz, 2007).

The heart also has a special status. But this status is hard to describe directly (Peyrovi; Raiesdana; Mehrdad, 2014). The heart is often described as a 'symbol of a totality' (Kaba; Thompson; Burnard; Edwards; Theodosopoulou, 2009). Whether the heart figures as the emotionally laden cultural symbol of humanism or rather as the religiously inspired idea according to which the heart is the locus of the soul, is, however, unclear (ibid.).

A survey we conducted among 750 students indicates a significantly lower acceptance of 'adopting' a heart in the case of an illness than other complex organs such as kidneys and lungs. Furthermore, the students found the general transplantation of the face and genitals scarcely acceptable (Wöhlke; Inthorn; Schicktanz, 2015). The willingness to donate complex, internal organs was comparably high (liver (73.1 %), kidney (75.7 %)), while it was lower in the case of the heart (57.6 %) (ibid.). Among those survey participants who said that the heart is the locus of the soul, the willingness to post-mortal donation of the heart was even lower (8.3 %). In addition, the survey shows a significant gender difference. The general high willingness to donate organs differed with respect to the types of organs: women were more willing than men to donate internal organs, while men were more willing than women to donate external organs such as eyes or extremities. These variations

in willingness to donate organs can be explained through different conceptions of the body: where a holistic conception is prevailing and coupled with the idea that there is a connection between identity features and externally visible organs, the unease about organ donation was stronger.

The identification with an organ can further be seen as a strategy for justifying and motivating organ donation on both the sides of the relatives and the recipients. Because the actually deceased person *partially* lives on through his or her donated organ—a tiny bit of him or her—his or her social death becomes more bearable for the relatives. This is, in any case, what relatives report in interviews and focus groups (Schicktanz, Schweda 2009). Recipients in particular report that the transplanted organ is some sort of incorporation of the deceased donor. They describe this as the feeling that the dead person who donated his or her liver would not really be dead as he or she would live on in their body (Wöhlke, 2017). Thus, the construction of continuity has a strong explanatory function for transplant patients as well as relatives of post-mortal donors. Especially parents seem to find something comforting in when they say they would know that a part of their child breathes and lives on in another body (BZgA, 2012).<sup>11</sup>

Notably, recipients and relatives of post-mortal donors are more inclined to choose such wording. By contrast, unaffected and lay people (who mainly identify as potential organ donors) would rather dismiss these, as some say, 'ghost stories'. For them, the clear distinction between life and death has priority in the hypothetical scenarios. If this were not so, ideas of continuity and living on could be interpreted as a narcissist or mere egoistic motivation for organ donation. This would, in turn, be in opposition to the ubiquitously prevalent altruism motive.

Proponents of the idea of a physio-psychic continuity between donor and recipient think that their view gets scientific support by expert statements emphasising that organs of brain-dead donors are still *fully adequate* if they are transplanted quickly<sup>12</sup>. The medical talk of a vital, full-valued organ cannot only be interpreted as a physiological continuity (preservation of the cell functions) but also as psychological continuity (preservation of the identity function).

A number of recipients of a living kidney reported that they noted to have undergone a kind of personality change, in a positive sense (Wöhlke, 2015). They felt calmer

and more balanced. According to their descriptions, this was not only a sign of relief after the successful operation but also related to their bodily comfort and feeling of being complete now.

### 3.4. *Tabooing*

In addition to the three basic patterns already discussed, there is also a diametrically opposed opportunity: negating and tabooing the significance of the organ (Tetlock, 2002). Negation involves dissociating from others as this already happens in the case of pathologising. Tabooing typically involves the social practice of non-naming that is also subject to strong moral regulation. Taboos serve to establish and perpetuate affiliation (Svenaeus, 2012): someone who breaks a taboo is sanctioned and excluded by the community. Taboos demarcate a boundary which is at the same time always controversial. The dead human is one of the greatest social taboos since dying and mortality reveal an existential threat (ibid.). Organ donation means an inevitable interference in terminal care and violation of graves.<sup>13</sup> Being confronted with the dead person after the explantation, on average at least three organs have been explanted in this situation, is for many relatives the violation of the taboo of peace of the dead (Svenaeus, 2012). Factual information alone cannot ease the tension between compassion, wanting to help, interpersonal responsibility on the one hand and the – subjectively felt – violation of the taboos of killing and peace of the dead, as well as the violation of death rituals on the other (ibid.). Taboo-governed feelings are a response to what is perceived as an existential chaos: taboos are supposed to provide magical protection against every incursion into the existing and life-sustaining order (Douglas, 2002). The death as a social-normative taboo is considered to be unutterable, at most implicitly referred to or only alluded to by pregnant silence. The realm at hand is thus something rationally incomprehensible (or unexperientable). In this ‘pre-rational’ context it is, therefore, *impossible* to address death, to see, hear, touch, or otherwise haptically recognise the ‘other world’. Making unauthorised contact with the deceased would amount to an encroachment on the world of the ‘complete other’ (Svenaeus, 2012).

Tabooing as a process manifests itself by living organ donors and recipients remarking that they forbid themselves to think about the whereabouts of ‘their’ organ. There are implicit suggestions indicating such a taboo. One recipient, for example, describes that she retrospectively interpreted her donor’s remark ‘she

should take care' as an indirect demand not to forget that she had received a kidney from her. Another recipient was so upset by his donor's general questions that he almost broke off contact with her.

As should have become clear, the public discourse ignores and does not address the cultural and emotional meaning of organs. While organ recipients constantly find ways to somehow express these anthropological perspectives on the body, it is very difficult to do so in the public sphere. This can be illustrated in how patients who received a post-mortal organ refer to sceptics about organ transplantation. For them the critical claim that the human body is then regarded as made up of spare parts store can evoke strong emotions such as shame or anger. For this reason, disregarding critics or alternative opinions amplifies the interpretative pattern of tabooing among those affected.

Even an anonymous survey among students showed remarkable results: Concerning possible view and imaginary effects after the transplantation of a specific organ: up to one third answered 'I'm uncertain' or 'I don't know' (Wöhlke; Inthorn; Schick Tanz, 2015). This uncertainty can be interpreted as a narrow uncertainty – which is what the default categories of quantitative surveys suggest. However, it could instead mean 'I prefer not to say' or 'That's not something we speak about'. The answering behaviour using so-called 'evasive answering option' in quantitative surveys can indicate that people do not want to deal or discuss the relevant questions. Following such an interpretation, this appears to imply the unutterable.<sup>14</sup>

#### 4. Discussion

The theorisation of the basic pattern is supposed to provide a tool for shedding more light and analysing in more detail the organ donation, transfer, and integration from the perspective of the affected people and their notions of identity. These basic patterns (or categories) differ with respect to their 'presence' or utterableness in the discourse: while thingification in general seems to be quite utterable, the explicit description of donated organs as 'things' is not entirely unproblematic, for the latter could be part of a contempt for the moral merit of organ donation. Thus, it should not be surprising if we only rarely encounter an explicit articulation of this basic pattern. Personalisation and identification are often readily ironised and pathologised in the

public discourse. So they are, at best, addressable in the private sphere. Tabooing of anthropological considerations about the body is presumably the most dominant pattern since on closer examination it is in play whenever notions of transfer are dismissed as 'irrational'. In modern discourse, this very label i.e. the charge of irrationality, functions as the punishment for breach of the rules.

Furthermore, one could ask how the theorisation of the different perspectives could help in understanding the reasons for the lack of willingness to donate. Our ethical assumptions about consent are, we believe, based on anthropological basic patterns insofar that they generally concern decisions relating to ourselves.

We think that thingification and tabooing have a positive and stabilising effect on the current practice of organ transplantation. Thingification is broadly in accord with the objectified and fragmented view of the body as it is presupposed in mainstream medicine. Tabooing of possible shifts of boundaries in terms of identity and body supports the hegemonic medical discourse by negating alternative forms of experience and interpretation or dismissing them as irrational.

Assumptions about personalisation and identification, on the other hand, have a greater potential for creating uncertainty. This would affect transplant patients because they get only little appreciation of their experience and integration work. Both experience and integration could likely become relevant to lay people who are potentially willing to donate organs, but do not feel that they can express their thoughts on continuity. This group of not-affected people may appear rather non-specific so far, yet it could be part of a group that is important and not to be underestimated: people who in principle are in favour of organ transplantation but are deterred from affirmatively filling in a donor card.<sup>15</sup>

Medicine has neglected taking up interdisciplinary approaches to address the phenomena of the anthropological-psychological explanatory models of those affected by organ transplantation. By framing organ transplantation as an exclusively medical action and thereby ignoring its social, cultural and psychological implications, it cannot adequately be accounted for the *intermediate* state in which the patients and their relatives find themselves.

It would also be worth examining whether explicitly addressing these basic anthropological patterns about the body can bring relief to the affected people and foster destigmatisation. It is conceivable that, as a consequence, organ donation

would get more support in general. From the point of view of an empirically informed bioethics that explicitly takes the patient's needs and interests into account it is certainly crucial to integrate these needs and interests to the expert discourse. Even if there were good legal arguments for rejecting cardiac death and holding on to brain death as the decisive criterion to define death, medicine in a late-modern society should confront itself more directly with this cultural arbitrariness as it does now. If the affected donors and recipients knew more about what they might be facing as part of immunosuppression, managing everyday life and risk assessment, they would be enabled to make much better informed decisions.

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## Notas

1. This is a focused and slightly revised and abridged version of the book chapter: *Leben im Anderen: Körperanthropologische Deutungsmuster in der Organtransplantation zwischen kulturell Sagbarem und Unsagbarem*. In: Kahl, Antje; Knoblauch, Hubert; Weber, Tina (eds.) (2016): *Transmortalität. Organspende, Tod und tote Körper in der heutigen Gesellschaft*, Juventus, pp. 75-106.
2. Este artículo es una versión focalizada y ligeramente revisada y reducida del capítulo: *Leben im Anderen: Körperanthropologische Deutungsmuster in der Organtransplantation zwischen kulturell Sagbarem und Unsagbarem*. In: Kahl, Antje; Knoblauch, Hubert; Weber, Tina (eds.) (2016): *Transmortalität. Organspende, Tod und tote Körper in der heutigen Gesellschaft*, Juventus, pp. 75-106.
3. This term was coined by the ethnologist Brigitte Hauser-Schäublin. It captures the notion of living on in others after one's death. This concept of transvitality would probably be more accurate in this context as it emphasises the living as a state rather than laying stress on mortality as a *rite de passage*. However, our interest in the specific context of organ transplantation justifies the focus on the *rite de mortalité* and thus transmortality.
4. These mainly are studies we have conducted over the last decade. They are concerned with a) Medical ethical and animal ethical aspects of xenotransplantation (DFG 1999-2000), b) Challenges of

biomedicine (EU 2004-2007); c) Decision-making processes in the context of living kidney donation (self-funded, 2008-2013); d) Organ donation between unease and criticism (DFG 2014-2016).

The basis of our theoretical deliberations here is primarily formed by the following original works: Schicktzanz, 2006; Schicktzanz; Schweda, 2009; Schicktzanz; Schweda; Wöhlke, 2010; Schweda; Schicktzanz, 2009a, 2009b; Schweda; Wöhlke, 2013; Wöhlke, 2013; Wöhlke, 2017; Wöhlke, 2015; Inthorn; Wöhlke; Schmidt; Schicktzanz, 2014; Wöhlke; Inthorn; Schicktzanz, 2015.

5. *Anthropological* considerations refer to the philosophical sense of reflecting on what it means to be a human being (and e.g. how it can be distinguished from other entities). *Epistemic* considerations are about the accessibility of knowledge about the body.
6. Our empirical data of medical lay and affected people in the context of organ transplantation was collected and analysed between 2005 and 2014. Alongside semi-structured interviews, we conducted focus group discussions. The empirical data we are working with in this paper originate from the following three projects: a) Challenges in Biomedicine (EU project): Overall 8 focus group discussions with lay and affected people on organ transplantation, conducted in Germany, the Netherlands and Cyprus (n= 166) between 2005 and 2011; b) Decision-making processes in the context of living kidney donation: Overall 6 focus group discussions (n= 41) and 31 individual interviews with affected people only (recipients and donors of living kidney transplantations), conducted and analysed in Germany between 2008 and 2013; c) quantitative survey with students at a university (approx. 23,000 students enrolled) in a medium-sized city in mid-west of Germany. This survey was undertaken during the winter term 2008/09 (n=755) and the winter term 2014/15 (n=648), both times with the same questionnaire. The sample group consisted of medical students and economics students (Inthorn; Wöhlke; Schmidt; Schicktzanz, 2014; Wöhlke; Inthorn; Schicktzanz, 2015).
7. It should be pointed out that the unutterable is considered here from the perspective of affected people. The possible interpretations, on the other hand, refer to the expert discourse.
8. Our concept of thingification refers to the social theoretical works of Gesa Lindemann (2010), who describes the material body as a thing and further as the condition for utilising technology. We prefer the concept of thingification to the one of objectification since the latter evokes the pejorative connotation of an illegitimate instrumentalisation in moral philosophy.
9. A chimera is an organism containing a mixture of genetically different tissues (Schicktzanz, 2006).
10. Thought experiments of this kind are invoked in neuro-philosophy to discuss the question of personal identity: if the brain is transplanted from X to Y, is X then in fact Y, or XY, or does it remain X? (Cf. Shoemaker, 1963)
11. This aspect is described in numerous internet forums (see, for example, <http://beschreiber.de/herzenssache/> [accessed: 23.11.2016]).
12. 'Short cold ischaemia time' means that, in order to avoid cell death and vascular occlusion, an explanted organ stays outside the body for shortest amount of time possible (Weithofer; Kliem, 2011).
13. Violation of graves (Störung der Totenruhe) is a legal term for necrophilia which according to German law (§ 168 StGB) is a criminal offence.
14. If rating scales have a 'I don't know'- or 'Not sure'-category, then that can be problematic for the interpretation because not only people without a relevant attitude but also people with a relevant attitude can choose this category owing to avoidance or evasion behaviour (Menold; Bogner, 2015).
15. Public surveys suggest that the group in between the so-called passive and active organ donors is very large (Wöhlke; Inthorn; Schicktzanz, 2015).