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## Critique in statu nascendi? The Reluctance towards Organ Donation

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## All articles published in this Special Issue:

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Going Underground: Merging Collaboration with Micro-Resistance.

doi: [10.12759/hsr.42.2017.3.41-61](https://doi.org/10.12759/hsr.42.2017.3.41-61)

Patrick Sachweh

Criticizing Inequality? How Ideals of Equality Do – and Do Not – Contribute to the De-Legitimation of Inequality in Contemporary Germany.

doi: [10.12759/hsr.42.2017.3.62-78](https://doi.org/10.12759/hsr.42.2017.3.62-78)

Rainer Diaz-Bone

Discourses, Conventions, and Critique – Perspectives of the Institutional Approach of the Economics of Convention.

doi: [10.12759/hsr.42.2017.3.79-96](https://doi.org/10.12759/hsr.42.2017.3.79-96)

Laura Centemeri

From Public Participation to Place-Based Resistance. Environmental Critique and Modes of Valuation in the Struggles against the Expansion of the Malpensa Airport.

doi: [10.12759/hsr.42.2017.3.97-122](https://doi.org/10.12759/hsr.42.2017.3.97-122)

Sascha Münnich

Outside Powers: The Moral Economy of Anti-Financial Movements 1870-1930 and Today.

doi: [10.12759/hsr.42.2017.3.123-146](https://doi.org/10.12759/hsr.42.2017.3.123-146)

Philip Wallmeier

Exit as Critique. Communes and Intentional Communities in the 1960s and Today.

doi: [10.12759/hsr.42.2017.3.147-171](https://doi.org/10.12759/hsr.42.2017.3.147-171)

Isabel Kusche

The Accusation of Clientelism: On the Interplay between Social Science, Mass Media, and Politics in the Critique of Irish Democracy.

doi: [10.12759/hsr.42.2017.3.172-195](https://doi.org/10.12759/hsr.42.2017.3.172-195)

Henrik Dossdall Et Byron Z. Rom-Jensen

Letting Lehman Go: Critique, Social Change, and the Demise of Lehman Brothers.

doi: [10.12759/hsr.42.2017.3.196-217](https://doi.org/10.12759/hsr.42.2017.3.196-217)

Insa Pruisken

Institutional Logics and Critique in German Academic Science Studying the Merger of the Karlsruhe Institute of Technology.

doi: [10.12759/hsr.42.2017.3.218-244](https://doi.org/10.12759/hsr.42.2017.3.218-244)

Thomas Kern Et Thomas Laux

Revolution or Negotiated Regime Change? Structural Dynamics in the Process of Democratization. The Case of South Korea in the 1980s.

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# Critique *in statu nascendi*? The Reluctance towards Organ Donation

Frank Adloff & Larissa Pfaller\*

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**Abstract:** »Kritik *in statu nascendi*? Die Zurückhaltung gegenüber der Organ-spende«. This article offers a differentiated characterization of those who are uncertain, skeptical, or reluctant in their attitude to organ donation. We explore if and how skepticism about organ donation can be expressed and enacted against the background of moral imperatives in favor of donation. To that end, we take a closer look at one paradigmatic case from our sample and discuss the sense of 'unease' experienced with regards to organ donation as a form of critique that finds itself in a major conflict: the moral imperative to help and to 'save lives' confronts an unbearable disregard and disrespect for personal integrity and leads to a feeling of trouble and shame. People are often unable to show that the ethical value of the integrity of the person has equivalent value to the rightness of saving lives. This is related to the fact that the pure materiality of the human body is such a dominant theme in the medical discourse that positions that speak of the dignity of the person (and this includes the body as well) beyond the grave are not only marginalized but lack the very vocabulary they need to argue this position. Thus, the article contributes to our understanding of the affective, physical bases for unease and critique.

**Keywords:** Organ donation, unease, validity claims, disrespect, integrity of the person, focus groups, interviews.

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## 1. Introduction

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Amongst the general public, the impression exists that ethically speaking there can be no question – it is even seen as a moral imperative – that everyone should demonstrate their willingness to donate their organs. There are many people who feel uneasy about this, without, however, being able to precisely articulate what the source of their discomfort is. They find it difficult to translate this feeling into intersubjectively comprehensible arguments and are thus

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unable to convey their misgivings about the dominant discourse into a determined critique. This is related first of all to the fact that they lack the appropriate ethical language to be able to formulate their unease. Secondly, this disquiet is dismissed within the medical discourse – it is relegated to the realm of private idiosyncrasy. We intend to show, based on this example, that skepticism, unease, and reluctance vis-à-vis organ donation can be reconstructed as a critique in *statu nascendi*. Reference is made here (even before any propositionally formulated argument) to the value of the human person and its bodily integrity. This critique is located in propinquity, affect, and corporeality, and not in the rational, academic discourse of distance. However, it remains to be seen whether in future this actually leads to a credible discourse position of explicit criticism and thus of changing the dominant discourse.

This is the starting point for our study. We aim to offer a better understanding and differentiated characterization of those who are uncertain, skeptical, or reluctant in their attitude to organ donation. In the course of the study, we conducted focus groups and interviews, and we supplemented our data with documentations of congresses, document analyses, and expert interviews. We explore if and how skepticism about organ donation can be expressed and enacted against the background of moral imperatives in favor of donation. We reconstruct different types of ‘saying no’ to organ donation – the *no killing* position, the *information deficit* position, the *mistrust* position and the (*bodily*) *integrity* position (for details see: Pfaller et al. under review) – and unveil the difficulties in expressing skepticism regarding organ donation, which do not relate exclusively to the concrete praxis of implementation (keyword: scandals).

In this article, we set out to get closer to an answer to why the ‘no’ to organ donation is so difficult and whether a form of critique is articulated in the act of repudiation. To that end, we take a closer look at one paradigmatic case from our sample. In doing so, we discuss the sense of ‘unease’ experienced with regard to organ donation as a form of critique that finds itself in a major conflict: the moral imperative to help and to ‘save lives’ – rightness as a ‘validity claim’ (Habermas 1985) – confronts an unbearable disregard and ‘disrespect’ (Honneth 1972) for personal integrity and leads to a feeling of trouble and shame. Yet the people interviewed in the study were unable to show that the ethical value of the integrity of the person has equivalent value to the rightness of saving lives. This is related to the fact that the pure materiality of the human body is such a dominant theme in the medical discourse that positions that speak of the dignity of the person (and this includes the body as well) beyond the grave are not only marginalized but lack the very vocabulary they need to argue this position. The article should be seen then as a contribution to our understanding of the affective, physical bases for unease, defiance, and critique (the emotional base of critique and the difficulties expressing critique are also analyzed by Schwarz (2017) and Wallmeier (2017) in this volume).

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## 2. Background: Organ Donation in Germany

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In Germany as well as in other Western countries, organ transplantation is seen as an integral part of modern medicine. However, post mortem organ donation is a comparatively rare incident and only a very few of those who signed an organ donor card will actually end up being organ donors. This is because post mortem organ donation is only possible if the person in question is reported brain dead. In 2015 the German National Medical Association replaced the better known and more frequently used term ‘brain death’ with the term ‘irreversible loss of brain function’ (*irreversibler Hirnfunktionsausfall*) and drew up stricter guidelines for its detection (Bundesärztekammer 2015). Germany still holds to the definition that this state equates to the death of a human being, as the Ad Hoc Committee of the Harvard Medical School first described it in 1968 (Ad Hoc Committee of the Harvard Medical School 1968). The use of brain death as a legal definition of decease allows a person to be declared legally dead while being kept on life support, where all the organs apart from the brain are still working, thus making organ donation possible. In Germany, brain death is recorded about 2,000 times per year.<sup>1</sup> Bearing in mind that there are about 900,000 deaths altogether (Statistisches Bundesamt 2016), only about 0.2 per cent of all deceased are potential organ donors. About half of them – for example, 877 people in 2015 (DSO 2016) – actually become donors.

Although these facts and figures are known, ‘organ shortage’ – the gap between transplantable organs and the number of patients on the waiting list for organ donation – is commonly reduced to a lack of willingness among the German population to donate and is subject to public censure. This is exemplified by a headline that appeared in *Die Zeit*, a widespread German weekly, in 2013: “Germans are stingy with their organs” (*Deutsche geizen mit ihren Organen*) (Powell 2013). The common interpretation of people’s reluctance to donate their organs reduces this phenomenon to a lack of information (e.g. Tumin et al. 2013) or the mistrust and dented confidence felt after the so-called allocation scandals of 2012 (e.g. Hyde 2012; Pondrom 2013; Schwettmann 2015).

In Germany, the permission to explant organs depends on the explicit consent of the donor, made during his or her lifetime. Here, as in other countries with an ‘opt-in’ model, the will of the deceased is accepted as legally binding, and if it is not documented on a donor card or otherwise, the relatives are asked to reconstruct the presumed will of the (potential) donor.

The German Organ Transplantation Foundation (DSO) is responsible for coordinating organ donation in Germany, while Eurotransplant is responsible

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<sup>1</sup> <<https://www.organspende-info.de/organ-und-gewebespende/verlauf/hirntod>> (Accessed 21 March 2016).

for the allocation not only in Germany but in and between eight European countries. The Federal Centre for Health Education (BZgA) is charged with providing information and promoting organ donation among the public. Up until 2001 it was allocated a sum of 2.4 million marks (Deutscher Bundestag 2003, 42). But the funding was greatly increased after the German Transplantation Act (*Transplantationsgesetz* – TPG) was restructured in 2013. Today, the BZgA receives approximately 7.5 million euro per year for the design and distribution of campaigns (Deutscher Bundestag 2014; see also: Hansen et al. under review).

The public discourse in Germany (and elsewhere) suggests that donating organs after one's death is an altruistic and normatively correct act (Motakef 2011). Therefore, in the public discourse as well as in most academic approaches, the reluctance to donate seems merely to be something that is to be overcome. Thus, it comes as no surprise that public campaigns only show moral arguments in favor of organ donation like altruism, responsibility, or social conformity, and do not refer to uncertainty, reluctance, or critique (Hansen et al. under review).

The decline in the actual number of organ donations since 2010 (2010: 1,296; 2012: 1,046; 2013: 876; now stabilized at a lower level – 2014: 864; 2015: 877) (DSO 2016) was repeatedly interpreted as a significant drop after the 2012 German allocation scandals and put down to public mistrust in the system by the media as well as in academic articles (Hyde 2012; Schwetmann 2015). But the evidential basis for the mistrust induced by the scandals and resulting decrease in donation rates and the public reluctance to hold donor cards has rarely been questioned (Schicktanz et al. 2016). It was considered to be an understandable and politically consistent position and was also the subject of international discussion (Neuberger and Murphy 2013; Pondrom 2013; Shaw, Neuberger and Murphy 2013).

Before the scandals, the explanation for the low number of donor cards and donation rates in Germany was mainly based on the *information deficit* paradigm, the idea that reluctance is caused by a lack of information about the need for organs, the credibility of the brain-death diagnosis, or the reliability of the allocation system (Hoeyer, Jensen and Olejaz 2015). In August 2012, therefore, an important revision in the German TPG in favor for the so-called 'information rule' was enforced (Siegmond-Schultze 2013). This law obliges the health insurance companies in Germany to send the relevant materials to all insurees including an organ donor card.

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### 3. Material and Method

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By means of qualitative social research, we explore whether and how skepticism about organ donation can be expressed and enacted against the background of moral imperatives surrounding the theme of organ shortage. Our findings are based on interviews, focus groups, expert interviews, documentation (of congresses, workshops, and events), as well as self-portrayals (e.g. websites) of organ donation critics and supporters. Participants in the interviews and focus groups cover a broad spectrum of attitudes regarding organ donation: this ranged from the statement “Organ donation is an interesting topic, which is worth talking about,” or undecidedness, to a discomfort that cannot be articulated, a guilty conscience or helplessness, and ultimately to skepticism, feeling queasy, or arguments overtly based on unequivocal opinions. But also proponents of organ donation were interviewed – keeping in mind that also people who decided to be an organ donor can have ambivalent attitudes regarding organ donation.

We conducted nine focus groups and 17 interviews with those who are undecided, are skeptical, or have negative feelings regarding organ donations, as well as laypeople who are interested in the issue as well as with experts on the field (60 participants in total, status September 2016) within the framework of the project “‘I would prefer not to.’ Organ donation between unease and criticism. A sociological and ethical analysis,” funded by the German Research Foundation (DFG - AD 318/5-1, SCHI 631/7-1).

All of the interviewees and participants in the focus groups were recruited through leaflets and posters, as well as announcements in specific online forums and organizations, and snowball sampling. Recruitment took place in accordance with the grounded theory approach of theoretical sampling, in which the search for minimal and maximal contrasts serves as a leading principle (see Glaser and Strauss 2009). Similar and diverse cases were sampled to reconstruct the smaller sections of the field, as well as to understand the entire spectrum of cases. Thus, the overall sample was developed step by step, iteratively referring back to the ongoing data analysis. During the recruiting process, all of the respondents were informed about the consultation method, data protection, and incentives.

In the selection of participants and the composition of the focus groups, we aimed for a balance of both age (21-86 years, average 46 years) and gender (39 female and 21 male). The selected participants signed an informed consent sheet that explained the aims and the setting of the project in detail. Before the study was launched, it was approved by the institutional review board (IRB) of the University Medical Center in Göttingen, Germany. The interviews and focus groups were conducted in different German cities (Berlin, Hamburg, München, Nürnberg, Erlangen, Göttingen, etc.) in 2015 and 2016. The focus



groups were moderated by two facilitators using a semi-structured questionnaire on attitudes and experiences regarding organ donations, current campaigns, the donor card, the scandals, and reactions on expressed criticism or uncertainty, as well as everyday life scenarios – for example, on filling out a donor card. The discussions and interviews were audiotaped and the recordings transcribed. The respondents were given pseudonyms, and only information regarding their gender (Mr./Ms.) and age (in parentheses behind the pseudonym initial) has been provided here.

In the interpretation of the data, we followed the implications of the documentary method (Bohnsack 2010) and thus a reconstructive paradigm. Taking into account that meaning is always created in the course of a concrete sequence of speech acts, both the focus groups and the interviews were analyzed using a sequence analysis (Nohl 2009), and individual statements could be interpreted as ‘documents’ of overarching orientations. In an ongoing process of comparing the analyzed cases, typical argumentation and orientation patterns of “saying no to organ donation” could be reconstructed as we describe them in the following section.

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#### 4. Four Types of Rejection

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As we discuss elsewhere in detail (Pfaller et al. under review), we actually find the argumentation patterns ‘information deficit’ and ‘mistrust’ used by the participants in interviews and focus groups: the *information deficit* position refuses to take decisions under uncertainty and claims that true decisions can only be made if all the consequences can be foreseen. In the case of organ donation the proponents do not feel sufficiently informed to decide whether they are for or against organ donation. The *mistrust* position says no to organ donation in light of suspicions about a corrupt and devious medical system. This can be the result of human error as well as fraud and corruption, as was experienced during the German “organ allocation scandals.” The proponents don’t reject organ donation as such: some err on the side of caution by selecting the ‘no’ option on the card, but for others the imperative to help is much stronger than their reservations, and they admit to being organ donors for supererogatory reasons. Besides these well-known arguments, we find two strong forms of critique that are not addressed in campaigns or in public discourse: the first one, the *no killing* position indicates that brain death is not the definitive moment of death for human beings and thus the current practice of organ donation is comparable to homicide. The position does not reject organ donation as such but the concrete practice of using brain-dead persons as donors. Unlike the other types, this form of critique can be found organized in different groups and is voiced in open letters, self-made documentaries, and the like, trying to

inform the public about wrongdoing and to perform educational work. Proponents of this type of critique sometimes carry “alternative organ donor cards” documenting their will to not even undergo brain-death diagnosis. The second type of critique we found that was not discussed broadly in public discourse we have called the *(bodily) integrity* position. This position puts saying no to organ donation on a level with protecting one’s own bodily and personal integrity. Unlike the other positions, it doesn’t refer to the current practice of organ donation and its proponents may also feel uneasy with living organ donation, as the mere idea of transferring one organ from one body to another contradicts their *Weltanschauung* (world-view) and lived concepts of the body. The moral imperative of campaigns is experienced as infringement. As a consequence, these people do not carry a donor card or have decided against organ donation but some of them tend to feel guilty about their defensiveness and reluctance because their position often cannot be articulated in terms of a propositional argument and thus cannot refer to acknowledged ‘justifications’ (cf. Boltanski and Thévenot 2006).

The *information deficit* position and the *mistrust* position can base their line of reasoning on high-profile arguments explaining the lack of willingness to donate organs in public and academic discourse and thus offer, first and foremost, effective justifications. The critique of brain death (*no killing* position) and the *(bodily) integrity* position refer to more intrinsic, irreducible, and generalizable values relating to the inviolability of the person and human dignity. The former represents a morally justified and consistent position, but the unease underlying the *(bodily) integrity* position is particularly difficult to articulate and put forward as a reasoned argument. The interviewees and focus group participants who feel ‘uneasy’ with organ donation find it extremely hard to express their reservations. This becomes especially obvious when confronted with organ donation poster campaigns, as the following sequence from a focus group shows:

Ms. Schröder (40): You have to pluck up more courage to say no.

Ms. Neumann (59): Yes, the suggestion is that you are rejecting something – you’re saying no to something that is actually good. That means you don’t understand what good is.

Ms. Schröder (40): Yes, you’re a bad person, an evil person.

In order to understand the difficulty of this critique of organ donation, we mainly focus on one paradigmatic case and provide an in-depth interpretation to discuss the ‘unease’ as a form of critique in the following section. We chose this interview because it reveals fundamental and deep ambivalences regarding organ donation in one person. We have a theoretical understanding of the ambivalences and conflicts that are evident here based on Habermas’s ideas (1985), seeing them as a specific, strained constellation of contradictory but equally

credible “validity claims.” The nascent critique, which still has no clearly defined vocabulary, comes out of an ethical perspective that nonetheless is deflected by the hegemonic truth and rightness discourse of medicine and politics.

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## 5. “A Little Bit Creepy” – The Position of Bodily Integrity

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For this article, we chose the case of Ms. Fischer (interview). Ms. Fischer is thirty-four years old, is married, and has one child. Although she thinks organ donation is important and right, she doesn’t hold a donor card. She also finds the ‘no’ position a difficult one: she feels under pressure from the campaigns but sees them as positive because she would actually like to see herself as a supporter and advocate of organ donation. The campaigns made it look as though

it was a completely normal or straightforward thing to do, *without thinking twice about it*. As if it were an easy decision, but somehow it’s not for me, is it? I’d love to be so laid-back. [...] Actually, I feel pretty much *ashamed* that I don’t have one [a donor card]. I have a bad *conscience* about it. (Interview with Ms. Fischer [34])

Against this background – the wish that she could fill out a donor card with the same degree of ease that one sees in the campaigns, coupled with her own procrastination and the shame that results from it (more on this below) – we will now examine the first part of the interview:

Interviewer: We are especially interested in your personal experience, your personal thinking about organ donation and about donor cards. What got you interested in that?

Ms. Fischer: I’ve been interested in it for a long time and always have a bad conscience walking past the cards you can fill out. And as it’s on my mind and my thoughts are a bit of a *muddle* and I kind of can’t really *make up my mind*, I thought it could be a great option to get a bit more information by talking about it with you. Or maybe get a bit clearer through the interview or from talking about it – that’s what I was kind of hoping. And if I’m right to have my, you know, worries about it or am I totally mistaken? Yeah, that’s it.

Interviewer: What are the *worries* you just mentioned? What are the things that are bothering you or make you anxious?

Ms. Fischer: I don’t know if it’s maybe true – quite a few people are kind of saying it – that you maybe worry a bit that, with donating an organ, when it turns out you’re dying, that somehow ... I dunno, if you’ve got a donor card, they somehow pull the plug on you quicker or something like that or just ... Mind you, I’m no big fan of major life support measures, but somehow you’ve maybe heard two or three creepy stories at some point in your life, right? One stupid story or another. And somehow they *stick in your mind* and I’m actually a really caring person and really committed to that kind of thing. And my

husband's just the same. And neither of us have donor cards and we don't really know exactly why that is.

Interviewer: Ok. And have you talked about that?

Ms. Fischer: Yeah, but only recently. When I told him about the study being done here, and then he said, yeah, he didn't have one either and he was hoping I could clue him in about it because the reasons he doesn't have a card are just the same as mine. You hear things like, I dunno... is that something common? Are there maybe lots of people with these worries, that maybe they won't put you on life support?

Interviewer: Of course.

Ms. Fischer: That's the main reason. Yeah, that's actually one of the only reasons, I reckon, that you just don't know enough. *What's* going to be done with the organs? *When* do they get removed? What about when I'm laid out in the coffin? How's that gonna be? Will I look all hollowed out without eyes? Or will I get gutted as a source of spare parts? It's all a bit like that, a bit kind of creepy. On the one hand, you don't care what happens to you because you're not there anymore but, on the other, you maybe have these kind of slaughterhouse thoughts that are a bit of a turn-off. Yeah. But for all that [laughs], I actually still *want* to do it. I want to maybe find out in this conversation whether I'm going to go ahead and take the plunge.

Ms. Fischer starts the interview by mentioning that she feels guilty about not having an organ donor card. The cards feel like a challenge. Her own feelings and thoughts that are "muddled" and might possibly be "mistaken" are contrasted with neutral "information" and getting "clearer." The talk documented the widespread interpretation of the *information deficit* paradigm: for her own part she adapts this and makes a separate interpretation ("quite a few people are kind of saying it") and reduces her own insecurity, vacillation, and worries to a lack of information, because the argument in the media discourse on organ donation and in the advertising campaigns, as described earlier, is that making a decision is simply a question of reading up about it. At the same time the suggestion is that agreeing to organ donation is a correct decision ("to save lives") (Hansen et al. under review). She seeks to put her worries down to "creepy stories," but she does not elaborate or give more detail about these stories and refers to possible irregularities in organ transplantation (turning off life support too soon). The first part of the interview is thus characterized by the two prevailing patterns of interpretation behind an unwillingness to become an organ donor – information deficit and mistrust.

However, Ms. Fischer has not set her mind at rest with this interpretation, as the conversation documents a fundamental underlying sense of crisis: she describes herself and her husband as "really caring" and committed people and contrasts this positive identification with the fact that neither she nor her husband has a donor card. Here she presents a disparity that does not tally with the explanations she offers, as caring and committed people can also decide against

a practice that is acknowledged as (in fact) positive and correct when they have good reasons for it (for example, shortcomings in the actual practice of organ donation). But the reasons she cites for hesitating to fill out a donor card do not seem sufficient to her as she and her husband “don’t really know exactly why” they don’t have a card. There seem, then, to be other motives at work here, which set the possibility of becoming an organ donor apart from, say, giving blood or registering as a potential bone marrow donor (Ms. Fischer reports that she is persuaded by both of these and makes no reference to the role information plays).<sup>2</sup>

In the final paragraph Ms. Fischer abandons the level of argumentation. She imagines herself in a possible future organ donor scenario, in which she views her position with concern: “What about when I’m laid out in the coffin? How’s that gonna be? Will I look all hollowed out without eyes?” Here it is clear that Ms. Fischer believes that her own person will also endure beyond the grave and may be exposed to possible violation. This violation constitutes an act of dehumanization: “source of spare parts” refers to degrading the human body to mere material, “slaughterhouse” to being reduced to livestock. Reference can be made here to Ralf Stoecker’s concept of human dignity: Stoecker describes human dignity as something that proves its validity first and foremost in the violation of it. He describes this violation above all as a form of procedure that no longer treats the other as a person (i.e. as someone who has a *persona*, a self) (Stoecker 2003). In Ms. Fischer’s case we can construe that when it comes to organ donation, it is not merely her body but her own person and its dignity that are at stake.

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## 6. Truth, Rightness, Truthfulness – and Ethical Validity Claims?

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In Habermasian terms, the crisis that emerges as a paradigm in the interview with Ms. Fischer can be theoretically understood as a specific constellation of different “validity claims” (Habermas 1985): the discourse surrounding organ donation is characterized by medical interpretations, which lay claim to validity in hegemonic style. Thus in the first instance the ‘truth’ is brokered from statements.<sup>3</sup> This naturally includes the statement that the level of information

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<sup>2</sup> Whether Ms. Fischer actually is a blood donor and a registered bone marrow donor is beside the point, as the focus here is on the moral and emotional position to such procedures, before any action is taken.

<sup>3</sup> The relative success (groups, institutionalization) of the critique of the brain death concept also has a bearing here. With regard to the acceptance of brain death as a person’s decease, arguments can be formulated on the level of theoretical (medical) ‘truth.’

is a crucial factor in the decision to become an organ donor (indeed, taken on its own, the way the attitude to organ donation is framed as a decision makes this clear). One is prompted to obtain information in order to be able to make a decision; however, there is no support for normative questions. Thus Ms. Fischer can only explain her attitude to organ donation as an *information deficit*, in the terminology offered by the discourse. This discourse provides no language that would make it possible to really interrogate one's own ideas about corporeality, violability, and transmortality – in fact, the reverse is true: the decision is put across to us as “completely straightforward” (Hansen et al. under review). Ms. Fischer also questions her own misgivings (validity claim: truthfulness) in terms of whether they are “right” or “mistaken,” thus connecting them to a factual situation; she is looking for (“true”) scientific, i.e. “neutral” and “reified,” information to enable her to decide (“correctly”) against donating.<sup>4</sup> This contradiction – reference being made only to the search for further (true) information as a means to answer normative questions – is expressed in “muddled thoughts,” as Ms. Fischer puts it.

The level of normative ‘rightness’ is also not discussed, but merely posited, in the public discourse, since organ donation is assumed in principle to be a morally correct and pro-caring stance. This normative rightness is accepted as a given by Ms. Fischer so that her conflict is presented as a conflict between the validity claim of the rightness of “saving lives” by donating and the feeling of unbearable disregard and “disrespect” (Honneth 1996) of the personal integrity and dignity of the individual person (Joas 2013; Stoecker 2003). Since this conflict cannot be resolved, because the moral imperative of “saving lives” cannot be weighed against the dignity of the individual person, Ms. Fischer experiences constant feelings of shame and guilt, her “bad conscience.” Here she fails to acknowledge that her self-caring attitude and resonance towards her own person is justified (cf. Rosa 2016).

There are good reasons (human dignity) for her unease about organ donation, which she repeatedly describes – both in the passage quoted and throughout the interview – with the expression “creepy”; however, this correlation is difficult to articulate in everyday life.<sup>5</sup> She expresses a desire for body integrity

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<sup>4</sup> In our everyday discourse ‘anxiety’ would be a good place of refuge, because an irreducible validity is ascribed to our own experience, against which it is seemingly impossible to formulate arguments. It cannot, however, become a generally valid argument in a discourse, because as personal experience it is difficult to generalize and as a result no great validity is attached to it in the discourse (Boltanski and Thévenot 2006). In the discourse repeated explication is also given of the fact that – despite it being morally correct to donate one's organs – there may well be individual reasons for not donating; but since these are ‘individual’ and thus cannot be generalized per se, they cannot be used as potent arguments in the discourse.

<sup>5</sup> A rare example, and thus an exception in the material, is a nurse who has worked for years with brain-dead patients and concluded her address at the 2015 DSO congress with the

even after death and therefore makes a reference to the vindicatory character of human rights and dignity – without being able to name this explicitly. It is impossible to find a way to enter into discourse for this idea: at the latest since the two major Christian churches came out in support of organ donation and declared that it was not in conflict with the resurrection of the body, it has been difficult to formulate reasons against organ donation from the point of view of bodily integrity. So this position does not have the same status as the ‘rightness’ argument of saving lives. Bodily integrity is relegated to the status of an ethical motivation. If ideas of rightness are violated, it is usually quite easy to criticize them normatively, since it is possible to relate to and rely on a measure that is broadly shared between different subjects. Ethical questions are, so to speak, at the midpoint between judgements of taste, which it makes no sense to debate, and general moral dos and don’ts (cf. Jaeggi 2013). However, this ethical position cannot be recognized: Ms. Fischer actually abandons her normative activity and goes to the limits of her ability to express herself. Her resonance towards herself and critical competence is restricted by the inadequacy of an openly accessible form of semantics.

In the final sentences of the interview extract, the constellation of validity claims is pointedly expressed with “on the one hand,” “on the other,” and “actually”: on the one hand, we have the interpretative power of modern medicine (truth), which equates the death of the human with brain death and brain death with the end of the personality as a site of experience. The result of this has been that “you don’t care” what happens to your own body “because you’re not there anymore.” On the other hand, there are the irreducible feelings (truthfulness) of violation, dehumanization, and degradation that are tied up with the idea of organ donation and can be reconstructed as an ethical (and not as a private or idiosyncratic) motivation. In contrast to the medical interpretation, the possible future treatment of one’s own dead body is experienced as a constituent part of the integrity of the individual person. At the same time there is a fundamentally positive attitude to organ donation as morally correct behavior (normative rightness), which honors those who comply with it as part of a community of values. That this constellation – the simultaneous validation of irreconcilable claims – is experienced as strained and contradictory can be seen not least in the little laugh that accompanied the interviewee’s “but for all that” at the end of this section of the interview.

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words: “I refer to article 1 of the German Basic Law when I say that the dignity of the human being is inviolable, even beyond the grave” (own notes).

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## 7. Conclusions

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Even if the value system on which their negative response is based cannot always be named by the actors or formulated as an argument, the skeptical attitude towards the practice of organ donation reflects the ethical ideas of a comprehensible conduct of life; the ‘unease’ expresses values relating to the inviolability of the person (Joas 2013). However, such ethical pluralities surrounding concepts of the body and notions of death do not find acceptance in the organ donation discourse.

The attitude towards organ donation is framed as a decision that should be taken by each individual. A negative response is thus viewed as the product of ‘private’ or ‘individual’ arguments. Individual particularities or sensitivities, however, cannot be formulated in a discourse as a generally valid argument and can therefore have no recourse to any recognized “system of justification,” as the recognition of an argument increases with the level of generalizability (cf. Boltanski and Thévenot 2006; Boltanski 2010). The acceptance of the negative response to organ donation as the consequence of a generalizable ethical value (human dignity and bodily integrity, even of the deceased) would enable this to become a possible position, one that is recognized in the discourse.

Ms. Fischer attempts to articulate the idea that the violation of an individual’s dead body and thus their identity and personhood constitutes a violation of human dignity, as personhood and human dignity are inextricably intertwined (Joas 2013). This might explain why the proponents of this position experience the mere imperative to take a decision on organ donation as an infringement, since values like human dignity are not up for negotiation or a question of decision. This kind of ‘no’ can be described as a “judgment of the body” (Solomon 2009) – it is affectively anchored, pre-propositional, and difficult to articulate. It manifests an assessment: one feels bodily repelled, has a feeling of uneasiness, and uses indeterminate words like “creepy.” Affects can signal values and their violation just as much as the semantics of justification (Thévenot 2011, 549). Affectively anchored values can thus be seen as pre-semantic forms of critique that must not be overlooked (something which is underestimated by Habermas in his optimistic view of our ability to verbalize explicit arguments).

Ms. Fischer feels shame since she cannot satisfy the standards of a worthy person who wants to save others’ lives. Shame is a social emotion per se; it is based on one’s perception of oneself from the perspective of others (Scheff 1997). It originates from an evaluative assumption of roles and perspectives and thus represents a sense of value and a moral emotion (cf. Wollheim 2001). If the evaluation of our own self turns out to be negative from the assumed perspective of others, this typically leads to a feeling of shame, causing us to



experience ourselves as worthless, contemptible, or wretched. The background to this feeling of shame is a value quality with which the person should actually comply in accordance with his or her own self-image but which he or she is unable to do. In the case of organ donation, the value of saving a life, which one actually aspires to, leads to feelings of shame based on a lack of readiness to donate one's organs, without – from the point of view of the person in question – being able to give sufficient reasons for this reluctance.

Thus in the case of Ms. Fischer and other interviewees, we observe that they move along a continuum of critique (cf. Potthast 2011). For many, the brain death criterion thus represents a critical starting point that can, to some extent, find resonance in the medical system. By contrast, the bodily integrity position is in the liminal area of verbalization. Historically speaking, this must also have been the fate of the initial critique of racism or feminism. These critiques started with sensitivity, individual experiences, and affectivity before they managed to overcome their inarticulacy and create a language of argumentation (cf. Terkessidis 2015, 283 ff.). Here it is necessary to be able to translate an individual into a universal position. It is important to overcome individual differences and particularities by way of identifying forms of equivalence and comparability (Boltanski 2010, 69). The case of organ donation also makes it clear that sociology should take an interest in the affective and physical bases of ethical value systems and critiques. A critique is never simply a verbally elaborated criticism, never just based on distance and reification, but is rooted in experiences that must be articulated and translated from the subjective into the collective. A sociology of critique (Boltanski) should take notice of these processes since they often substitute or accompany semantic forms of critique.

This process of translation is obstructed by institutionalized knowledge production, which specifies an inside and an outside: anyone who wants to speak the 'truth' must bow to the control principles of a legitimate discourse, satisfy certain requirements, and be qualified to engage in the discourse (Foucault 1970). However, when two differentiated justification discourses come into conflict, we can see that the one exerts pressure on the other, and the latter may be discredited. A sociology of critique must, as Thévenot (2011) rightly argues, also make an unformulated critique visible: "It helps to situate public critique within a range of reactions to the feeling of oppression, from mute humiliation to outbursts of violence, from words of anger to argued statements" (ibid., 62).

Following Boltanski (Boltanski 2010, 155 ff.), it can also be assumed that people like Ms. Fischer see themselves as subjected to an existential examination: faced with the question "Organ donation – yes or no?", it is not a matter of making a lapidary decision – Ms. Fischer is affected, i.e. upset, experiences shame, sees her position as scarcely communicable and is disqualified in her feelings. In essence, she rebels against the testing of the value of her person without being able to directly challenge the examination (the exhortation to be

willing to donate her organs) or to eliminate this examination. It would now depend on translating these feelings (or: critique *in statu nascendi*) into an explicit language of critique, which then would enable social change. And sociology could certainly take an active part in such processes and help to formulate a critique which may contribute to a change of discourse.

In *Knowledge and Human Interests* Habermas formulated a program that is still of great interest to us today (Habermas 1972). He discusses the notion of critique with regards to the attitude psychotherapists take towards their clients and analysands. According to Habermas, one of the tasks of therapy is to put the people involved in a position to take part in discourses by virtue of the fact that it helps the analysands to overcome their own delusions about themselves. The critique aims at a practical reorganization of the client's self-image, whereby the latter has the last word in deciding what interpretation is applicable. Sociology would also be well suited to the task of critique – firstly to identify the positions that are systematically excluded from the discourse and secondly to put the parties involved in a position where they are able to obtain clarity about the reasons for their reluctance – in the case of organ donation: so that they can have faith in the integrity of their judgement and introduce this into the discourse. This process of reconstruction depends on establishing a dialogue with the people affected. A second-order reflection of this kind thus aims at symmetrical participation (Celikates 2009), such that a sociology of critique and critical theory should both no longer only speak *about* and *for* the actors but also constitutively depend on a dialogue *with* them.

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