

WORKSHOP

The Importance of Being Dead - The Dead Donor Rule and the Ethics of Transplantation Medicine

Convenors:

Bettina Schöne-Seifert (Münster) and Ralf Stoecker (Bielefeld)

September 12 to 14, 2013

IN COOPERATION WITH:



Thursday - September 12

12:00 - 14:00 - Lunch -

14:00 - 14:15 Welcome Address by Britta Padberg, Executive Secretary of the ZiF, and the Convenors

14:15 - 15:00 **Nikolaus J. Knoepffler (Jena):**
I Am Dead When I Am Dead

I am dead when I am dead sounds like a cheap truism, but it means something different: If my "I" never can be realized, if my consciousness will never function, then I am dead. In my talk I will present some arguments for this thesis.

15:00 - 15:30 - Coffee Break -

15:30 - 16:15 **Klaus Steigleder (Bochum):**
Death As the End of an Embodied Being

Death is the end of an embodied (leibhaft existierendes) being or of the embodied existence of a being. There is a fundamental difference between an embodied organism and a mere organism as a functioning whole.

16:15 - 17:00

Claudia Wieseemann (Göttingen):
What Is an Organism As a Whole?

The White Paper by the President's Council on Bioethics "Controversies in the Determination of Death" from 2008 defends the thesis that a person is dead when brain death has occurred. The paper argues that in brain death, the organism as a whole is no longer present. In my paper, I examine the notion 'organism as a whole'. What constitutes the organism as a whole from a physiological point of view? Is there an organizing principle of the organism as a whole (OPO)? I will discuss three candidates for OPO: the nervous system, an 'inner drive', and the apparatus of intensive care medicine.

17:00 - 17:30

- Coffee Break -

17:30 - 18:15

Alan Shewmon (Los Angeles, USA):
Proposed Framework for a Philosophy of Integration

Although the traditional mainstream rationale for equating brain death with death has been the loss of bodily integrative unity, the concept of biological "integration" has never been systematically developed and remains vague. A tentative framework for a philosophy of integration is proposed, with a fundamental distinction between "level" and "type" of integration as well as a subcategorization of key types. As a separate matter, detailed clinical data will be available for informal presentation and discussion regarding four extraordinary cases of chronic brain death.

18:15 - 20:00

- Dinner at ZiF -

20:00

James F. Childress (Charlottesville, USA):
Difficulties of Determining Death: What Should We Do About the "Dead Donor Rule"?

This lecture, which is aimed at a wider public, provides a critical overview of the difficulties of determining death in the context of organ procurement. Major challenges arise regardless of whether the determination of death is made according to neurological standards or circulatory standards. Critics charge that organ procurement practices under either set of standards often violate the "dead donor rule." In focusing on the ethical implications of current practices and proposed alternatives, this presentation considers several important questions. For example, if we retain the "dead donor rule," what changes must we make in the process of informed consent for organ donation? Or, if we abandon the "dead donor rule," how will we be able to sustain organ transplantation, which saves many lives?

- Champagne Reception -

Friday - September 13

09:00 - 09:45	<p>Sabine Müller (Berlin): The Importance of Veritable Information About Brain Death</p> <p>From a mere biological point of view, a human being diagnosed as brain-dead is not classified as dead if due to artificial ventilation the organism's main integrative functions are maintained. But for an ethical decision about how to deal with presumably brain-dead human beings, issues beyond the biological determination of death have to be considered, particularly their quality of life, how to protect their autonomous decisions with regard to their dying process, and the society's duty to protect its most vulnerable members. These issues should be discussed frankly not only by medical and ethical experts, but also with the general society, since people need veritable information in order to decide about their ends of life, particularly about organ donation.</p>
09:45 - 10:30	<p>Franklin G. Miller (Bethesda, USA): Crisis in the Ethics of Vital Organ Donation: Where Do We Go from Here?</p>
10:30 - 11:00	- Coffee Break -
11:00 - 11:45	<p>Eckhard Nagel (Bayreuth, Essen): Dead Donor Rule as Universal Requirement for (Post-Mortem) Organ Removal</p>
11:45 - 12:30	<p>Jürgen in der Schmitt (Düsseldorf): Why Organ Transplantation is Well Advised to Abandon the Concept of Brain Death</p> <p>The notion of brain death as a criterion for death has been seriously flawed from the beginning, and needs to be abandoned sooner rather than later, together with the dead donor rule. Full transparency and disclosure of what factually happens when organs are retrieved, rather than euphemistic labels, are of paramount importance for informed decisions to become a potential donor, and should be on our scientific and political agenda. The German organ transplantation community, as in other countries as well, has clutched desperately at the dead donor rule and thus at abstruse constructions intended to stabilize the brain death concept, but increasingly at risk to render its proponents noncredible. Maybe it is time to understand that trust, not euphemistic labelling, is the fundament for any long-term perspective of organ transplantation in our society. Organ transplantation will still be ethically and legally feasible once the dead donor rule has been abandoned. On the other hand, uncorrectably maintaining the flawed defense of brain death as a criterion of death jeopardizes the long-term acceptability of organ transplantation altogether.</p>
12:30 - 14:15	- Lunch -
14:15 - 15:00	<p>Tanja Krones (Zürich, SUI): DCD and Determination of Brain Death in Switzerland</p>
15:00 - 15:45	<p>David Rodríguez-Arias (Madrid, ESP): The Unnoticed Problem of the Duality Between Neurological and Circulatory Death</p> <p>International laws accept a "bifurcated criterion" for declaring death: Irreversible loss of circulatory function and irreversible loss of brain function are considered sufficient in that there is no legal requirement for both criteria to be simultaneously fulfilled. It is frequently assumed that irreversible loss of brain function is the 'gold standard' for the determination of death. Many authors accept donation after circulatory death (DCD) because they believe that loss of circulatory function is an adequate surrogate marker for total brain failure. In DCD, organ donors are considered dead while there is no direct evidence that they have a total and irreversible brain failure. Brain and circulatory-based criteria for determining death are not the same diagnosis. While in most settings this is un consequential, it becomes troublesome in the context of organ donation. The objective of this presentation is to discuss whether or not this is problematic in general, and for health professionals involved in organ donation in particular.</p>

15:45 - 16:15	- Coffee Break -
16:15 - 17:00	<p>Bettina Schöne-Seifert (Münster): Against Confounding BD and DCD Debates</p> <p>Some critics of the brain-death-as-THE-death conception tend to support their position by adducing arguments from the DCD debate. In both realms, they hold, one finds converging arguments to abandon the dead-donor rule (DDR). In this statement I probe an argument against confounding both debates. I suggest accepting brain death as full-fledged mental death and to separately debate conditions of ethically legitimate DCDs.</p>
17:00 - 17:45	<p>Don Marquis (Lawrence, USA): What's Wrong with So-Called "Cadaver" Organ Donations and How to Fix It</p> <p>I shall defend three theses:</p> <ol style="list-style-type: none"> 1. The merely brain dead are not dead. 2. Those pronounced dead in accordance with a controlled DCDD protocol are not known to be dead. 3. There are many accounts of why it is wrong to kill you and me that do not entail the dead donor rule. All these accounts are superior to accounts that do entail the dead donor rule. Therefore, it is not wrong to kill organ donors in categories #1 and #2 if consent is obtained.
17:45 - 18:15	- Coffee Break -
18:15 - 19:00	<p>Dieter Birnbacher (Düsseldorf): Reservations About Organ Donation and the Fear of Death</p> <p>The starting-point of my contribution is the diagnosis that one of the factors responsible for the widespread unwillingness to donate organs post mortem is to be found in various fears and uncertainties surrounding brain death and organ extraction after brain death. My proposal is to ask how far these fears can be given a rational backing. A preliminary answer is given in two steps: first, by probing into the logical relations between the concepts of brain death and death and the logical status of their identification; second, by introducing a distinction between two kinds of fear, experiential and propositional, and arguing that both are involved in fear of organ extraction after brain-death but differ greatly in the extent to which they can be given a rational justification.</p>
19:00 - 19:45	<p>Ralf Stoecker (Bielefeld): The Brain Death Problem - Which Are the Right Questions to Ask?</p> <p>The brain death problem is the problem of determining whether at all and under which circumstances it is morally permissible to explant solid organs from brain dead people. When the problem emerged for the first time by the end of the 1960s, it seemed to be obvious to frame the problem as the question whether brain-dead patients are dead or not. And still, to date, the bulk of the debate on the brain death problem is concerned with this question, in biomedical ethics but even more in public discourse. Yet, the arguments have notoriously led to inconclusive results. Perhaps, asking whether brain-dead patients are really dead wasn't the right kind of question to be asked in order to solve the brain death problem. But then, which is the right question?</p>
20:00	Dinner at a restaurant downtown

Saturday - September 14

09:00 - 09:45 **Hartmut Schmidt (Münster):** tba

09:45 - 10:30 **Thomas Gutmann (Münster):**
Playing Dumb (The Dead Donor Rule)

The law needs a clear-cut criterion of death. The whole-brain death criterion is a highly plausible one (if you don't accept that premise, my argument will need a little addendum). The American mainstream's double standard concept, which replaces irreversibility (cannot return) with a normative notion of "permanent" cessation (will not return) of circulation and respiration, is not. It misses the basic meaning of "death" and destroys its unified concept. You cannot have donation after circulatory death and sustain the dead donor rule at the same time without playing dumb. It can be ethically and legally appropriate to procure organs when permanent cessation of circulation and respiration has occurred but before irreversible cessation (or whole-brain death) has occurred, but the justification of such a policy requires to give up the dead donor rule, which does not carry any normative weight. In the end, it is not that important to be dead in order to be an organ donor, which is an end-of-life-decision anyway. Giving up the dead donor rule, however, will hardly be compatible with opting-out solutions for organ procurement.

10:30 - 11:00 - Coffee Break -

11:00 - 11:45 **Karen G. Gervais (St. Paul, USA):**
Redefining Death and Expanding Living Donation

A recommendation to (i) redefine death to achieve coherence and consistency among concept/criteria for determining death and the DDR, and (ii) expand living donation for "DCD-type" cases under strict guidelines for fully informed consent and prevention of donor harm.

I shall rely on my arguments in *Redefining Death* (Yale University Press, 1986) that we *implicitly and acceptably* redefined death as the irreversible loss of the capacity for consciousness (and not for the integrated functioning of the organism as a whole) when we adopted the brain death criterion. A pregnant brain dead woman giving birth demonstrates that integrated organismic functioning is surely present in a brain dead individual, yet brain death is rightly considered human death because that which is essentially significant to human life – the capacity for consciousness – is irreversibly lost. Using technology as we now are, we must make normative choices, sometimes redefining a core societal construct like our definition of death or qualify an established rule like the DDR, and cease pretending that there is nothing new going on under the sun.

I shall recommend a coherent, consistent policy framework of concept/criteria for determining death, including a conscience clause, supporting multiple donation practices consistent with the DDR, including PVS donation. "DCD-type" cases, however, should be considered *sui generis*, since the irreversible loss of the capacity for consciousness is not assured in either controlled or uncontrolled DCD. I shall argue that cases currently considered ripe for DCD donation should be addressed as an expansion of living donation. Potential donors or their surrogates should be invited, in a value-neutral way uncharacteristic of current OPO methods, to consider living donation (after decisions to withdraw life-sustaining treatment and to refuse CPR), through a process of full disclosure and fully informed consent to the multiple, complex modifications in EOL best practices such donation requires. Only with these changes can the inconsistencies and fictions surrounding donation be corrected, and donors and their survivors be adequately protected from harm. And, we will have ceased supporting practices that commit us to the oxymoron, "This patient is dead, but possibly still conscious."

11:45 - 12:30 **Robert M. Veatch (Washington, D.C., USA):**
Conscientious Choice of a Death Definition

It is now clear that the choice of a definition of death depends on personal beliefs and values. Three major options exist: whole-brain, higher-brain, and somatic definitions. There are many variations for each of these options. No one view commands majority support, let alone consensus. We should address this problem the way we address matters of individual conscience and establish a default definition (probably whole-brain) and then permit individuals through an advance directive choose among a reasonable range of alternatives.

12:30 - Lunch -
