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Advance Refusals of Treatment and Organ Donor Cards: an Ill-Matched Couple?

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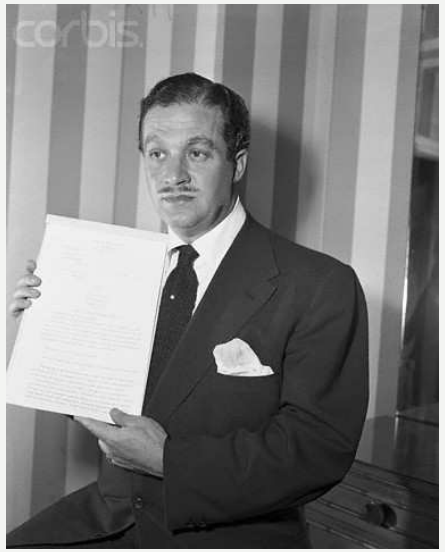
Outline

1. Advance directives & organ donor cards: the societal phenomena
2. Relationship in general
3. Conflicts in specific situations
4. Ethical appraisal

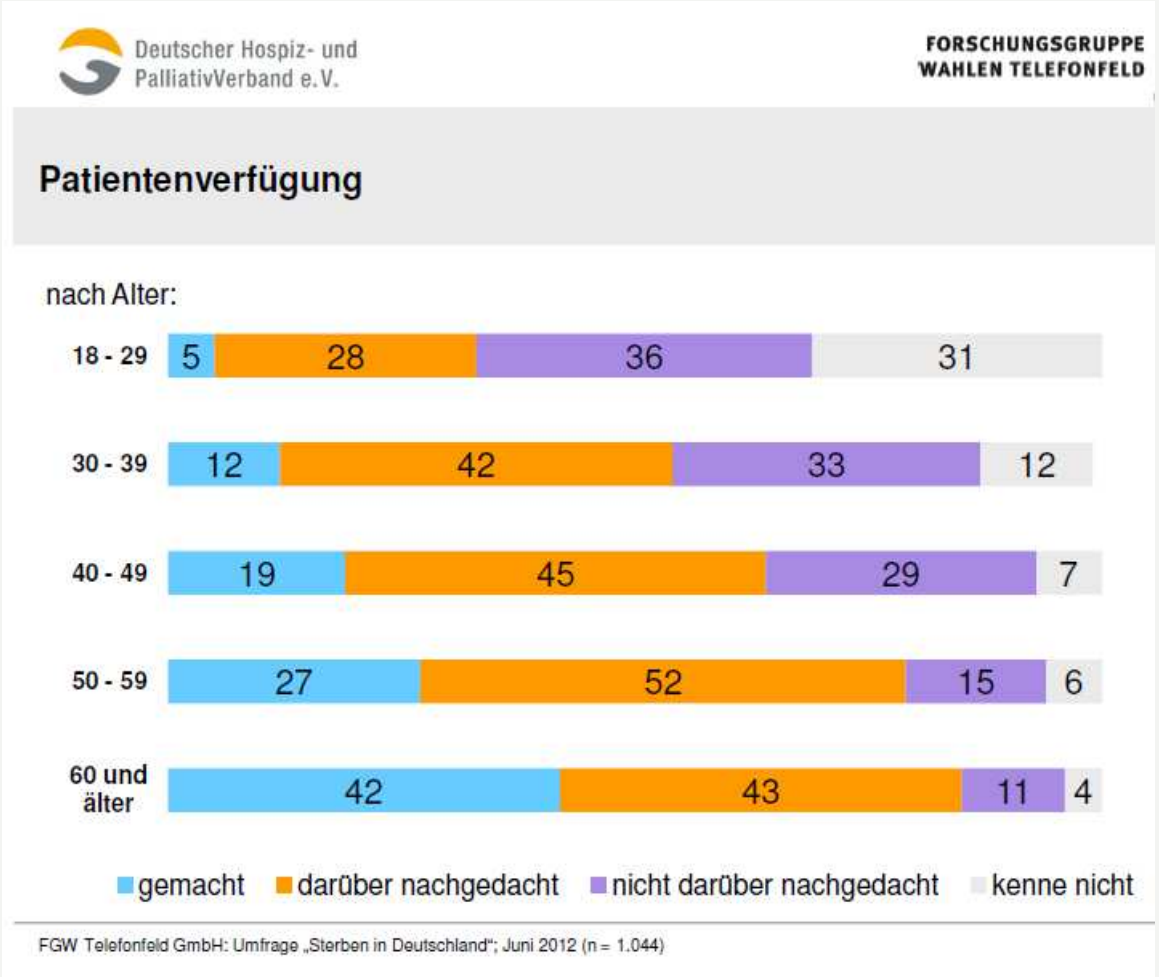
Advance Directives

- Originally part of a *human rights movement* (Kutner 1969)
- Expresses right to refuse life-sustaining treatment at the end of life (*liberty right*)
- Main motive is to ensure a *dignified dying* (self-determined, natural, in a more human than technological context)
- Directives are *legally binding* in Germany (if they are applicable to the situation)



Luis Kutner 1951

Prevalence in Germany



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<u>Umfrage 12/2012:</u>

- >65-year-old: 54% have an AD
- Prevalence higher in privately insured

Post-Mortem Organ Donation

- Originated in the *medical need* for transplant organs since the 1960s
- Donor cards/registries do not express a right, but a *voluntary wish* to help others (arguably a moral duty)
- Main motives are *altruism, solidarity*, and feelings of fairness
- Prevalence of organ donor cards in Germany 20%, declining *(DSO 2013)*

Post-Mortem Organ Donation

Reasons for refraining from brain death assessment in brain injured patients	%
No brain stem areflexia, spontaneous breathing	38 %
Medical preconditions not met	24 %
Irreversible circulatory failure	18 %
Limitation of life-sustaining treatment	**15 %**
Advance directives	**9 %**
Transfer from ICU to other ward	8 %
Organ donation refused by patient/relatives	7 %

Dt Krankenhausinstitut 2012: Inhouse Coordination for Organ Donations

Relationship

- Both advance directives (AD) and organ donor cards (ODC) are forms of end-of-life planning
- Many advance directive forms contain statements about organ donation (but not the other way!)
- End-of-life counselling and advance care planning often includes both forms of medical directives
- Superficially seen they cannot conflict as the AD refers to a *living* person (with a *terminal illness*) and the ODC to a *dead* person (*no* terminal illness)

Conflict

- *But*: ODC have consequences for the last phase of life:
  → Post-mortem organ donation is usually based on **brain death**
  → Brain death can only be diagnosed in the context of **intensive care medicine** (ventilation etc.)
  → Post-mortem organ donation requires intensive care, yet **ADs usually refuse intensive care** during dying

- Organ donors are increasingly older/sicker and people issuing ADs are increasingly younger/healthier
  → **both may apply!**

Summary

Advance Directive

Main intention: Natural dying (outside of ICU, without technological life support)

Organ Donor Card

Main intention: Save the lives of others

Precondition: Brain death, context of ICU and technological life/organ support

1. Ambivalent/conflicting intentions?
2. Insufficient information of citizens?
3. Insufficient documentation of the wish?

Situation 1

The 41-year-old, previously healthy Mr. F. suffers a severe head trauma with an intracranial bleeding. He already shows signs of herniation in the ambulance car. When arriving at the hospital, the physicians suspect brain death. In the patient‘s wallet there is an organ donor card documenting his wish to donate all of his organs after death. On the other hand, the patient‘s wife (who had a lasting power of attorney) presents an advance directive that refuses life-sustaining treatment for the case of severe cerebral injury with poor prognosis. – How should the team proceed?

Situation 2

The 39-year-old, previously healthy Mrs. W. suffers an acute intracerebral hematoma of unknown origin. The bleeding is so large and massive that there are signs of elevated intracranial pressure. Mrs. W. is deeply comatose, and the doctors estimate that brain death may occur during the next hours to days. Mrs. W. has registered as a potential organ donor in a national registry. At the same time, she has an advance directive clearly refusing life-sustaining treatment for such a severe brain injury as this. Her husband confirms this preference of hers. I particular, she never wanted to fall into a persistent vegetative state. – How should the team proceed?

Suspected brain death

- Suspicion of brain death requires diagnostic assessment → may take some hours (up to 12 hours)
- Intensive care measures (e.g. ventilation) needed until and during the diagnostic assessment
- **Ethically appropriate** because diagnosis is needed to clarify the patient's status (alive or dead?)

  (1) If diagnosed to be brain dead, the AD does not apply

  (2) If diagnosed NOT brain dead, it is the same situation as in expected brain death:

Expected brain death

- Intensive care measures needed to sustain life until brain death *possibly* evolves (organ-centered treatment, “elective ventilation”)
- Legally, only the AD is applicable, not the ODC
- No benefit for others justifies treatment against patient autonomy (instrumentalization)
- Life support **only ethically justifiable** if the patient

  (1) explicitly gave priority to organ donation over AD or

  (2) documented his wish for organ donation, was well informed about the conflict with the AD and presumably prioritizes organ donation


Thank you for
the attention!
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