LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

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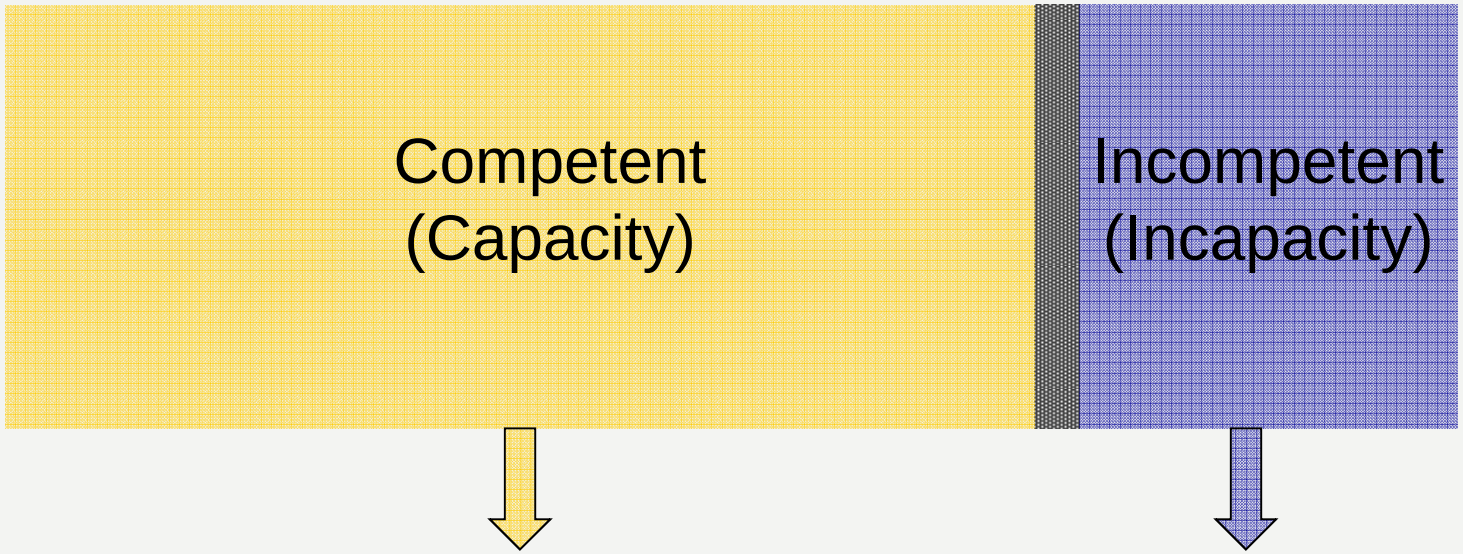
Deciding for incompetent patients: whose best interests are we talking about?

Ralf J. Jox
Institute of Ethics, History and Theory of Medicine
University of Munich, Germany

Outline

1. Decision-making capacity
2. Surrogate decision makers
3. Criteria for decision making
4. Incompetent patients' behavior
5. Interests of patient and others

Societal Divide



Right to self-determination

Infringements on right to self-determination permissible

Prevalence

- 40% of acutely hospitalized patients

Raymont V et al, Lancet 2004

- 70% of older adults for whom treatment decisions are required

Silveira MJ et al, N Engl J Med 2010

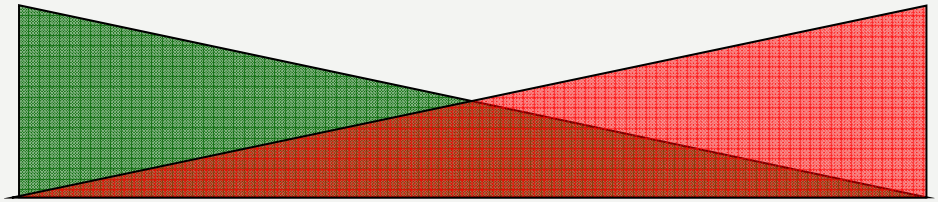
- 95% of critically ill patients

Smedira NG et al, N Engl J Med 1990

Prendergast TJ et al, Am J Respir Crit Care Med 1998

Ethical Relevance

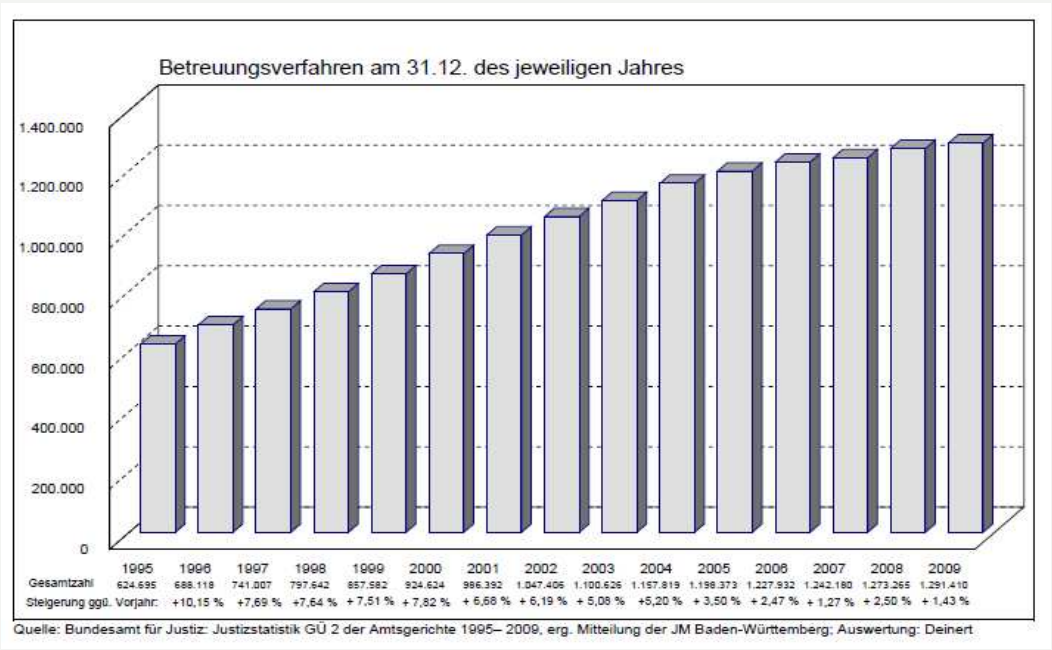
Capacity to decide for yourself



Existential weight of the decisions

t ⟶ *Course of life-limiting diseases*

Rise of guardianship cases per year in Germany



Guardianship cases 1995-2009 (official statistics)

Ethico-legal Standard

Elements of capacity:

- Understand and retain information
- Deliberate benefit and harm
- Make a stable decision
- Communicate the decision

Determined via communication

Rules of capacity determination:

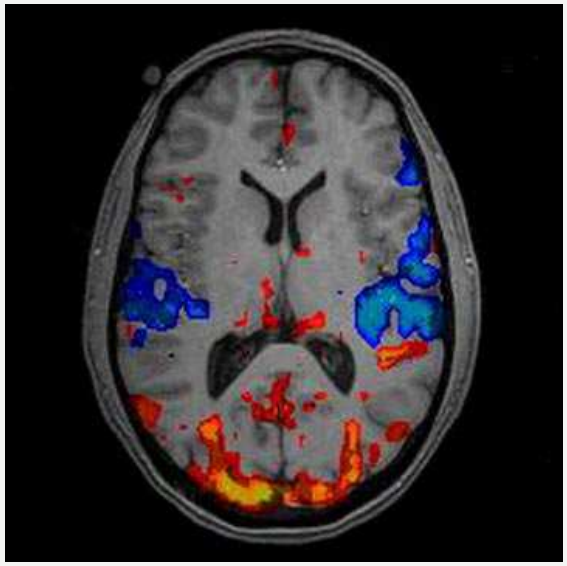
- Individual & just-in-time determination
- Based on process, not result of decision making
- Requirements depend on complexity and gravity of decision

Open Questions

- Is decisional capacity purely cognitive? Emotions play key role in decisions!

  Damasio A 2003, Northoff G, J Med Ethics 2006

- Can we determine capacity by measuring brain function?

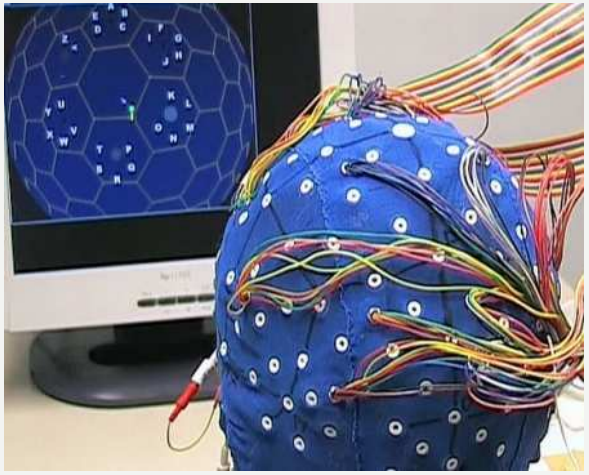


fMRI

- Can we determine capacity by brain-computer-interface?

  → *for locked-in syndrome*

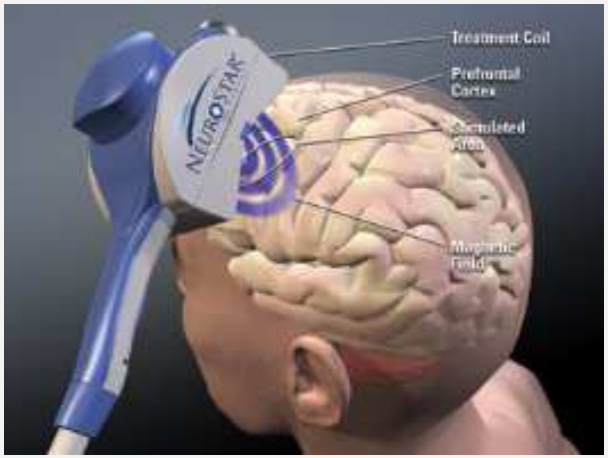
  → *for minimally conscious syndrome*



Brain-Computer-Interface

Open Questions

- How should we deal with fluctuating capacity?
- Can we treat dysfunctional decision making, thus allowing otherwise incompetent patients to give informed consent?
- Can we enhance decisional capacity?



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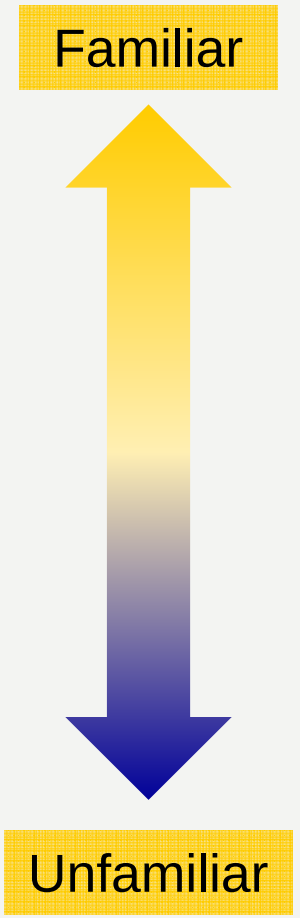
Candidates

- Family proxies
- Relatives via durable powers of attorney
- Legal guardian (court-appointed)
- Physician as quasi-proxy
- Court



Who should speak for the patient?

Familiar surrogates	Unfamiliar surrogates
Knowledge of patient (common narrative, whole person)	Legal and medical knowledge/training
Existentially affected	Emotionally detached
More time and availability	More experience
Subsidiary solution, less costs	Execution of social control

→ Does it matter? Do they come to different decisions?

Study

RESEARCH ARTICLE

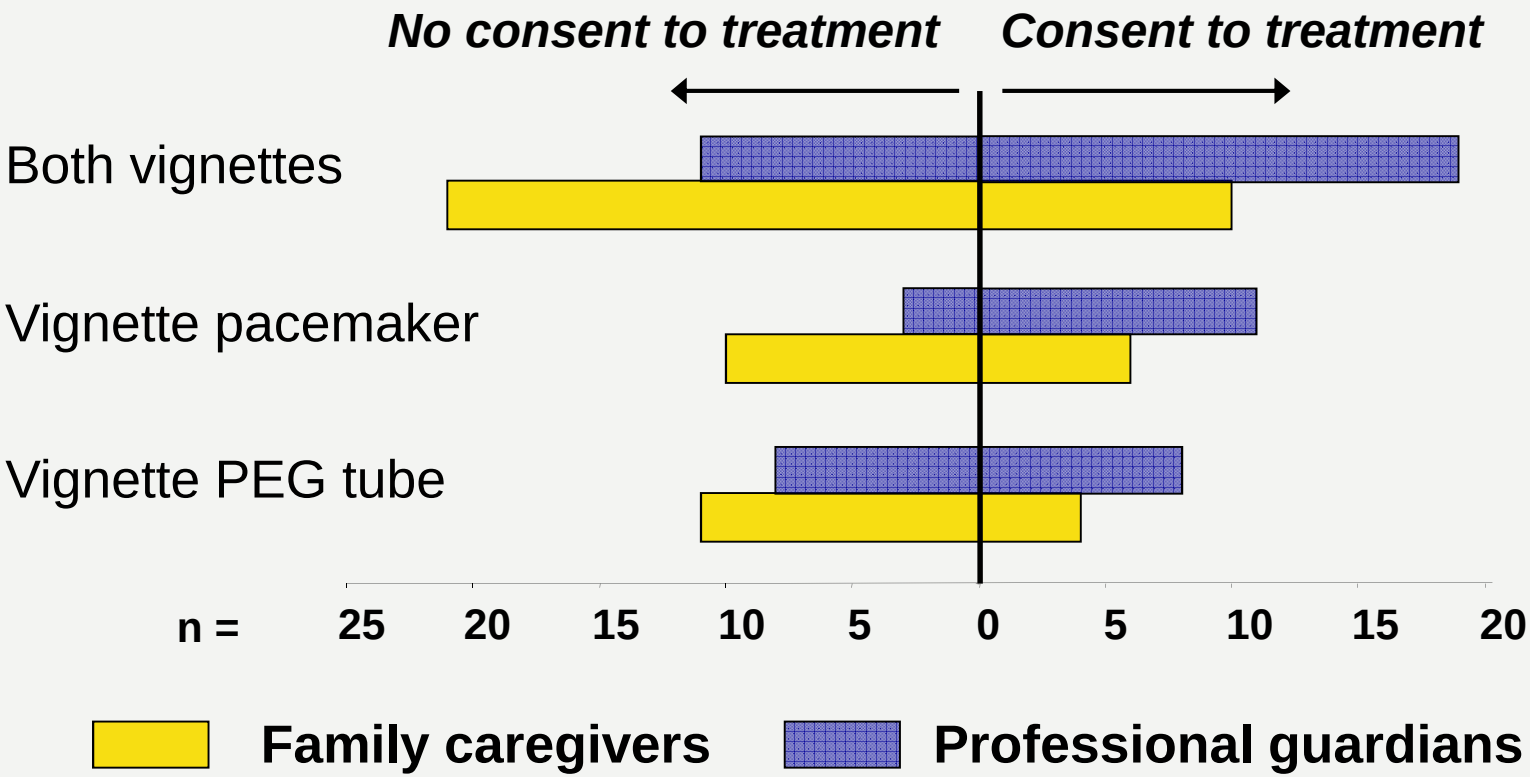
International Journal of Geriatric Psychiatry

Surrogate decision making for patients with end-stage dementia

Ralf J. Jox[1], Eva Denke[2], Johannes Hamann[3], Rosmarie Mendel[3], Hans Förstl[4] and Gian Domenico Borasio[4]

- Social science experimental study
- Family caregivers and professional guardians (deciding for dementia patients), n=32
- 2 case vignettes (end-stage dementia)
- Think aloud method

Results



Jox RJ et al. (2012) Int J Geriatr Psychiatr 27:1045

Results

Professional guardians	Family caregivers
Take time to decide	Decide quickly and intuitively
Try to disregard own values	Consider own values, interests
Focus on patient autonomy	Focus on patient wellbeing
Consult with clinicians	Consult with relatives
Request court decisions	Do not ask the court

⬇ **Professional role**

⬇ **Emotional role**

Jox RJ et al. (2012) Int J Geriatr Psychiatr 27:1045

Conclusions

- The choice of surrogate decision maker critically affects life-and-death decisions
- Surrogate decision making may vary according to emotional attachment
- Yet, legally & ethically, decisions should uniformly be based on the same criteria

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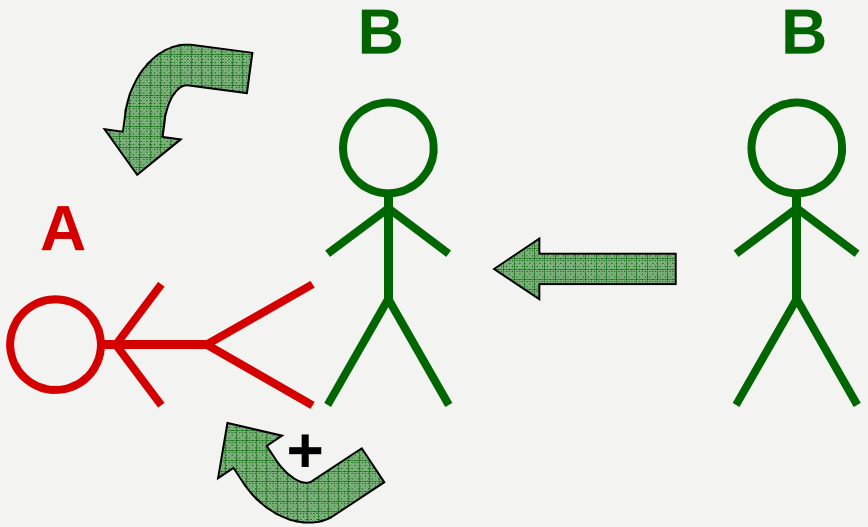
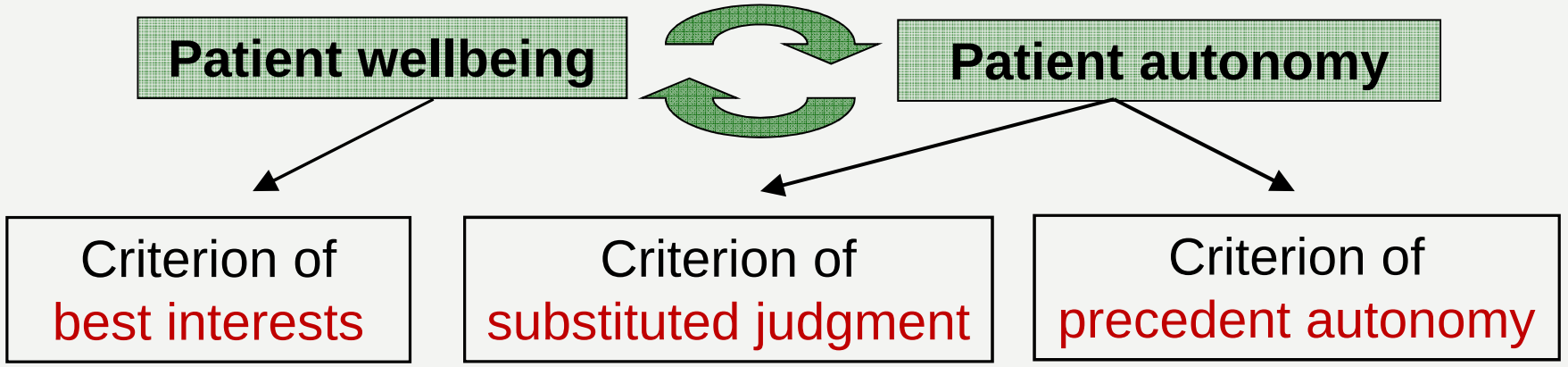
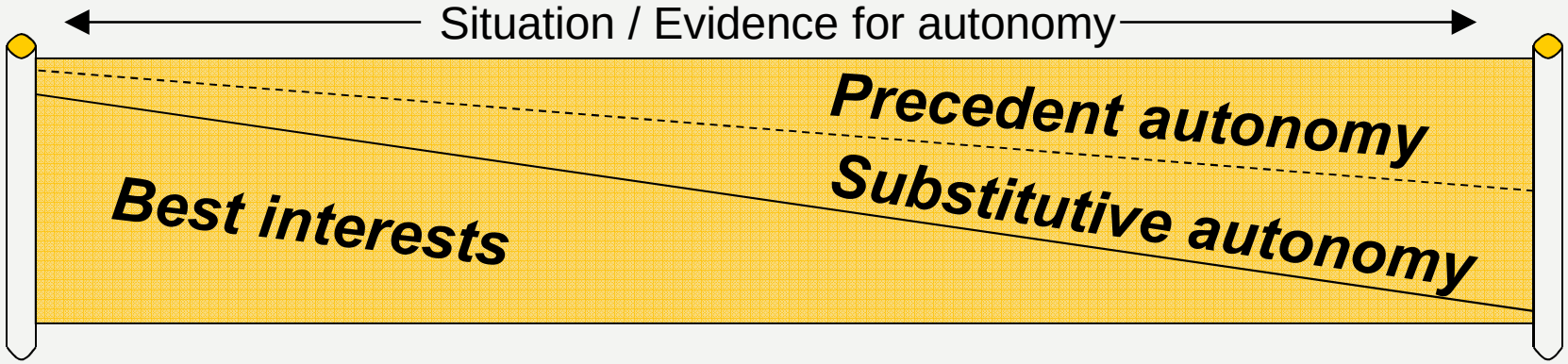
Rationale



Ethical Criteria





Jox RJ, Ethik Med 2004

Challenges

1. Are these criteria currently realized in practice and if not how could this be improved?

2. How should incompetent patients' behavior inform decision making?

3. Are these patient-centered criteria sufficient – Are the interests of others ethically relevant?

Precedent Autonomy

Advance directives – practical problems:

- Barriers for the less well-educated
- Often not available when needed
- Often no informed decisions (questioning autonomy)
- Often not applicable (too vague, too narrow)

Best possible solution:

Structured Advance Care Planning programs

Advance Care Planning

BMJ

RESEARCH

The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,[1] Andrew D Hancock, project officer,[1] Michael C Reade, physician,[2] William Silvester, intensive care physician and director[1]

- Randomized study, n = 309 patients > 80 years
- After 6 months 56 have died: Patient preferences respected in 86% (ACP) vs. 30% (no ACP)
- Relatives (ACP): ↓ distress, anxiety, depression

Substituted Judgment

Practical problems:

- Only 68% accuracy (even by closest relatives)

  Shalowitz et al, Arch Int Med 2006

- Choosing your own surrogate and discussion treatment preferences in advance do not increase accuracy

  Ditto PH et al, Arch Int Med 2001, Shalowitz et al. 2006

- Predicting decisions is problematic due to situational factors

  Brostrom L et al, MHCP 2007, Mendelson D, J Law Med 2007

- Relatives consider own values and interests (psychological biases like projection)

  Vig EK et al, J Am Geriatr Soc 2006, Rid A et al, J Med Philos 2013

Patient Preference Predictor

Idea:

1. Preferences are correlated with personal and health characteristics *(age, gender, ethnicity, marital status, place of residency, income, education, religion, disease, prognosis…)*
2. Collect large data sets via surveys
3. Calculate individually predicted preferences by way of matching patient with data pool

→ **Result:** Accuracy of preference prediction is the same or higher than that of closest relatives

Rid A et al. Hast Cent Rep 2010, Smucker WD et al. Med Dec Mak 2000

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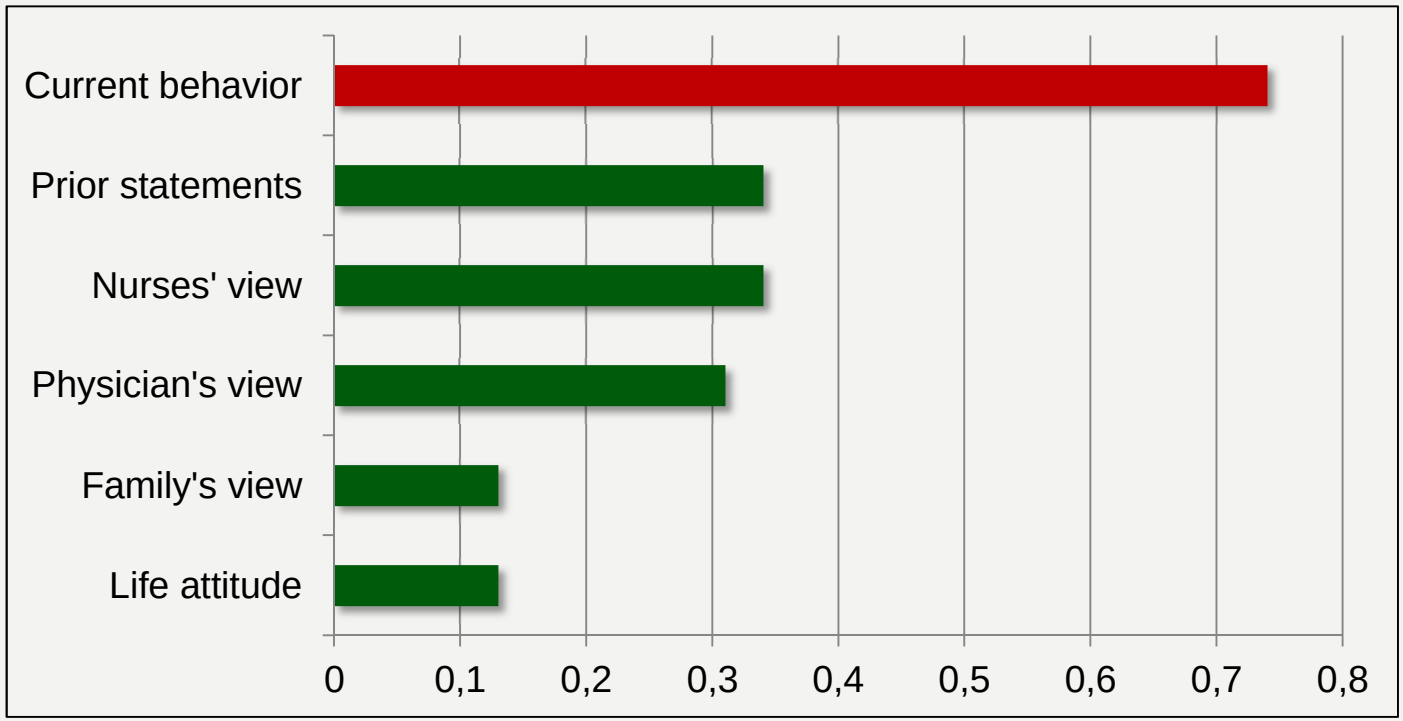
Incompetent patients' behavior

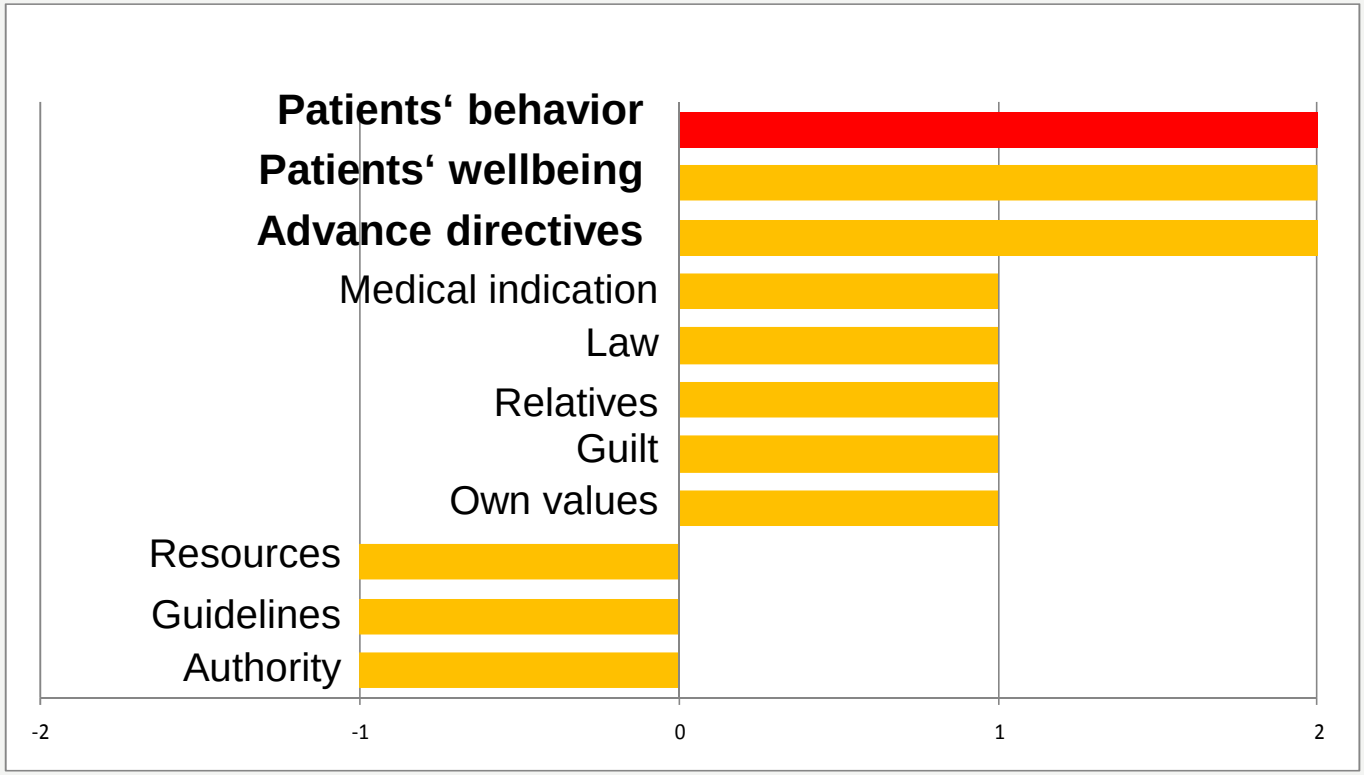
Variables with highest impact on substitute decisions (guardians and relatives):



Jox RJ et al. (2012) Int J Geriatr Psychiatr

Incompetent patients' behavior

Survey among nurses in German dementia care homes:



Not important

Moderately important

Very important

Kuhelmeyer K et al (in preparation)

Common examples

Dementia patients:

- Refusal of nutrition (turning head, closing mouth)
- Physical defence against nurses, pulling PEG tube
- Smiling, laughing, crying, moaning

Kuehlmeyer K et al. (in preparation)

Vegetative patients or neonates:

- Complex reflex movements
- Autonomic reactions (sweating, tachycardia…)
- Survival of critical situation

Study

Interviews with family surrogates of patients in the persistent vegetative state:

- Many surrogates know patient preferences *against* life support, but don't act accordingly
- Justified by (unrealistic) hopes for recovery and their own emotional attachment
- Reflex behavior of PVS patients was interpreted as expressions of a will to live

Kuehlmeyer K et al. J Med Ethics 2012

Study

Case interviews with a pediatric palliative care doctor

Case: Neonate, progressive CNS disorder, septicaemia

That‘s a statement you often hear by parents: „My child has to decide this.“ (…) I think, parents have to develop a sense for the right time, the feeling „Now my child doesn‘t want any more, the vital force is gone (…).” You also often hear: „He still wants to live. He is at home now and he survived that last crisis on intensive care, so he wants to live.“

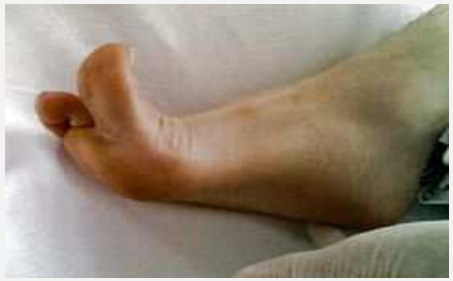
Jox RJ in: Simon/Wiesemann, Springer 2013

Ethical question

How should behaviour of incompetent patients be interpreted and what role should it play in treatment decision making?

Involuntary motor behavior

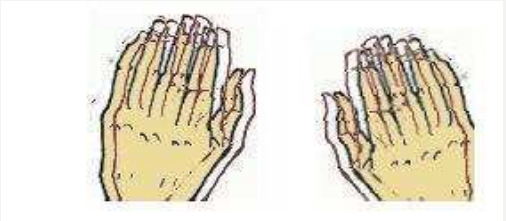
Examples of involuntary motor behaviour:



Plantar reflex

Grasp reflex

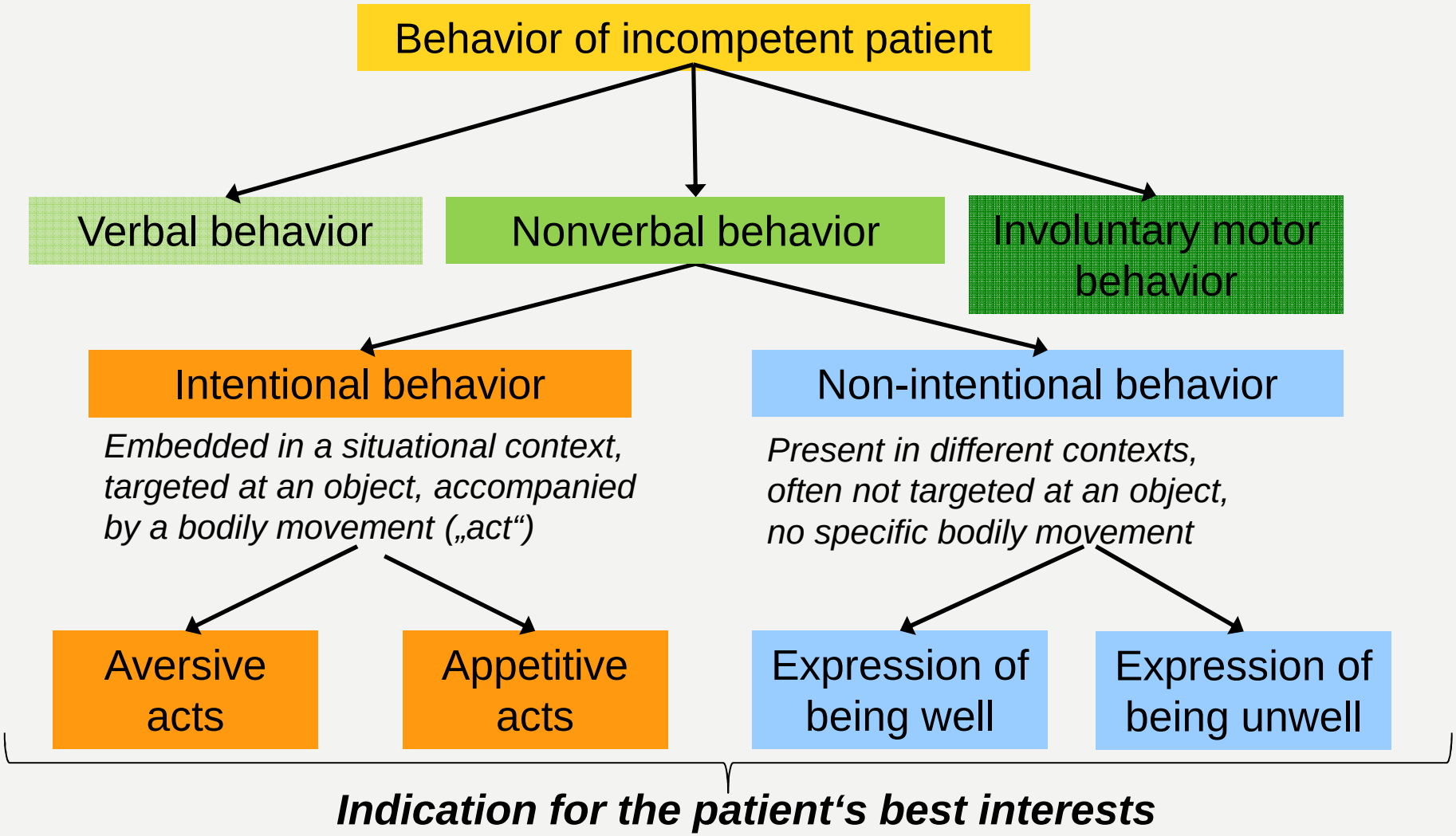
Pathological crying/laughing



Tremor

+ epileptic seizures, dystonia, tics…

Classification



Assessment

Criteria for assessment:

- Situational and non-intentional behavior should not be taken as autonomous decision about treatment
- *Reliability:* Does the behavior occur reliably?
- *Consensus:* Do different caregivers interpret the behavior in the same way?
- *Consistency:* Is the behavior consistent with the person's values and previous expressions?

Assessment

Conflict with advance decisions:

- *No general priority* of previous autonomous expressions or current non-autonomous expressions
- Advance decisions depend on (tacit) assumptions about the future wellbeing, which may not be realized → advance directive not applicable
- People may specify in advance which weight they want to give to their behaviour when incompetent

Conclusion

It seems that the patient's behaviour is often used to "rationalize" moral decisions based on the caregivers' own best interests. – Should their best interests be considered and what if they conflict with the patient's best interests?

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Whose best interests?

Paradigmatic case A

Miriam is a 61-year-old teacher who has been caring for her demented 85-year-old mother for the last seven years. Her mother still seems to enjoy the simple pleasures of life, but she now acquired severe pneumonia and Miriam has to decide whether to consent to intensive care treatment and ventilation. The two always had a loving relationship and the mother always wanted the best for her daughter. Miriam, however, is so exhausted by caring for her mother that she cannot cope with the situation any more (even her marriage is at risk). She therefore wants to let her mother die.

Whose best interests?

Paradigmatic case B

Paul is a 49-year-old part-time taxi driver. His 77-year-old mother Lydia has fallen into a vegetative state due to a brain hemorrhage. In her advance directive, she specified that she does not want to be kept alive in a state of irreversible unconsciousness. She also conferred durable powers of attorney to her only son Paul who now cares for her at home. The doctors are inclined to forego life-sustaining treatment, but Paul wants everything to be done because caring for his mother has become the meaning of his life and he would suffer tremendously by losing her.

Outline

How do you judge these cases?

Is it ethically justifiable to administer or withhold treatment in the interests of the relative?

Whose best interests?

Ethical considerations

- From a utilitarian view the wellbeing of caregivers (even the professionals) might count the same as that of the patient
- Do health care professionals have a special obligation towards the patient (and not on the relatives)…

  - depending on the size of benefit?
  - depending on the health care needs of the patient?
  - depending on a specific contract?

- According to Kant it would be wrong to instrumentalize the patient for the sake of caregivers

Whose best interests?

Ethical considerations

- Would it change the ethical judgement if the patient explicitly – or presumably – prioritizes the best interests of his caregivers over his/her own?
- What if the patient explicitly or presumably prioritizes his/her own best interests?
- Do the obligations towards family caregivers depend upon the closeness of the caregiver to the patient?

Thanks to:

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G.D. Borasio

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E. Racine

Thank you for the attention!

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ralf.jox@med.lmu.de