LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

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# Making Treatment Decisions for Vulnerable Older Persons

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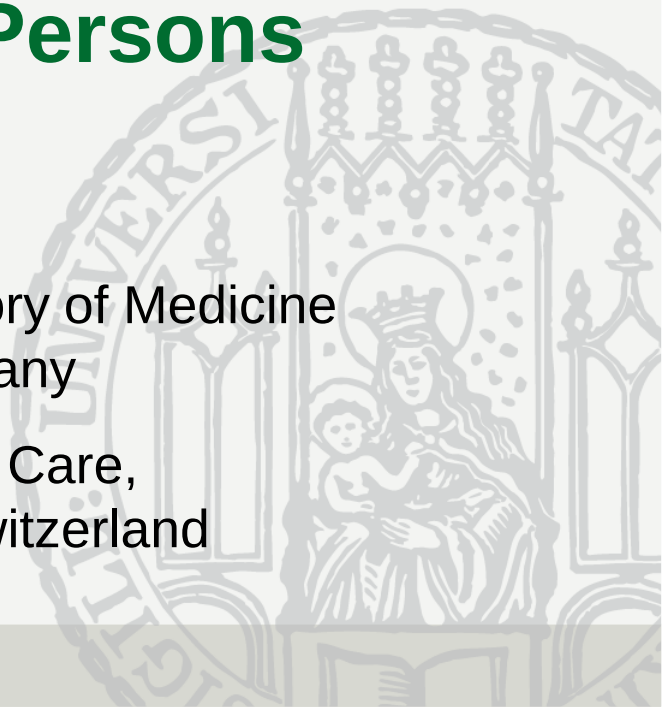

# Outline

1. Why are older persons vulnerable?
2. What about their capacity to decide?
3. Who should decide for them?
4. Which criteria should guide decision making?

# Case

- Mrs. D, 79 years old, former ballet dancer
- Admitted to hospital after found lying in her apartment for several days
- Neighbor reports memory problems for the last two years, disorientation and frequent falls
- Diagnosis: severe dementia syndrome, rigidity
- Hallucinations, dehydration, non-communicative
- Suspected Lewy Body Disease

# Case

- Mrs. D refuses to eat and drink (does not open mouth), shows resistance to any examination or treatment

  ⇒ **Further exams? Enteral nutrition (PEG tube)?**

- No relatives, court-appointed guardian hardly knows patient and defers decisions to the clinicians
- No advance directive present

  ⇒ **Patient's will? Best interests?**

- Mrs. D suddenly dies at night due to suspected pulmonary embolism

# Vulnerability

Vulnerability in medical ethics means a heightened risk that a patient's interests are violated by the actions of others, such as health care professionals.

- Distinguish from vulnerability as *condition humaine* (deviation from the norm)
- Results from certain natural or social disadvantages (age, illness, disability, gender, poverty, migration etc.)
- Distinguish from the medical notion (heightened risk to suffer diseases, complications, injuries, etc.)

# The vulnerable old

- Vulnerability is always an individual characteristic, but certain groups are more at risk than others

**Older persons:**

- Age-related functional impairment (frailty, cognitive changes, senses & communication problems…)
- Often chronic multi-morbidity and associated symptom burden (supra-additive effect of diseases)
- Problems in mastering technology (IT, mobility technology…)
- Social network likely to be less tight (isolation)
- Societal respect in Western countries lower than for the young

# Consequences

**AUTONOMY** as capacity lowered

**AUTONOMY** as a right, other rights and welfare interests unchanged

*Joel Feinberg 1986*

## Risks:

- Insufficient information
- Less interest and care by health care professionals
- Undertreatment and neglect
- Overtreatment and exploitation for nonmedical reasons
- Unjustified involuntary treatment, restraints

# Consequences

**AUTONOMY** as capacity lowered

**AUTONOMY** as a right, other rights and welfare interests unchanged

*Joel Feinberg 1986*

## Obligations on others (special protection):

- Make use of age-specific expertise (geriatrics…)
- Create age-appropriate institutional contexts
- Invest more time and effort into information & decision
- Empower patients (using counseling, support…)
- Use “surrogates” to reinforce patients’ interests
- Support decision-making capacity

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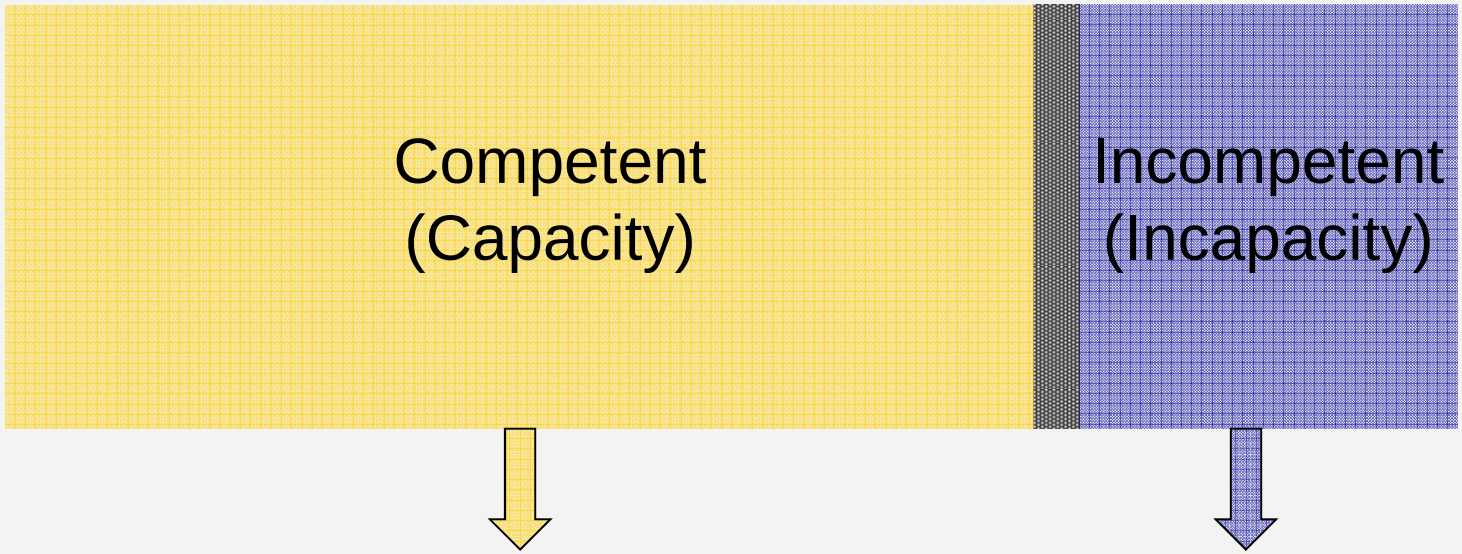
# Societal divide




*Right to self-determination*

*Infringements on right to self-determination permissible*

# Prevalence of incapacity

- 40% of acutely hospitalized patients

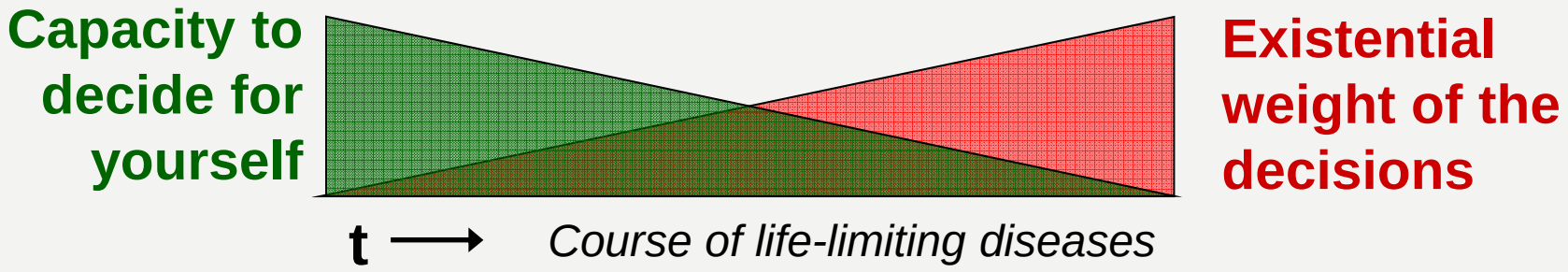
*Raymont V et al, Lancet 2004*

- 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*



# Ethico-legal standard

## Elements of capacity:

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

*Appelbaum PS NEJM 2007*

## Rules of capacity determination:

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

# Critique

- Neglected **emotions/intuitions**: key role in decisions
- **Inherent normativity**: values of both the society and the physician influence capacity determination
- Inherent **societal values**: autonomy, rationality (e.g. refusal of blood transfusion)
- Inherent **personal values**:

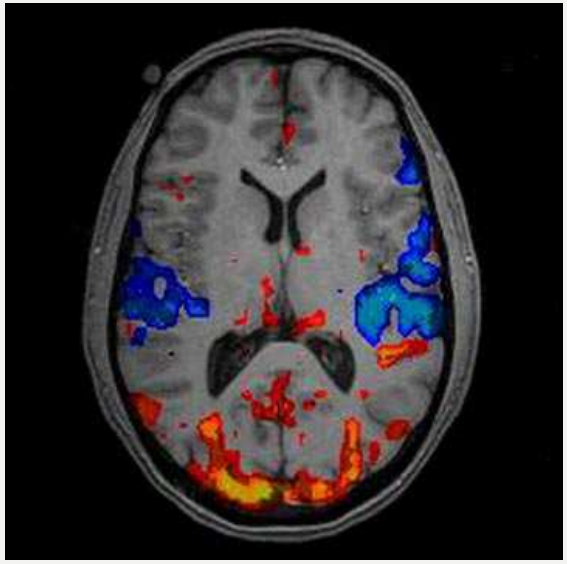
**Hermann H et al. J Med Ethics 2015:**

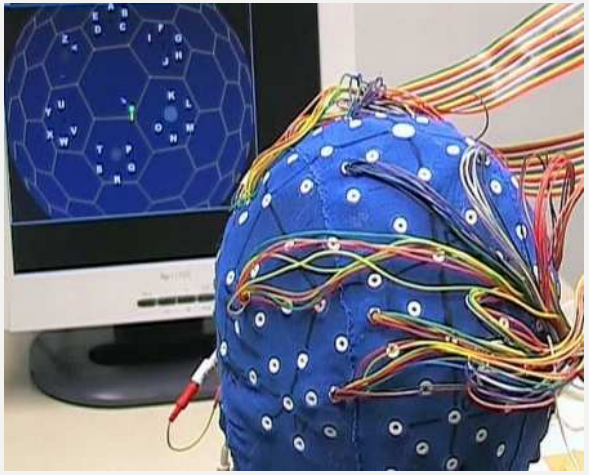
- *Physicians who value achievement and power more likely to require higher standards in high-risk situations*
- *Physicians who value hedonism more likely to apply equal standards irrespective of the risks of treatment*

# Open questions

- How to deal with fluctuating capacity?
- Can biological measurements help in determining capacity? (EEG, fMRI, BCI)
- Can dysfunctional capacity be restored by direct intervention with the brain (drugs, neuro-stimulation…)?
- Can functional capacity be enhanced by the same means?

*Petersen A et al. AJOB Neuroscience 2013*





# Clinical suggestions

- Physicians should be better **trained** in capacity determination
- Physicians should be **aware** of the normativity of capacity determination and the risk of paternalistic misuse
- Cognition-affecting **drugs** may be temporarily reduced for capacity determination
- Language and engagement in capacity determination should be **appropriate** to the patient
- **Narrative techniques** may be used to help the patient understand his situation *(Benaroyo L et el. Health Care Anal 2004)*
- A **team approach** should be used, intending to reach consensus

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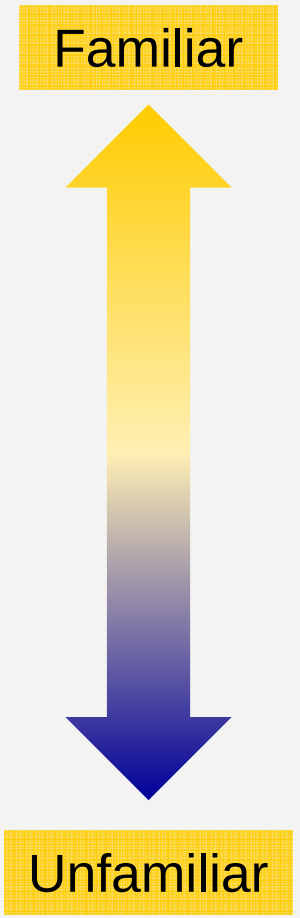
# Candidates

- Relatives via durable powers of attorney
- Automatic family proxies
- 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 |

→ **What is preferable? Does it matter?**

# 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]

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

# Results

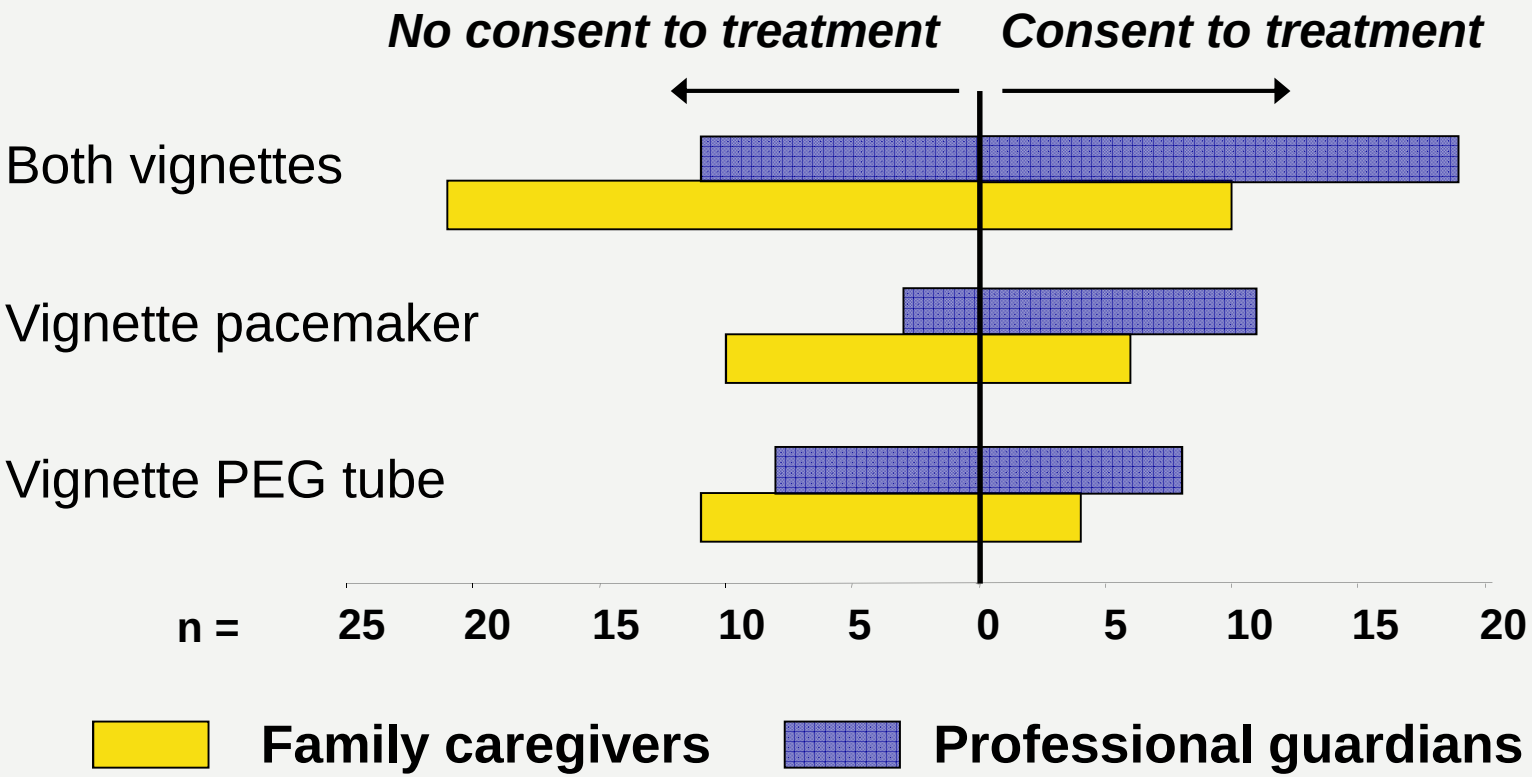
| Professional guardians | Family caregivers |
|---|---|
| Take time to decide | Decide quickly and intuitively |
| Try to disregard own values | Consider own values, interests |
| Focus on patient autonomy | Focus on patient wellbeing |
| Consult with clinicians | Consult with relatives |
| Request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

⬇ **Professional role**

⬇ **Emotional role**

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

# Results




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

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# Conclusions

- There are ethical and practical arguments for both “familiar” and “unfamiliar” surrogates
- The choice of surrogate decision maker critically affects treatment decisions
- Patients who issue lasting powers of attorney should be made aware of these differences
- All surrogates should be sufficiently instructed to adhere to ethico-legal criteria of decision making

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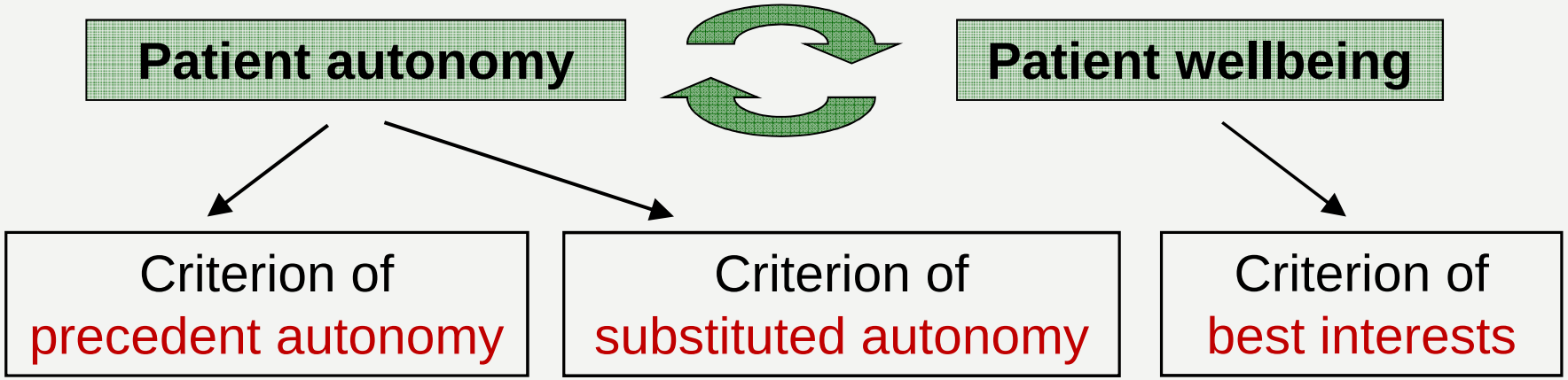
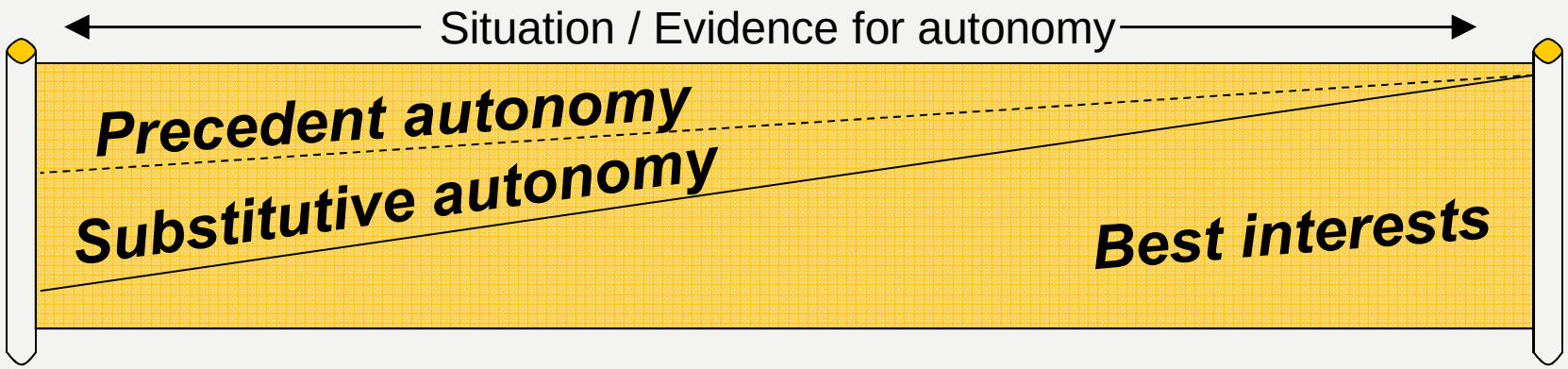
# Ethical Criteria




*Jox RJ, Ethik Med 2004*

# Precedent autonomy

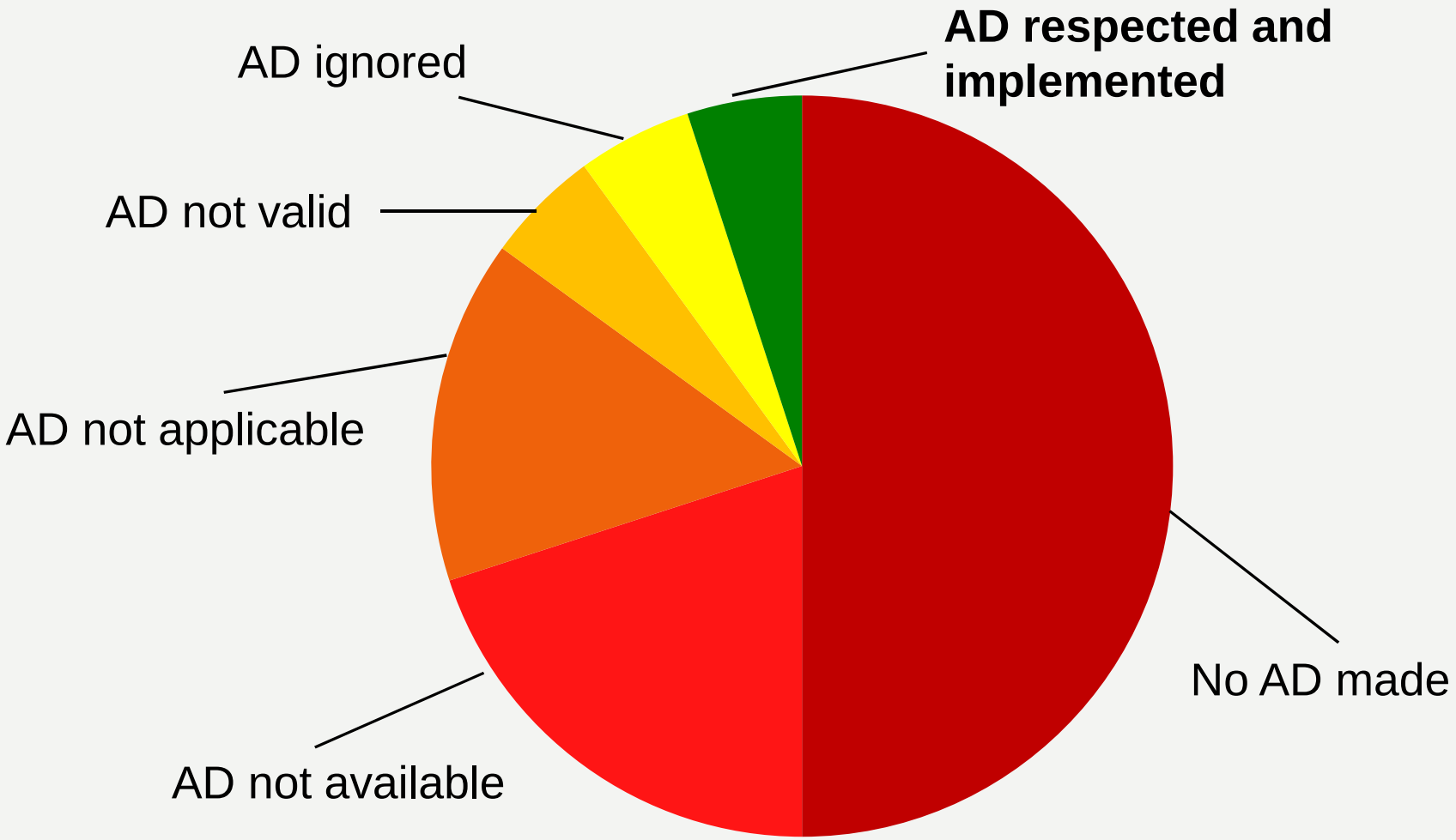
**Table 3**
Comparison of EOL therapy between patients with and without ADs

| | All patients n = 192 | No AD n = 128 | AD n = 64 | *P* value |
|---|---|---|---|---|
| DNR/DNI | 121 (63.0) | 72 (56.3) | 49 (76.6) | .007 |
| Withhold | 115 (60.0) | 75 (58.6) | 29 (45.3) | .092 |
| Withdraw | 90 (46.9) | 60 (46.9) | 30 (46.9) | 1 |
| CPR | 35 (18.3) | 29 (22.8) | 6 (9.4) | .029 |
| Circulatory support | 164 (87.2) | 109 (87.9) | 55 (85.9) | .818 |
| Mechanical ventilation | 164 (86.3) | 113 (89.7) | 51 (79.7) | .074 |
| Hemodialysis | 71 (44.7) | 44 (46.3) | 27 (42.2) | .629 |
| Median SOFA score | 10 (8-13.3) | 10.25 (8-13.4) | 10 (8-13) | .798 |
| Maximal SOFA score | 13 (11-16) | 14 (11-16) | 13 (10-17) | .487 |
| ICU length of stay, h | 118 (35.5-264) | 118.04 (26.8-247.5) | 117 (49.8-357.5) | .134 |
| Hospital length of stay, h | 219.5 (76-470.8) | 211 (75.5-459.8) | 263 (80.5-538) | .443 |

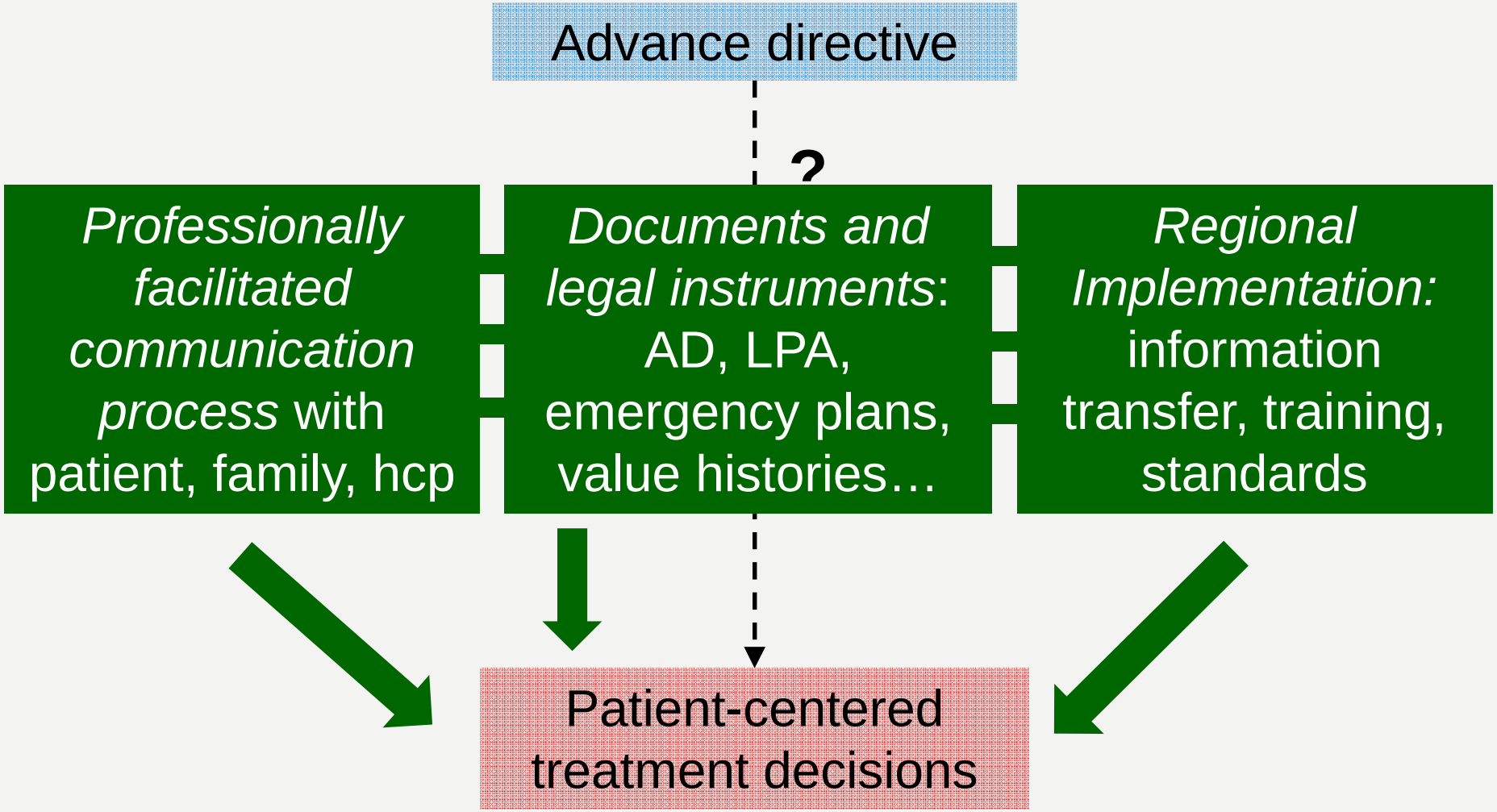
DNI = do not intubate.
Circulatory support includes vasopressor, intraaortic balloon pump, or extracorporeal membrane oxygenation.
Descriptive statistics as n (%) or median (interquartile range). *P* values obtained by Fisher exact test.

*Hartog CS et al.*
*J Crit Care 2014*

# Advances directives



# Advance Care Planning



# Effectiveness

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

# Ethical justification

## Principlist justification:

- Extending autonomy into states of incapacity
- Enhances autonomy in the present state
- Protecting from harmful overtreatment
- Psychosocial benefits (sense of security, preparedness, facilitation of communication…)

## Care ethics justification:

- Model of relational, longitudinal care
- Promotes attentiveness and shared responsibility
- Fosters virtues (mutual empathy, respect, modesty, courage…)

## Communitarian ethics justification:

- Strengthening subsidiary decision making
- Promoting common goods (reflection, judicious resource use, patient-centeredness)

# Substituted autonomy

## 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

## Concept:

1. Preferences correlate with personal 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

## Empirical studies:

- Accuracy of same/ higher than that of close relatives

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

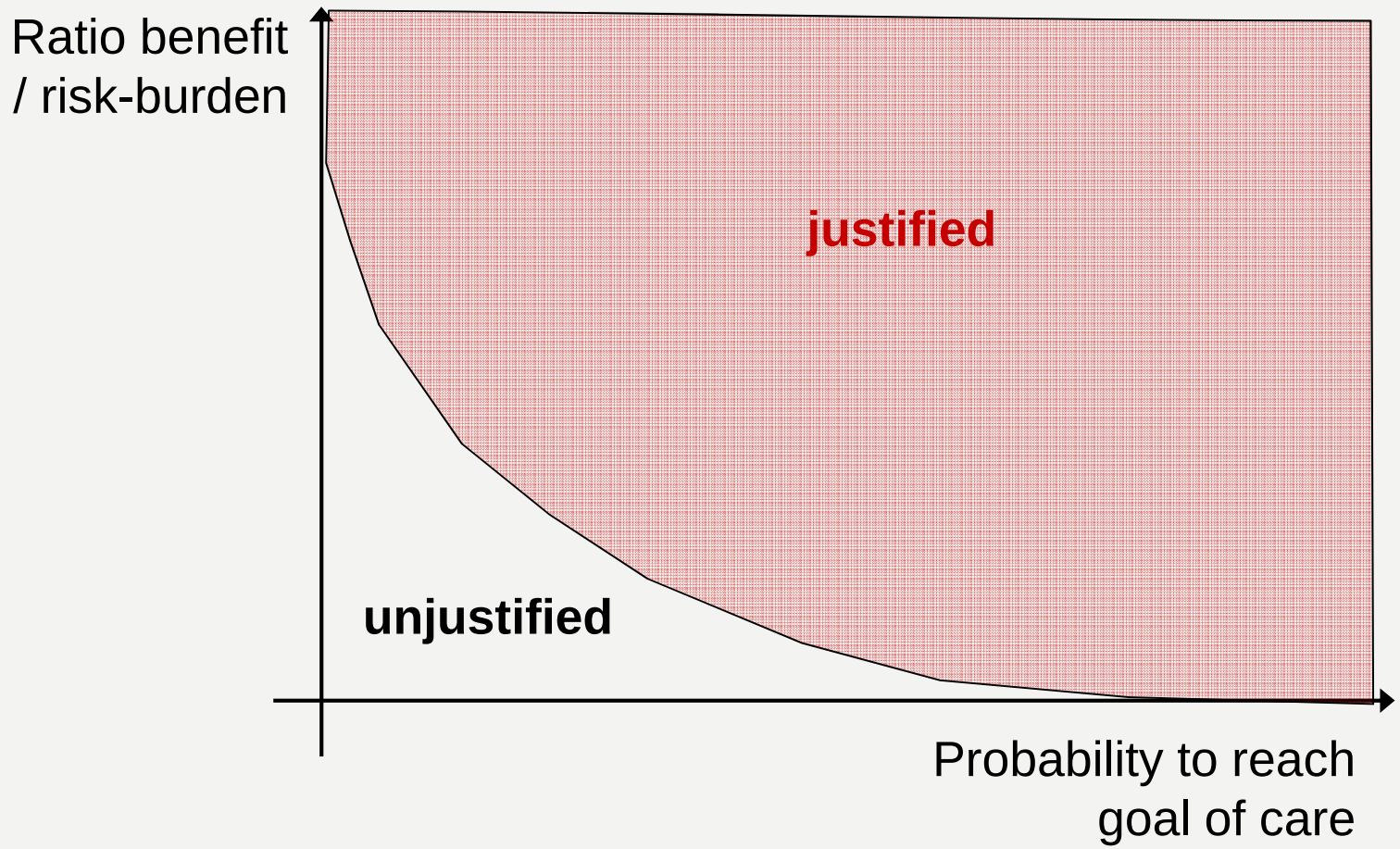
- 79% of surrogates welcome help by PPP

  *Wendler D et al. J Med Ethics 2016*

# Best interests

- Determination should focus on the **individual** instead of a diagnostic or prognostic patient group
- Includes more than health outcomes: **holistic view** of quality of life / human flourishing
- Encompasses both **current** wellbeing and the projection of **future** wellbeing (in relation to the probability of the prognosis)
- **Expressive behaviour** of incapacitated patients has to be taken into account after careful interpretation

# Future wellbeing




*Jox RJ. Sterben lassen. Rowohlt 2013.*

# Expressive behavior

## Aversive behavior:

- Refusal of nutrition (turning head, closing mouth)
- Physical defense against nurses, slapping…
- Pulling tubes, removing bandages...
- Crying, moaning…

## Appetitive behavior:

- Holding on to another one's hand
- Smiling, happy appearance, joy in eating

*Kuehlmeyer K et al. J Am Geriatr Soc 2015*

# Evaluation

## Criteria for evaluation:

- Situational expressive behavior should not be mistaken 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 other expressions?

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# Perspective

UNIL | Université de Lausanne

CHUV

COMMUNIQUÉ DE PRESSE

Jeudi 12 mai 2016

## Nouvelle chaire de soins palliatifs gériatriques

**Le Professeur Ralf Jox, palliativiste, neurologue et éthicien, et la Dre Eve Rubli Truchard, gériatre au CHUV, dirigent en tandem depuis le 1er mai 2016 la chaire de soins palliatifs gériatriques à la Faculté de biologie et de médecine de l'Université de Lausanne.**


Thank you for
your attention!
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