LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

2014 Minerva Summer Seminar
"End of Life: Between the Expected and the Unexpected"
Tzuba Hotel, June 23-25, 2014

Withholding and withdrawing life-sustaining treatment: ethical justification, intercultural differences, practical aspects

Ralf J. Jox, MD PhD
Institute of Ethics, History and Theory of Medicine &
Interdisciplinary Center for Palliative Medicine
University of Munich, Germany

Outline

1. Development and dimension
2. Ethical justification
3. Intercultural differences
4. Practical aspects

Allegories of death

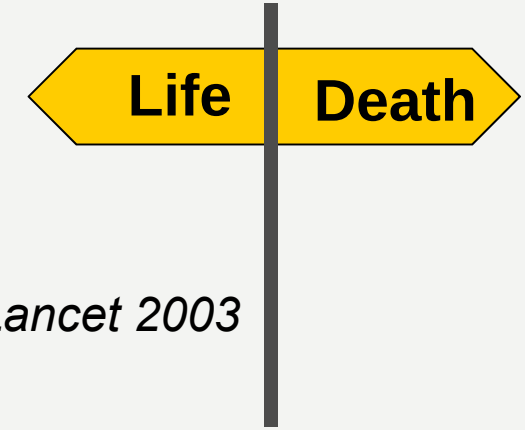
Thanatos
(Ephesos, Greece)

Grim Reaper
(Jean Fouquet, 1460)

Allegories of death

Allegory today?

Dying today



- **General population:**
  Two thirds of deaths are foreseeable
  23-50%: decisions to allow death to occur

  Van der Heide A et al, Lancet 2003

- **Intensive care:**
  50-90% of deaths based on decision to let die

  Sprung CL et al, JAMA 2003
  Vincent JL et al, Chron Respir Dis 2004

- **Palliative care:**
  70% of deaths based on decision to let die

  Schildmann J et al, Palliat Med 2010

Reasons

- Life expectancy ↑, demographic change
  → causes of death: chronic progressive diseases
- Unprecedented, highly effective options in life support
- Yet, less effective curative & rehabilitative options
- Patient & family as agents shaping the end of life
- Physicians‘ new role as companions at end of life (medicalization of dying)
- Increasing individualistic pluralism

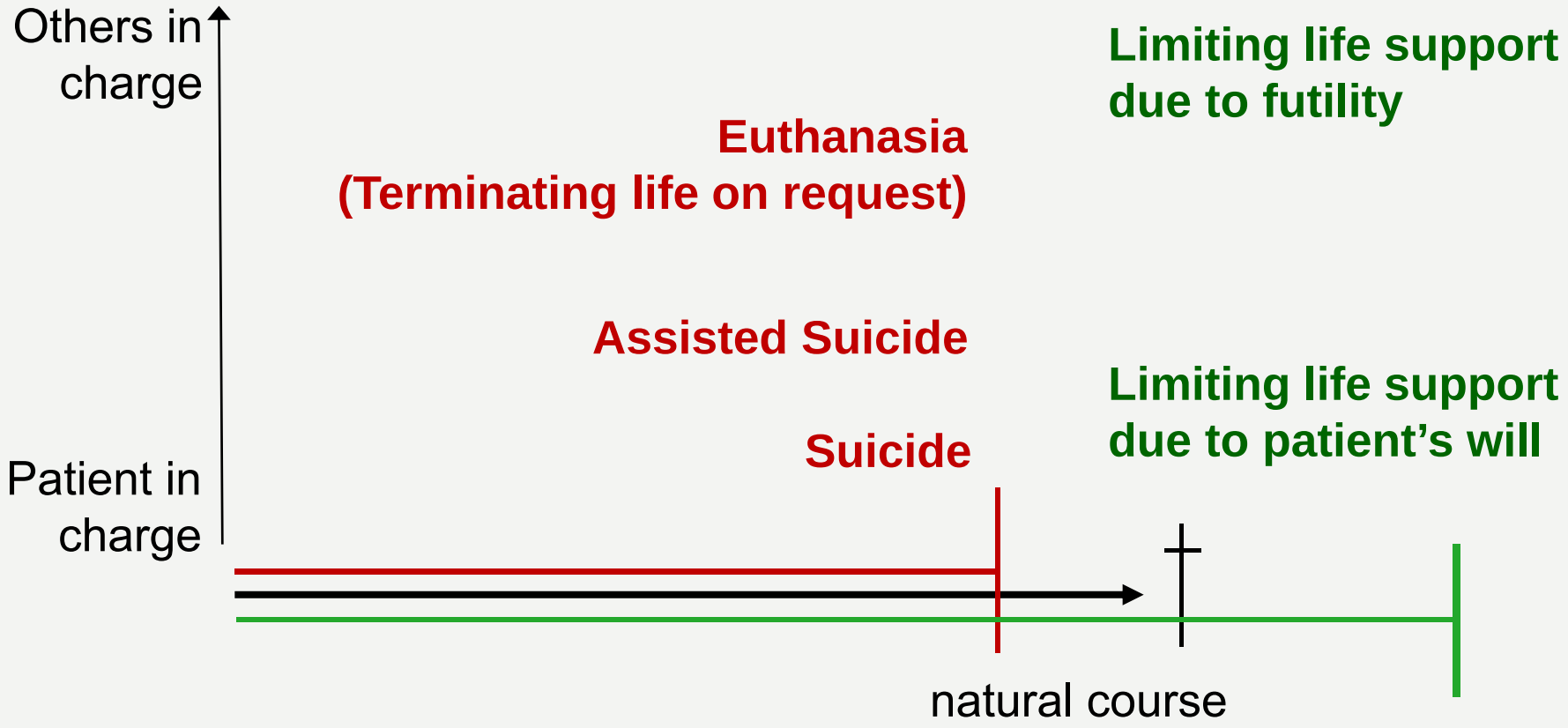
Need for regulation

Laws on Dying and Patients' Rights 1989-2009:

Laws passed

Laws discussed

End-of-life decisions



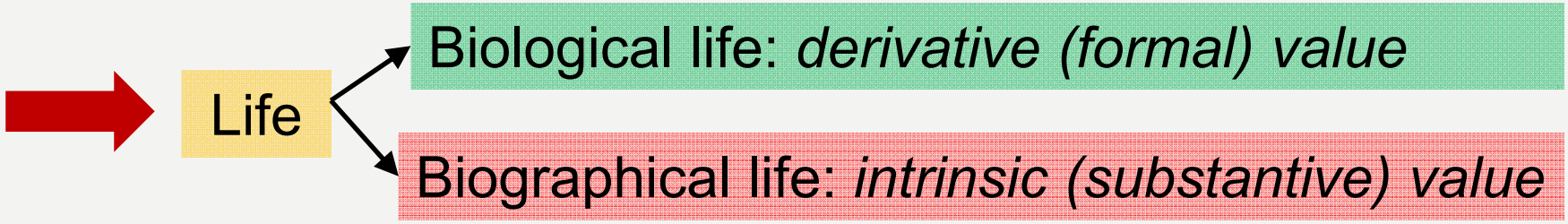
Outline

1. Development and dimension
2. **Ethical justification**
3. Intercultural differences
4. Practical aspects

Value of Life

In which circumstances, if ever, it is justified to let a person die (= to not take action to keep her/him alive)?

- Life = fundamental prerequisite for all (individual & social) human aims, goods, and values
- Life ≠ highest aim, good or value itself (can be trumped by others, e.g. life-shortening lifestyle, wish to die at the end of life, martyrs)



Normative implications

- Individual life plans, values and goals of life deserve protection → paramount right to self-determination
- This right logically entails openness to diverse individual preferences
- This includes preferences regarding quality of life, suffering, dying and ideas about transcendence
- Right to life therefore implies a right to waive one's life
- Condition: ability to develop, justify and balance one's preferences (decisional capacity)

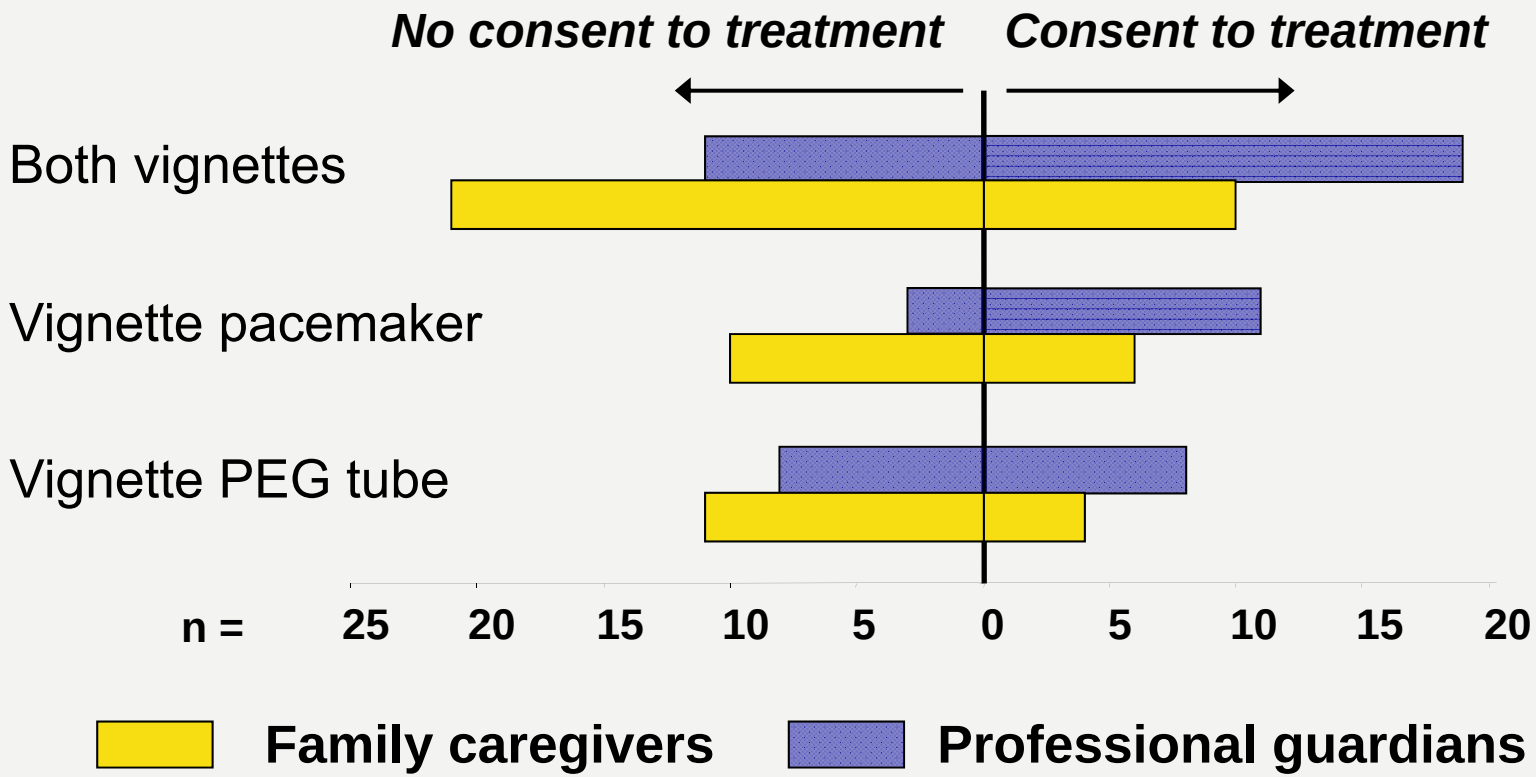
Letting die based on autonomy

A person with decisional capacity has the right to prefer dying over continuing to live according to his or her own preferences (irrespective of the health status).

Main questions:

- How can we safeguard respect for autonomy in states of incapacity? (*precedent/substitute autonomy*)

Surrogate decision making



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

Letting die based on autonomy

A person with decisional capacity has the right to prefer dying over continuing to live according to his or her own preferences (irrespective of the health status).

Main questions:

- How can we safeguard respect for autonomy in states of incapacity? (*precedent/substitute autonomy*)
- How can we best promote autonomy (as an ideal) and how strong is the duty to promote it? (*ACP*)

Advance Care Planning

Munich,
Germany,
Sep 9-12, 2015

Letting die based on autonomy

A person with decisional capacity has the right to prefer dying over continuing to live according to his or her own preferences (irrespective of the health status).

Main questions:

- How can we safeguard respect for autonomy in states of incapacity? (*precedent/substitute autonomy*)
- How can we best promote autonomy (as an ideal) and how strong is the duty to promote it? (*ACP*)
- Are people entitled to assistance in ending their lives, esp. if they want to hasten death *(assisted suicide/euth.)*

Killing vs. letting die

Thesis:

Terminating life on request ("euthanasia") is medically not needed and ethically inferior to assisted suicide and limiting life-sustaining treatment.

- All competent patients who want to die can do so either by refusing life support or assisted suicide
- All advantages of „euthanasia" are shared by the other options (e.g. controlled situation, dying w/o suffering…)
- Three social ethics arguments argue against euthanasia:
  1) Autonomy less safeguarded (no action control)
  2) Higher risk of abuse (→ mercy killings…)
  3) Negative feedback on agent (esp. if professional)

Letting die based on futility

A (life-sustaining) treatment is futile if it is either ineffective (*quantitative f.*) or will most likely produce more harm than benefit for the patient (*qualitative f.*).

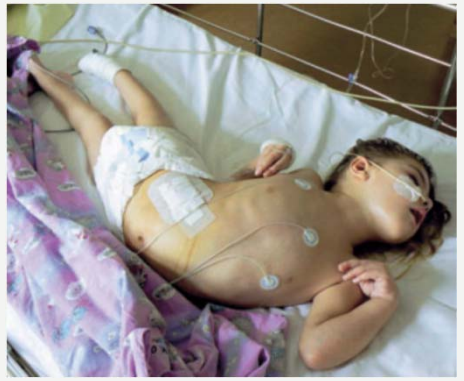
Main questions:

- *Quantitative futility*: e.g. PEG tube in end-stage dementia
  → for many treatments no evidence of effectiveness
- *Qualitative futility*: e.g. prolonging dying phase? Life support in irreversibly unaware patients? See Tony Bland (UK) or Jule (Germany) *House of Lords 1995, OLG Hamm 2007*

„Case Jule“

- Jule, 4-year-old girl, asthma attack
- Negligent intubation → hypoxic brain damage
- In persistent vegetative state (PVS) for several years, severe spasticity, therapy-refractory epilepsy
- Parents want to stop artificial nutrition & hydration
- Family court removes parental right of custody
- Regional supreme court Hamm reverses decision: *decision „justifiable in light of the child‘s wellbeing“, decision within (wide) scope of parental discretion*

Jule, before accident



Jule, in PVS

Letting die based on futility

Problems regarding qualitative futility:

- Physicians & law ignore futility as *value judgment*
- No clear theoretical criteria
- Susceptible to other motives (economic…)
- Considerable professional variability
- Based on cultural norms and physician's own values

Outline

1. Development and dimension
2. Ethical justification
3. **Intercultural differences**
4. Practical aspects

PVS: Divergent professional attitudes

Surveys among physicians:

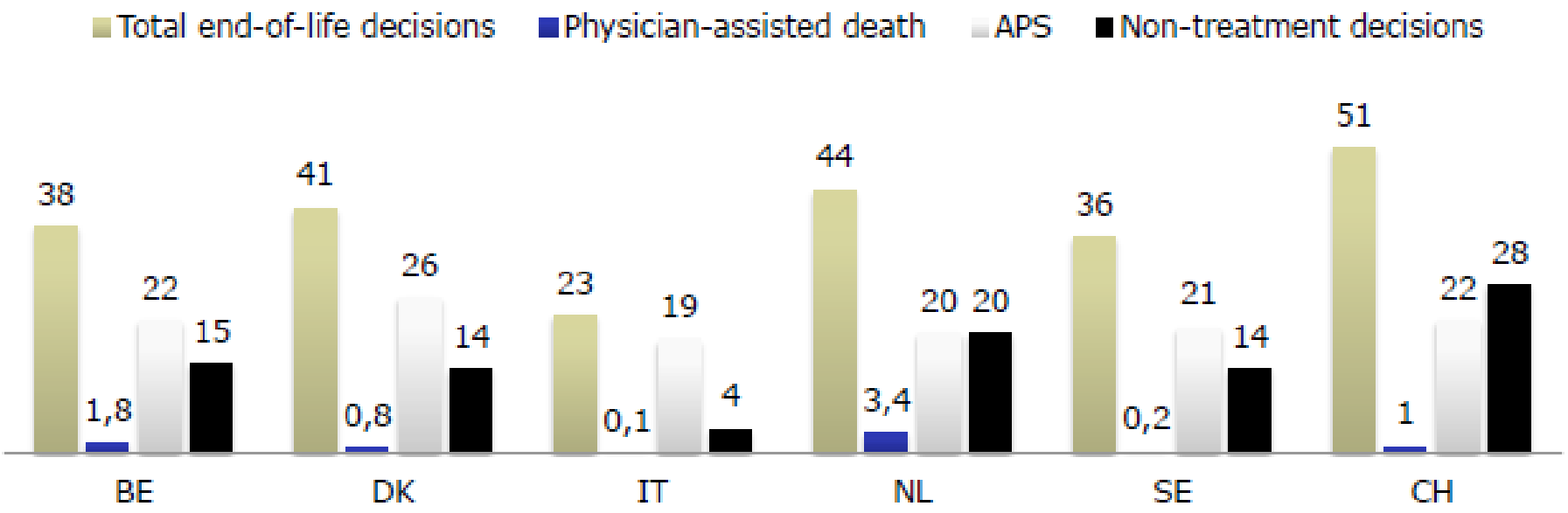
May withdrawing artificial nutrition and hydration in the PVS be ethically justified?

- *Canada:* *96%* (Kuehlmeyer et al. 2014)
- *UK:* *94%* (Grubb et al, Lancet 1996)
- *Belgium:* *94%* (Dierickx et al, Acta Neurochir 1998)
- *USA:* *89%* (Payne et al, Ann Intern Med 1996)
- *Germany:* *80%* (Kuehlmeyer et al 2012)
- *Italy:* *66%* (Solarino et al, Intensive Care Med 2011)
- *Europe:* *73% Northern Europe*
  70% Central Europe
  55% Southern Europe (Demertzi et al, J Neurol 2011)

→ ***Religion*** is a main determining factor (Demertzi 2009 and 2011)

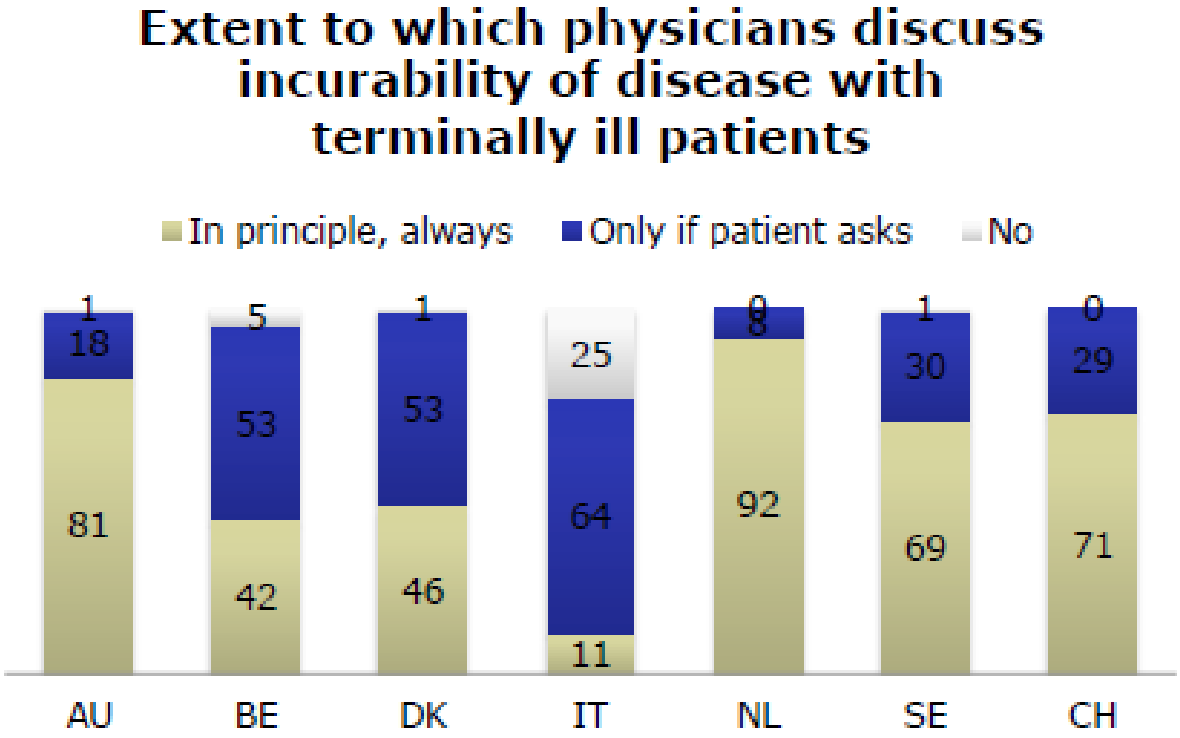
EURELD study

% of end-of-life decisions in patients who died non-suddenly



van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet Aug 2;362(9381):345-350.

EURELD study



Cartwright C, Onwuteaka-Philipsen B, Williams G et al. Physician discussions with terminally ill patients: a cross-national comparison. Palliative Medicine 2007;21:295-303

Withdrawing vs. Withholding

- ETHICUS study: Withdrawing life-sustaining treatment common in North Europe (48%), rare in South Europe (18%, incl. Israel), withholding equivally frequent

Spring CL et al. JAMA 2003

Thesis:
Withdrawing and withholding treatment is ethically equivalent.

- *Ethically relevant action is the treatment to the patient, not the movement of the physician*
- *Any treatment has to be justified at each moment of its administration (e.g. PEG tube, ventilation)*
- *Historical argument is a fallacy in normative ethics*

Intercultural differences

- Studies only reflect the majority culture in a region
- Globalization and European unification lead to converging attitudes on end-of-life issue

  Jox RJ et al. Med Health Care Philos 2008

- Reasons for intercultural differences: religion, group culture, traditions, professional ethos…
- Cultural traditions vs. universalist ethics?

  → *"Social laboratory": Which norms can be implemented?*

  → *Opportunity for intercultural discussions*

  → *Cultural sensitivity important to maintain social peace*

Outline

1. Development and dimension
2. Ethical justification
3. Intercultural differences
4. **Practical aspects**

Importance of words

How to talk about withdrawing and withholding life-sustaining treatment (letting die)?

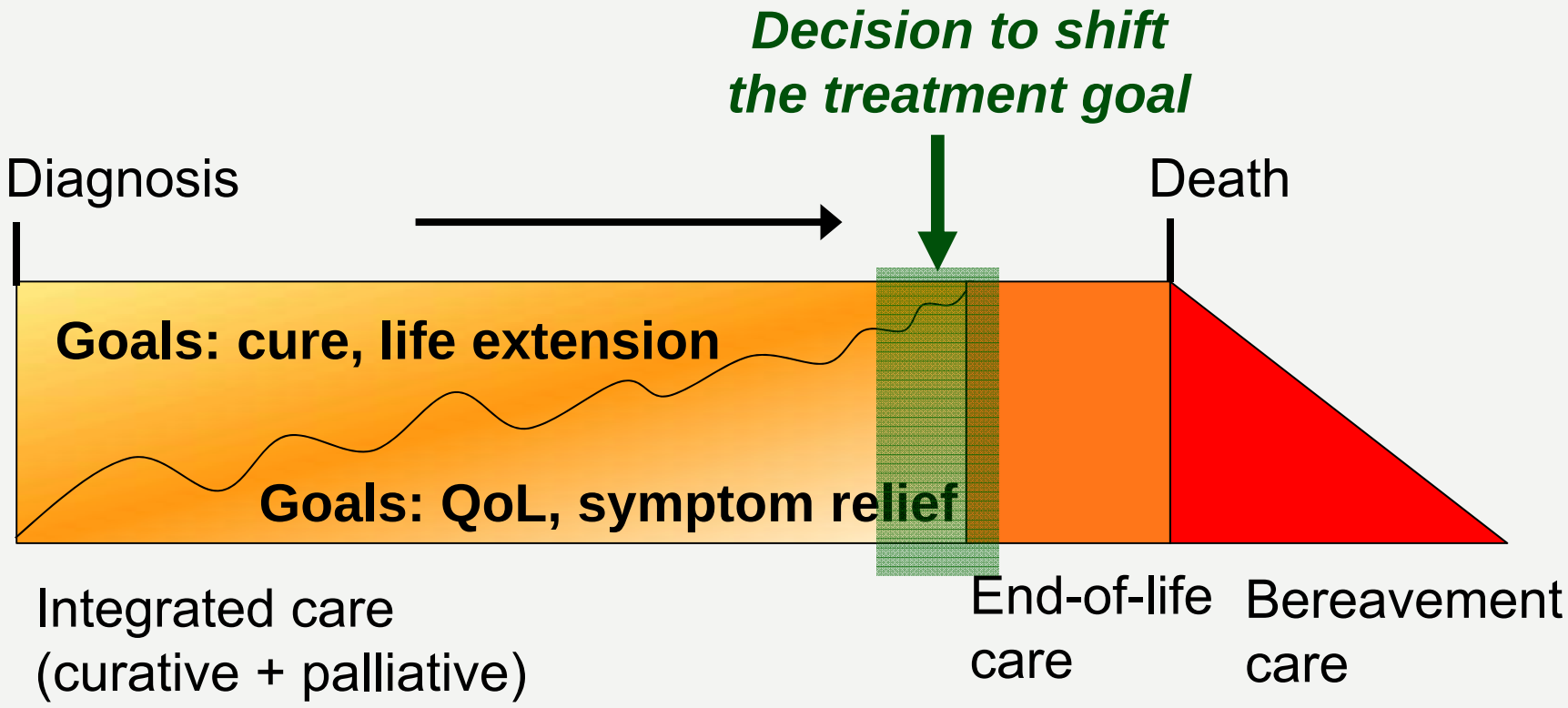
We cannot do any more for you…

We stop treatment…

We deescalate intensive care measures…

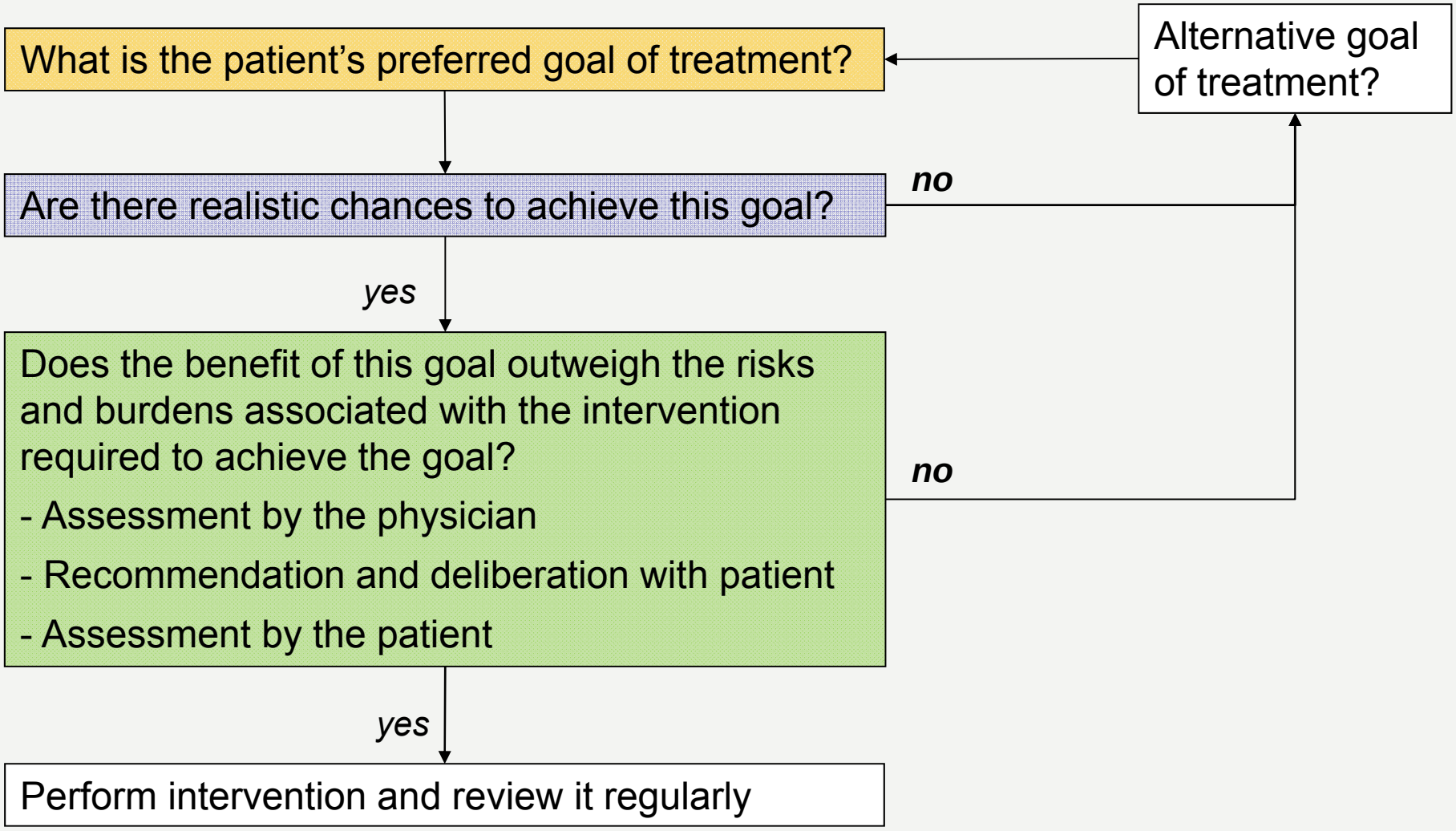
We withdraw / withhold treatment…

Shifting the goal of treatment



Adapted from: Murray SA et al, BMJ 2005

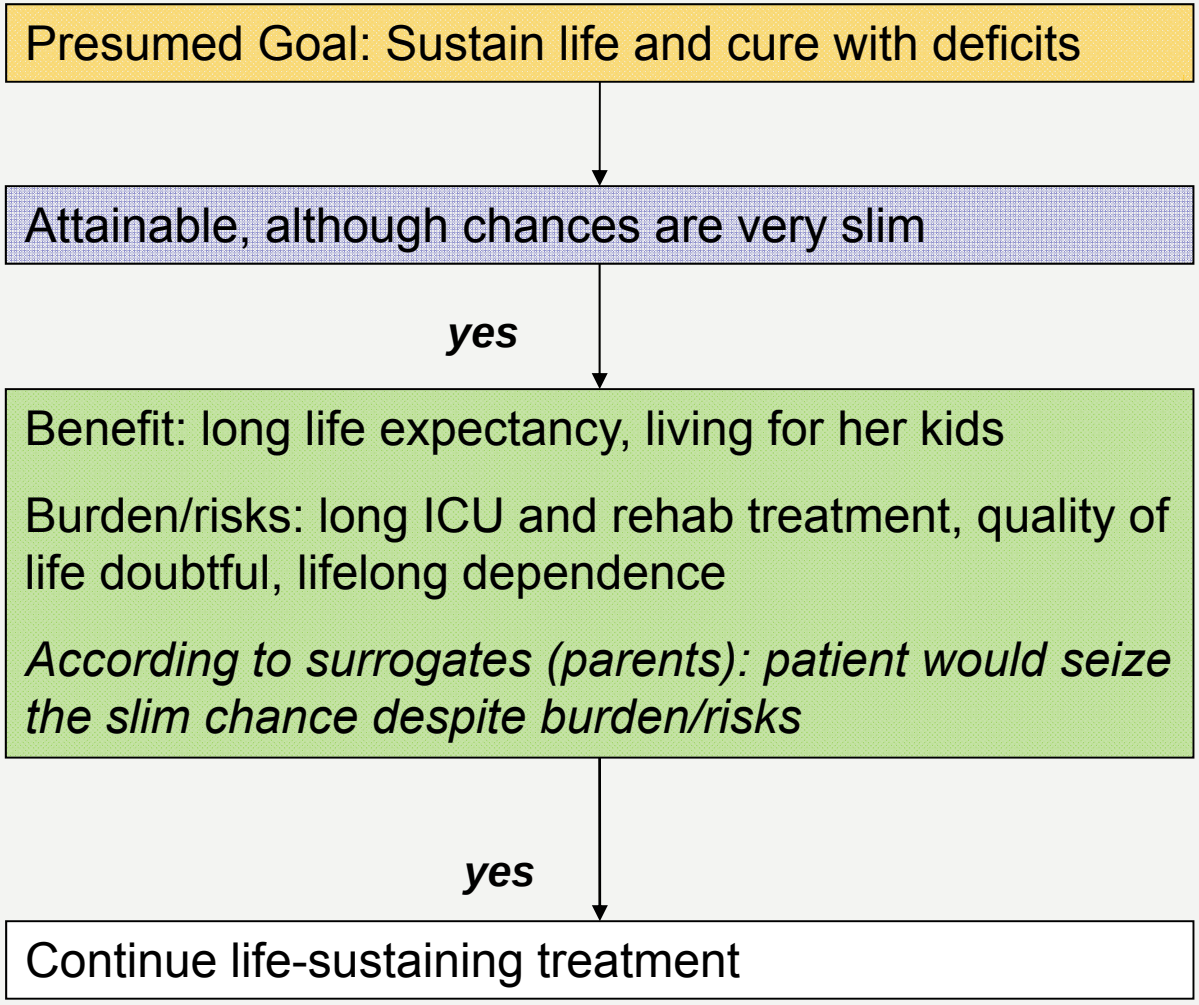
Decision making



Case

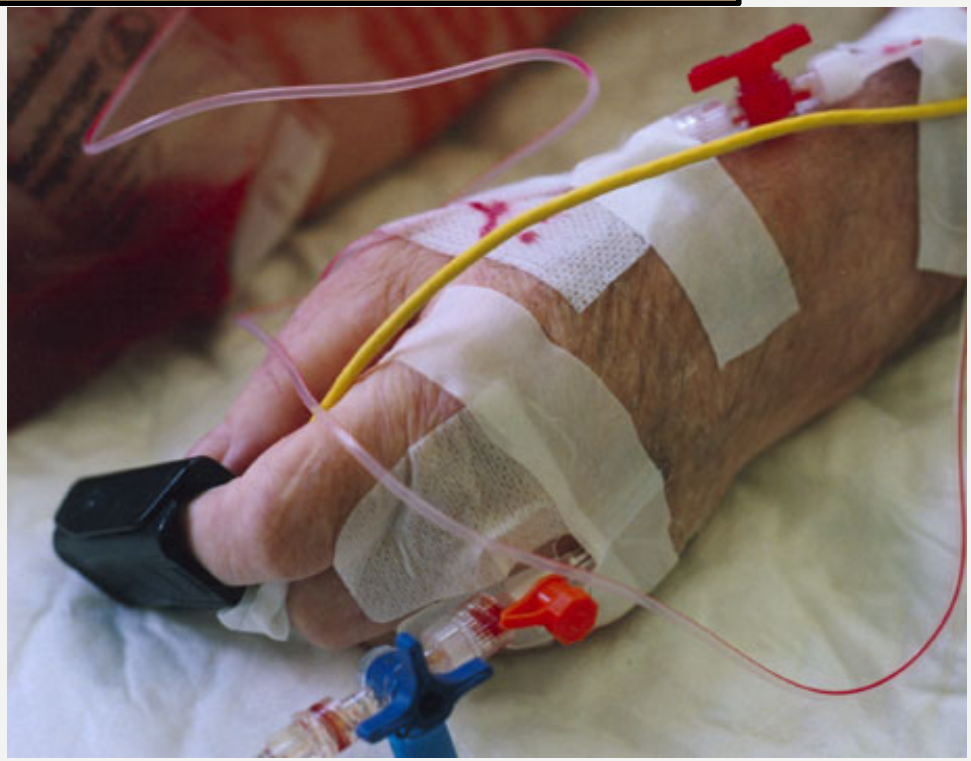
- 32-year-old woman, previously healthy, back from holiday
- Pain in left leg → ER: fever, malaise; Diagnosis: necrotizing fasciitis, emergency surgery
- After surgery: septic shock, multi organ failure
- Despite antibiotics spread to second leg, ischemias in all fingers (toxic-shock-like syndrome)
- Stabilization of vital signs 4 weeks later (12 surgeries, amputations of all long fingers, left thigh, right lower leg)
- New complication: sclerosing cholangitis → liver failure, transplantation impossible
- 2 kids (8/12 yrs), single parent, own shop, life-affirming

Case


Presumed Goal: Sustain life and cure with deficits
Attainable, although chances are very slim
yes
Benefit: long life expectancy, living for her kids
Burden/risks: long ICU and rehab treatment, quality of life doubtful, lifelong dependence
According to surrogates (parents): patient would seize the slim chance despite burden/risks
yes
Continue life-sustaining treatment

Conclusion

We need to learn and master the ethical art of letting die.




Danke für Ihre
Aufmerksamkeit!
ralf.jox@med.lmu.de