LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

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Ethical Issues in Neurological Palliative Care

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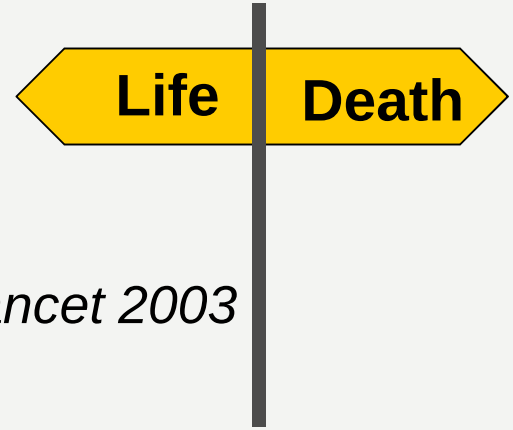
Outline

1. End-of-life decisions
2. Ethical criteria
3. Practical problems
4. Wish to hasten death

End-of-life decisions



- **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

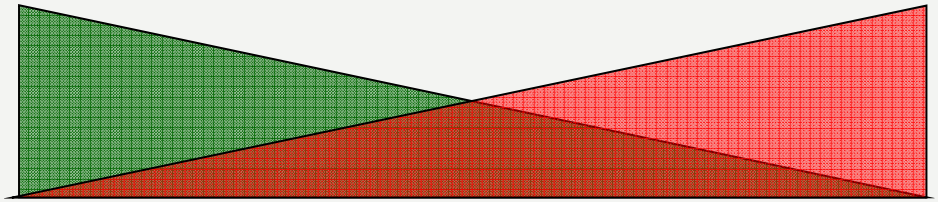
Globally leading causes of death (2008)

World Health Organization

High-income countries	*Deaths in millions*	*% of deaths*
Ischaemic heart disease	1.42	15.6%
Stroke and other cerebrovascular disease	**0.79**	**8.7%**
Trachea, bronchus, lung cancers	0.54	5.9%
Alzheimer and other dementias	**0.37**	**4.1%**
Lower respiratory infections	0.35	3.8%
Chronic obstructive pulmonary disease	0.32	3.5%
Colon and rectum cancers	0.30	3.3%
Diabetes mellitus	0.24	2.6%
Hypertensive heart disease	0.21	2.3%
Breast cancer	0.17	1.9%

Ethical Relevance

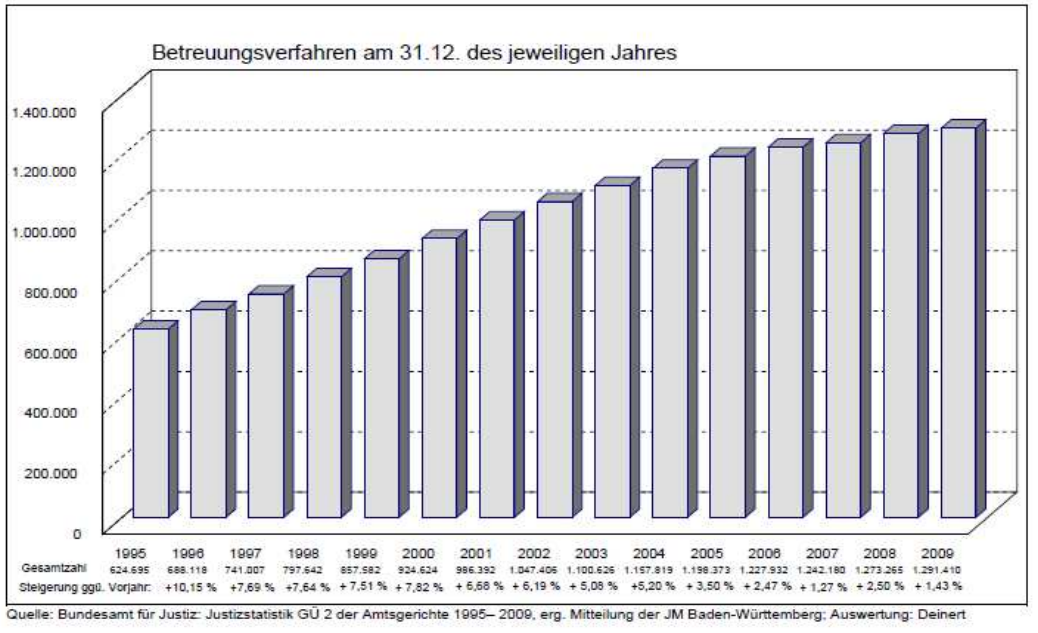
Capacity to decide for yourself



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)

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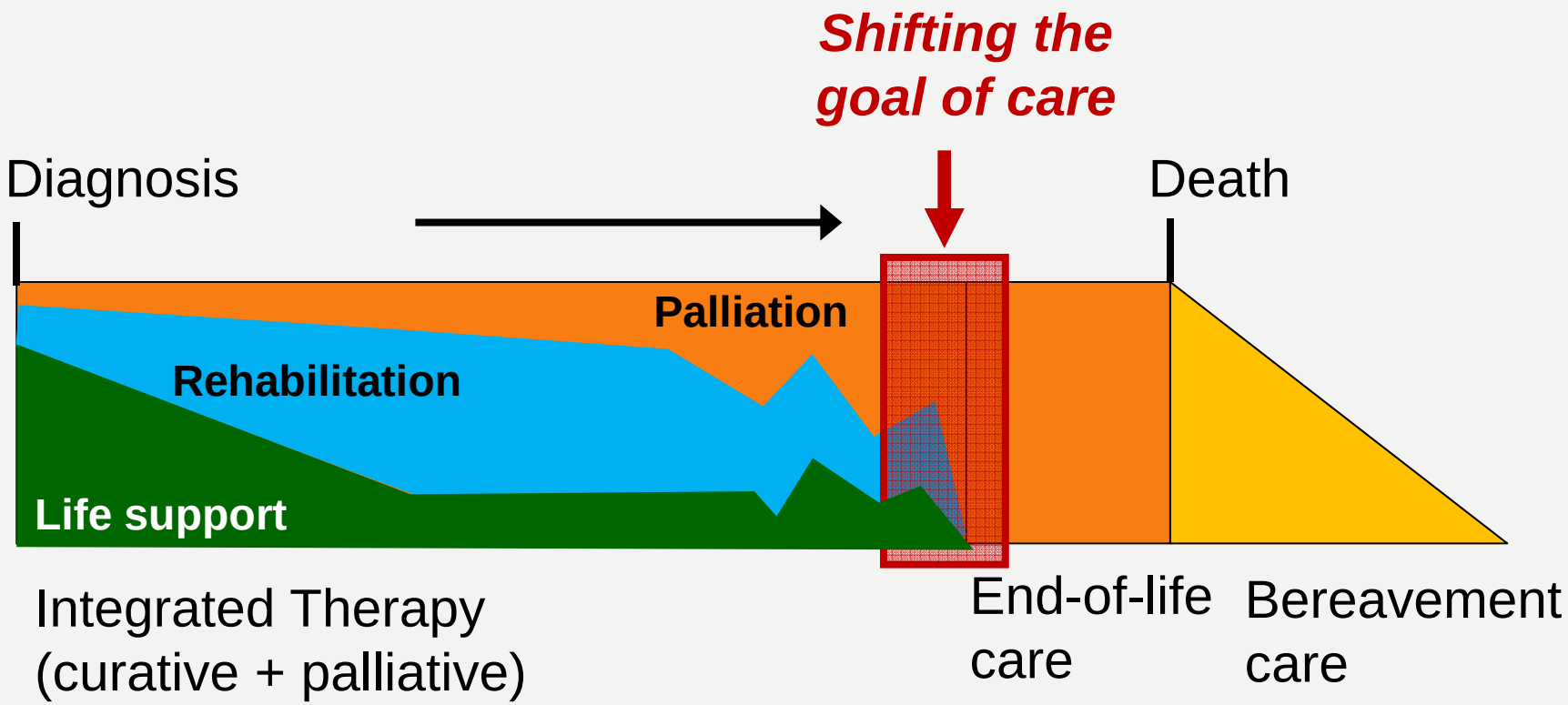
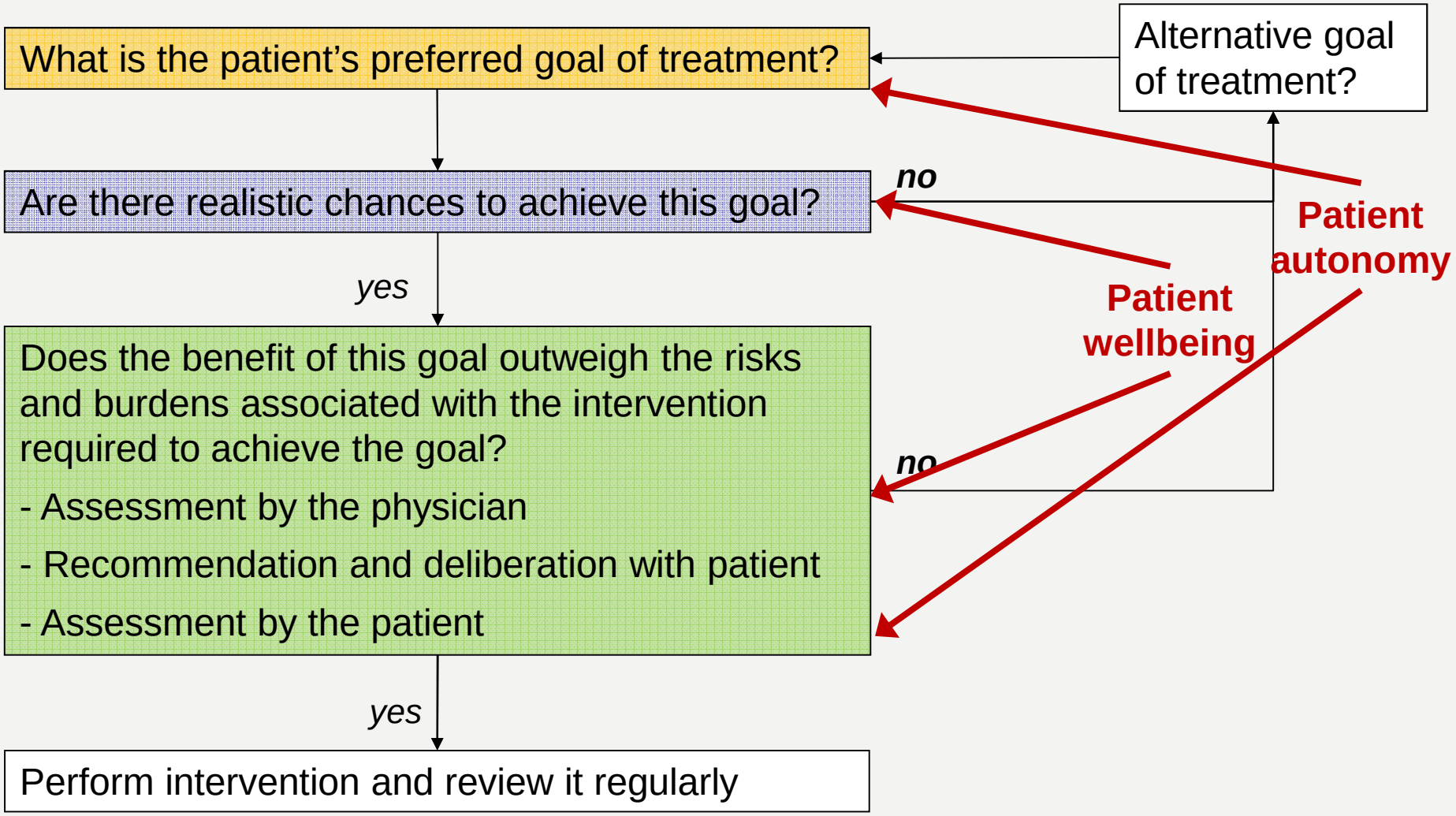
Shifting the goal of care

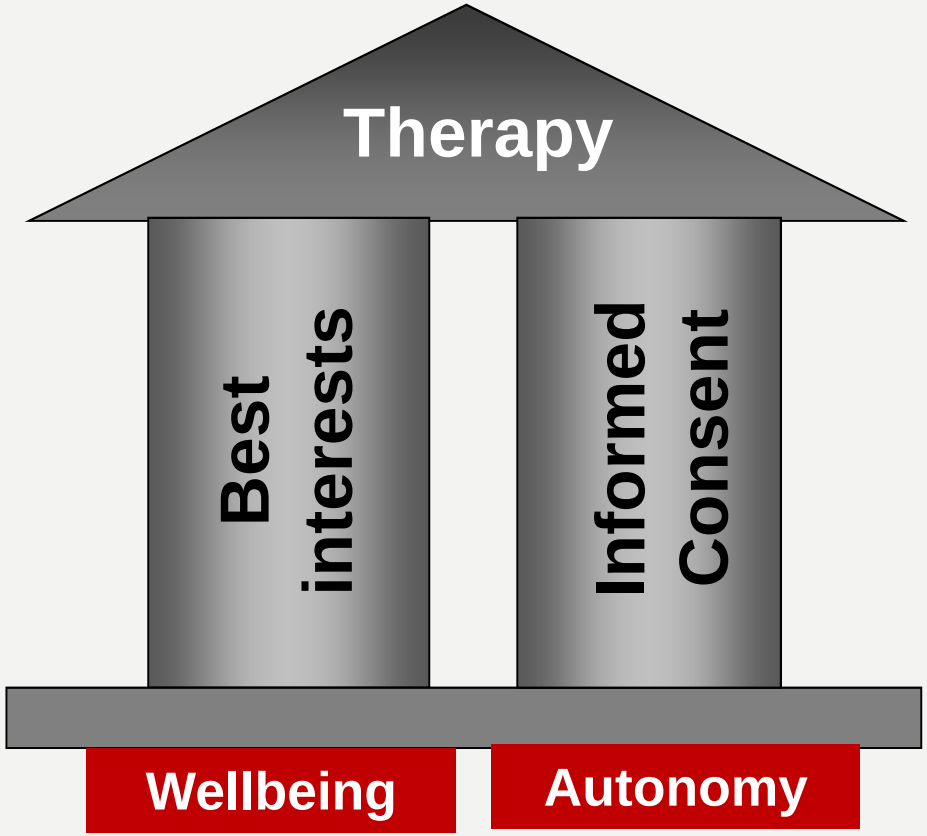


Adapted from Murray SA et al (2005) BMJ

Decision making



Ethical criteria



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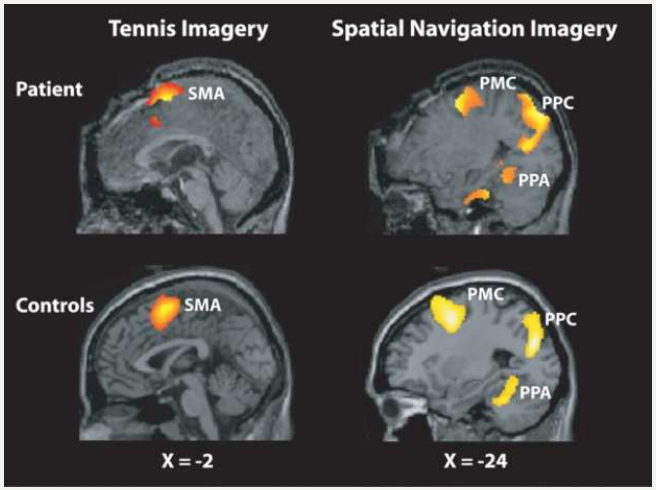
Assessing best interests

- Requires judgment about current and anticipated quality of life of the individual patient
- Quality of life is primarily subjective

→ Prognosis in neurology often unclear

→ difficult to assess in neurological patients with communication barriers

→ questionable in patients with disorders of consciousness



Owen AM et al. Science 2008

Uncertainty regarding mental state

I think patients with this diagnosis are able to:	Vegetative state (n=132)	Minimally conscious state (n=148)
Be aware of themselves	9	54
Be aware of surroundings	6	57
Interact with others	8	57
Have thoughts	23	72
Have emotions	35	87
Experience hunger/thirst	46	92
Feel touch	67	94
Feel pain	77	96

Kuehlmeyer K et al. J Neurol 2012

Controversy among physicians

Surveys among physicians:

May withdrawing artificial nutrition and hydration in the persistent vegetative state be ethically justified?

- USA:	89%	*Payne et al, Ann Intern Med 1996*
- UK:	94%	*Grubb et al, Lancet 1996*
- Belgium:	94%	*Dierickx et al, Acta Neurochir 1998*
- Germany:	46%	*Lanzerath et al, Ethik Med 1998*
	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 main determining factor *Demertzi 2009 and 2011*

Determining the patient's will

Currently expressed will of a competent and informed patient

If not present

Anticipatorily expressed will (advance directives)

If not present

Substituted judgment (presumed will)

If not possible

Behavioral expressions of will

Common examples

Dementia patients:

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

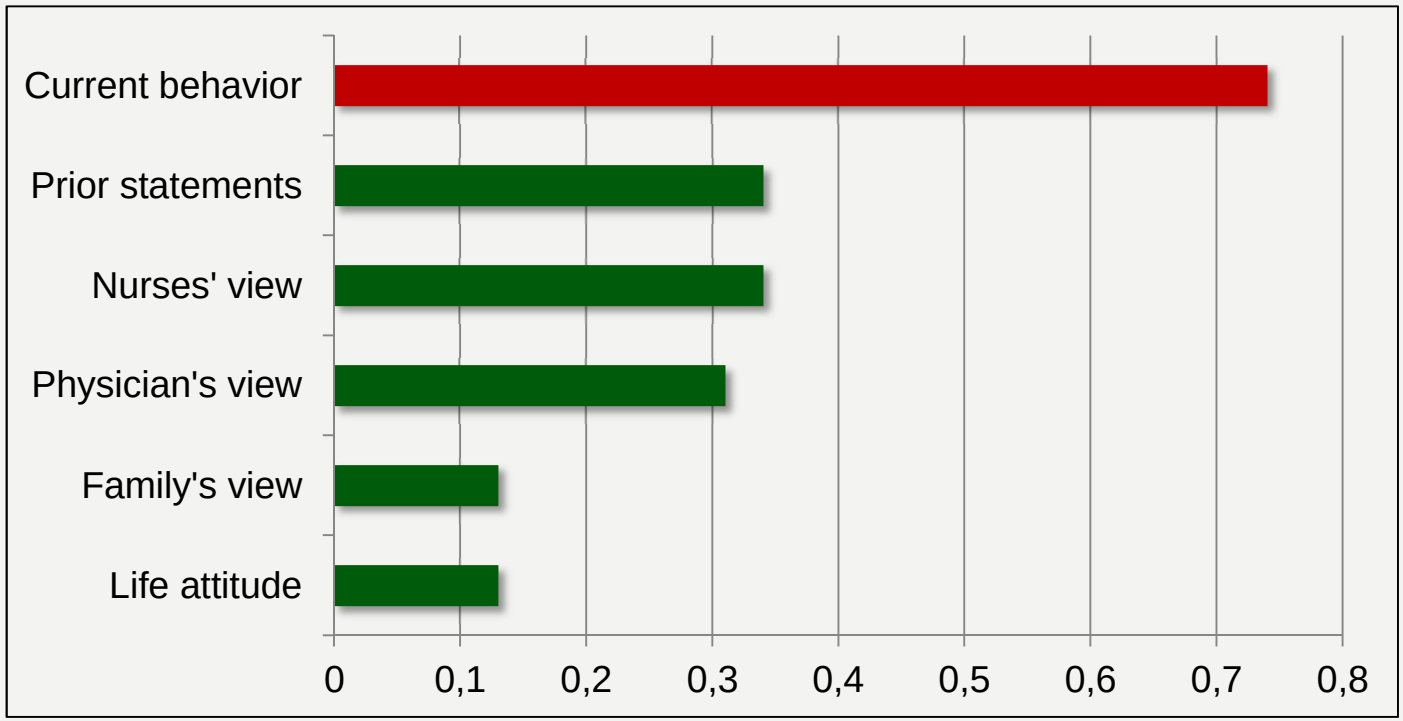
Kuehlmeyer K et al. (in preparation)

Severely brain-injured patients:

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

Patient Behavior

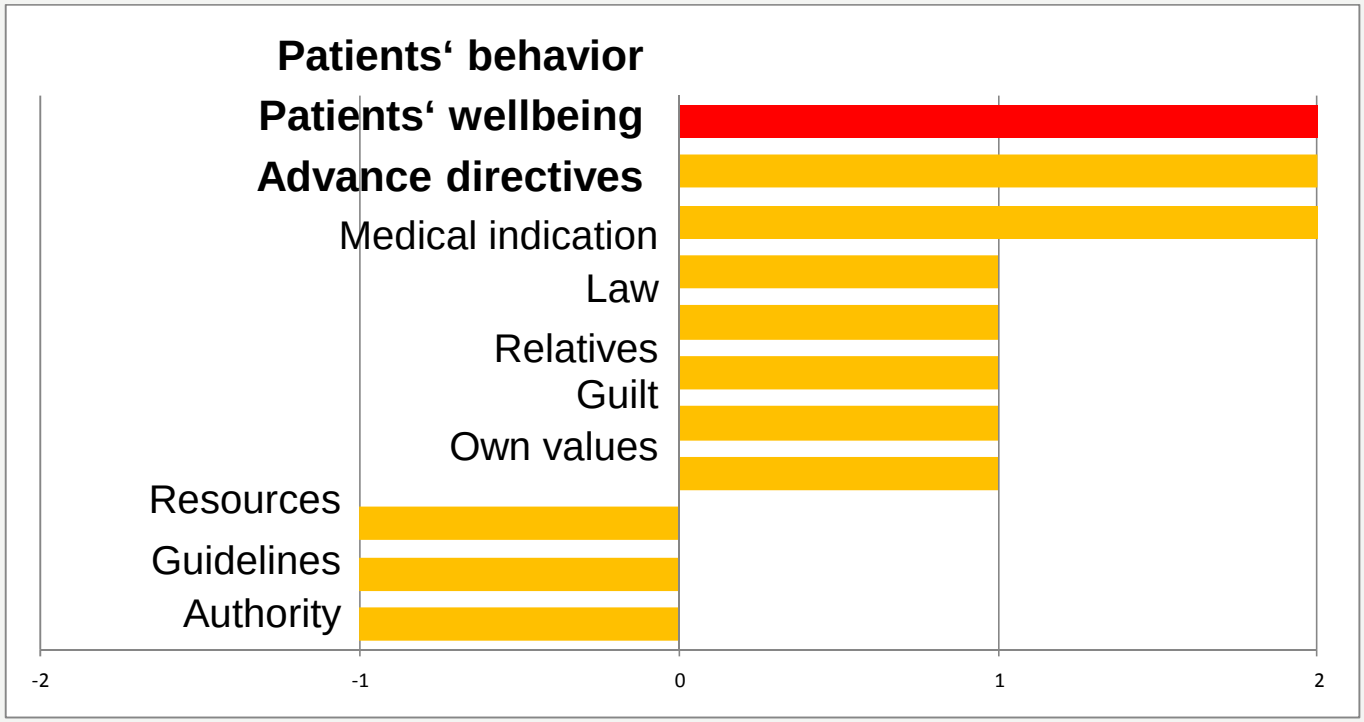
Study on surrogate decision making by guardians and relatives of dementia patients:



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

Patient Behavior

Factors for treatment decisions about dementia patients (survey of nurses in German care homes):



Not important | Moderately important | **Very important**

Kuhelmeyer K et al (in preparation)

Ethical appraisal

- Non-verbal behavior is often *situational and context-dependent*
- Expresses the *current state of wellbeing*, but not an autonomous treatment decision
- Should be carefully *interpreted* and taken into account if *reliable and consistent* with patient's personality
- May render an *advance directive* inapplicable if the clinical situation is different from the one anticipated

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Current Case

- Tony Nicklinson (UK), 58 years old
- Stroke 2005 → locked-in syndrome
- Asked court to allow his doctor to assist in suicide or perform euthanasia

"My life can be summed up as dull, miserable, demeaning, undignified and intolerable (…) Why should I be denied a right, the right to die of my own choosing, when able-bodied people have that right and only my disability prevents me from exercising that right?"

- Highest court rejected claim (delegates to parliament)
- Tony refuses to eat & drink, dies 6 days later

ALS Study

- Prospective questionnaire **study** of 66 ALS patients and 62 primary caregivers (Germany & Switzerland)
- 50% of patients could imagine asking for the physician to **assist in suicide**
- 14% expressed current **wish to hasten death** (correlated with depression, anxiety, loneliness, low QoL)
- Attitudes **stable** over 13 months
- None **talked** to physician about it, yet 50% would like to

Stutzki R et al. Amyotroph Lateral Scler (in press)

Legal Regulation?

Oregon (1997), Netherlands and Belgium (2002), Washington (2008), Luxemburg (2009) Vermont (2013)

Data from Oregon show:

- **25% of patients who wish to hasten death have depression**
- **33% of patients do not use the prescribed drugs**
- **No loss of trust towards physicians**
- **No increased depression or complicated grief in relatives**
- **No slippery slope towards vulnerable groups**
- **Regulation improved palliative care**

Dobscha SK, J Palliat Med 2004, Lindsay RA, Am J Bioeth 2009
Battin MP, JME 2007Ganzini L, J Pain Symptom Manage 2009

Thanks to:

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E. Racine

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Thank you for the attention!

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