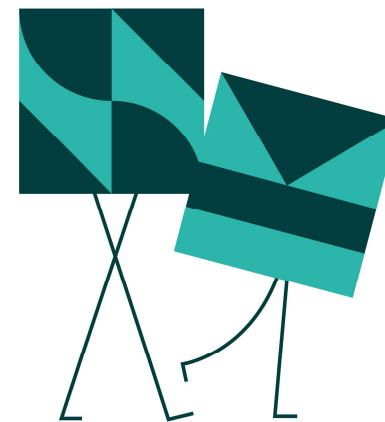
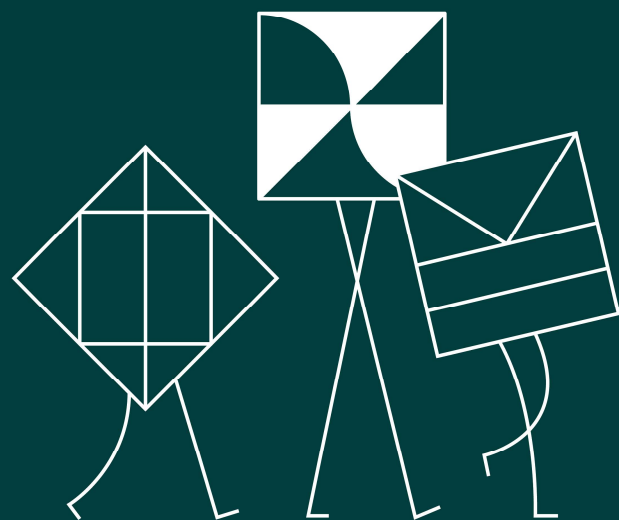


Swiss Summer Academy in
Palliative Care Research
August 23-24th, 2021
Münchenwiler



Département de médecine

Autonomy at the end of life

Dr Eve Rubli Truchard & Pr Ralf Jox
www.chuv.ch/cspg



Structure

Autonomy at the end of life

- 1) Ralf: Autonomy at the end of life: introduction
- 2) Eve: 2 research examples from our Chair

Dying the other day

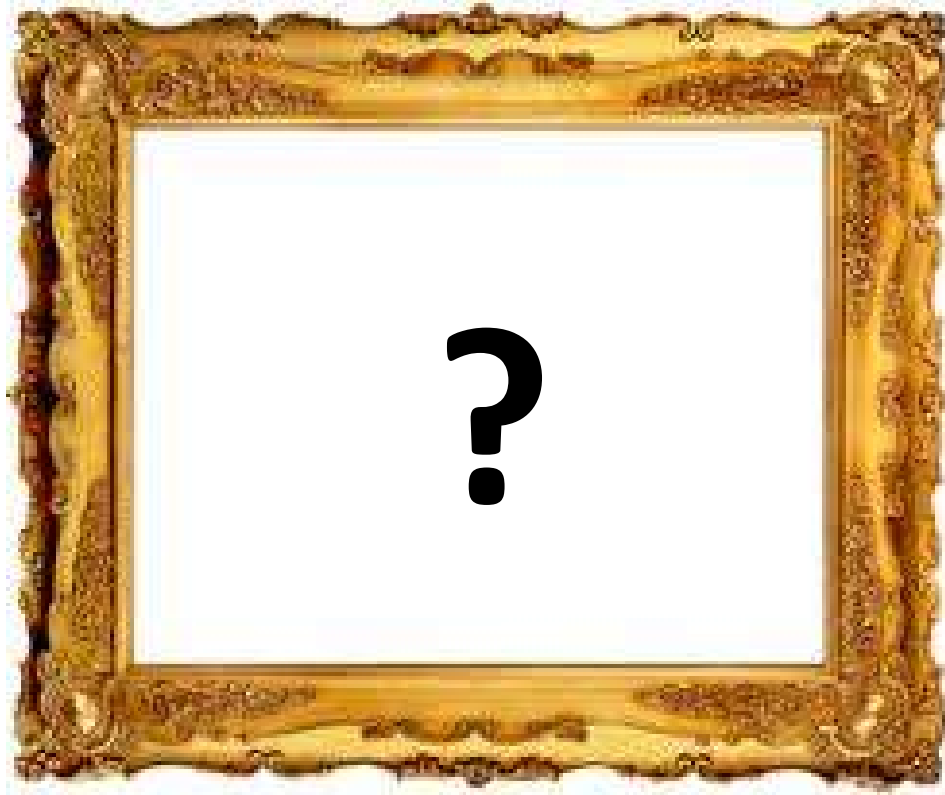


Thanatos
(Ephesos, Greece)



Grim Reaper
(Jean Fouquet, 1460)

Dying today



Deliberately allowing death

■ Population:

2/3 of all deaths are predicted, 23-50% occur after care decisions

*Van der Heide A et al, Lancet 2003,
Bosshard G et al. JAMA Intern Med 2016*

■ Intensive care:

50-90% of all deaths due to the withdrawing or withholding of life-sustaining measures (LST)

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

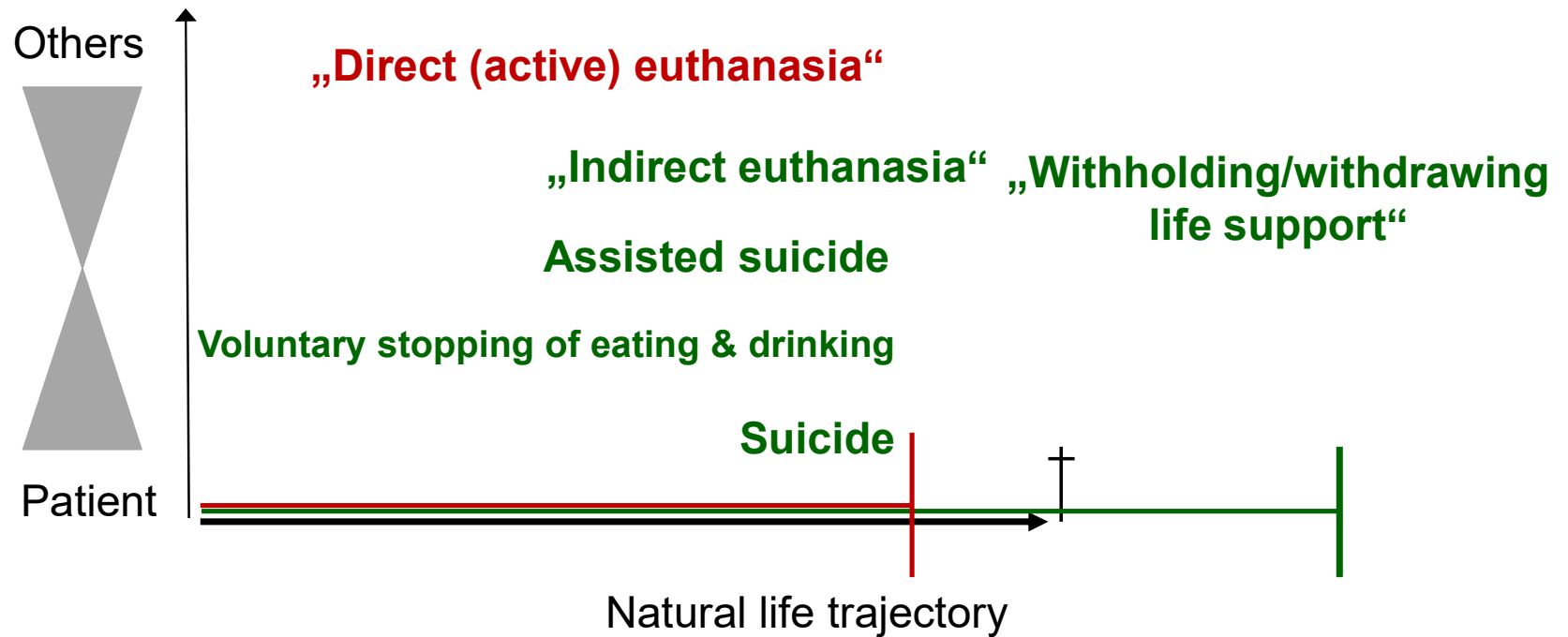
■ Palliative care:

70% of deaths related to withholding/withdrawing LST

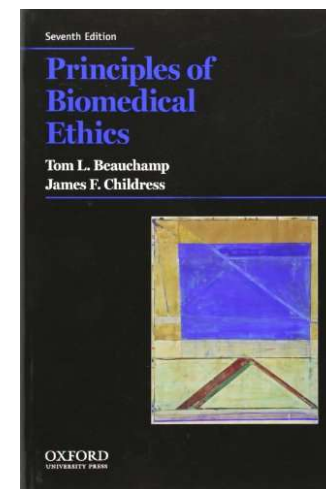
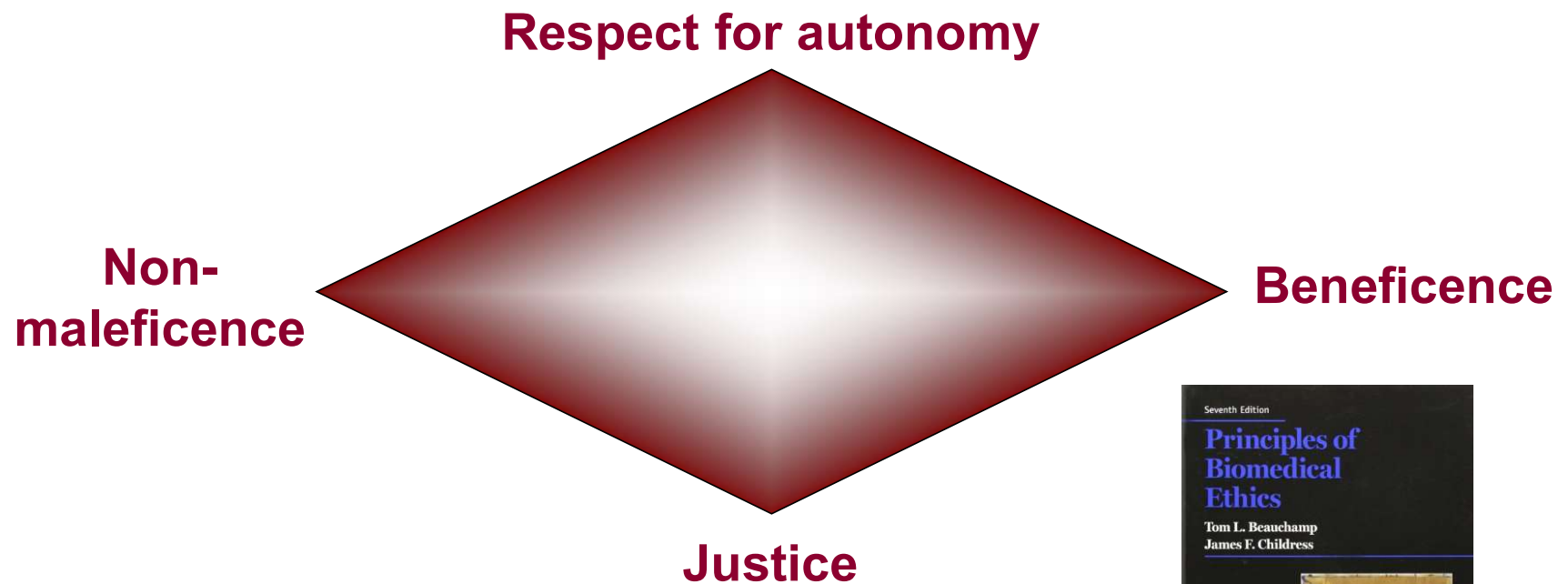
Schildmann J et al, Palliat Med 2010, J Med Ethics 2011

End-of-life decisions

Control of the action



Principles of biomedical ethics



Beauchamp TL & Childress JF 1979, 72013

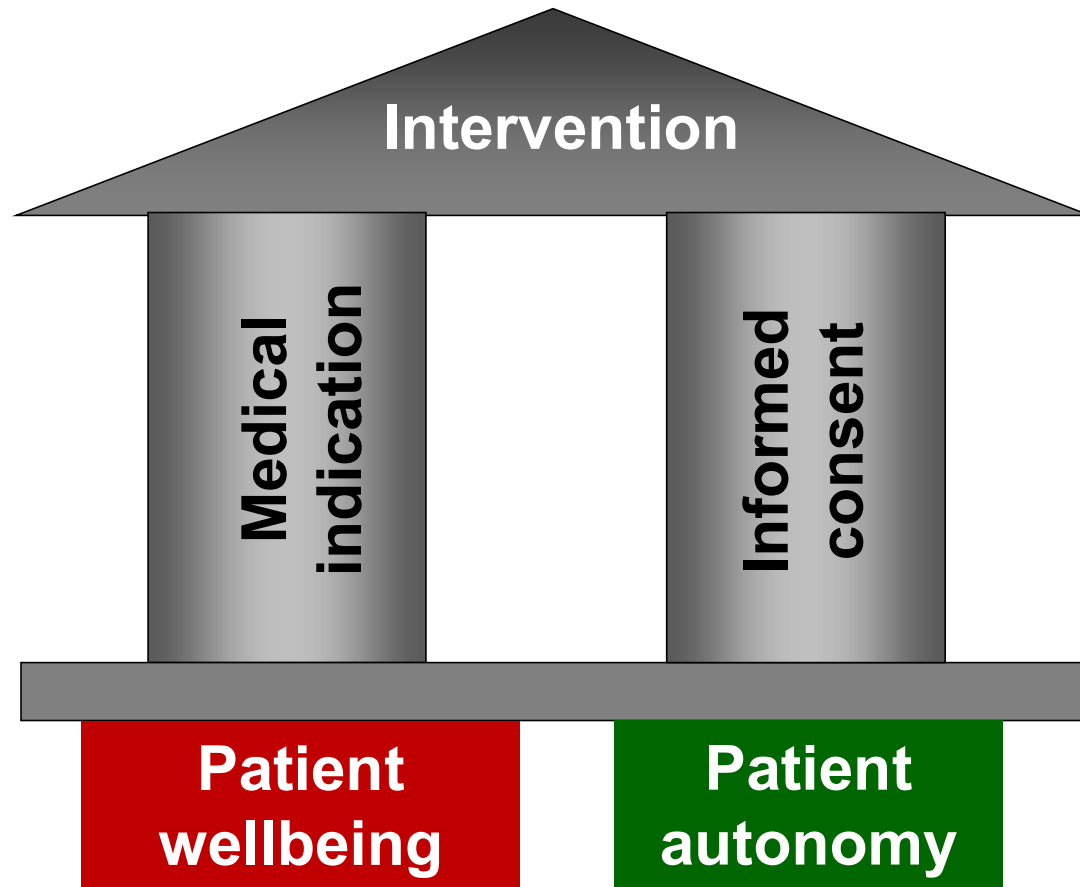
History of autonomy

- Etymology: gr. autos + nomos = self + law
- In antiquity only applied to collectivities: political independence of the Greek polis
- In Humanism and Renaissance (15-16th century) starting to be applied to the individual as marker of his/her human dignity (e.g. Pico de la Mirandola, Erasmus)
- In the Enlightenment (17-18th century) conceptualized and popularized, esp. by John Locke, Christian Wolff, Immanuel Kant
- In the 20th century bioethics influenced by Anglo-Saxon liberalism

Respect of autonomy today

- Autonomy = individual liberty to act according to one's own norms and values, one's life plan (not arbitrariness)
- Liberty right (free from violence, pression, manipulation) AND claim right (*shared decision making, empowerment*)
- Includes the freedom to delegate a decision to others
- Understood as relational autonomy (since feminist philosophy)
- Forms the basis of many patient rights (and professional obligations), including the right to bodily integrity, the duty to obtain informed consent, the right to confidentiality and data protection

Ethico-legal basis of health care



Forms of patient autonomy

Actual autonomy: Expressed will of a patient who has decision-making capacity and is fully informed and voluntary

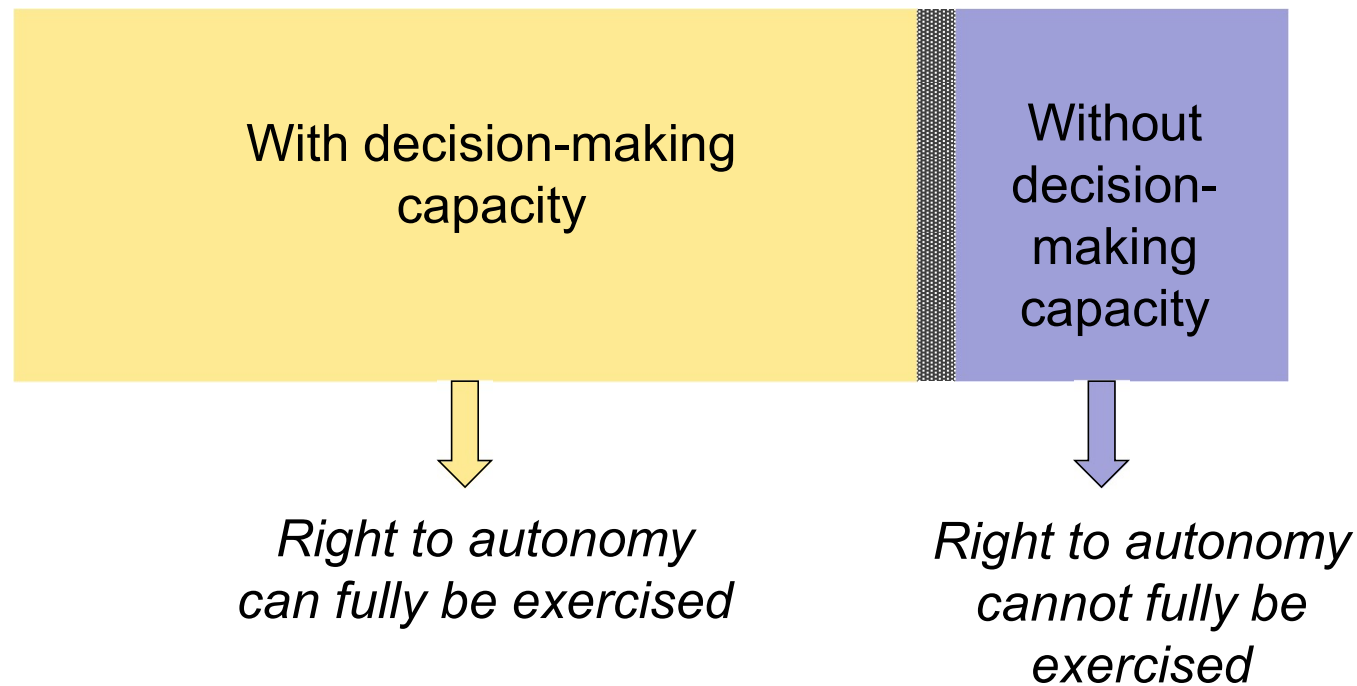
If absent

Precedent autonomy: anticipatory decisions made in advance directives

If absent

Substitutive autonomy: based on substituted judgment of surrogate decision makers

Decision-making capacity



4 essential elements of capacity

1. Understanding:

- *understanding the situation and information*
- *understanding one's own disease*

2. Deliberation/Appreciation:

- *weight consequences of the alternatives*
- *link to one's own values*
- *rational process of deliberation*

3. Make a choice:

- *able to make a stable choice*
- *not being constraint by inner forces*

4. Communicate the decision

Practical judgment

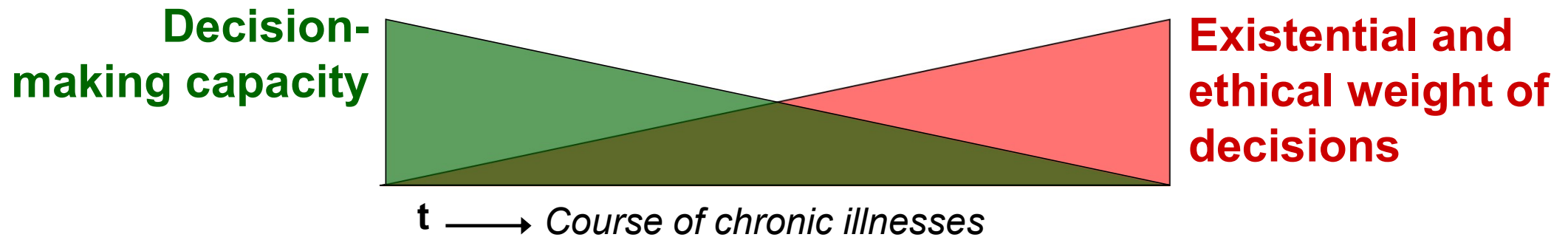
Literature

Assessment of capacity
in medical practice

 **SAMWASSM**
Schweizerische Akademie der Medizinischen Wissenschaften
Académie Suisse des Sciences Médicales
Accademia Svizzera delle Scienze Mediche
Swiss Academy of Medical Sciences

*Swiss Academy of
Medical Sciences
November 2018*

Tension



Illnesses:

Dementia

Cerebrovascular disease (strok etc.)

Cancer with cognitive sequelae

Acute delirium

...

Decisions regarding

Place of life and death

Anticipatory decisions

Emergency interventions

End-of-life decisions

...

Loss of decision-making capacity

- 40% of all patients in hospital emergency departments

Raymont V et al, Lancet 2004

- 70% of older patients for whom medical decisions have to be made

Silveira MJ et al, N Engl J Med 2010

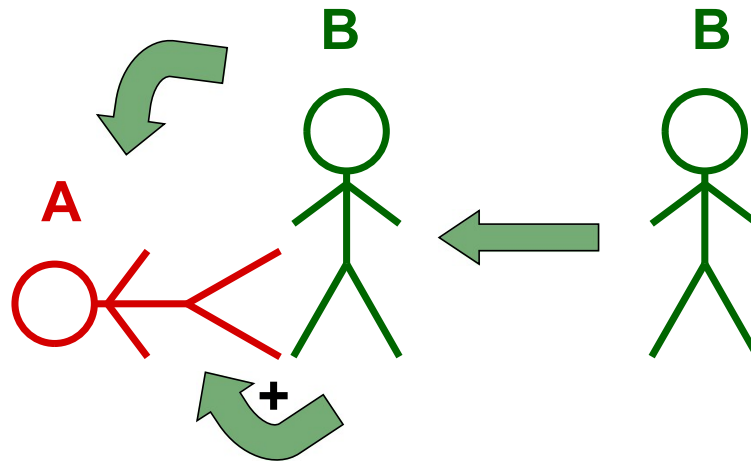
- 95% of all patients in intensive care units

Smedira NG et al, N Engl J Med 1990

- 54% of patients for whom end-of-life decisions have to be made
(survey among Swiss physicians)

Bosshard G. et al. Swiss Med Wkly 2016

Making decisions for others

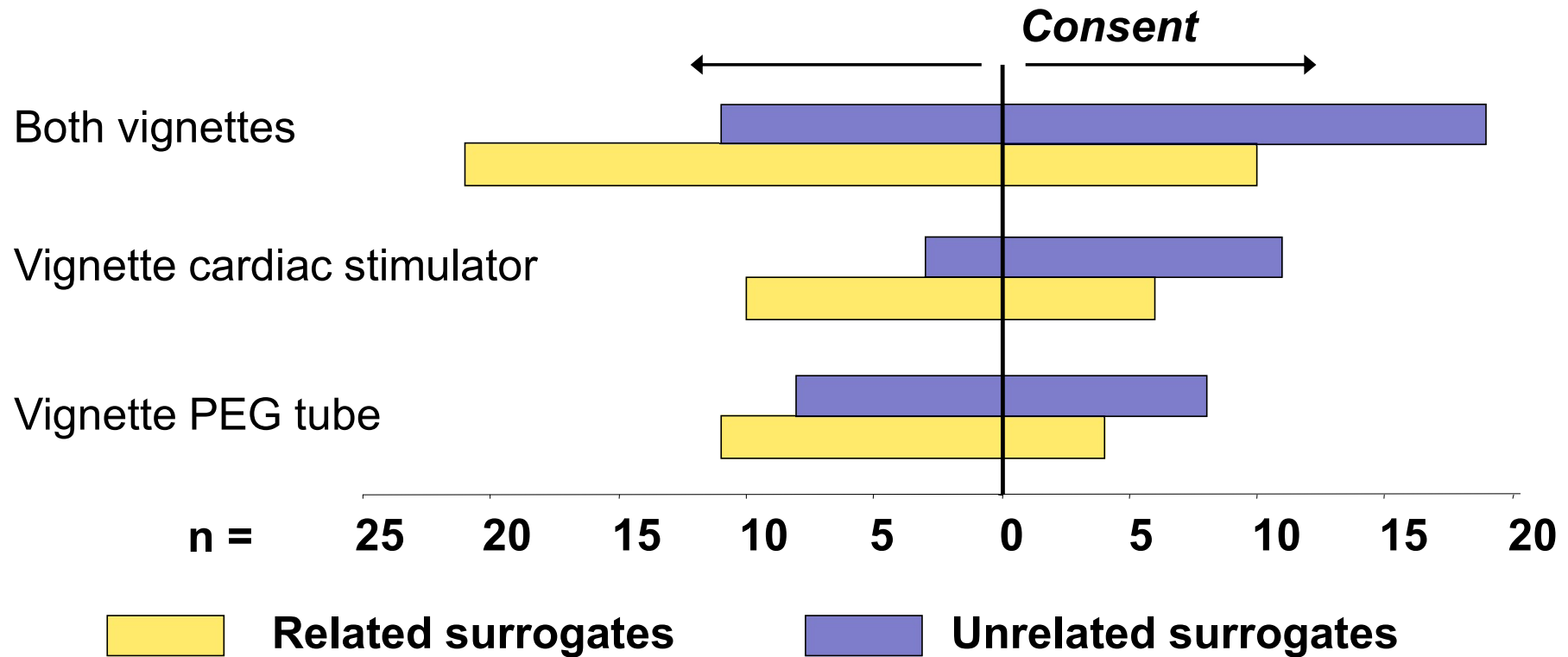


Surrogate decision makers

Related surrogates	Unrelated surrogates
Decide intuitively	Take more time to decide
Consider their own values	Try to ignore own values
Focus on patient wellbeing	Focus on patient autonomy
Consult other relatives	Consult healthcare professionals
Never call the courts	Often delegate decision to judges
↓	↓
Existential role	Professionnal role

Jox RJ et al. Int J Geriatr Psychiatr 2012

Surrogate decision makers



Jox RJ et al. Int J Geriatr Psychiatry 2012

Structure

Autonomy at the end of life

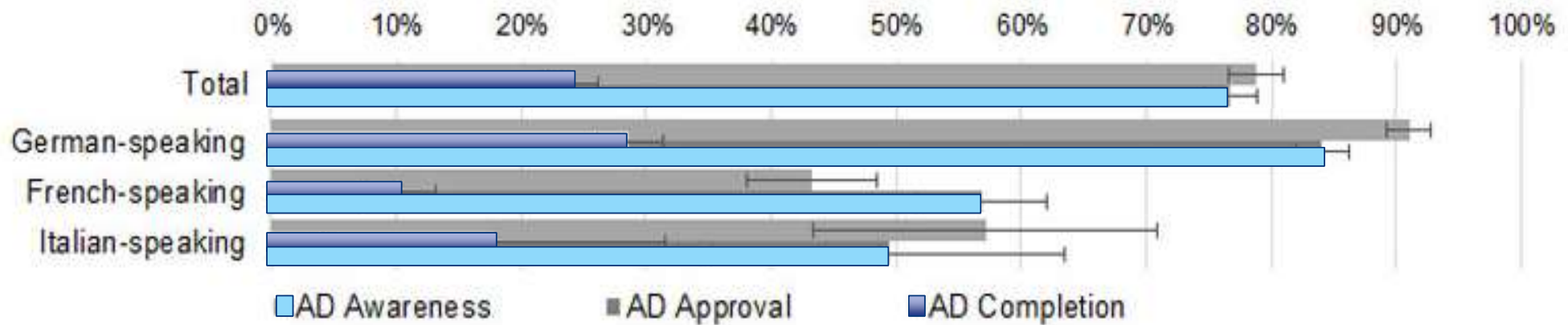
1) Ralf: Autonomy at the end of life: introduction

2) Eve: 2 different research projects from our Chair

Culture and advance directives

Awareness, approval and completion of advance directives in older adults in Switzerland

Vilpert Sarah^{a,b}, Borrat-Besson Carmen^b, Maurer Jürgen^c, Borasio Gian Domenico^d
Swiss Medical Weekly, 2018



Advance Care Planning (ACP)

Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care

Judith A C Rietjens, Rebecca L Sudore, Michael Connolly, Johannes J van Delden, Margaret A Drickamer, Mirjam Droger, Agnes van der Heide, Daren K Heyland, Dirk Houttekier, Daisy J A Janssen, Luciano Orsi, Sheila Payne, Jane Seymour, Ralf J Jox, Ida J Korfage, on behalf of the European Association for Palliative Care

Extended definition

Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.

Lancet Oncol 2017;18:e543

ACP

Primary objectives:

- Respect patient's autonomy by providing care which is coherent with their preferences
- Support people and families in the exploration and documentation of preferences before a decision is necessary
- Guide health professionals when medical decisions need to be made for patient who no longer have decision making capacity

Secondary objectives:

- ↑ Quality of life, communication, confidence in the health system
- ↓ futile/ relentless care, anxiety

ACP and dementia: 2 studies

Specific challenges in dementia: (1) long trajectory, (2) short window of opportunity, (3) crucial role of the family, (4) specific decisions

1. ADIA: Alzheimer's Disease-specific
Intervention of Advance care planning

2. PROSPECT: Promoting Self-determination for
Persons with dementia near the End of
life: a Clinical Trial (ACP by proxy)

ADIA Study

Alzheimer's Disease-specific Intervention of Advance care planning

Objectives

- **Develop** a dementia-specific ACP intervention
- **Identify** the ideal moment for initiating it
- **Explore** the feasibility and acceptability of the intervention and suitable outcome criteria for a later trial

Method

- **Pilot** one-arm clinical trial
- **Sample:** patients after diagnosis of dementia and close relatives (20-30 dyads)
- **Intervention** adapted from USZ ACP model
- Multi-method evaluation:
 - **Quantitative:** HADS, Zarit burden scale, decisional conflict
 - **Qualitative:** semi- structured interviews

ADIA Study: Challenges

- **Recruitment** : 105 screened, 46 exclusions by physician gatekeeping, 16 patients included and 11 patients completed the study
- **Gatekeeping** by professionals: (1) Taboos around dying, (2) Hostility and ignorance towards palliative care, (3) Dementia not seen as terminal disorder, (4) Competing for research participants, (5) Lacking interprofessional team culture
- **Outcome measures** appropriate for people with dementia and their relatives: balance between quantitative outcomes measure and the qualitative assessment of patients and proxies' experience

ACP by proxy - Pioneer example

Advance Care Planning by Proxy for Residents of Long-Term Care Facilities Who Lack Decision-Making Capacity

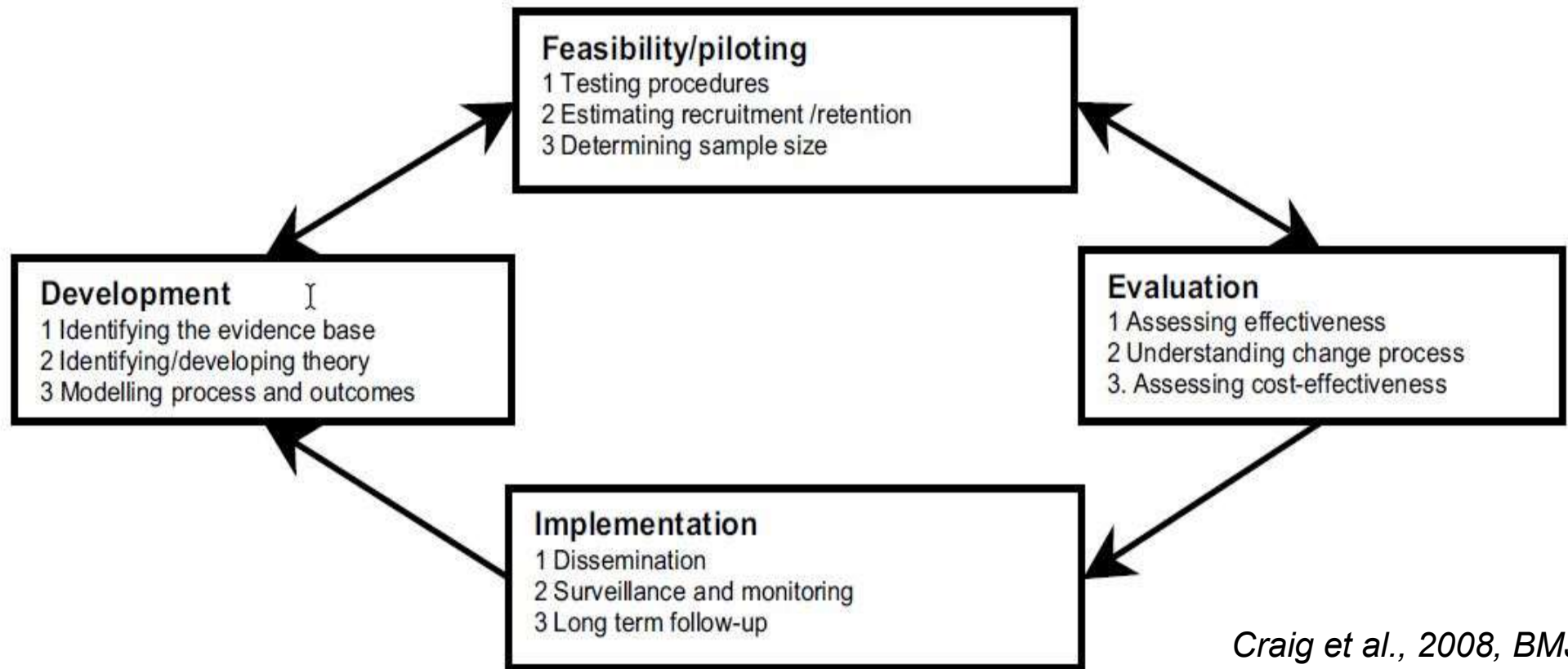
Ladislav Volicer, MD, PhD, Michael D. Cantor, MD, JD,† Arthur R. Derse, MD, JD,‡ Denise Murray Edwards, RNCS, ARNP, MA, MEd, MTS,§ Angela M. Prudhomme, JD,|| Dorothy C. Rasinski Gregory, MD, JD,¶ James E. Reagan, PhD,† James A. Tulsky, MD,** and Ellen Fox, MD† for the National Ethics Committee of the Veterans Health Administration*

“To apply the concept of advance care planning to patients who lack decision-making capacity, several Veterans Affairs Medical Centers (VAMCs) have successfully pioneered and implemented what they call “proxy plans”— a type of advance care planning in which a surrogate decision-maker or proxy represents the patient’s interests in specifying treatment preferences on behalf of a decisionally incapacitated patient.”

Volicer L et al. J Am Geriatr Soc 2002;50:761

ACP by proxy

Figure 1 Key elements of the development and evaluation process



Craig et al., 2008, BMJ

Development: Exploratory study

- **Aim:** Identify current practices, needs and potential facilitators and barriers for ACP by proxy in nursing homes
 - **Methodology:** Thematic analysis of
 - semi-structured interviews with health care proxies (n=19)
 - 3 focus groups with nursing home nurses (n= 23)
 - 2 focus groups with physicians (n=13)
- **Development of an ACP by proxy model**

PROSPECT pilot study

- **One arm clinical trial pilot**
 - 3 nursing homes (14 facilitators trained)
 - Target population: 20 health care proxies
- **Outcome measures:**
 - Feasibility and acceptability from the perspectives of health care proxies, facilitators, nursing home care directors, treating physicians
- **Data collection:**
 - Decisional Conflict Scale (proxies)
 - Self-efficacy numerical rating scales (facilitators)
 - Semi-structured interviews with proxies, facilitators, care directors, physicians

PROSPECT: Challenges

- Difficulty accessing nursing homes during Covid-19
- High turnover of nursing home staff (trained as facilitators)
- Nursing home staff facing high workloads (ACP by proxy "just another thing to do")
- Proxy reluctance to participate in research

Literature

Established in 1871

Swiss Medical Weekly

Formerly: Schweizerische Medizinische Wochenschrift
An open access, online journal • www.smw.ch

Review article: Biomedical intelligence | Published 12 November 2016, doi:10.4414/smw.2016.14369

Cite this as: Swiss Med Wkly. 2016;146:w14369

Choosing wisely at the end of life: the crucial role of medical indication

Gian Domenico Borasio^a, Ralf J. Jox^b

DOI: 10.1111/jgs.17147

Journal of the
American Geriatrics Society

Advance care planning by proxy in German nursing homes: Descriptive analysis and policy implications

Jürgen in der Schmitten MD, MPH¹ | Ralf J. Jox MD, PhD^{2,3} |
Michael Pentzek PhD⁴ | Georg Marckmann MD, MPH⁵

Swiss Medical Weekly

Formerly: Schweizerische Medizinische Wochenschrift
An open access, online journal • www.smw.ch

Review article: Biomedical intelligence | Published 30 December 2018 | doi:10.4414/smw.2018.14706

Cite this as: Swiss Med Wkly. 2018;148:w14706

Planning ahead with dementia: what role can advance care planning play? A review of opportunities and challenges

Bosisio Francesca^{ab}, Jox Ralf J^{abcd}, Jones Laura^{ab}, Truchard Eve Rubli^{ac}

Withholding and Withdrawing Life-Sustaining Treatment

15

Ralf J. Jox

*In: Creutzfeldt CJ et al. Neuropalliative Care,
Springer Nature 2019*

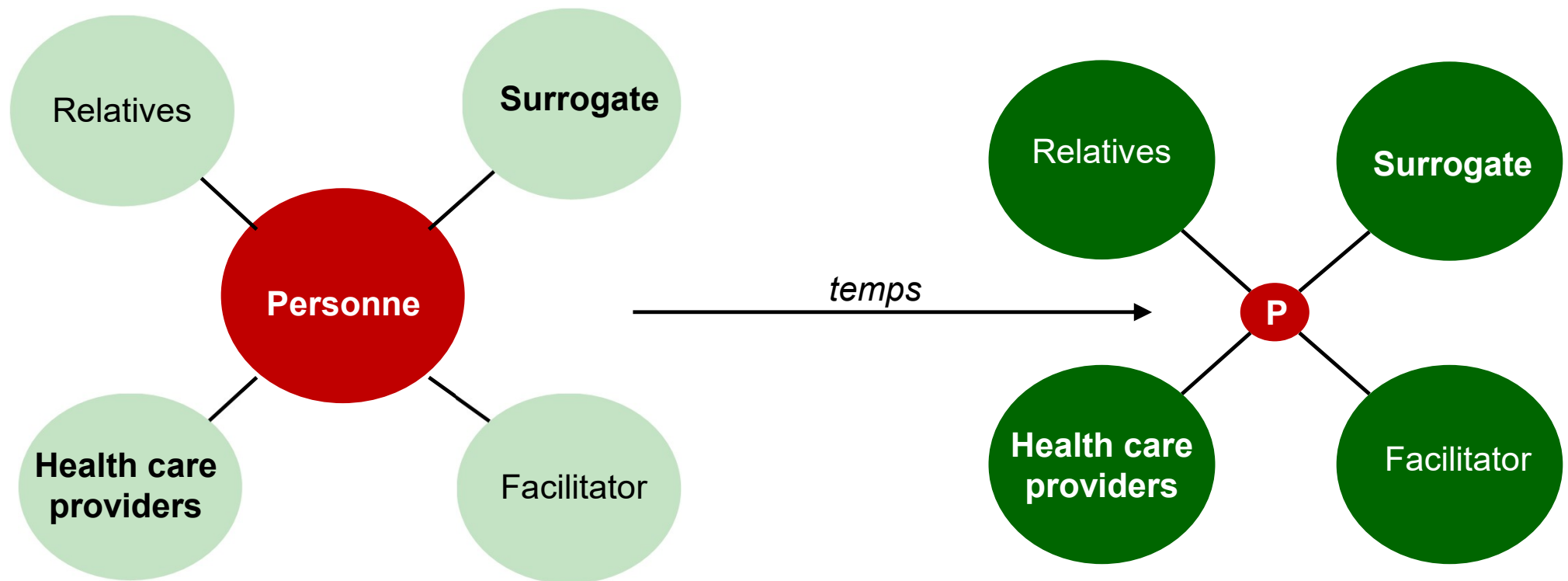
A scenic view of a Swiss town, likely Lucerne, with a large church and snow-capped mountains in the background. The text is overlaid on the right side of the image.

Thank you for your attention
eve.rubli@chuv.ch, ralf.jox@chuv.ch

Relational autonomy

*Prepare and make
advance decisions*

*Appliquer et implémenter les
décisions anticipées*



Temporal autonomy

