Right to live, right to die ?
The medicalisation of the end of life

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"O Lord, grant death to each in one's own way.
Grant that one may pass away from a life
that was filled with love, meaning, and desire.

For we are only hull and leaf.
The large death, which each carries within,
is the fruit around which all it spins."

Rainer Maria Rilke, Das Stundenbuch, Von der Armut und dem Tode

**O Herr, gib jedem seinen eignen Tod.
Das Sterben, das aus jenem Leben geht,
darin er Liebe hatte, Sinn und Not.**

Yesterday

It could be your mother, sister, friend…

Maria K.; age 82, academic, physically active, socially engaged,
- Heavy smoker, COPD, since 4 years suffering from lung cancer
- Decision with her family physician for only symptomatic treatment,
- Advanced directive notarized against any invasive therapy, artifical ventilation
- Lately increasingly problems of breathing (COPD)
- One evening in February admission at (her usual) private hospital - where the advance directive is known - because of pneumonia

- During the night cardiac arrest, resuscitated by physician on night shift (with broken ribs and sternum), sedated and intubated in ICU
- Next day, tubes are removed, palliative care provided
- Maria K. dies within 24 hours

Today
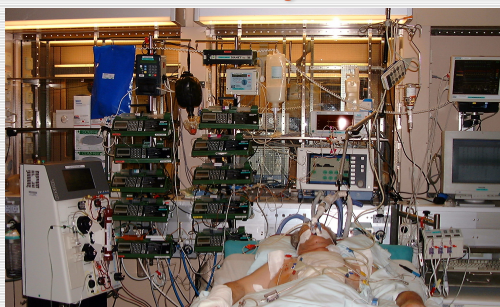
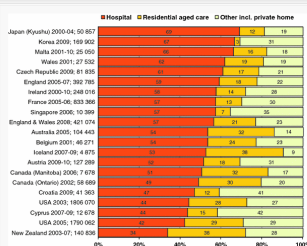## Medicalisation of the end of life

Disproportionate treatment
versus
„Salus aegroti *ultima lex*"

Place of death persons over 65 years

Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings.
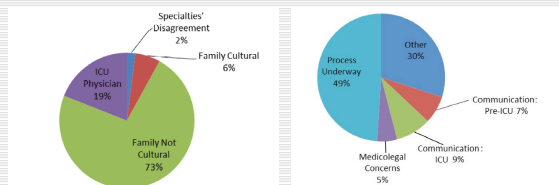*Broad JB et al; Int J Public health, 2013*

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A prospective determination of the incidence of perceived inappropriate care in critically ill patients

Singal RK. et al. *Can Respir J 2014;21(3):165-170.*

Perceived responsible parties for inappropriate life-prolonging treatment.

Perceived process issues leading to inappropriate life prolonging treatment.

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Disproportionate treatment

"**It is a clear and undisputed principle that treatments which are**
- **not (or no longer) indicated or**
- **treatments which the patient refuses must not be performed.**

There are still cases where disproportionate treatment is initiated.
This results in diagnostic, therapeutic or care-related interventions whose benefit for the individual patient is highly questionable and which may expose the patient to a stressful situation that becomes problematic."

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Causes for disproportionate treatment

- **Therapeutic ambition**
- **Justified and unjustified fear of legal consequences**
- Service invoicing logistics at the hospital
- Lack of communication within the healthcare team
- Lack of communication between healthcare team and patient
- Relatives request therapy
- Patient requests therapy

Disproportionate treatment is incompatible with two ethical principles, the principle of non-maleficence and the principle of justice.

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Austrian Bioethics Commission

2011

2015
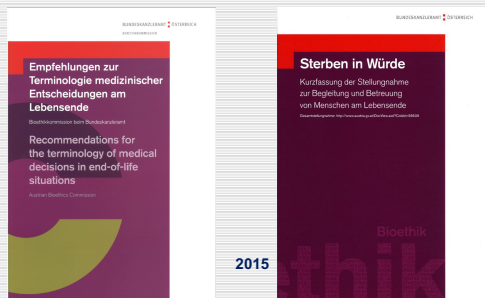
www.bka.gv.at/bioethik

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Recommendations I

Prevention of disproportionate medical interventions

- Medical interventions which provide no benefit for the patient or which are more burdensome than potentially beneficial to the patient, and which may lead to a prolongation of the dying process in end-of-life situations, **are ethically and medically unjustified** because they come at a disproportionate burden.

- The **legal conditions for complex end-of-life decisions** should take due account of this fact to allow for carefully weighed decisions without fear of criminal prosecution.

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Recommendations II
The terminology

The two following aspects are of crucial importance:

- The outdated and imprecise terms "active and passive euthanasia" need to be revised in accordance with the "Recommendations for the terminology of medical decisions in end-of-life situations" released by the Bioethics Commission.

- This shall be taken into particular account in the **education and training programs** for the legal and medical professions.

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Recommendations III

Trust and legal certainty in cases of limitation or discontinuation of medical measures which are no longer justified has to be established and to be exempted from legal punishment, when

- The therapeutic decision is based on a comprehensible, substantiated and to the individual situation corresponding decision-making process.
- ethical standards and guidelines by professional associations; academic ethical institutions or supranational institutions are followed.
- Adherence to decision-making process is guaranteed.

Compliance with clear guidelines should lead to the presumption of trust and to legal certainty for the treating physician.

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Planning for end-of-life care decisions
(living will, power of attorney, guardianship, …)

Advance planning of medical end-of-life decisions shall be promoted through the following initiatives:

- reducing the formal and financial hurdles to the establishment of legally binding living wills and powers of attorney
- defining and checking quality standards and qualifications to assure proper information of healthcare and legal professionals
- raising public awareness through a national program

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Confusion of terminology in German language

Tabelle 1. Falsche Zuordnung zu ‚aktiver Sterbehilfe'. Quellen: [20–22]

Handlung	Ärzte [20] n = 727	Richter [21] n = 479	Studenten [22] n = 85
Verzicht auf künstliche Beatmung	10,5	7,8	12,9
Beendigung einer künstlichen Beatmung	39,8	34,5	44,7
Verzicht auf Flüssigkeitszufuhr über Sonde	11,2	8,8	–
Beendigung der Flüssigkeitszufuhr über Sonde	24,8	34,0	45,9
Verzicht auf Nahrungszufuhr über Sonde	8,0	8,4	–
Beendigung der Nahrungszufuhr über Sonde	19,8	31,9	40,0

Anmerkung: Die Prozentzahlen geben die Zuordnungen der jeweiligen Handlung zum Begriff ‚aktive Sterbehilfe' durch die Befragten wieder.

Wallner J,
Finding the right words for medical decisions at life's end
Wien klin Wochenschr 2008

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Terminology of end of life decisions

Intensive Care Med (2006) 32:1304–1310
DOI 10.1007/s00134-006-0256-9   **REVIEW**

Andrej Michalsen
Konrad Reinhart

"Euthanasia": a confusing term, abused under the Nazi regime and misused in present end-of-life debate

NAZI-EUTHANASIE = Murder

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**Do we need to change?
Do we need a new culture for the end of life?
For dying in „one's own way"?**

**Respect of the patients' will
Appropriate care for the patient**

Doctors' Personal End-of-Life Preferences

Thank you for your attention!

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