



**University  
of Basel**

Institute for  
Biomedical Ethics

# **Respecting the Autonomy of Elderly Patients in Switzerland: Hindering and Promoting Factors in Clinical Settings**

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# Agenda

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1 Background

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2 Objective & Methods

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3 Results

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4 Conclusions

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5 References

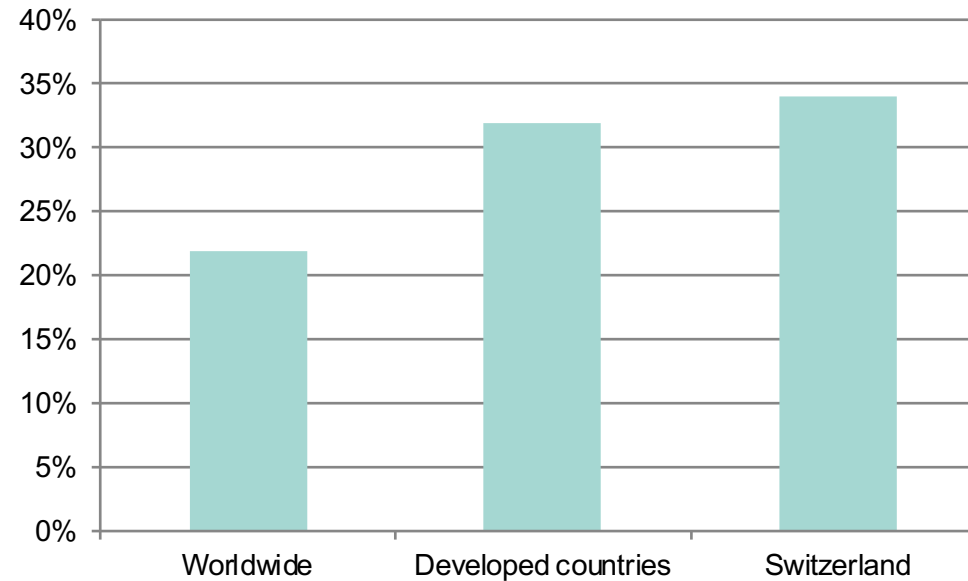
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# 1 Background

- a) Demographic Shift and Chronic Diseases
- b) Autonomy
- c) Palliative Care (PC)
- d) Swiss National Strategy on PC and Autonomy

## a) Demographic Shift and Chronic Diseases

In 2050 > 60 years



- **Ageing of population & shift of dying process**
  - ✓ Lingering dying process
  - ✓ Quality of life discussions
  - ✓ Increased need of formal & informal care
  - ✓ Institutionalized deaths

## b) Autonomy

- Central role in healthcare ethics & decision-making
- Self-governance or self-determination
- Different philosophical foundations: I. Kant vs. J.S Mill
- Prime principle in Beauchamp & Childress
- Individualistic approach (non-interference, free choice)
- Relational approach (social & “embodied” context)
- **Respect for autonomy: patient-centered care**
  - ⇒ Quality of life ↑

### c) Palliative care (WHO 2002)

- Holistic approach
- Focus of life quality
- **Respect for patients' autonomy**
- Advance directives & advance care planning



<https://goo.gl/images/scCwrU>

## d) Swiss National Strategy on Palliative Care and Autonomy

- A central aim of the Swiss national strategy on palliative care (BAG and GDK, 2012) is to favor patient self-determination. Chapter 3 of the national strategy describes the
  - „Förderung der Selbstbestimmung des Einzelnen als gesellschaftliche Aufgabe“

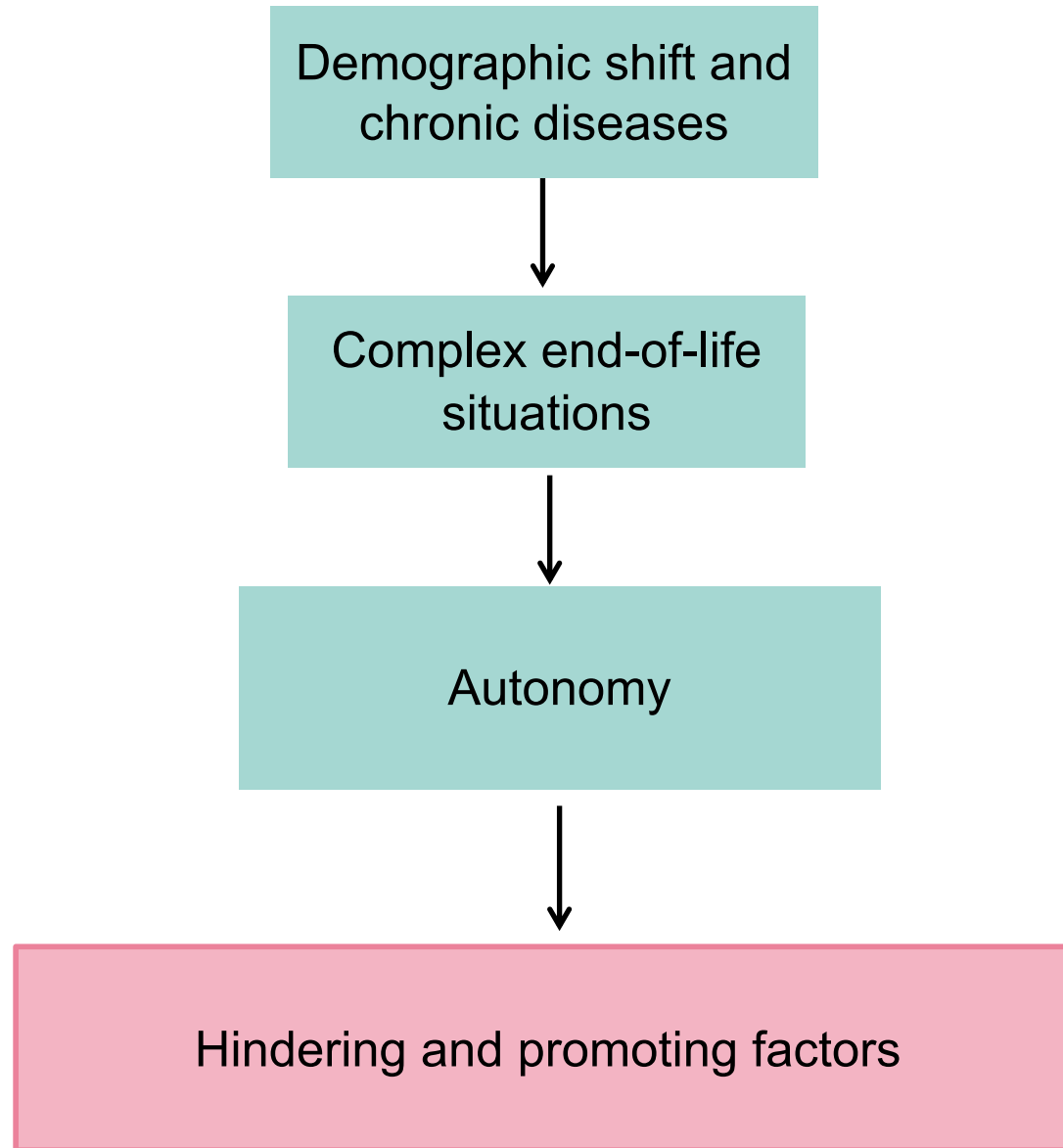
## d) Swiss National Strategy on Palliative Care and Autonomy

- «Ziel ist es, die Selbstbestimmung des einzelnen in der letzten Lebensphase zu stärken. Dieses **Bedürfnis nach Selbstbestimmung** - auch in der letzten Lebensphase - entspricht den **moralischen Grundwerten der heutigen Gesellschaft**. Die Generation, die in den kommenden Jahren das Rentenalter erreicht, hat sich stark für die Selbstbestimmung des Einzelnen engagiert und **wird sie im Bezug auf das Lebensende auch vermehrt einfordern**» (BAG & GDK, p. 11 ; Bundesrat, p. 35).
- “Palliative Care entspricht dem Wunsch vieler Menschen nach Selbstbestimmung“ (BAG & GDK, 2012, p. 11).
- “Selbstbestimmung des Einzelnen bedeutet unter anderem auch, dass die **verschiedenen Betreuungsangebote in der letzten Lebensphase bekannt sind und in Anspruch genommen werden können**“ (ibid, p. 12).

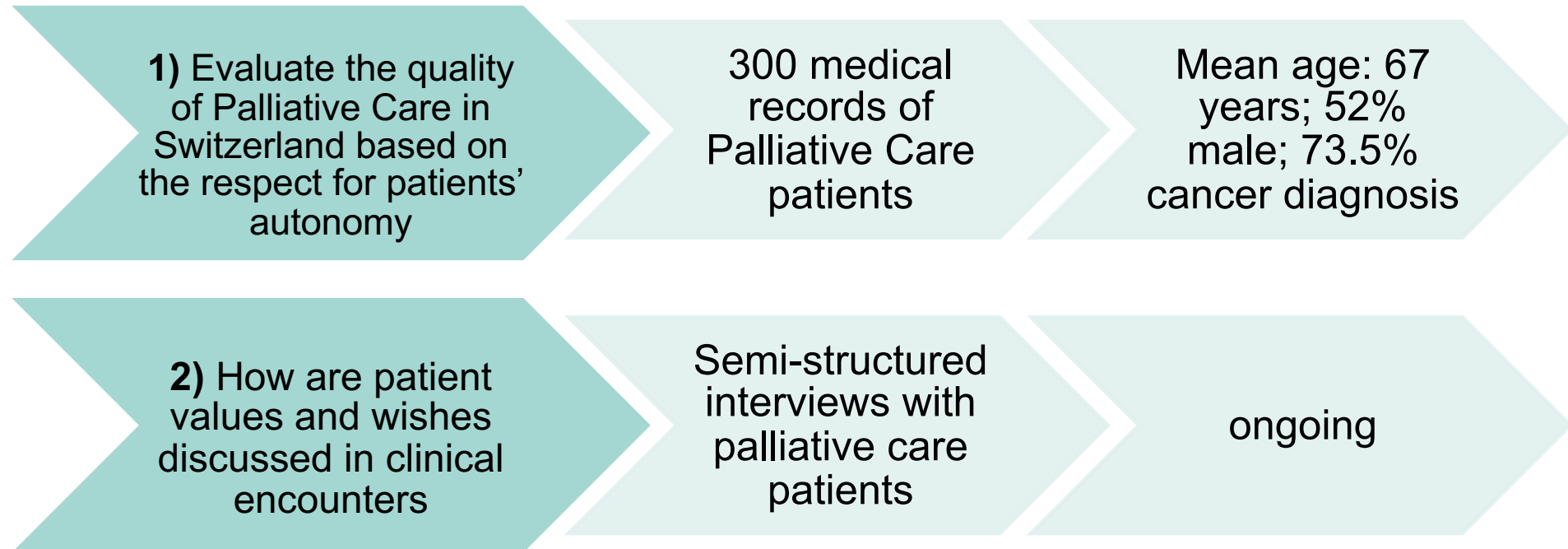


## 2 Objectives & Methods

- a) Objectives
- b) Empirical Methods



## a) Objectives and Methods



### 3) Philosophical-ethical analysis

## **b) Empirical Methods – Data Analysis**

### **1) Evaluate the quality of Palliative Care in Switzerland**

(respect for patient autonomy, 100 medical records from each site)

- Mobile palliative care consultant service at the University Hospital of Basel (USB) which provides decentralized consultations for inpatients
- Consultation at the University Hospitals of Geneva (HUG main acute care site Cluse-Roseiraie)
- Palliative care provision at the (iii) University Hospital of Bern (Inselspital).

#### **Quantitative**

- Descriptive and inferential statistics

#### **Qualitative**

- Thematic analysis of notes in medical records

## **3 Results**

Hindering and promoting factors  
for respect of patient autonomy  
in a Palliative Care context

## General findings (1)

- The majority (73.5%) of patients had a cancer diagnosis.
- Patients were on average 67.6 years old (range, 22-98 years).
- From the qualitative entries in the records burden and overburden emerged as main categories and were further divided into the two subcategories: burden for patients and families.
- According to the written notes, patients often felt burdened by financial problems, the situation at home, and families' reactions to their disease. Patients felt particularly overburdened by their own disease.

## General findings (2)

- Findings in the palliative care patients' medical records are important, as they point at factors that interfere with patient autonomy.
- Health-care personnel must be particularly aware of possible weights and tasks that might be burdensome for patients and as well of patient families and influence of these factors on decision making.
- Medical records reflect communication and permit to identify recurrent difficulties, to help discuss these and find the best possible solutions.

## Hindering Factors

### In a Palliative Care context

- Lack of mental capacity
- Burden due to a variety of factors, including medical decisions, lack of time and other resources etc. (question: how much is this the perspective of health care personnel as compared to patients?)
- Possibly too narrow concept of autonomy as individualistic and active, i.e. autonomy as active planning vs. the right to passivity (not to know, delegate decisions)
- Paternalism of formal and informal caregivers
- Hope against hope (in the form of denial of facts)



## Promoting Factors

### In a Palliative Care context

- **Advance Care Planning and Advance Directives**
  - Enabling active participation in decision-making
  - Restore autonomy
  - Restore hope (hope as positive attitude towards life)
  
- **Autonomy as empowerment**
  - Relational aspects in patient decision making
  - Taking families' and friends' perspectives into account (cave: distinction between patient wishes and wishes of the relatives)

## Example (Autonomy and Hope)

DE GRUYTER

Spiritual Care 2018; 7(2): 181–185

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### Essay

Isabelle Wienand\*, Milenko Rakic, Sandra Eckstein, Monica Escher, Nadia Pacurari, Susanne Zwahlen und Bernice Elger

## The variety of hope: findings in palliative care patients' medical records

- **Hope as a coping strategy:**
  - “Patient hopes for possible radiotherapy of the arm in order to reduce the pain; talk with patient and partner: patient exhausted, does not participate in the talk” (Medical Record [MR] Patient [Pat] 81).

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- **Hope as an active will for health improvement to happen**
  - Hope concerning surgery: “Patient hopes that his [blood] values will become better, so that he can undergo surgery” (MR Pat 30);
  - Hope for organ transplant: “Patient wishes further clarification for another liver; patient sees her severe illness and hopes for further years of quality of life and a further transplantation” (MR Pat 74);
  - Hope to have a better functioning organ: “Patient speaks of his hope that his intestine will function normally again” (MR Pat 55).

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- **Hope and other feelings (anxiety etc.), ⇒ autonomy?**
  - “Patient oscillates between hope (transplantation of the lungs) and the awareness of having reached his ‘final destination’ ” (MR Pat 60).
  - “Patient hopes time and again that the situation will improve and that he can go home; actually he knows, too, that this will not be possible” (MR Pat 92).
  - “Patient admits a form of resignation in her state, even though she asserts preserving the hope for a better state” (MR Pat 27).

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## The variety of hope: findings in palliative care patients' medical records

- **Hope as an expression of one's relation to transcendence**
  - “Son speaks of the family's hope for recovery, for a miracle, and also of the belief in the good energy which allows healing” (MR Pat 81).

Hope is not a mere coping strategy, but also a positive commitment towards life, a disposition that is present together with fear, anxiety, and lucidity. It can be related to confidence or reliance on transcendence. Hope, like imagination and belief, gives patients a kind of mental robustness or resilience to have life-oriented goals until the end of their life.

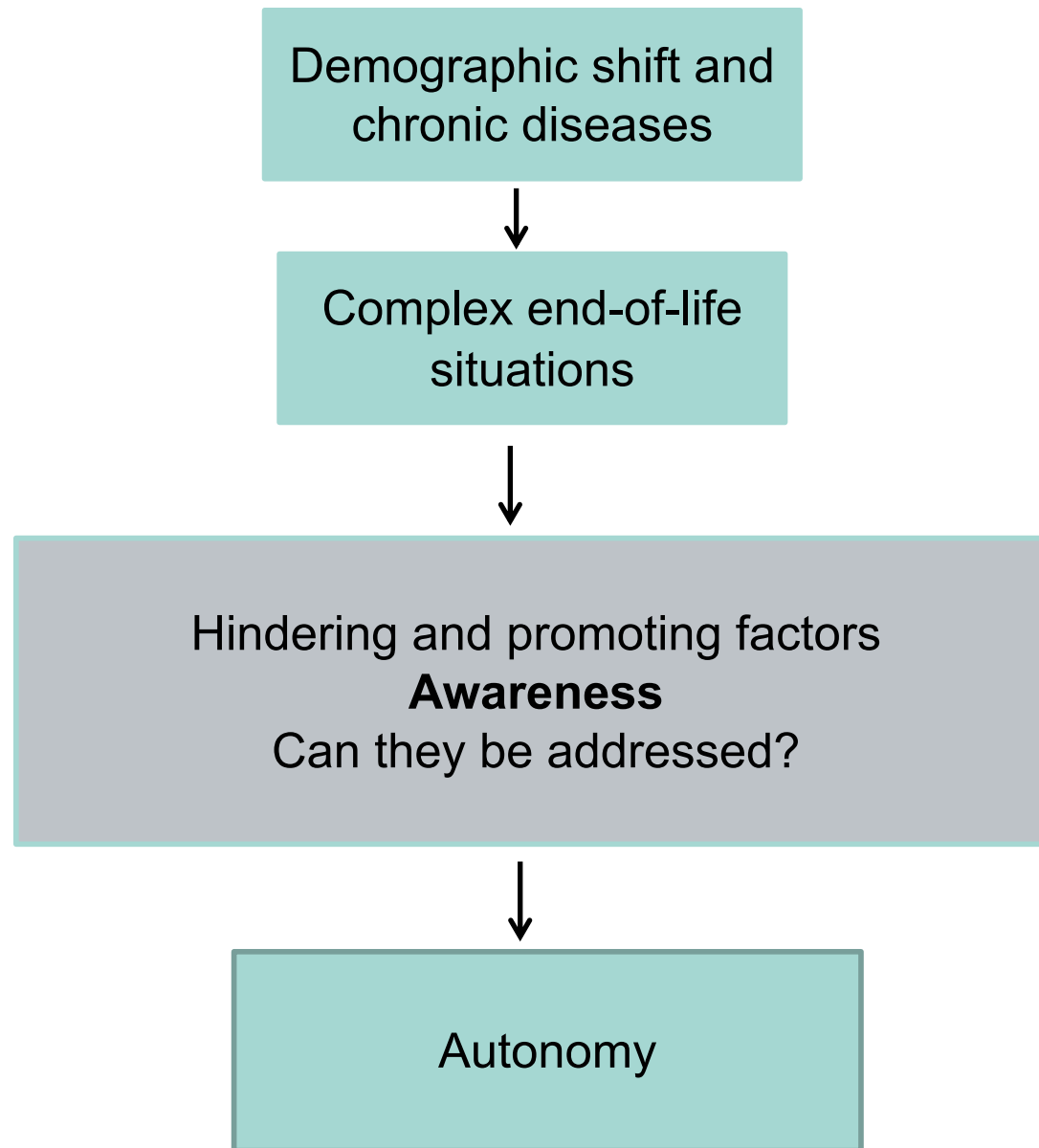
...we should diminish the contrast between the realm of the imagination (the realizable) and the realm of 'cold facts' (the realistic, Capps 2005). Patients move from one realm to the other without great difficulty (e.g. MR Pat 92).

...The coexistence of hope with other feelings is in a palliative care setting particularly important for healthcare professionals to recognize, as families are confronted with suffering and end-of-life issues, and experience hope and despair concomitantly. (Wienand et al.)

## **4 Conclusions**

- **Patients' autonomy**
  - **Shift throughout the disease**
    - Communication among the different parties involved
  - **Address explicitly burden of patients and caregivers**
    - Awareness of limitations as prerequisite for addressing them
  - **Hope: autonomy vs. paternalism**
    - Hope (mis)used as argument not to tell the truth (paternalism) vs. hope as a positive attitude to life
  - **Respecting patients' wish for a more active or more passive type of enacting autonomy**
    - Awareness of “social desirability” and social expectations





## Future steps

### Regarding research

- Qualitative research for a more in-depth understanding of autonomy
- Testing of findings through quantitative research

### Regarding practical implementation

- Workshops with clinicians
- Significance within clinical practice



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# Thank you

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