

**HfH** Interkantonale Hochschule für Heilpädagogik

# End-of-life decisions in Swiss residential homes for adults with disabilities

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## End-of-life decisions

“whether to **withhold or withdraw potentially life prolonging treatment** (e.g. mechanical ventilation, feeding tubes, and dialysis), whether to **alleviate pain and other symptoms** with, for example, opioids, benzodiazepines or barbiturates in doses large enough to hasten death as a possible or certain side effect” (van der Heide et al., 2003: 345)

- **physician-assisted suicide**
- **Palliative Sedation**

## End-of-life decisions for people with ID

- delays in receiving the diagnosis and treatment of illnesses (Heslop et al., 2014; Emerson and Hatton, 2014).
- complexity of chronic illnesses and their implications,
- ethical issues involved in terms of decision making and consent for treatment (Bekkema et al., 2013; Stein, 2008; Tuffrey-Wijne, 2003).

## Intellectual Disability (ID)

A significant impairment of cognitive functions, which is associated with limitations in learning, adaptive behaviour and skills. This disability originates before age 18 (Salvador-Carulla et al., 2011; Shallock et al., 2013).

## State of the art

- In 57% of cases (27 out of 47 cases), one or more end-of-life decisions had been made.
- People with ID were hardly involved in the end-of-life decisions.
- Relatives, legal representatives and paid care staff often played an important role (Wagemans et al., 2010; Wagemans., 2013; Bekkema. et al., 2014).

## Decision making capacity

- Patient must give informed consent to a proposed medical intervention.
  - If a person lacks decision making capacity,
    1. declaration of values or
    2. legal representative, as a surrogate decision maker
    3. Family members also have a decision making power with medical decisions (Naef et al., 2012).
    4. Action has to follow in accordance with the person's best interest.
- Best interest:  
"carrying out measures that seem to be indicated, medically and in connection with the care of the patient, and to which a hypothetical reasonable person in a similar situation would presumably agree" (SAMW, 2013b, 11).

## Palcap – Palliative Care for People with ID

### Aim of the study

- To explore the prevalence and nature of end-of-life decisions for people with disabilities in Swiss residential homes.
- To explore whether residents are involved in making these end-of-life decisions.
- To explore if there is a difference in end-of-life decisions and involvement between people with intellectual disability and people with other disabilities (sensory, physical, psychological).

## Sample and method

A cross-sectional survey with written questionnaires (N = 437; all residential homes for adults with disabilities) (Oct. 2012-Jan. 2013)

- Number of places
- Number and causes of deaths, age at death (2007-2012)
- Disability and degree of disability of person who died
- End-of-life decisions taken
  1. pain relief and symptom control,
  2. abandoning treatment,
  3. not to use artificial nutrition or respiration,
  4. palliative sedation or
  5. assisted suicide.
- Involvement of different persons in decisions

## Data analysis

- Missing data completed by multiple imputations (linear interpolation).
- Descriptive statistics, SPSS software (release 21.0).
- Chi-square tests and Mann-Whitney tests (differences between end-of-life decisions made for people with ID and for people with other disabilities or differences in involvement)
- Binary logistic regression (likelihood of experiencing the decision to withhold life prolonging treatment).

## Summary of results

- High prevalence of end-of-life decisions (70.4%)
- For people with ID the decision to abandon life prolonging treatment was more often taken (46.2%, 72 out of 156 residents) than for people with other disabilities (24.7%, 19 out of 77 residents)
- Factors influencing the decision to withhold life prolonging treatment are
  1. Presence of advanced directives ( [OR] 2.998; 95% CI 1.629, 5.518),
  2. Degree of disability ([OR] 1.677; 95% CI 1.247, 2.256)
  3. Intellectual disability ([OR] 2.265; 95% CI 1.064, 4.823)

## Conclusion

The study has implications on surrogate decision making for people with ID living in residential homes in Switzerland.

For relatives, legal representatives and formal carers it will be important to document the patient's wishes and values concerning end-of-life decisions, to assess the decisional capacity of people with ID and to document the decision making process.

## Limits of the study

- Retrospective design which favors recall bias
- Decisions were reported by directors of residential homes not by physicians
- Cross-sectional study: not possible to draw conclusions about trends in prevalence or involvement in end-of-life decisions
- Only few factors that could determine the prevalence of the decision to withhold life prolonging treatment are assessed
- Only people living in residential homes included

## Further investigations

Evaline – Development and Evaluation of an instrument to assess the decisional capacity of people with ID in medical decisions.

Investigation on factors determining the prevalence of abandonment of life prolonging treatment for people with ID will have to be carried out.

Longitudinal and trend studies will be necessary and it will be important, to analyse the decision-making processes.

Study on health status of people with disabilities at the end of their life will be needed.

## End-of-life decisions for people with intellectual disability – a Swiss survey

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