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Introduction:

- Scientific literature concerning end-of-life care shows a broad diversity in terminology and theoretical and practical concepts.
- A (new) classification has to be conceptualized, usable and practical for every participant working in a palliative care environment, comprehensible for every patient.

Methodology:

- Search in scientific databases for definitions and concepts in end-of-life care (PUBMED, EBSCOHOST en SCIEDIRECT).
- Recent articles (from 2000 on) were screened for conceptual elaborations and put in spread sheets to compare their semantic meanings.(table A)
- Proposition of the examined definitions to a group of palliative care experts (Delphi -method)
- The consensual definitions were tested in a pilot study for caregivers(n=193) (table B)

Table A: Example of spread sheets to compare semantic meanings

Table 3: SEDATION		
AUTHOR	USED TERMINOLOGY	DEFINITION
QUILL, 2000 Annals of Internal Medicine 132:488-493, USA	terminal sedation	the patient is sedated to unconsciousness to relieve severe physical suffering and is allowed to die of dehydration or some intervening complication
National Hospice and Palliative Care Organization (NHPCO).2002	Total/Terminal/Palliative Sedation	the application of pharmacotherapy to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering.
MATERSTVEDT, 2003 Palliative Medicine 17:97-101 Norway	terminal sedation	the use of sedative medication to relieve intolerable suffering in the last days
RIETJENS, 2004 Annals Internal Medicine 141:178-185 The Netherlands	terminal sedation	the administration of sedating medications with cessation of nutrition and hydration
etc	etc	etc
Proposed definition for the discussion in the Delphi group:		
Chosen definition with consensus:		

Conclusions:

An integrated conceptual approach in end-of-life care is beneficial to multiple groups:

- professionals and patients can rely on the same conceptual basis, this will enhance their mutual relationship.
- within the scientific community, a well-defined working instrument would clear out the theoretical misunderstandings that interfere with end-of-life care-situations.

A first proposition to discuss is shown in table D.

Table D:

Proposal of possible options for terminal care (for the dying)
(=aim of medical care practice in correlation with the (Belgian) laws concerning the practice of medicine)

1. Optimal support of the natural death. Allow Natural Death (= patients' rights)
2. Avoidance of medical obstinacy through withdrawing or withholding of medical futile life-lengthening acts and/ or administer of drugs with life-ending effect for a mild death with dignity. (= medical decision)
3. Avoidance of disproportional treatments (by shared decision making)(= medical decision + patients' rights)
4. On the basis of refusal of consent: withdrawing or withholding of a treatment which is futile for the patient (patients' rights)
5. On the basis of living will or request: Withdrawing of futile treatment for the patient and/or helping to take/administer of drugs with life-ending effect for a mild death with dignity. (=the juridical applicable euthanasia).
 - Administering of necessary individualized total comfort care, with inclusion of analgesic and sedative medication necessary for a good pain- and symptom control and a peaceful death with dignity which concerns each option (= patients' rights and rights of palliative care).
 - Before, during and after the process of dying, palliative care can have a supporting role for the significant others of the patient (regardless the decision made in consultation) (= rights of palliative care)

Results:

- For 10 definitions, a consensus was possible in the Delphi-group. For euthanasia and palliative care the Belgian juridical definition was chosen
- The tested care givers had most difficulties with the description of futile therapy and therapeutic obstinacy The juridical definitions were contested too.
- Key question: Can end-of-life care evolve in integrated pathways where every step to be taken leaves the chance open for (other) solutions of equal value. May palliative care, avoidance of therapeutic obstinacy, active life-ending acts etc, become part of such integrated pathways of the patient? Conceptual clarity would be a first step in this process.



Table B: Examined definitions (Delphi method) (the ten used definitions (n= 193) that agree with the description of the percentage of caregivers)

- Natural death (93 %)
- Dying peacefully, dying in dignity
- Palliative /total/terminal sedation , (93 %)
- Voluntary active/ passive euthanasia (90 %)
- Life ending acts with the patient explicit request
- Involuntary active/ passive euthanasia
- Involuntary medical killing
- Life ending acts without the patient explicit request
- Physician assisted suicide (88 %)
- Hastened death
- Futile care/ therapy (82 %)
- Therapeutic obstinacy (68 %)
- Palliative care (98 %)
- Quality of care
- Quality of life (83 %)
- Supportive, terminal, hospice care
- Advance care planning
- Pain and Symptom control (83 %)
- Alleviation of pain and symptoms
- Withdrawing or withholding life-sustaining/ life prolonging therapy (84 %)
- End-of-life decisions
- End-of-life care
- Do-not-resuscitate decisions / orders
- Non-treatment decisions
- Refusal of treatment
- (Advance directives)

