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End-of-Life-Decisions - Ethical Aspects -

Menschen sind unser Leben.

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Starting Point: Human Dignity

Normative-descriptive: inherent in each human being
Normative-prescriptive: right to respect and fulfillment

Core of human dignity:
Respect and protection of self-determination

In case of medical decisions:
physician-patient relation
as balancing act between self-determination and care
“self-determination-enabling care“ instead of paternalism

Descriptive-empirical Concept of Self-determination in Hospital

“able to do it the other way“

“I want to exhaust all medical possibilities“

“I don‘t want any further curative treatment, but palliative terminal care“

having reasons

“I want this because I cling to life“

“I want to die peacefully without much medical treatment“

accepting one‘ s own authorship

“It‘ s me who makes the decision, and not the doctor or my family“

Attitude and Tasks of the Physician

Respect

for the patient as a person who is able to decide for him- or herself

“Tell me what I can do for you“ (Mk 10, 46-52)

Information obligation

(prerequisite for self-determined decision of the patient)

Right to know – Right to not know

Prerequisite: information about the consequences of not knowing

“Right to know“

Communicating diagnosis and possible treatments

(including infaust diagnoses and limited possible treatments)

Information alone, however, is not enough
also **explanations, counselling,
accompaniment, support and encouragement**

Self-determination in case of not being able to express oneself ?

Living will declaration:

Maintenance of self-determination if the person is no longer able to express him- or herself

Problems:

- **Difficulty to predict a situation occurring at a later point of time**
 - **Possible change of attitude in case of severe illness**
 - **Difficulty to realise the will**

Only a very few living wills are applicable to specific situations and thus need interpretation.

If there is no living will or a living will is not applicable, the **presumed will** must be determined based on concrete individual reference points.

Ethical Aspects of Decisions in the Area of Medical Futility

“Medical intervention that does not lead to success“

But: what is success?

„Unsuccessful in the last 100 cases, so a likelihood of less than 1%“

Schneiderman, Jecker and Jonsen 1990

?

Futility = unclear definitions

from “barely promising“ to “very unlikely“

from “a few days“ to “several months“

including the question about the quality of life?

Shared decision finding =

individual process of assessment of prolongation of life – strains– quality of life

supported by physicians and nurses

Prerequisites to realise self-determination

Securing the basis of decision-making

Does the patient have all pieces of information?

Has the patient understood all pieces of information?

Is the patient able to sufficiently assess strains and risks?

Taking fears seriously and responding to them

Fear of pain and a painful death

Fear of a treatment without dignity

Satisfying existential needs

Not to be left alone while dying

Dying in a familiar place surrounded by familiar people

Settling unfinished things

Asking the question of meaning and communicating

Best Practice: Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

<http://who.int/cancer/palliative/definition/en/>

- **improvement of quality of life**
 - **patient and environment**
 - **pain treatment**
- **physical, psychosocial and spiritual support**

Hospice movement:

“Dying is a normal part of life”

Leaving the hospital – dying in domestic environment

Normative und Ethical Prerequisites of Palliative Care

Recognition of Basic Dignity:

„The dignity of the dying shall not be touched by his vulnerability and frailness“

Recognition of Personal Dignity:

- Taking hopelessness, fear, anger, grief, desperateness seriously
 - “being able to let go“ and support to “live here and now“
 - Strengthening self-awareness and self-confidence
 - Encouraging self-determination wherever possible
 - No paternalistic patronising
 - No unnecessary treatment and medication

Cicely Saunders
(1918-2005)

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

END

Thank you very much
for your attention