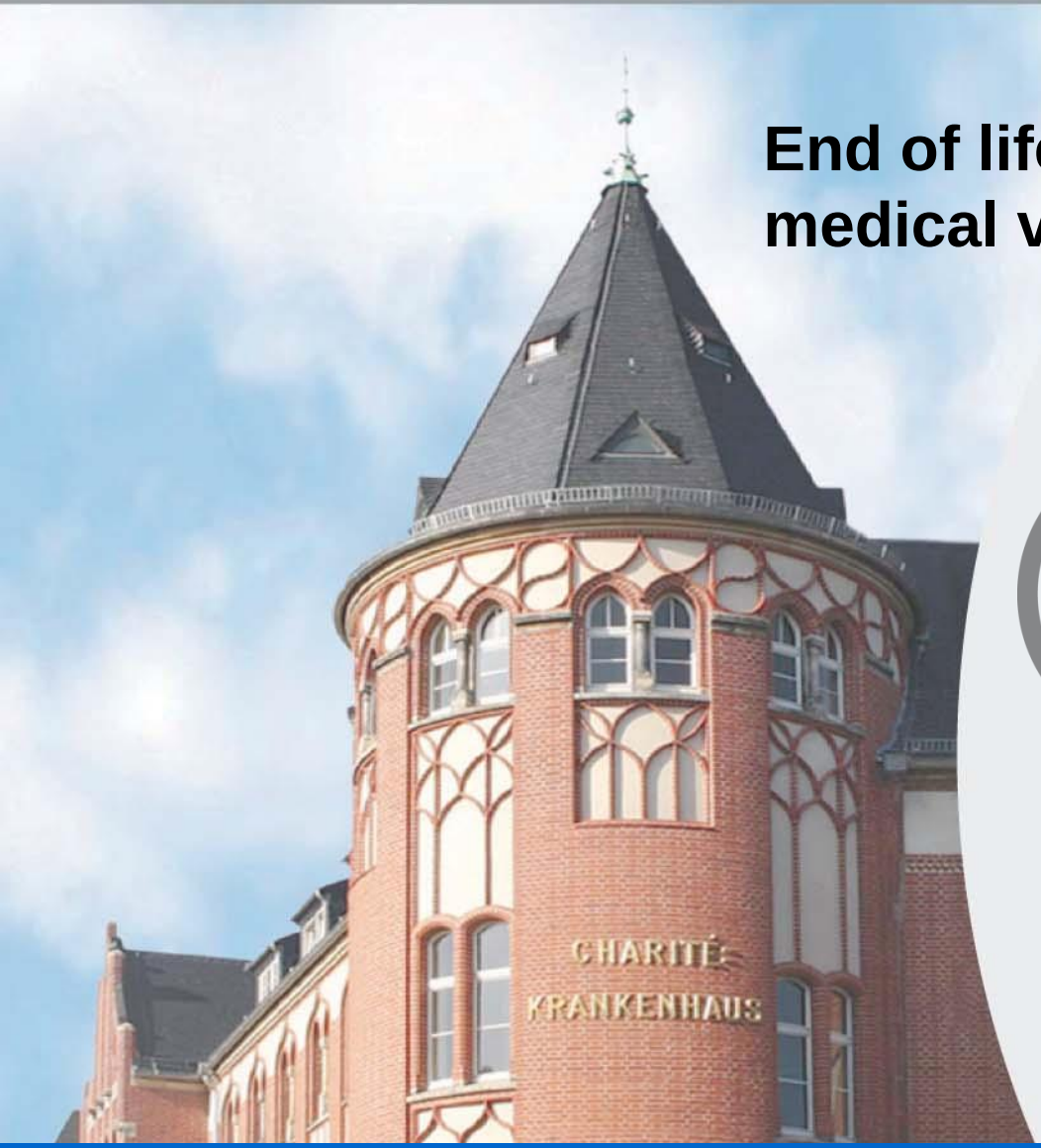
End of life decisions – from a medical view



CHARITÉ
UNIVERSITÄTSMEDIZIN BERLIN

Deutscher Ethikrat
Istanbul 26.3. – 27.3.2015

elisabeth.steinhagen-thiessen@charite.de

Truth at the end of life

- Older people think more about their own death and how to spend the end of life
- Debate: refusal, revolt, acceptance of the notion of one‘s own death –emotions are experienced in different orders

End of life decisions – from a medical view

- Situation in Germany
- Roles of the dying persons, caretakers, family members, nurses and physicians
- Palliative medicine in Germany

End of life decisions – from a medical view

- **Situation in Germany**:
- **Where are people at the end of life?**
- At home, in hospital, in nursing homes, in facilities for seniors in palliative stations, in hospices
- **Who is involved in the care of people at the end of life?**
- General practitioners and specialists in private practice or hospitals, oncologists and geriatricians in particular
- Nurses and therapists working in ambulant settings or in institutions, in mobile nursing services, in facilities for seniors in palliative stations, in hospices
- Family members, social workers, volunteers, chaplains

Institutional dying in Germany
-at home, in hospital, in nursing homes-

- Dying is often referred to as „social death“
- 92 % wish to die at home
- People with close family contact wish to die at home
- Internationally, depending on culture and morbidity, 87% opt for death at home
- 2000 65 % died in institutions,35% at home
- 2009 51% died in hospital, 20% in nursing homes, 29% at home

S.Sauer,R.Müller,H.Rothgang;ZGG, 2,2015,169-175

Dying in hospital and institutions

Whenever possible, dying should take place at home. In familiar surroundings, burden is reduced for the dying person

Dying in hospital

- Need for care and dying is often separated from family
- The notion of dying disappears from public awareness
- Contact with dying people is delegated to professionals
- The dying person becomes a patient, which can infer conflict

Last stages of life – 3 progressions-

- Oncology patients often know about their diagnosis and the majority live today with few limitations; then within few months physical deterioration and death occurs

- Progressions of non oncologic patients: acute deteriorations occur repeatedly, hospital stays and insufficient recovery

- „Frail“ old people, frequently with dementia, who are completely dependent and in need of care for a long time, low quality of life

Truth at end of life

Recipients for end of life arrangement

- **Dying persons**
- Family members and friend, the role of family
- Nurses, the role of professionals
- Therapists, the role of professionals
- Physicians, the role of professionals

-

Politicians, decision makers, all responsible for structures in hospital, in nursing homes, in hospices and palliative stations

The role of professionals

Regarding medical care of the dying:

It has to be kept in mind, that the stages of death are also experienced by the caretakers and family members and determine activity and contact with the dying person.

The role of professionals:
the most common symptoms and ailments

- Thirst: if the patient is not able to drink – deliver fluids intravenously, by pipette or sponge
- Hunger: dying people seldom complain about hunger, offer food to the very end, even if only small amounts are accepted
- Pain: any expression or gesture indicating pain must be taken seriously

Assistance and support at end of life

- There is no general instruction how assist and support a dying person!
- Signal readiness to talk
- Listen actively to the dying person
- Pay attention to non verbal signals
- The patient decides when he wants to talk
- Being silent together is also active support of the patient
- Create a calming atmosphere with cordiality and kindness
- Respect the patients even in advanced stage of physical deterioration

Dying at home, the role of professionals and family members

- Is preferable
- Considerable task for the family doctor
- Family members, friends, pastoral ministers work together
- All must have knowledge and adhere to ground rules regarding handling end of life
- Continuous and close visits of family doctor and ambulant nursing care

Dying at home in hospital or nursing home

- The dying person needs extensive care
- It is usually best to have only one caregiver for this patients and prevent frequent changes in staff
- No transfer of severely sick and dying patients to other departments or institutions
- Do not put dying person in „special rooms“
- „Rooming in“ for family members
- When patients have died, family members and other patients have to be informed (physicians‘ task in hospital)

The ethical case consultation – patients incapable of consent

- **Problem:** Patient cannot agree to or control treatments - restriction, attitude -
- Identify putative intention of patient

- **Case consultation:**
- structured approach with caregiver of patient, treating physician and senior physician, therapist, caregiver and, if applicable, spiritual guidance of 45-60 min. duration; create protocol
- One physician, not involved in the case consultation, checks the planned approach

- **Aim:**
- Bridge the gap between deficit– and resource management, as well as between frailty and resilience

The three most importent rules for good decisions at the end of life

1. Talk
2. Talk
3. Talk

nach Borasio

SPIKES – Protocol

6 Steps breaking bad news (Baile et al. 2000)

S
- **S**etting up the interview

P
- Assessing the patient‘s **p**erception

I
- Obtaining the patient‘s **i**nvitation

K
- Giving **k**nowledge and information to the patient

E
- Addressing the patient‘s **e**motions with empathic responses

S
- **S**trategy and summary

SPIKES – Protocol

1. Sep: SETTING up the interview

S

Setting up the interview

Main focus: set up sheltered environment

- e.g. provide a **quiet and undisturbed** surrounding, e.g. a doctor´s room with several seats
- Turn of beeper and avoid „transient traffic“ – avoid interruptions
- If the talk takes place in the patients' room, there should be no other patients present
- The possibility for being at par with patient should be ensured
- There should be seats available for close family members, which should also be involved in decision making

Center for palliative medicine

- Palliative care unit
- Ambulant palliative care
- Palliative medical consultation
- _____
- Day hospital
- center for grief counselling
- Training and education
- Research

Palliative medicine – ethical and legal aspects

- Self-determination of patient
- Physician and patient relationship
- Limits of treatment (chemotherapy, radiotherapy, therapy discontinuation)
- Intensive debate with questions of communication and ethics on individual base
- Assisted suicide and assistance during dying

Palliative medicine – treatment for improving quality of life

Physical aspects:

Medical control of symptoms – as pain, dyspnea, nausea, emesis, obstipation, confusion, death rattle…

Palliative medicine – physical aspects

- Fluid substitution in terminal stage
- interventional therapy, e.g. stents, laser therapy
- Physiotherapy in palliative medicine

Palliative medicine - mental, social and spiritual aspects:

During disease, during dying and the time after, the mental, social and spiritual requirements of the patient, his family and the treating team must be considered.

Palliative medicine – current recommendations

- Development of an independent and national palliative strategy for this novel discipline
- specific methods of interdisciplinary health services research, development and support
- Involvement of concerned patients and their families for working out a research agenda

Union der Deutscen Akademien der Wissenschaften, Februar 2015

Hospice movement

- Dying in hospitals and nursing homes has become common
- More than 90 % of Germans wish to die at home in a familiar environment
- Since this cannot be often not be realized, hospices have filled this gap

Aim of hospice movements

Aim of the hospice movement is to offer and realize the possibility of a conscious death. Life should remain worth living until the very end.

Aims – hospital and hospice

Hospital	Hospice
Cure - Functionally orientated	Care - matching the needs of the individual patient -integral
Patient care - to restore independence	Care - Alleviating measures
Functional care	Patient centered integral care