How palliative care is organized in Belgium.

Prof. dr. Simon Van Belle
Dept. Medical Oncology and Palliative Care
University Hospital Ghent
Belgium
Some definitions

- Palliative care
- Supportive care
- Terminal care
- Euthanasia (later)
Some definitions

• Palliative care:
  – WHO definition:

  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.
Definitions

• Palliative care (extended definition WHO) =
  – provides relief from pain and other distressing symptoms;
  – affirms life and regards dying as a normal process;
  – intends neither to hasten or postpone death;
  – integrates the psychological and spiritual aspects of patient care;
  – offers a support system to help patients live as actively as possible until death;
  – offers a support system to help the family cope during the patients illness and in their own bereavement;
  – uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
  – will enhance quality of life, and may also positively influence the course of illness;
  – is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
Definitions

- Terminalcancer.net:
  
  Palliative care is an approach that aims to help a patient diagnosed with a terminal illness. This help comes in the form of pain relief, holistic measures, care and attention to a patient’s symptoms and more. The overall goal is to improve quality of life. The goal of palliative care is not to cure, treat or otherwise delay the disease.
Definitions

• Supportive care:
  – Dictionary of Medicine:
    • treatment given to prevent, control, or relieve complications and side effects and to improve the patient's comfort and quality of life.
  – NCI:
    • Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and symptom management.
Definitions

• Terminal care (Webster dictionary):
  – Medical and nursing care of patients in the terminal stage of an illness

  – This is a branch of medicine and nursing that deals with the treatment of patients who are suffering from fatal, incurable illnesses. **Terminal care** deals heavily with issues such as pain management and addressing the emotional and psychological needs or the patient and his or her family
So what’s the difference?

The answer:

- **Curative therapy**
- **Palliative care**
- **Supportive and palliative care**
- **Etiological therapy**

Old model vs. Current model
Some historical data (Belgium)

• 1985: first palliative care unit Brussels
  – recognized in 1990
• 1985: first palliative care home-team

• 1985-90:
  – multiplication of number of in hospital PC units and home-teams (big cities)
  – creation of in hospital PC teams

• 1991: Royal decree granting “experiments” in PC
Some historical data (Belgium)

• 1993: federal working-group about PC
  – prepares structuring of PC in Belgium

• 1997: installation of regional networks of PC
  (1995 for Flanders)
  – 25 regional networks
  – per 300,000 inhabitants
  – coordinates all local projects around PC
  – representatives from authorities and caregivers
Some historical data (Belgium)

- 1997: installation of a PC function in hospices and revalidation homes
- 1997: installation of PC units in hospitals
- 1998: structuring of the PC home – teams
  - including granting of the working of the teams
  - 28 teams (at least 1 per regional network)
Some historical data (Belgium)

- **1999:** installation of “mobile support-teams” in every hospital

- **1999:** special “package” for PC
  - 483 € /month (now 589) extra for palliative patient, staying at home, max 2 months
  - no supplements for medical support (physician, nurse, ...)

Some historical data (Belgium)

- 2002:
  - “law about the rights of the patient”
  - “law about the right of patient for palliative care at the end of live”

- 2002:
  - “law about euthanasia”
Structure of PC in Belgium: background

• 3 important laws (2002):
  – Law about rights of the patient
  – Law about the palliative patient
  – Law about euthanasia
Rights of the patient

• Gives explicitly the rights to the patient for:
  – Guarantee of good quality medical services
  – Free choice of a caregiver
  – Understandable information
    • right to refuse information
    • use of an confidence person
  – Informed consent for medical “interventions”
  – Refusal of an “intervention”
  – Copy of the medical record
  – Medical secret
  – Installation of an ombudsperson in every hospital, ...
Rights of the palliative patient

• Regulates:

– the right for good quality palliative care at the end of live
– the right for information about his situation and about the possibility of having PC
Law about Euthanasia

• Definition of euthanasia (in the law):
  – making an end to one’s life by a “third” person on voluntary demand of this person

• Basic principles:
  – the third person can only be a physician
  – this physician is not prosecuted if all regulations are forefilled
  • is different of saying that euthanasia is legally allowed!
Law about Euthanasia

• Conditions:
  – patient: > 18 j, mentally competent
  – written demand for euthanasia (or with two witnesses)
  – demand: deliberately and repeated
  – hopeless situation of persistent unbearable disease (physical or psychological)
Law about Euthanasia

• Conditions:
  – patient must be informed about medical situation
  – patient must be informed about other possibilities
  – medical situation must be verified by a second independent physician (and a third if psychological based); advice noted in medical record
  – advice of treating nurses, psychologist ...
Law about Euthanasia

• Conditions:
  – at least one month between demand and execution
  – demand is revocable

• Stipulates:
  – conditions of execution of demand for euthanasia in case of coma or an situation of incompetency
Law about Euthanasia

• Describes way of reporting the euthanasia to a federal commission

• Describes this commission and way of reporting to the parliament
Law about Euthanasia

• Stipulates also:
  – No physician is obliged to execute an euthanasia
  – No other person is obliged to cooperate
  – If refused: patient has the right to consult other physician, medical record must be passed
  – Euthanasia = natural death (insurance!)
  – Law enters into force from 28/08/2002
Euthanasia: some figures

- 50% at home
- 80% cancer
- 19% of deaths = 0.82%
Organization of PC in Belgium

Intramural

Extramural

Home

Hospital + Hospices

Dayclinic
Organization of PC in Belgium

• Intramural services:
  – Hospice: palliative team
  – Hospital:
    • Palliative support team
    • Palliative Unit
Organization of PC in Belgium

• Extramural:
  – Palliative home teams

• In between:
  – Palliative dayclinic
Hospital situation

- PC Units:
  - In most hospitals
  - 6-12 beds (rooms)
  - Total number beds: 375 beds / Belgium
  - 1.5 nurses per bed (nl: 0.67) + 1 head nurse
  - dedicated psychologist, social worker, spiritual workers
  - support from volunteers
Hospital situation

- PC Units:
  - admissions from in- and outside hospital (regional physicians, home teams) (65/35%)
  - not disease driven
  - expected survival: < 1 month
  - mostly: home situation impossible to give good PC
  - patient and family friendly:
    - no limitation on visiting hours (7/7 d, 24/24 hrs)
    - separate from hospital units
Some views

UZ Ghent
Some figures (UZ Ghent)

- Cancer: 94 %; cardiovascular: 3 %, neurological: 3 %

- Male/female: 51/49 %; median duration: 11 days (1-50 d)
- Age distribution:

92 % dies in unit
18.6 % demand for euthanasia
9 % execution of euth.

60 % older than 70 y
Some figures

Referral of patients

- pneumo
- gastro
- med-onco
- radioth
- hemato
Palliative Support Team

• Mandatory for each hospital
  – Composition:
    • 0.5 phys, 0.5 nurse, 0.5 psy if < 500 beds
    • can be integrated in other team (geriatric)

• > 500 beds: proportional

• UZ Gent: 1 phys, 2.25 fte nurses, 1 psychologist
  – 600 interventions per year, 375 patients followed
Palliative Support Team

• Tasks (outside PC unit):
  – treatment and support of PC patients
  – advice other caregivers about therapy
  – implementation of PC culture in hospital
  – responsible for education and training
  – important for continuity of PC (in- and outside hospital)

  – Intervention on demand (phys, nurse, other)
Palliative team in hospices

• 2 types of hospices:
  – for “older people” without special care (ROB type)
  – for less fit people (RVT type)

• In each type:
  – at least 2 people responsible for PC
  – in connection with palliative network
  – dedicated physician
Home PC teams

- Are the extra-mural component of the system
- 1 per 200,000 inhabitants
- 2.6 fte per team; for 100 pts per year
- Typical constitution:
  - 1 physician (part-time)
  - 1 coordinator
  - 3-4 nurses, 1 psychologist, 1 adm. coworker
Home PC teams

- Responsible for the coordination of PC at home
- Are on demand
- Work together with intramural system
- Work together with patient’s physician

- Have dedicated training, can direct supportive and palliative therapy
Palliative dayclinic

• Place where palliative patients and family come together for several types of activity
• Gives limited care
• No overnight stay
• Patients return at home

• Limited number of dayclinics
Other important measures

• PC package for the patient:
  – supplementary grant for the last months (2 max): 589 € (for extra expenditures)
  – no supplements on medical or pharmaceutical costs

• Possibility of palliative leave for relatives
  – 1st degree relative
  – max 3 months
  – reimbursed: 600-900 € per month
Summary

• System build on in- and outhospital services
• Should cover all aspects
• Should encourage dying at home
• Should be of high quality (all trained caregivers)
• Does not forget the relatives of the PC patient

• Perfect?
Summary

• Never perfect!

• Problems:
  – Does not exclude futile treatment
    • Very costly!
  – Depends on voluntary entering in the system
    • Even with a law in the background!
  – Medicine is still curatively oriented, not trained for caregiving
  – Cost for the authorities
What does it cost?

• Estimation:
  – Known costs:
    • PC Units: 3,500,000 €
    • PST: 6,000,000 €
    • Home teams: 2,000,000 €
    • Hospices: 7,000,000 €
    • Networks e.o. 5,000,000 €

• Total= 23,500,000 €
What does it cost?

• Estimation:
  – unknown costs:
    • Package for patients
    • Package for relatives

• Total cost estimated: 35,000,000 € per year

• Cost of 3 months futile therapy: 10,000 €
What does it cost?

• Whole PC cost = 350 futile therapies (per year)

• = 3 / hospital per year (in Belgium)

• What is the best solution?
Thanks for your attention!

Tänan teid tähelepanu eest!