



Problems at the end of life

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Introduction

- Literature shows that many patients are hospitalised during the final months of their lives (De Korte-Verhoef et al., 2013) although preferably patients want to die at home (De Korte-Verhoef et al., 2013)
- Most common problems are respiratory problems (De Korte-Verhoef et al., 2013)



Guaranteeing quality of care at the end of life remains challenging





Introduction (2)

- No valid methods to predict death thus difficult to streamline patient management (Coombs & Long, 2008)
- Use of pathways has no proven positive effect on quality of care
- Different opinions on care options at the end of life



Need to define hospitals approach to care
Need for clear terminology / frameworks

A conceptual framework



- Flemish Palliative Care Federation takes active part in discussion since start of euthanasia debate
- Ethical issues at the end of life are not just restricted to euthanasia
- Still a lot of confusion about different aspects of end-of-life care

Development of conceptual framework:
'Treatment decisions at the end-of-life'





A conceptual framework (2)

3 Major categories are distinguished

1. Choices with regard to curative or life sustaining treatment: is such a treatment initiated or withheld, continued or withdrawn?
2. Choices with regard to palliative treatment and symptom control: all treatments aimed at maximizing, in an active way, the incurably ill patient's quality of life and comfort
3. Choices with regard to euthanasia and assisted suicide, where lethal medication is purposefully administered.

1. (Foregoing) life sustaining treatment



- Life threatening disorder often evolves in an adverse way
- Physician and patient face a number of difficult choices

First series of choices relate to curative or life sustaining treatment

Whether or not to withhold a treatment will have an effect on quality of life and time one has left.



(Foregoing)life sustaining treatment

1.1 (Non)-treatment decisions

- Rarely clear cut decisions
- Depending on:
 - Success rate?
 - Meaningful vs futile?
 - Quality versus quantity?
- Importance of values and appreciations of patient
- Imperative to involve patients in decision making

- Initiating or continuing a curative or life sustaining treatment
- Non-treatment decision: “withdrawing or withholding a curative or life-sustaining treatment, because in the given situation this treatment is deemed to be no longer meaningful or effective

(Foregoing) life sustaining treatment



- ## 1.2 Refusal of treatment

- The right for physical integrity implies respect for the choice of a patient
- Health care workers have the duty to express their concern

Refusal of treatment: “withdrawing or withholding a curative or life-sustaining treatment, because the patient refuses this treatment”





2. Pain and symptom control

- Sometimes treatment fails
- Care shifts from curative to palliative
- Palliative care is:
 - Active care
 - With focus on comfort
 - Interdisciplinary and comprehensive
 - Treatment of symptoms

Pain and symptom control



- 2.1 Pain Control

- A lot of attention for treatment of physical pain
- Nevertheless still a lot of patients die with substantial pain due to lack of experience in palliative care
- Importance of principle of proportionality

Pain control is: the intentional administration of analgesics and/or other drugs in dosages and combinations required to adequately relieve pain.”



2. Pain and symptom control

- 2.2 Palliative sedation

- Sometimes patients experience refractory symptoms
- Administration of palliative sedation can be considered
- Importance of consent of patient and family
- Importance of principle of proportionality

Palliative sedation:

“the intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms”

3. Euthanasia & assisted suicide



- Exceptional category - often controversial
- Aim at shortening or terminating life
- 3 kind of acts can be considered in this category



3. Euthanasia & assisted suicide

- 3.1 Voluntary euthanasia
 - Always an active intervention
 - Action is carried out by another person than the patient himself
 - Patient requests a termination of life
 - Implies competent patients

Voluntary euthanasia:

“The administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at this patient’s request”.

3. Euthanasia & assisted suicide



- **3.2 Assisted suicide**

- Patient performs the action
- Legal status of assisted suicide in Belgium is obscure because it is not mentioned in the euthanasia law
- Switzerland and Oregon (USA) allow assisted suicide under certain circumstances
- The Netherlands allow voluntary euthanasia and assisted suicide in the same way

Assisted suicide:
“intentionally assisting a person, at this person’s request,
to terminate his or her life”.



3. Euthanasia & assisted suicide

- 3.3 Non-voluntary euthanasia

- Lethal medication is purposefully administered without the patient's request
- Cf. disproportionately raising pain medication

Non-voluntary euthanasia:

“The administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at this patient's request”.

Conclusion



- This framework tries to create a necessary foundation for a meaningful dialogue
- Palliative care offers best possible quality of life to patients and families
- Delicate ethical decisions have to be made
- Importance of being careful
- Patient's voice plays a central role
- Specialised advice and professional support
- Importance of advanced directives

