MDEL
- medical decisions at the end of life

Christine De Bosschere *

In the care practice various concepts and definitions are used regarding the end of life.

Not so long ago the words 'active' and 'passive' euthanasia were frequent concepts in assistants' language use.

Passive euthanasia was usually used when talking about stopping or not starting a medically useless treatment; while active euthanasia consisted of administering products which are known to cause death. The Belgian Law on Euthanasia of 28th May 2002 has provided clearer definitions for euthanasia. The previous concepts are outdated and are no longer used. This legal definition of euthanasia delimits other actions regarding the end of life. Now that we are clear about what euthanasia is, we of course also know what it is not. This legal clarification also has concrete consequences for the care practice. It is an incontestable fact that this has lead to a legalisation of the care practice (and care ethics).

Despite of the clarification of the concepts by the law, the translation to the care practice of assistants is an important challenge in every facility for health and wellbeing.

To be complete I will follow the route of the "Group of 6", in which I will however mainly elaborate on the practical side of 'euthanasia' and 'palliative sedation'. With in addition a focus on the nursing aspects. For further legal and ethical study I refer to the 'Law' and 'Ethics' classes.

Group of 6

The group of 6 is six actions at the end of life. The group of actions at the end of life consists of a broad spectrum of actions regarding the patient's (sometimes) nearby stage of dying.

The problem of euthanasia is part of the much broader topic of the ending life and dying. Euthanasia is however the only concept regulated by the Belgian law on euthanasia. This implies that a number of actions regarding the end of life are not euthanasia. Regarding this matter we distinguish five other categories:

- assistance in suicide
- termination of life by administering lethal (deadly) means without the patient's explicit request
- termination of life by intensivating pain and/or symptom relief
- non-treatment decisions
- controlled or palliative sedation.

In literature 'controlled sedation' is sometimes added to the category 'termination of life by intensivating pain and/or symptom relief'. We will however choose not to do this because of various reasons. On the one hand palliative sedation is exclusively aimed at relieving symptoms, but on the other hand a

*Comunicação proferida no encerramento da Pós-Graduação em Enfermagem Médico-cirúrgica da ESS-IPS, , 13 de Fevereiro de 2008.

narcotic state is strived after because of the refractary (untreatable) character is the symptoms This consciously wanted condition of sleeping adds no further dimension in comparison to the classical pain relief. So a separate group.

1. Non-treatment decisions (NTDs)

'The term NTDs or non-treatment decisions is used when the doctor decides not to start a treatment or to stop the treatment, because these actions do not contribute to solving the medical problem or maintaining and improving the patient's medical condition (Leenen, H.J.J.,1994). This is opposed to therapeutic stubbornness.

So we distinguish two categories:
1.On the one hand stopping (ceasing) a medically pointless treatment.
2.On the other hand not starting up (neglecting) a medically pointless treatment.
An example is a do-not-reanimate declaration (DNR).
If it is no longer medically sensible to reanimate someone, this decision is part of the so-called non-treatment decisions and this is not the same as euthanasia.

Non-treatment decisions are usually included on so-called limitation forms or DNR protocols. In certain cases we talk about protocols related to medical agreements at the end of life. In these protocols the spectrum of medical agreements at the end of life includes more than just non-treatment decisions.
Important: preliminary consent by the patient needed! The doctor is at least bound to the obligation of information to the patient or their representative (see 'law' classes). Good trend these last few years: Doctor and patient decide together and the family is also heard... The patient's interest is however the primary objective!

Purpose of a limitation form
-Striving after a dignified process of dying;
-Informing doctors on call and nurses;
-Creating clarity regarding agreements that have been made.

Steps

1.Code 1: do not reanimate:
- no external heart massage
- no defibrillation
- no intubation
- no artificial respiration

2. Code 2: not expanding therapy:
no: antibiotics, vasopressors, intubation, anti-aritmics, artificial feeding and administration of fluids, transfer to the hospital, dialysis, blood products, ...

3.Code 3: building down therapy:
Stop... treatments (to be determined individually)
This form should be kept in the medical and nursing file. With a clear message of the treating physician, responsible for the decision with their signature and stamp and date and time of the decision.

Remark: right to information! If the patient does not wish to be informed, they have the right to.

2. Termination of life by intensivating pain and/or symptom relief.

A common care practice at the end of life is administering pain medication.
The HALP study proves this (Actions of doctors at the end of their patients' life) (Deliens, et.al., 2000). This research has shown that most people die as a result/ by a side-effect of advanced pain relief.
The most frequent form is administering Morphine®. The question: "Does increasing Morphine® equal committing

euthanasia?"
The answer is much nuanced:
- Yes, if the doctor increases the Morphine®, at the patient's request and with the intention to cause death.
- No, if Morphine® is increased without the patient's request and only with the intention of shortening life. This is termination of life without the patient's request (in legal terms: murder).
- No, if Morphine® is increased for pain and symptom relief. Pain and dyspnoea are almost the only indications for the use of Morphine. And sometimes this can be hard to assess. If the Morphine® is increased to meet the pain problem, we are talking about pain and symptom relief. In some cases this has in fact a life-shortening effect, although research has shown that the life-shortening effect of Morphine® is not as big in practice (sometimes not, sometimes a few days, ..). (Deliens, et.al., 2000).
Administering painkilling medication with a possible life-shortening effect is considered to be medically correct and belonging to the normal medical practice.

3. Termination of life by administering lethal (deadly) means without the patient's explicit request

Assistance in suicide
The doctor hands the medication or assistance equipment over to the patient. The patient decides to take this (over)dose (out of free will). (Legislation depends on the country: Example: As opposed to the Netherlands the Belgian legislator has not opted to have 'assistance in suicide' fall under the law on euthanasia).
(consideration: psychiatrics... large amount of suicides). See 'Ethics' classes (PAS: physician assisted suicide).

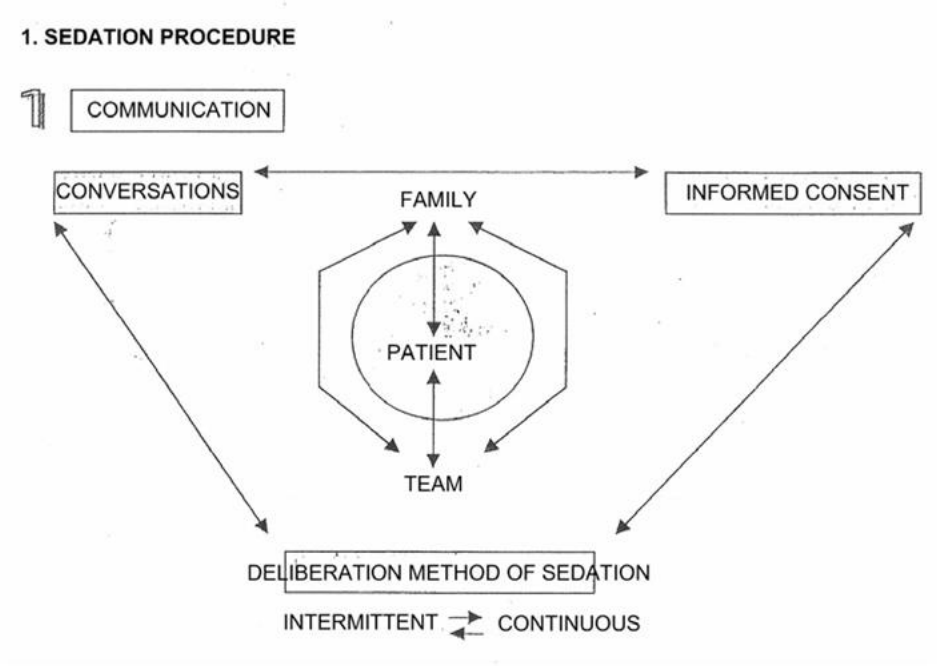
Controlled sedation or palliative sedation
What is palliative sedation?
Definition: Administering sedatives in dosages and combinations required to decrease the terminal patient's consciousness necessary to adequately control one or more refractary* symptoms. (Broeckaert, B. , 2000).
* refractary symptoms are 'untreatable' symptoms. These can be physical as well as psychosocial, emotional or spiritual symptoms.

In other words:
1. titrated administration of sleeping medication to a terminal patient
2. for unbearable (determined by the patient) physical and/or mental suffering for a person with a (pre)dying body.
3. pain that does not subside despite optimal palliative total care

Refractary symptoms
- any symptom that is perceived as unbearable by the sick person
- pain, dyspnoea, nausea-vomiting, constipation, diarrhoea, anxiety, confusion, terminal distress, haemorrhaging, psycho-social (no longer being able to..) (The latter was added).

Conditions
Explicit and repeated request by the terminal patient, unless the refractary symptoms make communication with the patient difficult or impossible.

Criteria of being careful
- PS is done in a PC team (multidisciplinary), after deliberation with the family doctor.
- The patient expresses a strong wish to 'go to sleep'; their doubts are taken into consideration at all times
- The patient, their family and persons providing care are clearly informed about what PS is and how it is done.
- The patient agrees with this procedure.
- The persons involved receive the time to get used to the idea, to talk about it,



to say goodbye.

- The administration is done with the family's knowing (objective: consent).

Objective: stopping the unbearable suffering / The objective is symptom control.

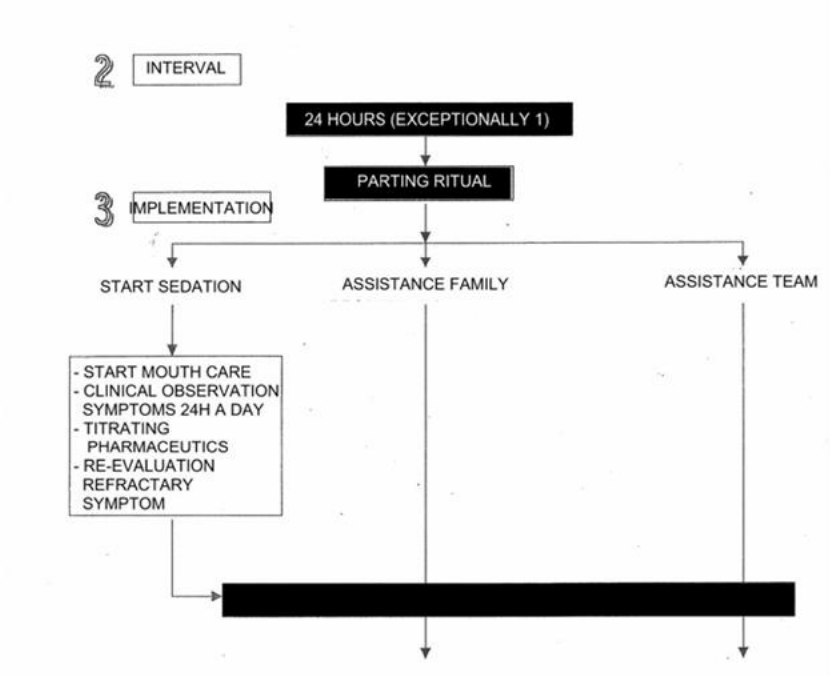
Remark: This is part of 'Medical actions' ** and can be done by any doctor.

Performing palliative sedation is part of the entrusted actions by nurses under the doctor's orders. No registration document is required.

** Medical action: any action intended to or supposed to intend to examine the condition of health of a human being, or tracking diseases and flaws, or making a diagnose, setting up or implementing a treatment of physical or mental, real or supposed condition, or inoculation.

Procedure (may differ for various countries and hospitals)

Possibly according to own plan of actions. First certainly having a conversation with the psychologist



(checklist).
First we examine whether there are no other possibilities; this is not applied lightly...

Generally: how?
- Intravenously or subcutaneously (especially in home care). If subcutaneously: usually in a second pump because if you increase the Dormicum® you would also increase the other medicines.
- Is also possible intermittently (e.g. having them wake up before a visit...).
- 'mild' sedation: Dormicum® tot 5 mg per hour: induces a light sleep; may be interrupted;
(Dosage depends on the weight, mental pain... and is considered day by day) The sensitivity for benzodiazepines, and also for Dormicum® is very different individually.
- 'deep' sedation (sleep): Pentothal® 2.4 up to 4 gr per 24 hours, depending on the need for the depth of sleeping: has to be given intravenously and very slowly! Certainly not for bolus because you would create a respiratory arrest. These are anaesthetics! (Dormicum® is not)
For instance: for ethylics this is used because benzodiazepines such as Dormicum® have no effect on them.
- initially has to be closely monitored by a doctor
- lasts in average 1.5 to 2 days (depends on the wishes). Cannot be predicted! (Especially for younger people it may last for several days)
- do decubitus prevention
- provide free airways (lying on the side)
- prevention of urine retention (bladder purge) (otherwise: unrest because of sensation of having to urinate in their sleep). Patient is asleep, but not anesthetized (unless for Pentothal®) whereby the sleep is hindered by the sensation of having to urinate... So: this is why we always have to place a purge!
- total care, also for beloved ones.
- serene "silent room" atmosphere
- guarding the dying person, calmly waiting for death to come (poss. volunteers).
- titrating the depth of the sleep
Remark: this still is not 'the' solution!
Example: young person unconsciously remaining to fight...

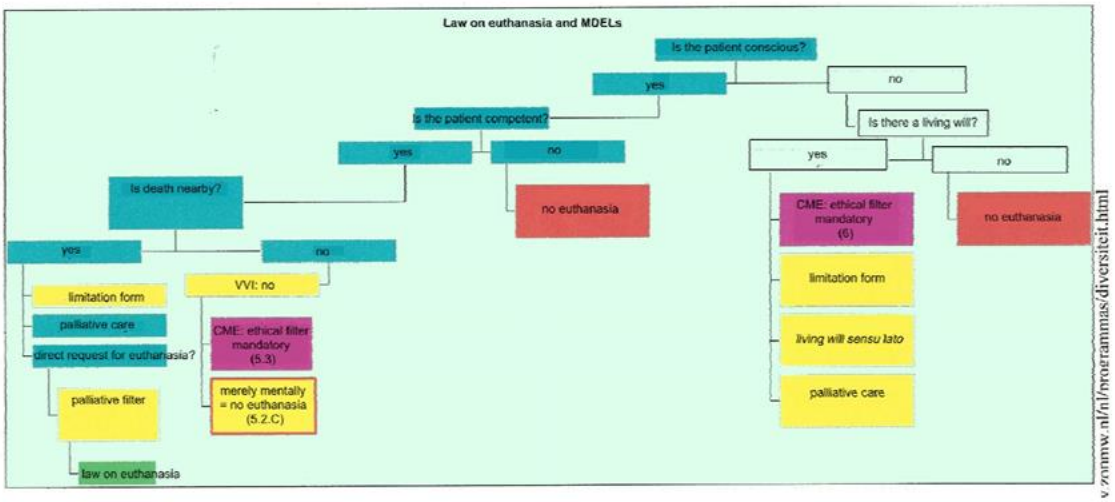
4. Euthanasia

When discussing MDEL I do not want to put the acts of committing euthanasia centrally. This is linked to the fact that certain other treatments at the end of life control the daily care much more.
It is however very important that the person providing care has enough medical, ethical and legal knowledge of the acts of euthanasia. Furthermore this knowledge also contributes to the correct delimitation of other actions of the Group of 6.
For any detail of the law I refer to the 'law' classes.
This is about the principal procedures enabling the person providing care to assess the actions at the end of life in a correct legal, medical and ethical way, with enough background information.

EU = good - THANASIA= death (Greek)

Definition: the wilful life-terminating actions by someone else than the person involved but on their request (Belgian law).
Conditions: The request has to be voluntary, considered and repeated. This has to be a condition of continuous and unbearable physical or mental suffering that cannot be stopped. The suffering has to be a consequence of a severe and incurable affliction or of an affliction caused by an accident or a

ANNEX 3: Chart



disease.
In other words: When? For unbearable suffering (usually) in a terminal patient. This suffering can be physical, mental, social, emotional, and spiritual. Objective? Terminating life.
Procedure: see legislation.

Remark: - Is *not* part of strict medical actions*** and no doctor can be obligated to perform euthanasia.
** Medical action: *any action intended to or supposed to intend to examine the condition of health of a human being, or tracking diseases and flaws, or making a diagnose, setting up or implementing a treatment of physical or mental, real or supposed condition, or inoculation.*

No other person can be forced to cooperate in committing euthanasia! Also pharmacists and nurses cannot be obligated to cooperate.

Clarification:
In doing euthanasia, a doctor does not commit a crime if:
The subject is not a minor!
Request: voluntary, considered and repeated and without external pressure.
This is about a medical condition without a future, caused by a severe and incurable affliction caused by an accident or a disease.
If the physical or mental suffering is continuous.
(Remark: for mental suffering a psychiatric label is necessary, e.g. a 90 year old person tired of life, cannot receive euthanasia by principle).

NECESSARY PLAN OF ACTION:
The doctor has to:
- consult with the patient: about the severity, the condition and the remaining options, including palliative care.
(e.g. Christian hospitals say there has to be a palliative filter so ordinary doctors cannot commit euthanasia by themselves because they might not know enough of the possibilities of 'palliative care'. So the palliative support team is always consulted).
- being convinced of the continuous mental and physical suffering and having had multiple conversations about this with the patient, spread over a reasonable period of time. (Very exceptionally this can sometimes be concluded in 2 days, but because of the very quick progression of respiratory problems in a quickly growing tumor..).
- consulting another, independent doctor; discussing the request with the nursing

team or members of the team (at least 2);
- discussing the request with the relatives the patient indicates;
- giving the patient the opportunity to discuss their request with the persons they wish to meet;
- the request has to be in writing!
- writing down everything in the medical file.
- Consulting a second doctor, if they believe the patient will not die within a short period of time. (If the patient is not terminal: a third doctor).
- The second doctor is a psychiatrist or a specialist of the affliction.
- If the patient is terminal, no set period of time is prescribed; however if this is not the case, the period between the written request and the implementation of euthanasia has to be at least a month.

How is this done concretely? (differences in different countries...)

- Best intravenously (takes maximum 15 minutes).

Principle:
1. induce coma
2. cause respiratory arrest
3. Heart arrest

(1. can cause death by itself; 2. and 3. never because this would be unethical actions! Not for comatose patients either).

Medication:
1. hypnotics: barbiturates or benzodiazepines e.g. Pentothal® (100 à 200 mg insert in bolus: check sleep!)
2. muscle relaxants: Nimbex® (Before: Pavulon®)
3. After a few minutes: overdose of Pentothal® : about 1800 mg (generally: 20mg/kg body weight)

More information about this on: www.leidraad.be

Remark: afterwards:

The legal registration form has to be sent to the federal commission for control and evaluation within four workdays. This proves that all the legal precautions have been taken.
See www.health.fgov/AGP

Article 15: Death certificate: natural death

Practical problem: sometimes if palliative sedation lasts too long, people are inclined to increase the dosage so it becomes in fact euthanasia. So if a patient determines a period of time beforehand (e.g. that it can last for two days maximum..), it is best to prepare all papers for euthanasia because by means of the palliative sedation you intend the objective of euthanasia, i.e. terminating life faster! In this way the doctor will have no conflicts of conscience afterwards.

Specific role of the nurse:

Every nurse is open to a number of direct and indirect requests for assistance by the patient and if necessary will have an (exploring) conversation.
Every nurse informs the treating physician of any direct or indirect request for assistance regarding the end of life.
Every nurse is informed of the procedure, and is able to fully inform the patient and their beloved ones about the questions they ask (within the nurse's competences!).
Every nurse understands the conditions of being careful in the procedure and advises the doctor in a structured deliberation.
Every nurse provides a careful report in the nursing file.
For reasons of conscientious objections a nurse has the right not to participate in the decisions or the implementation of euthanasia.

Christine De Bosschere
Prof de Enfermagem,
Artvelde Hogeschool, Bélgica