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**Public Health and End of Life: Ethical and Legal Aspects on  
Palliative Care and Euthanasia**

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**ABSTRACT**

Since more 10 years now, Luxembourg has passed simultaneously two laws on legal rights for palliative care and euthanasia. The debate was and still is very contradictory in the medical field. Since than a medical society for palliative care was created and some doctors are working more closely with the association for euthanasia. 1) Palliative care: Every person in our country can ask for optimal palliative care, when the diagnosis of an incurable disease is declared. The locations varies , as patients are not always in the same medical setting: either at home cared by the GP and specialized palliative home care teams; or in long term care facilities for persons with physical and/or neuro-cognitive decline (mostly organized by the GPs or in relation with some specialists (for an expert advice); or in hospitals, where the oncologists and palliative care specialists work hand in hand in the oncological and/or palliative wards; finally a 4th option: admission in the unique hospice (15 beds institution) in the country. From a legal point of view all patients can fill-in an “advanced directive”, where all details on his/her wishes concerning medical end of life decisions are notified and these personal wishes must be executed by the physician of confidence. For ethical reasons it is still very often a huge debate, as p.ex. in nursing homes, people with dementia are admitted and in less than 2% they have a advanced written directive, which makes the discussion on probable wishes of concerned patients very difficult and hypothetical. 2) Euthanasia: the debate on where (and if?) to practice euthanasia is still a regular field for discussion in the public and medical opinion, but the acceptance of this personal choice increases. Legal aspects arise sometimes, when the policy of a private hospital forbids the act, or if the physician refuses euthanasia for ethical considerations. In this specific situation, when the doctor refuses, it is up to the patient! To find another physician for the act and this is very unsatisfactory in some situations. Of course a lot more people are writing the “declaration for end of life”, knowing that maybe they will not ask for euthanasia, when their physical and emotional distresses are well managed medically. The most difficult ethical consideration happens when you are confronted to a patient (p.ex. with amyotrophic lateral sclerosis, or with a brain tumor), who writes the declaration, but in the

evolution of the disease, she/he might no more be able to express this death-wish. In conclusion: the patient's pathway will never be an easy one: sometimes patient's will is totally in accordance with the medical treatment till death, sometimes death appears before all wishes can be fulfilled.

**Keywords:** palliative care, euthanasia, ethical concerns

## **Introduction**

In our country, we have passed two major laws on palliative care and on euthanasia in 2009 (1). The first law covers the right for all persons to have access on palliative care, whenever needed, either at home, in hospital or in long term care facilities. The second law on euthanasia or assisted suicide, gives patients in advanced incurable diseases, under clear regulations, the possibility to choose this way for ending life, independently if living in our country or not.

Since 10 years now, we offer patients in our unique hospice the possibility to be admitted for their last months, weeks or unfortunately sometimes days in our 15 beds institution in order to get the most suitable medical treatment and care for the time being.

## **The Functioning of our Hospice**

The team includes over 20 nurses and nurse assistants, a psychologist and 4 physicians (3 GP and 1 geriatrician) and other professionals on regular basis: physiotherapists, chaplain, music therapist and volunteers. The mean number of admissions per year is about 120 and the length of stay around 6 weeks. The major categories of diseases are: cancers, neurological diseases (lateral amyotrophic sclerosis, Parkinson, brain tumours) and end-stage cardiac and pulmonary pathologies.

The philosophy of our hospice includes (2):

Respect of patient's dignity  
Right to live

The whole care is based on the four medical ethical principles (3):

Autonomia (autonomy)  
Bene facere (beneficence)  
Non male facere (non maleficence)  
Iustitia (justice, equity)  
Also including: truth telling and confidentiality (concept Haus Omega)  
(2)

## **The Physician as “Ferry-Man”**

As we physicians are weekly involved in caring for the 15 residents and also on duty every week-end, an intense relationship is often build up during the stay of the patients. Every clinical situation is unique due to the evolution of the disease or to the patient's feelings and emotions (fear, anger, despair, acceptance of their destiny or free choice for euthanasia). We

earn so much more every day from these patients and their relatives that we never can give as much. Long lasting discussions on a possible night sedation or continuous sedation are cornerstones in our daily visits in the ward and the situations are sometimes changing very rapidly. We try to foresee several acute situations: intractable pain, confusion, agitation, nausea etc., by prescribing medications on request, but sometimes the visits are 2 or 3 times a day for one specific patient.

In order to endure or tolerate the high level of burden, regular supervision and regular interprofessional exchanges are a must.

The complexity of our medical interventions can best be documented through 2 brief medical files, which happened either the last months ago or some years back, but still very present in our minds.

Of course in a hospice, we as physicians, are often confronted to end of life situations and so are we accompanying these patients to their last breaths in our world, before passing the river of Styx just as Charon in the description of Virgile (“portitor has horrendus aquas et flumina seruat terribili squalore Charon...”) (4)

### **A First Medical File**

A boy aged 11 years old was admitted from a paediatric ward to our hospice for palliative care. He suffered from an incurable brain tumour with gliomatosis cerebri and even chemo – and radiotherapy did not manage to cure the tumour. The young boy was very sleepy, with epilepsy from time to time and myocloniae, and was only some 1 or 2 hours awoken over the whole day. His mother was living with the boy the whole 4 months which he stayed in our hospice till death. The father still working came nearly every day even to feed his boy with personal soups, which the father believed could help improve the clinical situation of the boy. As the boy had a gastrostomy and a port – a - cath for fluid, if needed, so the father’s feeding had often the negative impact, that through vomiting, the child suffered of broncho-pneumonias.

One morning the boy entered in a kind of status epilepticus, and as this was an emergent situations, without any further discussions the boy was put in a deep sedation in order to stop the epilepsy. Increasing dosages were needed and finally on the 3<sup>rd</sup> day of sedation, he died in the arms of his mother.

Where have we failed?

- \_ no advanced care planning for this specific situation of an urgent sedation to stop the epilepsy? (dignity?)
- \_ were we outpacing the parents? (male facere?)
- \_ have we enough explained during the duration of the boy’s stay in our hospice, even when the communication in English was not easy? (Arabic origin for the family; not all the time a translator present; different cultural and religious backgrounds...) (iustitia, aequitas?)
- \_ have we been present enough to encounter the parents emotions of fear, anger, hope or despair? (bene facere?)

## **A Second Medical File**

This lady of 86 years was admitted for alteration of physical status, but with a non Hodgkin tumour that, at the moment of admission, was in remission; but the patient came into the hospice with her written request for euthanasia. As she insisted on euthanasia, we were unable to fulfil this wish as we needed a second advice from her oncologist, who refused the request, saying that from the oncological side, her medical situation was stable! After 4 weeks in the institution, she opened a hidden corner of her personal life: when she was very young, but already married, a rape occurred to her and the birth of her daughter followed this dramatic event. From the moment, when she told us this very weighty life event, she did not want to continue to live and decided, what we would call: stop eating and drinking and fasting to death (Voluntarily Stopping Eating and Drinking). She was very strict on this and no discussion could change her mind and after nearly 14 days she passed away, just after a last visit of her daughter.

What was our role in this situation?

- \_ we were the confident for her secret, she kept all life long (confidentiality)
- \_ we let the patient decide by her own an how to finish her life (autonomia)
- \_ we were 2 professionals chosen by her (a psychologist and one physician) to help her to die in a kind of contentment or serenity of her mind (truth telling)

## **Emotions and Feelings in End-of-Life Situations**

There are three major words when we speak about patient-physician relations in palliative care.

- a) Sympathy: a kind of “emotional concern for and sharing of the mental and emotional state of another person”; but often without emotional attachment (5)
- b) Compassion: C. Strauss was defining the concept: “five elements that refer to both self-and other-compassion: 1) Recognizing suffering; 2) Understanding the universality of suffering in human experience; 3) Feeling empathy for the person suffering and connecting with the distress (emotional resonance); 4) Tolerating uncomfortable feelings aroused in response to the suffering person (e.g., distress, anger, fear) so remaining open to and accepting of the person suffering; and 5) Motivation to act/acting to alleviate suffering (6)

Looking at these two terms, we might discover that in between both: sympathy (without much emotional attachment) and compassion (strong motivation to act), we find the term:

c) Empathy: as for physicians, this means several aspects, well described by J. Halpern (7)

- “emotional attunement helps physicians appreciate the personal meanings of patients' words and involves associative reasoning
- physicians' emotions focus and hold their attention on what the patient is anxious about and so on what is humanly significant
- facilitates trust and disclosure and can be directly therapeutic
- finally empathy makes being a physician more meaningful and satisfying”

So empathy can be seen with 4 components:

- Affective, emotional part: feeling into ...; to step imaginatively into the patient's shoes..
- Cognitive part: to understand another's feelings..; to have a detached concern...
- Behavioural part: to communicate this understanding with the patient and finally:
- Moral part: to have an authentic and altruistic concern

Can empathy be taught?

Yes, as empathy involves not only understanding the patient's situation and feelings but also being able to communicate that understanding; communications skills are now taught as part of the core curricula in most of medical schools.

## **Conclusion**

Palliative care and euthanasia are part of end-of-life medicine in our country. Each new encounter with a patient approaching death, is sometimes challenging or stressful, but always so rewarding for us as professionals: because we learn much more from the patients, as well for our daily practice, but as well for our future end-of-life through the patient's history, communication and dignity, which are all untouchable till the last breath of life.

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