Ethics in end of life: lesson from Geriatrics

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EOL of demented patients

- *Where ?*

EOL of demented patients

- *Where ?*
  - Most of those (90%) end their day *in an hospital*
- in acute wards where medical teams are ill-prepared to recognize:
  - geriatric syndromes (pain, delirium, dysphagia, denutrition) or
  - patients' terminal conditions and specific needs.

EOL of demented patients

- *How ?*

Sampson EL, Gould V, Lee D, Blanchard MR : Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. Age Ageing 2006 ; 35 : 187-9
Lloyd-Williams M : An audit of palliative care in dementia. Eur J Cancer Care 1996 ; 5 : 53-5McCarthy M, Addington-Hall J, Altmann D : The experience of dying with dementia : a retrospective study. Int J Geriatr Psychiatry 1997 ; 12 : 404-9

EOL of demented patients

- *How ?*
  - Often the diagnosis of dementia is not declared in the medical charts (75%)
    - No reflexions about the intensity of
      - Medical acts
      - Care
    - Patients escape to comfort care
    - Inappropriate control of pain and symptoms of the EOL

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Consequences

- patients with dementia who are approaching death compared, for example, with cancer patients, are most often subject to invasive interventions,
  - such as the placement of feeding tubes and in some cases the use of restraints
  - few limitations orders (ntbr) in medical charts (55%)
    - 1% order to limit hospitalization…

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Consequences

- patients with dementia who are approaching death compared, for example, with cancer patients, are most often subject to invasive interventions, Why?
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Barriers to the optimal approach of EOL-demented patients

1 Difficulty to *recognize* (or accept) that dementia could be a terminal disease

2 Difficulty to establish a *prognosis* with precision

- Dementia = malignant disease?
  - 1/3 of patients with MMSE between 19 to 23 will die within the year
  - Half of moderate demented patients (MMSE 18) admitted for pneumonia or hip fracture will die within 6 months

Mergam A-N, Pepersack T, Pétermans J. Risk factors for not benefiting from palliative care in end-of-life geriatric patients. Rev Med Brux, 2008. **29**(5): p. 481-5.

Neale R, Brayne C, Johnson AL : Cognition and survival : an exploration in a large multicentre study of the population aged 65 years and over. Int J Epidemiol 2001 ; 30 : 1383-8

Morrison RS, Siu AL : Survival in end-stage dementia following acute illness. JAMA 2000 ; 284 : 47-52

Barriers to the optimal approach of EOL-demented patients

3. Difficulty to communicate to assess expectancies and needs
4. Absence of anticipated directives
5. Ethical, cultural, and religious dilemmas

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The Clinical Course of Advanced Dementia

Susan L. Mitchell, M.D., M.P.H., Joan M. Teno, M.D., Dan K. Kiely, M.P.H., Michele L. Shaffer, Ph.D., Richard N. Jones, Sc.D., Holly G. Prigerson, Ph.D., Ladislav Volicer, M.D., Ph.D., Jane L. Givens, M.D., M.S.C.E., and Mary Beth Hamel, M.D., M.P.H.

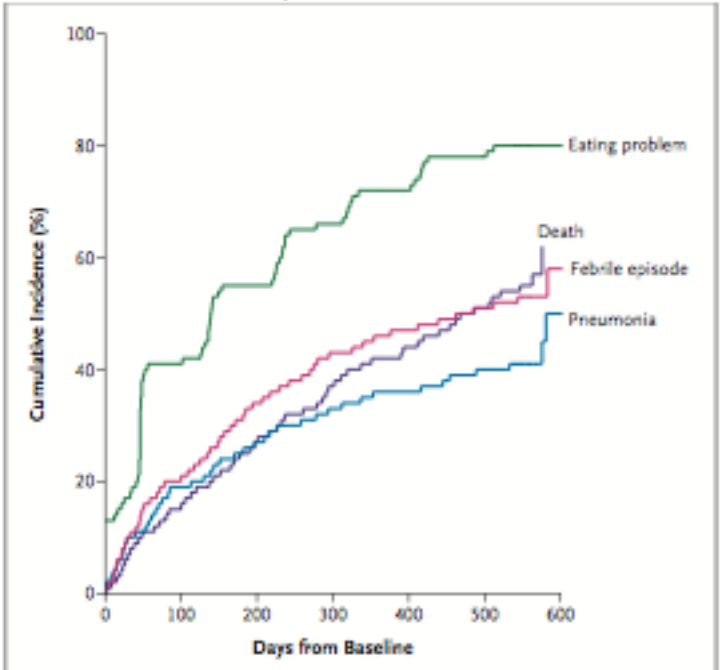
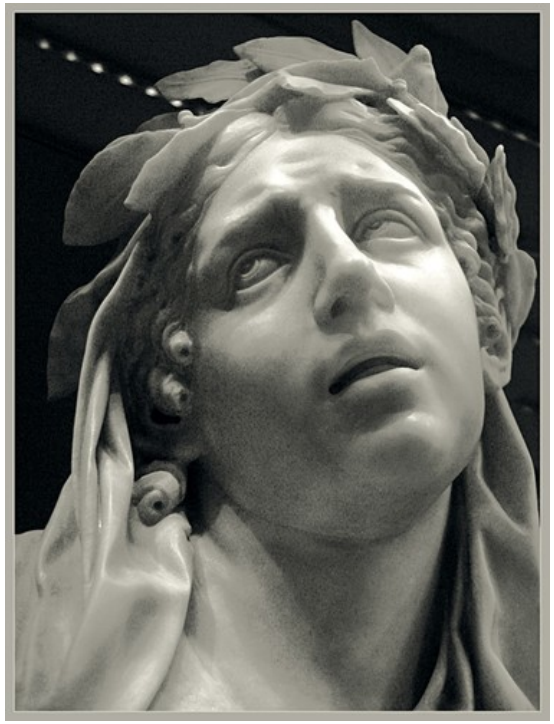


Figure 1. Overall Mortality and the Cumulative Incidences of Pneumonia, Febrile Episodes, and Eating Problems among Nursing Home Residents with Advanced Dementia.

Overall mortality for the nursing home residents during the 18-month course of the study is shown. The residents' median age was 86 years, and the median duration of dementia was 6 years; 85.4% of residents were women.

Distress Symptoms



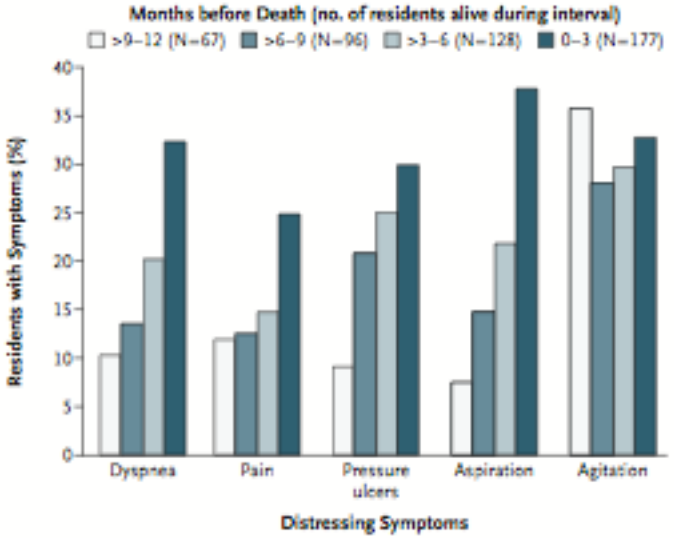


Figure 3. Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.

Case report

- 84 yrs, respiratory distress → ICU
- Deterioration of general status, cachexia
- Cognitive disorders
- apraxia - aphasia - agnosia
- Plan: rule out:
  - « Delirium »
  - Potentially reversible causes of malnutrition
  - Depression
  - Pain

Prerequisites

- Delirium ?
- Reversible causes of malnutrition?
- Depression?
- Pain?
- CAM
- Meals on wheels
- GDS, Cornell
- Doloplus, INVD, Painad, NCS

Case report

- 84 yrs, respiratory distress → ICU
- Deterioration of general status, cachexia
- Cognitive disorders
- apraxia - aphasia - agnosia
- Excluded:
  - « Delirium »
  - Potentially reversible causes of malnutrition
  - Depression
  - Pain
- *Intensity of the care????*

The field of ethics…

❶ References

– principles & values: world of the philosophers

❷ several schools of toughts:

– Utilitarianism (quality results)(Jeremy Bentham, 1781; John Stuart Mill)

– Moral imperatives: « moral obligation » (Kant): «*it is my duty to do so, whatever the results »*

❸ Method of analysis

– Ethical dilemma ≠ conflict

Principles

- Beneficience - non maleficence (iatrogeny)

Values

- respect for life
- Compassion
- love
- Sacredness of life

$\Rightarrow$

Base of professionalism

Risk/benefit ratio

« New » principles

- Autonomy
  - not mentioned by Hippocrates or Cl Bernard
  - in opposition to the therapeutic privilege
  - Needs the ability to:
    - communicate,
    - understand,
    - judge,
    - Decide
    - With full information, serenity, and… time

« New » principles

- Justice
  - Community, equity, distributive
- Proportionality
  - Balance between benefits and resources
- Confidentiality
- Veracity, Nonviolence, Rights of the child, of the elderly, …

Opposition between the principles

- Autonomy
- Autonomy
- Beneficience

- Beneficence (transfusion)
- Justice (waiting list)
- Justice (limitation of resources)

$\Rightarrow$ « ethical dialogue" needs to be focused on the <u>interests of patients</u>

Futility Triad

- Omnia
- Omnibus
- Ubique

- all
- For everybody
- Too far

futile treatment is a treatment that has not proved useful

Futility triad

- Germany, EN is imperative for vegetative status without vital organ failure (≠ Zwisterland)
- Paradox:
  - at the time of independence (autonomy) there has been an increase in the medical response

$\Rightarrow$ our role is to find <u>meaning</u> in our proposals interventional

Therapeutic abstention

- based on non-clinical ethicists:

  « there are no differences between treatment waive or suspend »

Ethical « determinants »

- drinking and eating are powerful symbols of life
- maintaining the relationship of trust
  - patient/doctors
  - patient/institution
  - doctor/family
  - team /doctor

We die of hunger?

Frequency of Symptoms in Terminal Cancer Patients*†

Symptom	TPCU	Referral hospitals	Hospices	"p" value
Pain	116/156 74 percent	300/639 47 percent	231/407 57 percent	<0.0001**
Activity	138/154 90 percent	561/624 90 percent	356/431 83 percent	0.0014**
Nausea	55/152 36 percent	125/636 20 percent	93/368 25 percent	0.0001**
Depression	87/148 59 percent	250/573 44 percent	179/391 46 percent	0.0042**
Anxiety	102/152 67 percent	288/583 49 percent	202/403 50 percent	0.0003**
Drowsiness	111/154 72 percent	394/621 63 percent	310/417 74 percent	0.0006**
Appetite	116/152 76 percent	502/617 81 percent	314/428 73 percent	0.0082
Well being	118/147 80 percent	390/540 72 percent	262/404 65 percent	0.001**
Shortness of breath	76/153 50 percent	206/630 33 percent	151/393 38 percent	0.0004**

* Symptoms were considered present when the visual analogue score upon admission was (30/100)

** P value significant after boferroni correction

† Reproduced with from Bruera, E, Neumann, CM. Respective limits in palliative care and oncology in the supportive care of cancer patients. Support Care Cancer 1999; 7:321.

We die of thirst?

Hydration?

+

- Dying patient more comfortable when artificial hydration (AH)
- AH extends life
- AH decreased metabolic disorders ⇒ less confusion, agitation
- Improves the quality of (late) life
- parenteral hydration is a minimum standard of care, judgment breaks a link with the patient

−

- No thirst perception of the dying patient
- ↓ diuresis = less catheters…
- Less GI disorders, nausea
- less edema, ascites
- Metabolic disorders decrease the level of consciousness thus suffering
- …

Ethical issues in hydration and nutrition. In: Topics in Palliative Care, Vol 2, Bruera, E, Portenoy, R (Eds), Oxford University Press 1998. p.153

Comfort Care for Terminally Ill Patients

- determine
  - Thirst **frequency**
  - Whether palliative approach can suppress symptoms without artificial
    - Nutrition
    - hydration
- Results
  - 63% never hunger
  - 62% never thirst
  - 100% of symptoms treated with success with small amounts of food and / or liquid, and / or ice, lubricating the lips

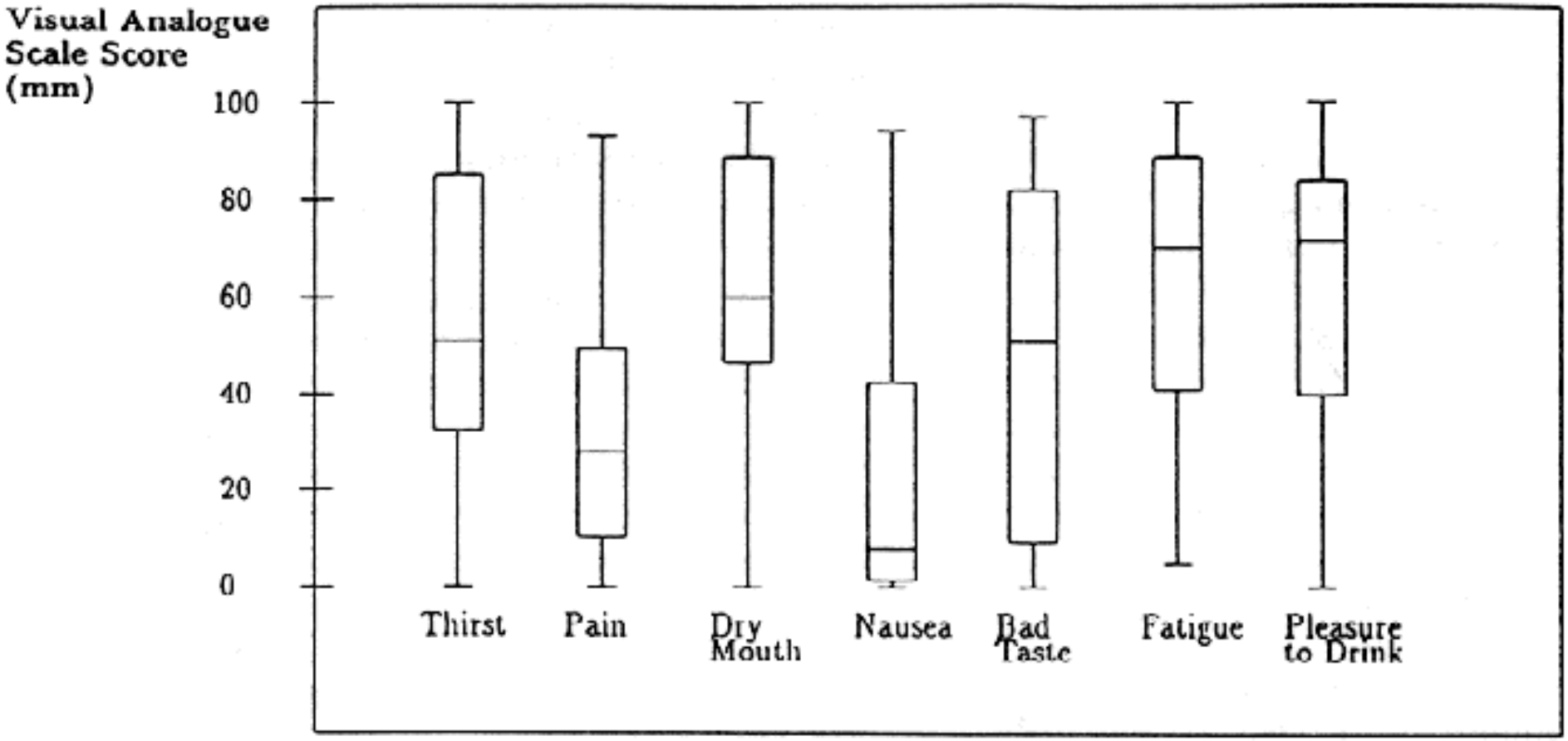
McCann et al. JAMA, 1994:272:1263

Dehydration symptoms EOL

- Transversal trial, N=52, cancers
- Determine **severity** of symptoms of dehydration
- VAS
- *First study to quantify the sensations*

- thirst: 53
- Dry mounth: 60
- Bad taste: 47
- nausea: 24
- Pleasure to drink: 62
- fatigue:62
- pain: 34

Burge. J Pain Symptom Manage 1993;8:454-464



Burge. J Pain Symptom Manage 1993;8:454-464

SYMPTOMS

- Lack of correlation between:
  - severity of symptoms and
  - fluid intake

Burge. J Pain Symptom Manage 1993;8:454-464

Effect of the infusion (IV)

- N=30, cancers
- Last 24H
- 19 answer
- Assessment of IV fluid volume
- urea, Na

- Light thirst: 6
- Moderate thirst: 9
- Severe thirst: 9
- No correlation between thirst and
  - Infused volume
  - urea
  - Na

Musgrave et al. J Palliative Care 1995;11:17-21

Thirst at EOL?

- Relation hydration and thirst in terminal patient:
  - modest
    - *Musgrave, CF, Bartal, N, Opstad, J. The sensation of thirst in dying patients receiving i.v. hydration. J Palliat Care 1995; 11:17.*
    - *Fainsinger, RL, MacEachern, T, Miller, MJ, et al. The use of hypodermoclysis for rehydration in terminally ill cancer patients. J Pain Symptom Manage 1994; 9:298.*

Thirst EOL?

- Well hydrated or dehydrated patients may experience intense thirst
  - other factors that systemic hydration?
  - Oral?
    - Thirst controlled by small amounts of fluids and oral hygiene
- *It is rare to have to begin an artificial hydration to calm the thirst!*

For an ethical debate...

On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far ?

- He asks an ethical reflection about terminal patients unable to meet their hydration and nutrition
- He said that palliative care advocate abstention hydration and nutrition
- dangerous drift at ethical, legal, medical and traumatic for family
- Public debate

Craig. J Medical Ethics 1994; 20:139-143

A reply to Craig

- dehydration is a physiological process of dying
- artificial hydration unjustified: unless thirst untreatable by other means
- natural oral hydration and nutrition should not be stopped
- sedation is not used to treat symptoms of dehydration

Ashby et al. J Med Ethics 1995;21:135-140.

A reply to Craig (2)

- cancer patients stop eating and drinking
- there is no evidence that artificial nutrition or hydration improve comfort, survival
- Hypodermoclysis if the family asks it (!)

Dunlop et al. J Med Ethics 1995;21:141-143

«What do apple pie and motherhood have to do with feeding tubes and caring for the patient ?»

- The health professionals must accept that artificial hydration and nutrition are medical treatments
- rather than basic care…

Slomba. Arch Intern Med 1995;155:1258-1263.

EN and advanced dementia: EBM

- Rare studies in which weight gain but no functional impact (cognitive or ADL)
- **No evidence that EN decreases**:
  - Aspirations pneumonia
  - The risk of bedsores
  - The risk of infection
  - Functional decline
  - bad comfort
- side effects of EN **outweigh the benefit**

Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. JAMA. 1999; 282:1365-1370.
Lauque S, Arnaud-Battandier F, Gillette S, et al. Improvement of weight and fat-free mass with oral nutritional supplementation in patients with Alzheimer's disease at risk of malnutrition: a prospective randomized study. J Am Geriatr Soc. 2004;52:1702-1707.
Finucane TE, Bynum JP. Use of tube feeding to prevent aspiration pneumonia. Lancet. 1996;348:1421-1424.

And yet…

- IV: limited by
  - venous access, comfort, pain, cost, frequent changes, immobilization of an arm, catheter infection, thrombophlebitis, etc.
- SC: Hypodermoclysis
  - safe, effective for advanced cancer, needle 5 d, 2x500 ml bolus of 2 h
  - 69 patients hypodermoclysis 14 d 1203 mL/j
  - *J Pain Symptom Manage 1994; 9:298*

! CAVE: 1 pulmonary edema, 3 anasarque (edema)

And yet…

- <u>Proctolysis</u>
  - 78 terminal patients: « faisable », well tolerated *J Pain Symptom Manage 1998; 15:216.*
  - 22 patients with intra rectal catheter, SP 250 ml/h 4 heures,
  - Minimal cost, no need for sterile device, can be administered by non-professional at home ...

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the strength of the ethical determinant of nutrition....

Is artificial nutrition a basic care?

It depends on the "values"…

- if "utilitarianism", you can use the medical data as a *moral* argument to stop
- Forces of cultural and anthropological representations of nutrition:
  - breastfeed, eat makes you strong, hedonism, religious symbols (bread, wine)

Case report

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  - « Delirium »
  - Potentially reversible causes of malnutrition
  - Depression
  - Pain
- *Intensity of the care????*

EOL

- life on earth
  - 4 billion years
- death on earth
  - 100.000 yrs
    - first grave in the Lafré caves of Israel
    - Homo sapiens = awareness of death
    - Ritual
- 1950 attitude of man % death changes

Concept of death

- 1950 is the death obscured, occulted
- the hearse "trivializes”
- Invitation (faire-part) discrete

- Death that was familiar lurks, is hidden, is delayed, prolonged to the hospital ...
- concept of "therapeutic obstinacy” Prof. Debré 1950

Reactions

- Right to die with dignity
- Past occulted death becomes "*mort bavarde*" (death chats) (Laborit)
- Palliative care
  - 1963 St Christopher Hospice
  - 1980 Belgium
- Euthanasia
- ***Advanced care planning***

PALLIATIVE CARE

"Palliative care is the total of active and integral care for a patient and his or her relatives that aims to alleviate and relieve suffering"

Advanced care planning

- Intensity of the diagnostic interventions
- Intensity of the therapeutic intervention
- Respect for the values of the patients

- Historical:
  - Concept developed for diseases such cancers, ALS, HIV
  - To implement to other conditions (dementia, …)

Pepersack T. [Ethics and artificial nutrition]. Rev med Brux. 2003 Dec;24(6):A491-3.
Mergam A-N, Pepersack T, Pétermans J. Risk factors for not benefiting from palliative care in end-of-life geriatric patients. Rev Med Brux, 2008. **29**(5): p. 481-5.
Pepersack T. Nutritional problems in the elderly. Acta Clin Belg 2009;64:85-91.
Pepersack T. End of life of demented patients: ethical aspects. Rev Med Brux. 2010 ; 31: 333-41.
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Anticipated directives

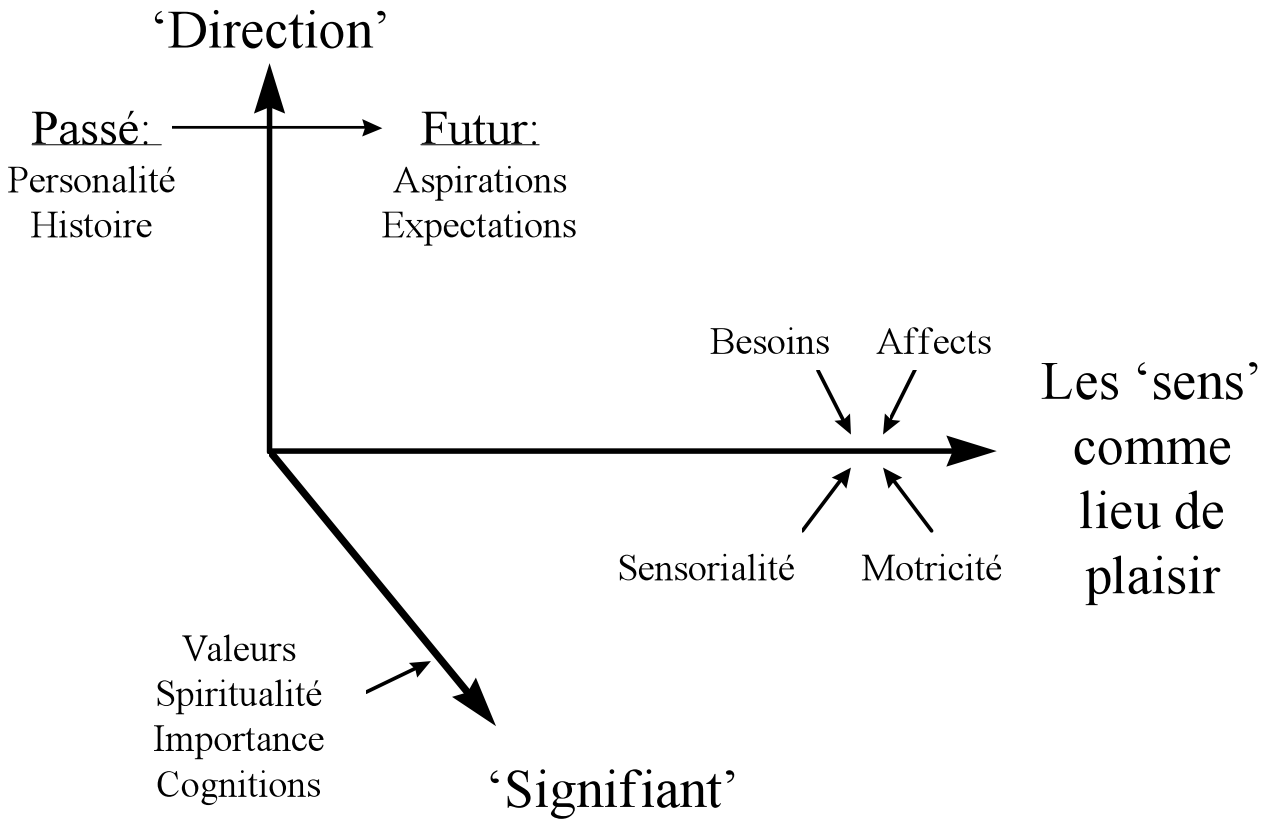
- Expression of healthy subjects
- What is the QoL at 80 yrs old ?

Qol: La qualité de vie

La vie est de qualité quand la vie fait sens

Quality of life is when life makes sense

‘La vie est de qualité quand la vie fait sens’



“si nous avons besoin de sage-femme à nous mettre au monde, nous avons besoin d’un homme plus sage encore à nous en sortir”

Montaigne, Essais

"If we need a midwife to give birth to us, we need an even wiser man to get us out"