A Patient's Journey through Complicated Pancreatitis

Nutritional support in the terminally ill

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Nutritional Support in the Terminally Ill

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Death across time:

Yesterday

- Tame death
Today

“Inverted death”

“Intervened, Medicalized Death”

- Hospital: Something must be done to prolong life”
- Prolong agony.
- Bitterness, obstinacy, therapeutical fury. Distanasia (bad death)
  - Stuffed full of tubes death
Marginalized Death, Denied

- ICU
- Emergency room.
- Oncology service
“Medical technology has created a twilight zone of suspended animation where death commences while life, in some form continues. Some patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity”

William Brennan, Associate Justice
US Supreme Court in Cruzan, 1990
from Barrocas A, NCP 2006; 21:109-112
.... in many cases:

- “postponed” death
- Patient’s suffering.
- Family burden:
  - Emotional
  - On budget
Medical attitude before death:

“I am dying with the help of too many physicians”

Alexander the Great
Medical attitude before death:

1. Repulsion
2. Denial
3. Acceptance

“I am dying with the help of too many physicians”
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Medical attitude before death:

1. **Repulsion**: hopeless patient: patient is abandoned
2. **Denial**
3. **Acceptance**

“I am dying with the help of too many physicians”

*Alexander the Great*
Medical attitude before death:

1. **Repulsion**: hopeless patient: patient is abandoned

2. **Denial**: fight death beyond the limits of factual possibilities, feeling of failure: Medical Obstinacy.

3. **Acceptance**
Medical attitude before death:

1. **Repulsion**: hopeless patient: patient is abandoned
2. **Denial**: fight death beyond the limits of factual possibilities, feeling of failure: Medical Obstinacy
3. **Acceptance**: Palliative Care:
   - Control over symptom.
   - Emotional support.
   - Communication:
     - Patient’s Autonomy: **Informed consent**
Prior to the advent of nutritional support, the impossibility of receiving nutrients through the oral ingestion inevitably lead to wasting and death.
In patients suffering from a potentially curable illness, nutritional support becomes an important and even critical part of the integral health care plan.
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On the other hand, nutritional support may render very limited effectiveness when it comes to terminally ill
Teminaily ill

- Prognosis of approximately six months’ life left:
  - Advanced, progressive, incurable sickness.
  - Appearance of intense, manifold, changing symptoms.
  - Strong emotional impact on the patient, on their family and even on the medical team, in connection with death.
Ethical Principles

- Autonomy
- Beneficence
- Nonmaleficence.
- Justice:
  - Social
  - Distributive.

Mod. Beauchamp & Childress, 1994
Autonomy

The patient is a valued interlocutor.

- Right to be aware.
- Moral right to choose.
- Legal aspect.

- Patient can refuse food and fluids, provided the refusal is informed, voluntary and the patient has adequate decision-making capacity; even if death may be hastened

Informed consent
Autonomy

- Living will

- Incompetent patients have the same rights: surrogates exercise those rights
Beneficence

“DO GOOD”

- The medical action should benefit the patient.
- Benefits may include improved quality of life and/or enhanced survival.

“Do to others what you expect others to do to you”
Beneficence

- **Avoid Paternalism!!!**

  Intentionally overriding one person’s preferences or actions aiming at benefiting them or preventing harm.

  The doctor thinks they can decide for a patient better than the patient would.
Nonmaleficence.

- First: Do no harm ("Primun non nocere")
- Do not kill
- Do not prolong suffering.
- Do not cause pain.
- Do not cause incapacity
- Medical care should benefit the patient rather than burden them.

"Do not do to others what you do not want others to do to you"
Principle of Justice

- Resources management based on efficiency and equity, thus setting priorities.
- **Social Justice**: determining what is good for society as a whole. Access to healthcare.
- **Distributive Justice**: the distribution of limited resources.
Inviolability of life

Life preservation takes precedence over the rest of issues to be considered
Inviolability of life

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But.....
Inviolability of life

Life preservation takes precedence over the rest of issues to be considered

But.....

Is prolongation of human life a synonym for survival?
Medicine is not always obliged to do as much as possible to prolong a patient’s life.

The doctor is not obliged to give treatment which he or she considers futile or against the patient’s interest.

Principle of Proportionality
Is nutritional support a medical treatment or is it part of the basic care?
Enteral Nutrition: Basic Care

Food is essential to life.

- No other treatment compares with it:
- Cultural, religious and symbolic significance

- The members of the patient’s family cannot or refuse to see them “starve to death”.

- Must always be provided.

Gomez Rubí J 2002
Enteral Nutrition: Medical Therapy

- Invasive.
- Requires qualified personnel.
- Associated with complications.
- Require a consent from a capable patient.
- Doing without liquids or food not always increase suffering.

Couceiro A; 2004
The law

- Basic care:
  - Food and drink by mouth.

- Medical treatment:
  - Artificial means.
  - Requires special equipment.
  - Requires healthteam.
Three stages in treatment:

- **Curative**: obligatory nutrition and hydration.
- **Palliative**: quality of life. Nutrition and hydration may be possible.
- **Dying period**: quality of death. Nutrition is contraindicated

Nuñez Olarte JM 2004
From Cañizo Fernández-Roldán. Nut Hosp 2005 XX (2) 88-92
What changes at the stage of palliative care?

The aim of the nutritional support changes as the sickness progresses. The emphasis is on the quality of life and the control of symptom rather than a truly nutritional therapy.
Helping to die is also a function of Medicine
Helping to die is also a function of Medicine:

- Relieve symptom:
  - Control of pain
  - Control of dyspnea
- Provide emotional support.
- Open communication
Nutritional Support Options

- Oral feeding
- Oral Supplement
- Enteral Nutrition
- Parenteral Nutrition
- Hydration

Socializing
Comfort
Complexity
Oral feeding

- Individual preferences
- “A la carte” choice
- Attractive display
- Individualized portion
- Adapted consistency.

- Diet recommendation.
- Flexible time-tables.
- Nice atmosphere.
- Family recommendation.
- Personal participation
Oral ingestion difficulties: control over the symptoms

- Dysphagia  →  Adapt consistency  →  Liquids
- Nausea, vomit  →  Diet preferences, frequent ingestion of little quantities, enriched food, supplements
- Anorexia, satiety.
- Portion: overwhelming feeling.
- Xerostomy  →  Chewing gum, acid toffees, ice, stews, sauces.
- Taste and smell changes  →  Lukewarm and soft food
Enteral Nutrition

- **Recommended:**
  - Severe Dysphagia.
  - Severe anorexia.
  - Great decrease of ingestion.

- **Indications:**
  - Head and neck/esophagus tumours
  - Fistulas not to be operated on
  - Esophageal obstruction.

- **Evaluate:**
  - Survival chance.
  - Risks, complications.
  - Ethical problems.
Parenteral Nutrition

- Very selected patients.
- Enteral feeding is not possible
- Inoperable bowel obstruction
- Prolongs life (?)

Risks vs. Benefits

- Complications increase.
- Implementation difficulties in home health care.
- Costs.
- Ethical dilemmas

Torelli, 1999
Faisinger 1997, 2006
AN in the Care to Diseases

“Give me neither poverty nor riches
feed me with convenient for me”

*Book of Proverbs, 30:8*
Terminal Cancer

- Regarding advanced oncological patients who have not made adequate response to treatment and whose state has worsened to the point of not being able to get around on their own, enteral or parenteral nutrition support will not improve either quality of life or survival benefit and should therefore be avoided.

- Nutritional support may even increase urinary output, diarrhea and nausea.

- Can be uncomfortable.

Bachman P, Marti-Massoud C Br J Cancer 2003
Torelli GF, Campos AC Nutrition 1999
Finucane, 1999
ALS

- Usually have Decision Making Capacity
- Benefits of PEG:
  - more paliative than life prolonging
  - Recommended at onset of swallowing difficulties, before lung capacity declines.
  - Improve nutrition, lessens fatigue and fear of choking, alleviates the struggle and effort to eat.
- Burdens:
  - may increase nausea.
  - Decrease human contact.
- No evidence life prolongation.

Scott 1994
Mitsumoto 2003,
Linda Gandasi, 2006
Dementia and NE

- No reduce infection risk.
- No improve functional condition.
- Cannot overcome or delay progression of illness.
- No improve comfort.
- No improve quality of life.

Finucane TE, JAMA 282:1365, 1999
Gillick *New Eng J Med* 2000
Chernoff R *NCP* 2006
Advanced Dementia

- No randomized control trials
- No survival benefit.
- No reduce aspiration incidence
- No effect on the clinical nutritional markers
- May not improve pressure ulcers.

Finucane TE, JAMA 282:1365, 1999
Gillick New Eng J Med 2000
Chernoff R NCP 2006
Barriers to Reducing EN in Advanced Dementia

- Doctor’s beliefs on benefits of PEG in advanced dementia:
  - Decrease aspiration.
  - Improve decubiti.
  - Improve survival.
  - Improve functional status.
  - Standard care.
If death is not imminent but there is permanent unconsciousness beyond all doubt, after confirming precision of the diagnosis, it does not go against the ethics to interrupt the treatments that prolong life.

Council on Ethical and Judicial AMA
Is tube feeding medical treatment or is it a part of the humanitarian basic health care?

Is it ethical to deny or interrupt artificial nutrition?

How much room is left for the patient’s own prognosis and wishes as regards decision-taking?

How to make decisions about the patient with cognitive deterioration?

Is physical restriction necessary?

What is the symbolic significance of abstaining from feeding a patient who is not able to eat?

Does the tube feeding render any comfort to the moribund patient?
Physical Restriction

- Physical restriction should be effected only in case EN is indispensable to sustain life during acute and reversible illness.

- In progressive, irreversible illness when risks exceed the benefits the use of physical restriction might violate the basic fundamentals of humanitarian care and the patient’s dignity.
Each person has a moral duty to employ ordinary or proportionate means to preserve their life.

ANH is ordinary, not extraordinary measures, even when medically administered.

Therefore, should not categorically rule it out.

Can still forgo ANH if no benefit (e.g., death imminence)

Underscores need to have a better understanding of benefits and burdens of ANH

Mod from Linda Gandasi, 29th Annual Symposium of American Medical Directors Association, March, 2006
Suspend support

- It is usually more tolerable not to start a treatment then suspend it.
- More difficult than not to start: A justified reason not to begin would remain justified to suspend support.
- Identify medical benefits of treatment.
- Signed Informed Consent.
- Doctors:
  - They think these actions feel psychologically and ethically different.
- If no agreement: “time limits”.
- “When in doubt, don’t take it out”
“Food is life”

- Food
- Hydration
  - Symbolic significance
- Cultural, Religious differences about food and Enteral Nutrition
- Helping someone to eat can be an important nurturing act, and the use of artificial nutrition limits this opportunity
Suffering by starvation

- Anorexia is very frequent.
- They are not hungry.
- Total fast may even cause a certain degree of analgesia and euphoria:
  - Endogenous opioids increase.
  - Cetonic corps.
- Partial fast: sense of hunger

Bachman P, Marti-Massoud C Br J Cancer 2003
Printz LA Arch Intern Med 1992
Each particular patient must be closely evaluated!!!!!!
A patient’s death will not be caused by bringing nutrition to an end:

“The ill do not die because they do not eat. They do not eat because they are dying”

Couceiro 2004
Death is not a failure on the part of Medicine. Failure takes place when death is surrounded by anguish and suffering.
SCHIAVO
THERESA MARIE
BELOVED WIFE
BORN DECEMBER 3, 1963
DEPARTED THIS EARTH
FEBRUARY 25, 1990
AT PEACE MARCH 31, 2005
I KEPT MY PROMISE
The key:

- Good and communication among:
  - Clinicians/Healthcare team
  - Patients/Family members.
"I solemnly request that, when life takes its trust away from me, neither my pulse nor my weeping be heald steady, not even an instant after. I wish to live with the beautiful dignity with which has lived this being whom I gaze at, penetrating death in despair, not being left free by our sickly and cowardly gun dogs: mistaken love, stupid abnegation, fraudulent hope.
And I wish to die (I will never understand nor tolerate useless pain) with the beautiful dignity with which should die human being who has lived their life and who are to live their

Testamento poético-vital

Antonio Gala
If you can cure, effect cure
If you cannot cure, relieve
And if you cannot relieve, console

W. Osler
If you can cure, effect, cure; (sometimes)
If you cannot cure, relieve; (often)
And if you cannot relieve, console. (always)

W. Osler
Between so many tasks and so urgent I forgot of which also it is precise to die...

Irresponsibly I neglected that obligation or I assumed it of a superficial way...

As of tomorrow everything will change ...

I will begin to carefully die with intelligence and optimism without losing a single moment

Tadeusz Rosewicz
“And, in the end, the love you take is equal to the love you make”
The Beatles, Abbey road
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