It is my responsibility of physician :

”*to preserve the utmost respect for human life from its beginning even under threat and I will not use my medical knowledge contrary to the laws of humanity*”.

Declaration of Geneva (1948)
adopted by the World Medical Association, Geneva 1948,
amended in Sydney 1968

”The care involved in feeding is not, in strict sense, medical treatment, even if provided in a hospital.

It is ordinary care …”

British Medical Research Council, 1973

Sviluppo tecnologico e progresso scientifico in medicina

Progressi delle terapie intensive

Aumento delle condizioni di cronicità

Rischio di accanimento terapeutico

✓ **Calo della natalità e progresso della medicina hanno invertito la piramide demografica**

✓ **L’invecchiamento della popolazione e i successi terapeutici si sono tradotti in un vertiginoso aumento di persone con malattie croniche e con disabilità**

✓ **Mentre ciò si verificava declinavano il rispetto per la vita e la solidarietà sociale**

✓ **Conseguente inaccettabilità del carico finanziario per la società**

✓ **Insufficienza o mancanza di provvidenze per le famiglie**

↓

CRESCENTI PRESSIONI PER ELIMINARE IL FARDELLO DI VITE RITENUTE PRIVE DI SIGNIFICATO

Esseri umani e persone umane

«Not all humans are persons. Not all humans are self-conscious, rational, and able to conceive of the possibility of blaming and praising.

Fetuses, infants, the profoundly mentally retarded and the hopelessly comatose provide examples of human nonpersons.

Such entities are members of the human species. They do not in and of themselves have standing in the moral community.

They cannot blame or praise or be worthy of blame or praise. They are not prime participants in the moral endeavor. Only persons have that status».

ENGELHARDT H. T., *The Foundations of Bioethics*, Oxford University Press, New York - Oxford 1986, 104.

Una soluzione per la cronicità

"Il rifiuto della nutrizione può diventare, nel lungo termine, il solo modo efficace per assicurarsi che un largo numero di pazienti biologicamente resistenti venga effettivamente a morte. Considerato il crescente largo serbatoio di anziani resi inabili dall'età, cronicamente ammalati, fisicamente emarginati, la disidratazione potrebbe diventare a ragione il ***non-***trattamento di elezione."

(Daniel Callahan 1983,Hastings Center Report 22)

The Trojan Horse

“If we can get people to accept the removal of all treatments and care –especially the removal of food and fluids- they well see what a painful way this is to die and then, in the patient’s best interests, they will accept the letal injection”

(H. Kuhse, 1984)

Perché ciò potesse realizzarsi
2 PREREQUISITI:

- 1. assolutizzazione del principio di autodeterminazione, fino alla piena e totale disponibilità del bene vita
- 2. collaborazione della classe medica

MEDICAL PRACTICE GUIDELINES

The turning point for this change of attitude was the definition of assisted nutrition and hydration as “artificial” and no longer a form of basic ordinary care, but as a form of “medical treatment”, which, in analogy to other forms of life-sustaining treatments, “may be discontinued in accordance with the principles and practices governing the withholding and withdrawal of other forms of medical treatment” (self-determination Act)

Guidelines of the AAN and of the AMA allow physicians to withhold or to withdrawANH from terminally ill or permanently unconscious patients when it has been determined that patients or their surrogates have expressed informed refusal of ANH

A.A.N., *Neurology*, 1993 and 1995; A.M.A., *JAMA* 1990

- Having been defined as a form of medical treatment, ANH could also be refused by the patient (self-determination Act)
- Since VS patients are unable by definition to communicate their decisions, treatment could be refused by a surrogate or by somebody entitled to a permanent power of attorney.

IL CASO CRUZAN

- In the ***Cruzan*** case (1990), the Court held that death, **after surrogate refusal of ANH**, is neither euthanasia nor assisted suicide, but is simply the natural consequence of the exercise of a patient’s constitutionally protected right to refuse an unwanted treatment.

White et al., Arch InternMed, 1991

Lo and Steinbrook, Arch InternMed, 1991

THE SLIPPERY SLOPE OF DECISION MAKING PROCESS

- ✓ ascertain patients’ will about “artificial” treatment (formally written advance directives),
- ✓ any available evidence of previously expressed opinions about this form of “treatment”.
- ✓ surrogate could interpret the will of the patient, trying to act in search of the best interests of the sick person
- ✓ the judge (or the doctor !!) could decide that the “treatment” is meaningless and burdensome and that should be stopped regardless of patient’s previous opinions

ETHICAL AND LEGAL STANDARDS TO SURROGATES

- Surrogates first should determine what preferences patients have expressed, in the form of **written directives or explicit oral** statements.
- If these provide insufficient guidance, surrogates should attempt to **determine as precisely as possible what choice patients would have made**, taking into account patients’ values and expressed preferences about treatment.
- If such information is not available, surrogates should objectively weigh the benefits and burdens of proposed therapies and **assert a choice that is in the best interest** of the patients.

Bernat and Bereford, Neurology 2006

ETHICAL AND LEGAL STANDARDS TO SURROGATES ONE STEP FURTHER

- In 12 States of the USA, the “default surrogate” (the judicially appointed guardian or statutorily appointed next of the kin) is also authorized to withdraw treatment if a PVS patient did not execute an advance directive.
- In 18 additional States, PVS concept is extended with inclusion in the category of *permanent unconsciousness*
- In several additional States, PVS is included among *terminal condition.*

Larriviere and Bonnie, Neurology 2006

A paradigmatic case: Terri Schiavo

ANH is not part of basic nursing assistance

Patient’s autonomy had to be respected

Hwever:

Decision cannot depend on an informal conversation

The person who informed on the “will” of the patient was highly suspectable for a conflict of interest

ANH in VS is futile, disproportionate and excessively burdensome

- ✓ Ineffective: ANH is very effective if it can keep patients alive for years
- ✓ Futile: it is the patient's life to be considered futile, hence the need to find some way of ending that life
- ✓ Extraordinary: a consideration that should not normally arise in developed countries.
- ✓ Disproportionate: Is it PEG, a simple procedure, that is disproportionate, or is it the assistance to these chronic patients to be considered wasted?
- ✓ Burdensome: a “treatment” that can be continued for years without any trouble should be classified as non-burdensome for the patient. It is the life of the patient that is considered burdensome by society and (sometimes) by relatives.

LACK OF THESE CONDITIONS

MAKES WITHDRAWAL OF ANH

A FORM OF EUTHANASIA BY OMISSION

The hydration and starvation of Terri Schiavo can ultimately be admitted only on a judgement of a lower level of human dignity.

Why this case creates a dangerous antecedent?

It open the door to more merciful killing ("*This kind of death would not be inflicted even to a pet*")

It endangers the principle of solidarity in health care

It will permit discrimination of other human beings whose human dignity is no longer recognised (**Dementia**, severe MR, malformed newborns, prolonged coma…)

The real, but not always expressed, reason for the withdrawal of ANH is

- ✓ neither the respect of the natural course of a fatal disease,
- ✓ nor the indignity of tube-feeding in itself,
- ✓ **but the indignity of tube-feeding ability to keep alive patients whose lives are considered to be of insufficient quality to deserve treatment.**

Quality of life: intrinsic lack of objectivity.

✓ Differences among external raters

✓ Little correlation with the opinion expressed by the disabled person himself

Neurologically disabled persons:

- Embarrassment of able bodied people in trying to communicate with a severely neurologically disabled person

- Feeling that the disabled person would be better off dead

- ✓ Discussions about quality of life often hide a kind of evaluation typical of the interpersonal relationships based on the ability to produce and to be useful.
- ✓ Not only the lives of patients in VS, but also those of gravely disabled patients and of every person marginalized out of the productive system are considered less worthy.
- ✓ Health resources are considered well invested if they rehabilitate patients for productive, or at least independent lives, but are considered wasted when they only prolong a dependent chronicity.
- ✓ This especially in western societies, where any increase in expenditures related to health is opposed, and in countries with significant proportions of the population deprived of any kind of health assistance.

From quality of life to indignity of life:

- ✓ Psychological pressures that can be perceived by a disabled person's family
- ✓Biases in the family or in the judge in decisions regarding end of life issues in a disabled member
- ✓ Withdrawal of nutrition and hydration considered the best interest of patients, using the criterion of a presumed lack of quality of life
- ✓ Evaluations about quality of life can be transformed into judgments about the indignity of human life to be lived.

When the family, or any other surrogate in the decision making process, decides to put an end to the life of a person because of a poor quality of life:

Suspicion of a possible conflict of interests:

in the vegetative state, rather than asking what is the patient’s best or worse interest we can question whether he/she does actually have any interest (except for life and very little hope of recovery).

“*If this is the case, then the decisions are being made for the benefits of others, a dubious decision making process*”.

(Andrews, 1996)

Cultural changes

"So little and so much has changed in the past ten years.

In the era of Quinlan and Cruzan, the burden of proof lay on those who would deny basic care to the severely cognitively impaired.

Today, the burden of proof is on those who would continue it.

If that isn't a slide down the slippery slope, what is it?"

(S. Smith, 2003)

”To my mind the tube is simply a tool for daily living, similar to the specially adapted spoons that enable arthritic patients to feed themselves.

The relevance of this is that in identifying tube-feeding as treatment we have found a convenient method of shortening the life of a disabled person.

(K. Andrews, British Medical Journal, 1992; 305:1506)

Sospensione delle cure
=
Eutanasia mascherata

“Whatever semantics are used,withholding or withdrawing treatment will have the same outcome as euthanasia, i.e. the clinician will have taken a decision that the patient should die”

(Andrews 1996, Br Med Bull. 52: 280-288)

Sospensione delle cure
=
Eutanasia mascherata

“A succession of judgements, pronounced by Courts of Law in different parts of the world have in recent years, sanctioned the withdrawal of life sustaining procedures in cases of prolonged and irreversible unconsciousness… They have, therefore, pronounced euthanasia in these circumstances to be legally and ethically justified.”

(Roth 1996, Br Med Bull 52: 263-279)

Sospensione delle cure
=
Eutanasia mascherata

"L'impegno etico e legale verso la santità della vita ha portato i tribunali a impiegare diversi approcci a questa situazione, così da trovare il modo in cui permettere di morire alla persona in SVP. E' oggetto di discussione il fatto che ognuno di questi approcci è artificioso e in ultima analisi non di aiuto. Quello che la legge sta facendo è di favorire l'**eutanasia non-volontaria,** ma mascherarandola come qualcos'altro."

(McLean 1999, J. Clin. Pathol. 52: 490-493)

Una soluzione più umana

“Once the decision has been made by patient, family and clinical team that is is inappropriate that life should continue, then the quality of the dying process should be of the highest standard.

The present attitude of ending the patient’s life by withdrawal of nutrition and fluids is highly unsatisfactory, if not inhumane and the option of euthanasia would be a far more satisfactory solution”

(K. Andrews, 1996 Br Med Bull 52: 280-288)

CONSEGUENZE

Consequences for patients:

Weakening the ties of solidarity inside families and inside the social body

Withdrawal of nutrition and hydration extended to other neurological disabilities characterized by poor quality of life

Social acceptance of active euthanasia (it is better a lethal injection)

Silent practice of unvoluntary euthanasia (when a doctors rates someone’s life as of insufficient quality)

Consequenses for doctors and nurses:

If withdrawal of nutrition and hydration will not be considered a form of passive euthanasia, but rather good clinical practice, doctors and nurses who respect life could probably face charges of malpractice, having no right even to conscientious objection.

Doctors, and nurses especially, will be under pressure from families, hospitals and Courts, called to justify their refusal of hastening death in a condition for which there is no apparent reason to live, being the right to life based on the recognition from outside of a sufficient level of its quality. Financial considerations will create further pressures.

Consequences for democracy:

Is it human what is useless, purposeless, unable to have a social relationship?

If humanity may be weighted upon quality of life, and subject to evaluation based on usefulness and possibility of relationship, it is the concept itself of what is human that will be challenged (Engelhardt).

The confusion between the quality of human life and the inherent dignity of every human being, can only be the cause of a selective attitude in the recognition of human rights (discrimination).

UNA STRATEGIA BEN DELINEATA

LA PRESSIONE SUI LEGISLATORI

- Come in Olanda nel 1995, in Australia nel 1996 viene inviato per posta un Questionario per conoscere la posizione dei medici.
- In 30 % of all Australian deaths, a medical ELD was made with the explicit intention of ending the patient’s life, of which 4 % were in response to a direct request of the patient.
- CONCLUSIONS:

  Australian law has not prevented doctors from practicing euthanasia or making ELDs explicitely intended to hasten the patient’s death without the patient’s request.

Kuhse et al, Med J Aust, 1997

LA FORZATURA DEI TESTI: COSTITUZIONE ITALIANA

- La Repubblica tutela la salute come fondamentale diritto dell’individuo e interesse della collettività, e garantisce cure gratuite agli indigenti.

- Nessuno può essere obbligato ad un determinato trattamento sanitario se non per disposizione di legge.

- La legge non può in nessun caso violare i limiti imposti dal rispetto della persona umana.

Art. 32

LA FORZATURA DEI TESTI:
CONVENZIONE DI OVIEDO
sui diritti umani e la biomedicina

- Le **volontà** (*wishes*, *souhaits*) precedentemente espresse a proposito di un intervento medico da parte di un paziente che al momento dell’intervento non è in grado di esprimere la sua volontà saranno tenuti in considerazione

Art. 9

PERVERSIONE DEL PRINCIPIO DI AUTODETERMINAZIONE

Suicidio assistito anche per i depressi

- In Svizzera vi sono già casi documentati
- L’Alta Corte di Losanna ha emanato Linee Guida per le persone affette da “disturbi psicologici gravi, permanenti ed incurabili” (Novembre 2006)
- Ora si suggerisce che “*Se i valori insiti nelle scelte di suicidio assistito sono la massimizzazione della autonomia e la minimizzazione della sofferenza, ne consegue che i soggetti cronicamente depressi, mentalmente competenti possono essere candidati ideali per l’applicazione di tale procedura*”

JM Appel, Hastings Center Report, May-June 2007

PERVERSIONE DEL PRINCIPIO DI AUTODETERMINAZIONE

Trasformazione in “terapia” anche della idratazione e nutrizione “naturale”, e possibilità di sospenderla (nell’interesse del paziente !!!!!)

“The right to refuse life-sustaining therapies derives straightforwardly from a right to self-determination and bodily integrity.

From a moral standpoint, we argue that this right includes refusal of any unwanted therapies whatsoever, including ***oral*** *hydration and nutrition when it is feasible- as, for example, in some* ***patients with advanced dementia*** *who could be fed by hand, but are not for the sake of convenience and economy”*

(Truog and Cochrane, Arch Intern Med, 2005;
Cochrane and Truog Neurology, 2007)

PERVERSIONE DEL PRINCIPIO DI AUTODETERMINAZIONE

Diritto di vita e di morte sul paziente da parte del legale rappresentante

"If information [about patients' wishes] is not available, surrogates… should assert a choice that is in the best interest of the patients"

(Bernat JL and Beresford HR, for the AAN Ethics Subcommittee, Neurology 2006)

"Dylan Walborn, 5 y.o., disabled from birth, was dehydrated to death by his parents. Although there was no evidedence that Dylan wanted to be dehydrated to death, the procedure was apparently legal in Colorado, which allows the "best interest" form of substituted judgement to be applied in cases where incompetent persons cannot make their own decisions and have never expressed their wishes. Dylan was not in the vegetative state. Although he was severely disable, he went to school one day/week, where he was able to paint a duck for his father and to make a card for his mother. He was responsive to familiar voices. When he was uncomfortable he had tears …"

(Burke et al., Neurology 2007; Simpson, Denver Post,Dec 18 2005)

Autodeterminazione è libertà ??

È POSSIBILE UN DIVERSO APPROCCIO AL PROBLEMA?

TENER DURO SUI PRINCIPI FONDAMENTALI

- La vita umana è un bene indisponibile, indipendentemente dalle condizioni cliniche del paziente
- La gravità delle condizioni cliniche non altera la dignità ed i diritti della persona.
- Il paziente in SV non può essere considerato un malato terminale.
- Non sono quindi eticamente giustificabili né la sospensione, né l’affievolimento delle cure, non essendo né il tipo di patologia, né le probabilità di successo i fondamenti che giustificano il processo di cura.
- Al contrario, quanto più è fragile il paziente, tanto più cogente è il dovere sociale di occuparsi di lui.

CNB 30.09.05

METTERE IN ATTO UNA RETE DI SOSTEGNI

La Commissione Ministero Salute (14.12.05) avendo per fondamenti il Diritto alla vita, l’Equità e la Solidarietà sociale ritiene che il paziente in SV e SCM abbia diritto a:

- cure adeguate nella fase di acuzie;
- diagnosi accurata e precoce;
- interventi riabilitativi specifici, intensivi, mirati e proporzionati al bisogno nella diverse fasi di evoluzione del processo patologico, volti a favorire il massimo recupero funzionale;
- assistenza e terapie qualificate, appropriate e proporzionate in tutte le fasi di malattia;
- continuità delle cure nelle diverse sedi di intervento (compreso il domicilio).

MODIFYTHE MEDICAL AND SOCIAL ATTITUDES

The role of the medical profession must never be that of killing patients. Provisions for optimal palliative care at the end of life, especially for the weak patient, are mandatory for a society that wishes to be characterised as advanced. This care should be offered in a loving environment where the patient does not feel himself a burden to neither his relatives nor the society. It is the responsibility of the society to guarantee such care facilities.

Medical doctors should oppose euthanasia or physician assisted suicide and, at the same, be against any therapeutic obstinacy that cannot cure patients, but only prolong the process of dying.

Physicians should not be used to provide an unethical and unnecessary medical solution to a problem that is basically of a social nature: Solitude of the elderly and poor care at the end of life. It is exactly these problems that prompt demands for euthanasia and physician assisted suicide.

Recent medical research has shown that colleagues who are poorly trained in palliative medicine and colleagues who are overburdened are the ones seen to consider euthanasia and physician assisted suicide in difficult clinical situations[1, 2].

1. 1. Morita et al. J Clin Oncology, 2002; 2. Peretti-Watel et al. BMJ, 2003

DATEMI UN PUNTO DI APPOGGIO…..

Importanza della classe medica

“Whatever proportions [the Nazi war crimes] finally assumed,it became evident to all who investigated them that they had started from small beginnings.

The beginnings at first were merely a subtle shift in emphasis in the basic attitude of physicians.

It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived.

*Gradually the sphere of those to be included in this category enlarged….but it important to realize that the infinitely **small wedged-in lever** from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitable sick*

(L. Alexander, Neurologist, Office of the Chief Councel for War Crimes at Nuremberg, in NEJM, 1949)

To cure, if possible

To care, always

Curare, finché possibile

Aver cura, sempre

La libertà senza verità finirà con una verità senza libertà