Nutritional Therapy & Metabolism / Vol. 24 n. 2, pp. 60-63 Wichtig Editore, 2006

Editorial

Feeding the patient with an incurable disease: A voice out of the chorus

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When physicians (or health care professionals) debate on medical ethics, defined as moral obligations governing medical practice, they almost never reach an agreement.

This is due to the fact that, while in scientific research one usually tests the validity of a hypothesis through experiments, in the field of bioethics one only has hypotheses, or better still tenets, and nothing to test their consistency.

Consequently, whereas in scientific research what really matters is the result of an *ad hoc* investigation, in the field of bioethics what is relevant is the strength of the principles.

This is also the reason why only clinicians debate on their scientific researches, whereas every individual, of whatever culture, feels entitled to express his/her opinion on bioethical issues.

People with a wide compassionate view of all problems always deserve to be heard but, because of the ethical problems connected with the nutritional support, the people who are the actual users of the technology object of the debate, in this case nutritionists, are also entitled to express their opinion on the issue.

THE CORE OF THE DEBATE

It is my opinion that the core of the debate is the relationship between "Natural Alimentation" and "Artificial Nutrition" and the definition of the nutritional support as "therapy" or simple "supportive care".

There is, in fact, a tendency to consider the first as basic care (that is a procedure deemed essential to keep a patient comfortable, which should always be provided unless actively resisted by the patient or because responsible for an unacceptable burden to the patient) and the second one as therapy (i.e., equating it to the administration of a drug) and thus requiring formal medical recommendation to be initiated or withdrawn.

However, nutrition and alimentation are interchangeable terms: nutrition, according to the Indo-European root "*snanu , snu, sneu*" means to drip/give milk, and alimentation, derives from the root "*al*" which means to let thrive in arab. Furthermore, historically, the original procedure of intravenous feeding was known as "parenteral hyperalimentation" and only subsequently was defined as "parenteral nutrition". Consequently, any attempt to differentiate nutrition and alimentation by referring to the original meaning of the words appears to be fictitious and conventional, hence questionable.

It is probably more significant to differentiate Natural Alimentation from Artificial Nutrition by referring to the adjective.

What differentiates "natural" from "artificial " feeding: the nutritive substrates? How are they administered? Who recommends it?

The substrates?

Yes, but not always. Patients can receive by mouth an elemental diet, as can be see in a recent paper in Clinical Nutrition (1), or, on the contrary, they can receive chicken broth through their PEG!

The administration through a tube?

Yes, but not always. Occasionally, we all drink liquids through a straw, we have all been fed intravenously during the last six months of intrauterine life and, more importantly, feeding a dysphagic old relative using a spoon may prove to be so exhausting and dangerous that a nasogastric tube becomes preferable, this being a matter of convenience rather than medical necessity (2, 3)!

Who recommends it?

This is certainly true, or at least the technical definition and prescription of the nutritional regimen is up to the physician, but the recommendation or the request for the recommendation is not always so.

The irrelevance of the artificial versus natural distinction has been recently emphasised in the international literature (4).

Having said that the boundaries between alimentation and nutrition, and between natural and artificial are so overlapping that they tend to disappear (5), let us come to the central question: is nutrition "therapy" or "supportive care"?

Even if we would accept, as many of us do; that "artificial nutrition" is substantially different from "natural

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alimentation", could artificial nutrition be equated to a drug?

Why yes?

If we refer to the bible of pharmacology, the text on which many of us have studied, the "Goodman&Gilman" textbook of pharmacology (6), we find that the authors define drug as *"any chemical agent which affects living processes…"*. Again, according to the Italian Ministry of Health (Directive 2001/83/CE, Codice Comunitario dei Medicinali) a drug is *"a) any substance or combination of substances presented as having therapeutic or prophylactic properties of human diseases, b) any substance or combination of substances that can be used to correct or modify physiological functions, by exerting a pharmacological, immunologic or metabolic action, i.e., to establish a medical diagnosis"*.

So every kind of nutrition is of course a pharmacological therapy.

Why not?

As clearly stated in the ASPEN Guidelines (7) *"… a major distinction between therapeutic trials of efficacy of a drug or a procedure and the feeding of nutrients known to be essential to maintenance of human health and survival must be made. Withholding a drug or invasive procedure will not produce disease in otherwise healthy humans, whereas essential nutrients must be provided to both healthy and ill people…"* …

Since nutrition is essential, even to healthy people, this obviously precludes the evaluation of efficacy of total nutritional support through randomised clinical trials, i.e., the assessment of the strength of a recommendation by the rules of evidence-based medicine. As a matter of fact, less than 1/3 of the ASPEN Recommendations were classified as Grade A and, instead, the majority relied on experts' opinion.

Consequently, the ASPEN (8) is very subtle in distinguishing between "Nutrition Care" – *interventions and counselling of individuals on appropriate nutrition intake through the integration of information from nutritional assessment - and* "Nutrition Therapy" – *a component of medical treatment that includes oral, enteral and parenteral nutrition* –.

Let us now consider a patient with advanced cancer, harbouring a central venous catheter previously inserted for chemotherapy and blood sampling and now severely anorectic. If the clinician (or the relatives) suggests the intake of some additional calories through some oral supplements, this could be viewed as simple "support" but if we administer him a bottle of fat this would be "therapy".

What is conceptually inconsistent is that quality of nutrients or way of administration is more important, from the ethical point of view, that the determination of providing nutrition to the patient.

I know that my arguments are paradoxical but I did so to demonstrate that faced with these ethically crucial issues as the futility -meaning intervention without a goal- of feeding patients in the last phase of an incurable disease, we cannot rely on inconsistent bases to define the ethics of our behaviour.

As we reported elsewhere (9), a rigid definition of nutritional support as therapy would expose the scientific community (and the patient population) to consider scientifically adequate (and reimbursed by Public Health System) only the recommendations validated by the rules of evidence-based medicine, namely randomised clinical trials. In such a way, the value of the nutritional support as life-sustaining treatment could be denied to aphagic chronically ill patients simply because, in these conditions, studies comparing the outcome of feeding versus non-feeding are not possible for ethical reasons.

On the other hand, accepting the nutritional support as simply basic care would mean that this is always due, even in conditions where it appears clearly futile.

It is noteworthy that whereas almost all the medical societies considered artificial nutrition as therapy (it could not be otherwise!), patients and relatives, at variance with physicians, consider nutrition as an act of community (10-12). Nourishment is viewed as a symbol of love and care both for the living and the dying, while denial of food is associated with starvation, famine, and abandonment.

It has also been reported "*ironically the only reason that tube feeding has been identified as treatment has been so that it can be withdrawn. Much of the debate has concentrated on the argument that tube feeding is a futile treatment. I would argue that tube feeding is extremely effective since it achieves all the things we intend it to do. What is really being argued is whether the patient's life is futile, hence the need to find some way of ending that life…that is euthanasia*." (13).

Following the modern trend of society in western countries of considering autonomy (and freedom) of the individual as a supreme value (14-16), I do not understand why we should passively accept the definition "nutrition is therapy" of the medical societies rather than the patient-focused concept of the user "nutrition is care".

The British Medical Research Council too, in 1973 (17), a period in which nutritional support was certainly less "ordinary" than now, stated that "*the care involved in feeding is not, in strict sense, medical treatment, even if provided in a hospital. It is ordinary care*".

So the controversial view of the Irish Medical Council (18) as well as the report of the National Committee for Bioethics (19) and the previous statement by the Po-

pe (20) simply reflect, in my opinion, not only the sacredness of life but also mainly the respect for the expectations of patients and families against the overriding self-determinism of science.

It has been, in fact, pointed out by Truog and Cochrane (4) that "*when patients surrogates consider withdrawal of mechanical ventilation or dialysis, they typically are experiencing either pulmonary or renal failure, respectively. In contrast, withdrawal of tube feedings is typically considered in patients who have normal alimentary tracts, are fully capable of absorbing nutrition, and are not imminently dying unless this nutrition is withheld. The organ that is failing in these patients is the brain: while this does not prevent the patient from absorbing nutrition, it does not prevent the patient from eating and drinking independently*."

As a matter of fact, the withdrawal of artificial nutrition is more difficult from the ethical point of view, than the withdrawal of other forms of life-sustaining treatments (21).

If we are ethically obliged to respect the will of not being fed of a competent young woman with anorexia nervosa and we refrain from forcing her to receive any food through the mouth, we should equally respect the desire of a patient to be artificially fed even when the final outcome will not change.

Jonathan Rhoads, the father of parenteral hyperalimentation, when he realized at the age of oven 90 that he had an inoperable gastric cancer, asked for (and got) a central venous catheter and intravenous feeding at home.

In conclusion, medical and political communities should be aware not only that nutrition badly fits both categories of "medical therapy" or "basic care" but, both patients&family and physicians are equally entitled to set its pertinence to one of them.

A humanistic approach should be able to recognize and accept both sides of this dilemma.

Regardless of our definition of nutrition, it is simply a matter of common sense and sound judgment that it is inappropriate to provide artificial nutrition (and be allowed to withdraw it) when it clearly appears that the burdens of this treatment outweigh its benefits.

On the contrary we showed be ethically obliged to provide nutrition when it has been deemonstrated (or deemed) necessary.

In perspective, since the true autonomy of the patient relies on adequate knowledge of the diagnosis, prognosis and potential of the available treatment, the major cultural and political effort should be towards the implementation of these processes at the educational level in Universities and in everyday practice in hospital wards.

This will finally prove to be more useful and respectful of the expectations and duties of the patient and the physician, respectively.

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Received:
Revised:
Accepted: