

Non-Benefit of Active Nutritional Support in Advanced Dementia

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Active nutritional support using the technique of tube feeding in the elderly with advanced dementia is a common practice in Israel [1]. Nutritional support constitutes medical treatment, which by definition supports life, together with other medical and surgical treatments. Several levels of intervention exist, ranging from dietary manipulation to improve the quantity and quality of nutritional intake, swallowing rehabilitation, the addition of specific nutrients (such as iron, other minerals and vitamins, energy and protein in different forms), to providing a diet using artificial formulas of food containing all the nutritional ingredients in recommended amounts and defined as medical foods. When medical foods are delivered through tube feeding – nasogastric, gastrostomy or jejunostomy – bypassing the swallowing mechanism, nutritional support becomes active enteral feeding. Parenteral nutrition is another form of nutritional support, delivering the nutritional components by means of intravenous solutions, when there is gastrointestinal insufficiency and the gastrointestinal system needs to be bypassed in order to provide the patient with adequate nutrition.

The decision to embark upon active enteral feeding, as with any other medical treatment, has to be made in accordance with the four principles of medical ethics: patient autonomy, social justice, benefit, and lack of harm to the patient. Since most demented patients who need active nutritional support are not in a condition to express their wishes according to the first principle, and since society countenances the provision of active nutritional support to these patients, the decision must be made on the basis of medical experience and knowledge using the two principles of patient benefit and lack of harm. The specific questions that must be addressed are:

- Does the patient suffer from a condition that is likely to benefit from enteral nutrition?
- Will nutritional support improve outcome or accelerate recovery?
- Does the patient suffer from an incurable disease, but one in which quality of life and well-being can be maintained or improved by enteral nutrition?
- Does the anticipated benefit outweigh the potential risks?

Dementia is by definition a progressive degenerative state that can lead to an irreversible vegetative state and to death. There is no known cure for this group of diseases. In advanced stages of dementia most of the cognitive capacities are lost, commu-

nication skills have disappeared, and the basic functions such as swallowing and continence have diminished. Therefore, the appearance of dysphagia in these patients is a sign of further progression of their disease and the deterioration in their health. According to the guidelines of ESPEN (European Society of Parenteral and Enteral Nutrition) for the placement of percutaneous endoscopic gastrostomy published in 2005 [2], dementia is the most controversial issue with regard to PEG placement. The stated aims of tube feeding in advanced dementia include improving functional status, avoiding hunger, enhancing comfort, preventing nutritional decline and its consequences, preventing aspiration, and reducing the incidence of pressure ulcers and infection. There are no randomized controlled studies and a recent review concluded that there is no published evidence that these aims are achieved [3-6].

An inadequate intake of energy and nutrients is a common problem in demented patients. Malnutrition may be caused by several factors, including anorexia (frequently related to polypharmacotherapy), insufficient oral intake (forgetting to eat), depression, or apraxia of eating, or, less often by enhanced energy requirements due to hyperactivity. In advanced stages of dementia dysphagia may develop and become an indication for enteral nutrition.

Several studies of oral nutritional support have shown increases in body weight [7-9]. In tube-fed demented elderly patients, two studies reported weight gain [10,11], but two others reported no change [12,13]. Available trials regarding the effects of oral nutritional support [8,9] or tube feeding [12,13] on functional status report no improvement in terms of survival, and most studies show no benefit [13-15]. On the other hand, Rudberg and co-authors [16] reported lower mortality compared to controls, at 30 days and 1 year in enterally fed patients with severe swallowing disorders, including patients with cognitive impairment. Very low mortality rates have been reported in PEG-fed demented nursing home residents [17,18]. The Israeli study [18] demonstrated differences between patients with progressive dementia and others. On the other hand, in one retrospective study comparing mortality rates in different diagnostic groups, outcome was worst among the demented [4].

In contrast to demented patients, in patients with dysphagia due to acute neurologic deficits secondary to cerebrovascular accidents,

PEG = percutaneous endoscopic gastrostomy

the dysphagia is either reversible and will benefit from rehabilitation treatment like any other temporary neurologic impairment, or it will remain a permanent deficit. In the latter situation, bypassing the disturbed swallowing mechanism remains the only solution for feeding these patients. Nevertheless, these patients remain neurologically stable, in contrast to the dementia patients where dysphagia represents further continuous progression of their disease.

Recently a meta-analysis of protein and energy supplementation in older patients suggested that current evidence does not support routine supplementation at home or in any other setting, apart from the undernourished elderly in the acute care setting [19]. That study concurs with the conclusions in 1997 of the American College of Nutrition, the National Institutes of Health and the American Society of Parenteral and Enteral Nutrition [20] – namely, a lack of published observations providing direct evidence that wasting is a cause of death or that reversal of wasting improves outcome.

The Israel Medical Association Ethics Division recently published a position paper about artificial feeding in the permanent vegetative state [21]. The condition is characterized by conservation of brainstem activity without cortical activity and is thus defined as unconsciousness. Giving food and water has symbolic religious and sentimental value, which differs from other physiologic life support treatments; nevertheless, it is considered as a medical treatment that has to comply with standards of efficacy and effectiveness in the same way as any other medical treatment. Futile treatment in a PVS patient is permitted if it is in accordance with the previously expressed wishes of the patient or his or her legal representatives. Withdrawing nutrition in a PVS patient is permitted under the following conditions: the patient is diagnosed as PVS, a neurologist has confirmed the diagnosis, and the local ethics committee has approved the action.

There are certain questions concerning that paper: What are the similarities and differences between end-stage dementia and PVS? The main difference is that in PVS the patient has reached a stable state and further deterioration in his/her function is not anticipated. The development of dysphagia in dementia, by contrast, is a sign that the patient suffers from a progressive deteriorating condition with impairment of the vegetative system, and further deterioration of this function is expected. Thus, in the demented patient with dysphagia, active artificial feeding is at the same time both beneficial and maleficent, since it provides futile treatment to the patient and misleading information about the prognosis to the caregivers and the family.

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PVS = permanent vegetative state