



Enteral Feeding in Terminal Dementia – A Dilemma without a Consensual Solution

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Modern medical technology is a two-edged sword, and the treating physician often finds him or herself facing an apparently insoluble dilemma. For example, it is accepted by most physicians, as well as by ethicists, that “extraordinary” treatment such as cardiopulmonary resuscitation and dialysis should be withheld in patients with end-stage dementia. In those situations even a unilateral value judgment made by the physician is accepted as reasonable medical practice. However, does a consensus exist regarding the approach to “ordinary” treatment such as tube feeding in these patients? The dilemma has become even more relevant in the last two decades since percutaneous endoscopic gastrostomy tube feeding has become the most widely used method for long-term enteral feeding of patients with advanced dementia [1].

What are the points of conflict? The cardinal question of whether there is evidence for the benefit of tube feeding in end-stage dementia is discussed by Berner and by Shapiro and Friedmann in this issue of *IMAJ*. A survey among primary care physicians showed that a significant number believe that PEG feeding reduces aspiration pneumonia and improves pressure sore healing, survival and nutritional status [2]. The latter findings reflect a discrepancy between the feeling of the primary care physicians who take care of the demented patients and the contrary reports in the medical literature. It seems that in addition to the problem of the lack of controlled studies, a major problem, as pointed out by Shapiro and Friedmann, is the selection of patients for tube feeding and the timing of tube insertion. The long-term outcome of tube feeding in patients with pure refusal to eat due to advanced dementia is different from that of similar patients who, in addition, have an acute co-morbidity. There, the underlying medical condition, usually an infectious disease, is the cause of shortening of life and not the lack of nutrition. This explains the observation by many clinicians of the relatively long-term survival, sometimes even for years, of patients with end-stage dementia who were tube-fed and had no acute illness.

Alleviation of suffering is one of the paramount ethical principles. Therefore, the potential complications of tube feeding should be taken into account when considering this form of external nutrition. Most patients experience some kind of discomfort when exposed to nasogastric nutrition, mainly because of the need

for restraints, whereas in PEG feeding there is usually no need for restraints. On the other hand, life-threatening complications such as skin infections with necrotizing fasciitis, peritonitis or gastrocolonic fistula may occur following the insertion of PEG. However, the recent literature gives the impression that there is a tendency to exaggerate the potential hazards, and to underestimate the possible benefits [3]. Complication rates as high as 32–70% are cited [4,5]. In a large study of gastrostomy placement [1] the mortality rate after one month was nearly 25%, after one year it was over 60% and 3 year mortality was over 80%. But this high mortality rate was not caused by the PEG itself, but rather by the severe underlying and acute diseases from which the patients were suffering. On the other hand, recent large cumulative studies have demonstrated a mean procedure mortality of 0.6%, a major complication rate of up to 5%, and a minor complication rate ranging between 13 and 22% [6]. Complication rates such as those are reasonable and acceptable by any standards and PEG may therefore be considered a relatively safe procedure.

Despite the question of the benefit of tube feeding, it seems that the dilemma whether to provide tube feeding in patients with dementia is in many cases an emotional, cultural or religious decision. In a nationwide survey in the United States Mitchell et al. [7] found that more than one-third of severely cognitively impaired residents of nursing homes had feeding tubes. The use of feeding tubes in those patients was influenced by organizational, financial and demographic factors. Also, there exists a well-established consensus in modern secular medical ethics that external nutrition by tube feeding is a medical treatment, no different from any other treatment. It is therefore ethically justified to forego or withhold artificial nutrition and hydration, as with any other treatment regimen. This argument was raised by Berner in the present debate. Indeed, after the historical decisions of U.S. courts in the famous cases of Karen Quinlan (1976) and Nancy Crusan (1990), foregoing or withdrawing artificial feeding from patients, including the severely demented, has become common practice. However, for many generations, nutrition and hydration have been considered as basic human needs that should never be stopped. Why then, has this time-honored consideration undergone such a revolutionary change? As the basic medical and physiologic facts have not changed, we think that this conceptual change is basically a philosophical and religious one that has developed

PEG = percutaneous endoscopic gastrostomy

simultaneously with changes in attitudes of western society as a whole. It is therefore not surprising that in Israel, tube feeding in severely demented patients is still a common practice, both in hospitals and in nursing homes. Firstly, Israeli society as a whole (including its non-religious element) is still profoundly influenced by traditional Jewish ethics. Secondly, the Jewish medical community has a strong tradition of preserving life, even in the most extreme and difficult circumstances. Thirdly, Israeli society as a whole is extremely sensitive to life, especially considering Jewish history at large and taking into account the contemporary Israeli experience. These deep-rooted religious, cultural and philosophical beliefs should not be underestimated. In a study that assessed the attitudes of offspring of Jewish terminally ill patients in Israel, most of whom had advanced dementia, the majority of the offspring demanded the continuation of nutrition, with half of them even requesting forced feeding. The request to provide tube feeding was mainly affected by the degree of the family's religious observance: The more observant the offspring, the more aggressive the treatment they requested. With regard to other religions it is not clear whether or not the degree of religiosity plays a similar role in the decision-making process [8].

In a recent review on artificial nutrition and hydration in the *New England Journal of Medicine*, Casarett et al. [9] discuss the problems that arise when the preference of a patient is not known and an advance directive is not available. In that situation, they state categorically, the patient cannot be assumed to want artificial nutrition and hydration. This approach is clearly paternalistic. They propose to apply a "reasonable person" standard to the surrogate, instead of the "best interest" standard. By applying a "reasonable person" standard it is possible to evade the difficult philosophical question of whether a decision that could result in death is in the patient's best interest. But this is exactly the core of the problem, and in our opinion it is unethical to avoid a problem merely because it is difficult to deal with.

Should a patient with terminal dementia be treated differently from those with any other terminal disease? The answer is yes, mainly because of the difference in the survival expectancy, which is usually longer in the patient with terminal dementia. If so, what is the reason for the decrease over time of the overall use of PEG tube feeding for dementia patients in the United States [10]? Since 1991, U.S. federal law has required every hospitalized or institutionalized patient to be informed of his/her right to use medical advanced directives. This law enables the person with advanced dementia who prepared advance directives to withhold or even withdraw life-sustaining measures, including tube feeding. We assume this law has been applied particularly to the institutionalized elderly population.

The situation in Israel is different. Until recently there was no legislation dealing with the rights of patients, the obligations of healthcare professionals, or the authority of family members in the decision-making process regarding life-sustaining treatment in the dying patient. Proposed legislation that addresses the various aspects of the dying patient was recently introduced by the "Steinberg Committee" and approved by the Knesset (the Israeli Parliament) [11]. One of the recommendations relates to the

withholding of food. It was accepted by most of the committee members that withholding of food is not permitted under any circumstances, unless it was specified by means of an advance directive and, if in the terminal state, death would be imminent within less than 2 weeks. The committee was composed of physicians, bioethicists, philosophers, and rabbinical and legal authorities representing a broad spectrum of pluralistic and multi-cultural sections of Israeli society. The high degree of consensus achieved by the members of the committee reflects the attitude of the majority of the population in Israel regarding the provision of nutrition, even in a terminal state [8]. Since the patients in our discussion are by definition incompetent, the use of advance directives would be the preferred mechanism since in most cases it will reflect the patient's wishes and his/her moral and religious attitudes. However, in those patients without advance directives and whose preferences on this issue are not known, artificial nutrition should not be withheld or withdrawn unless it imposes suffering on the patient, in which case withholding food should not be considered a negative discriminatory act.

In this challenging area of terminal patient care, many difficult dilemmas are indeed not readily resolvable, and no real consensus exists.

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