The Use of Percutaneous Endoscopic Gastrostomy (PEG) in Demented Patients: A Halachic View

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The decision to use PEG in a demented patient should be based on medical, ethical and social considerations. Unfortunately, I believe that the medical literature has often confused between these various factors, giving medical "coverage" to personal values, i.e., medicalizing ethics, and thus leading to inappropriate conclusions.

From the medical point of view one needs to balance the harm/benefit ratio purely from the physiological point of view, without involving value judgements in the medical evaluation. Only in that way can one give appropriate consideration to the "pure" medical data in the overall decisions, which include also social and ethical factors. Some of the medical reports in the literature seem to have a clear, even if unintentional, bias, which colors the decisions they reach on insufficient, or erroneously interpreted, data.

There are clearly both serious and mild complications from PEG in demented patients which have been reported in the medical literature. But many of the reports have serious methodological problems, often even pointed out by the authors. Reports are mostly retropective, deal with small numbers of patients, without proper control groups for comparison, such as non-demented vs demented, purely demented vs demented with other illnesses. The serious complications often described are in series in which the PEG has been placed during late, almost terminal, stages of disease, rather than relatively early when the patient is fairly stable. The high death rate in these series is more indicative of the serious underlying disease rather than the result of the PEG.

From an ethical point of view there are a number of issues to be considered:

The value of life itself versus the quality of life, autonomy versus paternalism, and the significant differences between of fluids and nutrition and other forms of treatment in patient care.

In Judaism human life is of supreme value, overriding almost all other halachic considerations. This attitude contrasts to many current ethical philosophies which place a greater emphasis on quality of life. There are some halachic experts who view the value of life as absolute and infinite, therefore insisting that one must do all within ones power to prolong human life at any cost and in any condition.[1,2] But most authorities do not agree and do take other factors into consideration, which may at times take precedence over the absolute value of life. Nevertheless, even these authorities consider human life to be of primary importance. Thus the patient's age, mental capacity, socioeconomic status or other components of "quality" of life cannot be determining factors in continuation or cessation of treatment.[3] Only severe suffering and pain can be considered in the decision whether to extend the life of a terminal patient.

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1 הרפואה והיהדות, עמ' 152.

2 י. לייבוביץ, בין מדע לפילוסופיה, עמ' 286 ואילך; הנ"ל, הרפואה 106:119, 1990.

3 שו"ת אגרות משה חחו"מ ח"ב סי' עד אות א; שם סי' עה אות ז.

Quality of life is clearly a subjective factor and difficult to quantify or estimate.[4,5,6] Who may make such a determination - is it only the patient, or do family members and/or medical staff decide? Different individuals may arrive at diametrically opposing opinions. In dealing with demented patients the quality of life as perceived by observers may or may not reflect the patient's feelings.[7,8,9]

Autonomy versus paternalism - The modern era has witnessed the revolution in which autonomy has become the dominant value over paternalism. In the case of the demented patient one cannot obtain the autonomous view of the patient as to whether he/she wants to live or not, or whether he/she wants to be fed by one method or another. The decision not to offer such a patient nutrition when such feeding is able to sustain life would seem an unwarranted paternalistic decision which may take the patient's life without his/her consent. On the other hand if the patient is competent and expresses clear opposition to a PEG - it should be respected.

Significance of fluids and nutrition - Until just a short time ago no one would have dared propose cessation of fluids and/or nutrition even in terminal patients. This would have been considered highly unethical. But during the past few decades there has been an increasing tendency on the part of many ethicists to consider fluids and nutrition administered other than by mouth to be "medical " treatment which may be withheld or withdrawn in a variety of situations, such as in the persistent vegetative state and in severe dementia, among others.[10]

Other investigators are opposed to this decision for various reasons: Food and fluids are essential sustenance rather than a medical treatment, they have a different emotional significance, and depriving a person of nutrition is a direct cause of death unrelated to the dying process from the terminal illness.[11,12,13,14,15]

The Jewish view regards food and fluids as normal components essential to life and not as "medical" therapy. Therefore, deprivation of these to any but the very special case of gosses is strictly forbidden. Every human being, of whatever physical or mental state, requires these elements for life.

From social considerations we must be extremely careful not to devaluate any human being, no matter what his mental or intellectual state may be. If medical data indicate that PEG can maintain the life of demented individuals, society dare not deprive these individuals of the right to life. The danger of the slippery slope is obvious in deciding paternalistically who has the right to live.

To solve the controversy from a medical point of view what is needed is a prospective, multicentered, international study with appropriate controls.

Among the criteria that I propose for this study:

- Clear indications for use of the PEG
- Defined, optimal nutrient composition for the PEG
- Enough participants for statisitical significance
- Appropriate selection of demented patients, at a relatively early stage, when their physiologic condition is still satisfactory and comparison with groups in later stages, so that results for different subgroups can be evaluated
- Control groups will be similar patients without feeding, those with oral feeding, those with nasogastric tube feeding and those with parenteral feeding
- Clear exclusion criteria

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