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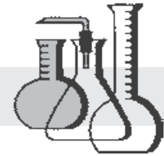

Percutaneous Endoscopic Gastrostomy in Hospitalized Incompetent Geriatric Patients: Poorly Informed, Constrained and Paradoxical Decisions

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Key words: geriatric patients, dementia, percutaneous endoscopic gastrostomy, decision making, physician attitudes

Abstract

Background: The frequency of performing percutaneous endoscopic gastrostomy in demented older people has increased in recent years. Several reports indicate flaws in the criteria for performing PEG and in the decision-making process, raising concerns about the adequacy of the consent.

Objectives: To assess the knowledge and attitudes of referring doctors and gastroenterologists, and to evaluate attitudes and feelings of family members concerning PEG insertion.

Methods: We conducted a survey of 72 doctors who referred 126 demented patients for PEG, as well as 126 family members and 34 gastroenterologists. Closed-ended questionnaires were designed for each study group, completed by the participants, and computer analyzed.

Results: Approximately 50% of family members expressed dissatisfaction with the decision-making process. Referring physicians reported that PEG insertion was often dictated by the need to transfer patients to a nursing home, with 50% admitting institutional pressure. Most of the referring physicians believed that PEG improved quality of life and increased longevity, whereas gastroenterologists did not expect an improved quality of life and thought that administrative demands should not intervene in the decision to insert PEG.

Conclusions: The decision-making process in the patient's families regarding PEG insertion for their demented relative is unsatisfactory, often takes place under pressure, and does not provide sufficient information about the procedure or its complications. Interpersonal communication between the patient's family and the medical team needs to be improved, and institutional demands should not play a major role in the medical decision to insert PEG. Gastroenterologists should take a more active role in the deliberations regarding PEG.

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For Editorial see page 881

The frequency of performing percutaneous endoscopic gastrostomy in demented older people has increased in recent years [1]. While these patients are unable to give their consent for the procedure, family members or guardians are required by law to do so. Several reports indicate flaws in the criteria for performing PEG and in the decision-making process, which raise concerns about the adequacy of the consent. These include: not respecting the feelings and attitudes of family members or guardians towards gastrostomy feeding, and providing insufficient information on alternative feeding options and on the complications of PEG [2,3]. Other points of concern are medical, ethical and administrative, which do not always benefit the patient [4,5].

The professional literature does not support claims that tube feeding improves quality of life and prevents aspiration pneumonia in demented patients [6-8]. Moreover, mortality among hospitalized patients during the first month following PEG insertion is high, ranging from 20% to 60% [8-12].

The role of the gastroenterologist in this process is mainly technical: performing the procedure at the request of the referring physician, but not taking any part in the medical assessment and decision [3,13]. The aims of the present study were to evaluate: the decision-making process regarding introduction of PEG in demented geriatric patients, the attitudes and feelings of family members or guardians towards PEG insertion in their incompetent relative, and the position of the referring physicians and gastroenterologists with regard to ethical and personal issues.

Patients and Methods

This survey was conducted in four major academic hospitals in Israel using closed-ended questionnaires. The study population comprised three groups: a) physicians who referred their patients for PEG (n=72) and who worked in the departments where the geriatric patients of this study were hospitalized, b) patients' guardians or relatives (n=126), and c) gastroenterology specialists (n=34). All were asked to answer questions on criteria, attitudes and feelings with regard to PEG in demented patients.

The target population comprised 126 demented patients (age ≥ 65 years) hospitalized in one of four medical centers in Israel – Kaplan in Rehovot, Soroka in Beer Sheva, Rambam in Haifa, and Hadassah (Ein Kerem campus) in Jerusalem – for acute illness, e.g., cardiovascular accident or cardiac event, and referred for PEG during their hospitalization but were unable to give their consent for the procedure. The sample included consecutive

PEG = percutaneous endoscopic gastrostomy

patients admitted during the year 2002. It should be noted that the decision to perform PEG was made by the treating staff, which included a senior physician.

Three different questionnaires were used. Most questions were structured on a scale from 1 to 5, with some of the demographic questions being open-ended. The questionnaire for referring physicians comprised questions regarding their updated knowledge about PEG, their considerations and attitudes, and their responsiveness in providing necessary information to the patient's family. Most questionnaires were completed immediately prior to the procedure. Physicians who referred several patients were asked to complete only one questionnaire. The questionnaire for the patient's relatives contained questions on the information they received about PEG, their reactions and attitudes during the decision-making process, and their position with regard to tube feeding of a close family member. The questionnaire was answered after signing an informed consent form. Most of the patients' relatives were also their guardians appointed by the court. In cases where the legal guardian could not be reached, another family member involved in the decision-making process answered the questionnaire. The gastroenterologists' questionnaire comprised questions on indications for performing PEG and their attitude on the subject. Gastroenterologists completed the questionnaires at their convenience, not necessarily immediately following PEG insertion. The study was approved by the Helsinki Committee of the Hadassah Medical Center.

Data analysis

Analyses were performed by SPSS for Windows, version 11 (Norusis M. SPSS for Windows V.11 SPSS Inc. 2001) and included: chi-square (two-tail), Fisher's exact test; and logistical regression.

Results

Over the course of 13 months, of the 350 distributed questionnaires 232 were fully completed (66% response rate).

Referring physicians

Seventy-two physicians who referred patients for PEG insertion participated in the study. Their reasons for performing the procedure were the need to prevent aspiration (82%), the desire to improve quality of life (85%), and an imminent need to transfer the patient from the medical ward to a nursing home (83%). Eighty-two percent of referring physicians felt they had provided family members with complete information about PEG. Only one-fourth of the referring physicians would consult with a gastroenterologist or a geriatric specialist prior to performing the procedure. Sixty-seven percent reported that they were under pressure to perform PEG and about 50% of them admitted that they would not honor the family's preference not to perform gastrostomy. Forty percent had reservations about the appropriateness of PEG in demented older patients, and only 23% would recommend PEG for their own relatives in a similar condition [Table 1].

Table 1. Referring physicians' reasons and attitudes for performing a gastrostomy (n=72)

	% Responding Yes	Total no. responding
Preventing aspiration	82%	71
Transfer to a nursing home	83%	72
Improvement in quality of life	85%	72
Felt that family received full information	82%	59
Need for gastroenterology consultation	24%	70
Need for geriatric consultation	29%	69
Would honor the family's wishes	50%	70
Feel pressured to recommend the procedure	67%	72
Would recommend the procedure to a relative in similar condition	23%	69
Has reservations about performing PEG in demented older patients	40%	72

Table 2. The guardians' decision-making process (n=126)

	% Responding Yes	Total no. responding
Felt they had received complete information	60%	124
Felt support from the staff	31%	97
Felt pressured to consent to PEG	58%	119
Received information about potential complications	26%	125
Received information about alternative means of feeding	35%	126
Felt they were given enough time to decide on PEG	56%	124
Felt part of the decision-making process	63%	125
Were satisfied with the decision-making process	54%	118
Felt the patient him/herself would have consented to PEG	26%	107
Would consent to having PEG performed on themselves	24%	105

Relatives/guardians

Questionnaires were collected from 126 family members or guardians. Sixty percent of the family members or guardians felt they had received complete information, yet only 26% reported having received information about complications and only 35% received information about alternative feeding options. Moreover, 58% noted that they felt pressured to give their consent for the procedure, and only 31% claimed to have received support from the staff when they expressed their reservations. Fifty-six percent of the guardians reported that they were allowed enough time to make their decision. The feeling of being part of the decision-making process was reported by 63% of the families and, overall, 54% reported satisfaction with the decision-making process. However, only 26% of family members felt that the patient him/herself would have wanted PEG feeding if this had been proposed to the patient prior to the illness and only 24% of the family members would agree to PEG insertion for themselves in a similar situation [Table 2].

Gastroenterologists

Thirty-four gastroenterologists participated in the study. Significant differences were found between them and the referring

Table 3. Comparison between attitudes of gastroenterologists and referring physicians regarding insertion of PEG

		Gastro-enterologists (n=34) [%] N	Referring physicians (n=72) [%] N	P
Improving the quality of life of the demented older patient	Yes	(41) 14	(85) 61	< 0.001
The need for a consultation with a gastroenterologist	Yes	(74)) 25	(24) 17	< 0.001
	Problematic cases	(23) 8	(46) 33	
Performing PEG in the demented older patient	Yes	(20) 7	(60) 42	< 0.001

Chi-square test [two-tailed] performed

physicians with regard to the reasons for performing gastrostomy. Consultation with a gastroenterologist before performing PEG was suggested by 25 (74%) of the gastroenterologists, while this attitude was favored by only 24% of the referring physicians ($P < 0.001$). Two-thirds of the gastroenterologists felt that transferring a patient to a nursing home was not an indication for performing PEG, as compared with one-fourth of the referring physicians ($P = 0.01$). Twenty of the 34 participants (60%) did not think that the procedure improved quality of life, while only 7 believed that there was a need to insert a gastrostomy in cases of advanced dementia [Table 3].

Discussion

Despite the vast clinical evidence that there is no benefit in performing PEG in demented older patients [1,7,14,15], most of the referring physicians in the present study recommended PEG because they believe it can prevent aspiration and improve quality of life. The majority of gastroenterologists, however, did not think that gastrostomy improves quality of life [Table 3].

The decision to perform PEG in demented older people can be influenced by administrative and/or institutional demands [3,16] and our study further confirms that referring physicians in hospitals frequently ask for PEG as a result of the pressure imposed upon them to facilitate patient transfer to a nursing home. In the United States, financial compensation is provided by the health insurance organizations for PEG insertion, which further encourages physicians to perform the procedure [4]. In Canada, gastrostomy is indicated only in demented patients with chronic neurological illnesses [5].

In Israel, different regulations prevail regarding the status of chronically ill bedridden patients. These patients are categorized as either simple long-term care patients or complex nursing care patients. The method of feeding determines the status of the patient: gastrostomy places the patient in the first group, while nasogastric tube feeding places him in the second. In addition, each category is financially supported by a different source. The financial support for simple long-term care patients comes from Ministry of Health resources, while financing of complex nursing care patients comes from the health management organizations. When planning the transfer of such a patient from the hospital to an approved facility, it is in the interest of the HMOs to put pressure on the hospital to perform PEG, which effectively changes the patient's nursing status. The HMO no longer needs to provide financial support, which now becomes the responsibility of the State. Nursing homes will not admit patients who are fed by a nasogastric tube and the change to PEG is often unavoidable [17,18].

Our study further highlights this situation, by demonstrating that the majority of referring physicians recommended PEG insertion due to this policy [Table 1]. Unfortunately, these physicians yield to administrative and institutional demands rather than applying pure clinical guidelines and judgment. This contrasts with the basic ethical principle of physicians to respect the patient's autonomy, provide comfort, avoid harm, and prevent them from suffering.

Surprisingly, only 23% of referring physicians would recommend PEG for their relatives in a similar situation, in contrast to their attitude towards their patients. In fact, about half of them expressed reservations regarding the procedure, further implying that non-medical factors such as institutional needs play a significant role in the decision to send patients for PEG.

In western society the focus on patient rights was prompted by improvements in health status, nutrition and quality of life, and an increase in longevity. In Israel, the Law of Patient's Rights was passed by the Knesset (Parliament) in 1996 [19]. Our findings, however, show that half of the referring physicians would not honor the preference of the patient's legal guardian or family to refuse PEG insertion, in violation of patient autonomy. Similarly, other studies reported that only 40% of referring physicians would honor the family's decision if they refused gastrostomy feeding [20,21]. Additionally, our study demonstrates that patients' families feel that the information they receive about PEG from the medical team is at best incomplete or unsatisfactory and is often presented in a terse manner [22,23]. This is particularly true regarding potential complications, alternative methods of feeding, and long-term benefits. Some families report feeling pressured by the staff to consent to PEG insertion, and complain that they were not given enough time to consider the matter despite the fact that gastrostomy is not an emergency procedure [20]. In our study, 46% of the families expressed their dissatisfaction with the decision-making process [Table 2].

The notion that the role of the gastroenterologist is merely to provide a "technical service" and not to participate in the decision-making process despite his/her up-to-date knowledge and experience [3,13] is reflected in the fact that most of the referring physicians did not feel the need to consult with a gastroenterologist prior to performing PEG [Table 3]. However, the gastroenterologists in the study felt that consulting with them could greatly contribute to the decision to perform PEG in demented older patients. It should be noted that the majority of the gastroenterologists would not have recommended PEG for this patient population.

HMO = health management organization

In 2003 the Professional Committee of the Association of Gastroenterology and Liver Diseases established appropriate clinical guidelines for PEG insertion for feeding [24]. It is recommended that geriatric patients be encouraged, while they have all of their mental faculties, to write a living will including preferred treatments in the event of dementia [25].

Conclusions

It would appear that clinical indications for performing percutaneous endoscopic gastrostomy are often violated by irrelevant considerations such as administrative interests and economic needs, coupled with deficient communication with the patient's family. As a result, there is an overuse of this technology despite the express wishes of the family, the referring physician and the physician performing the procedure. The process involves medical and legal criteria intertwined with ethical and moral values. The autonomy of the patient or his/her guardian, as well as the professional autonomy of physicians based on their knowledge and expertise, must be preserved and not compromised by any staff bias or institutional policies. The three primary principles of quality in medicine – that it be evidence based, patient centered and system minded – must always be preserved.

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