

## Ethical aspects of percutaneous endoscopic gastrostomy placement for artificial nutrition and hydration

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### Abstract

Of the many decisions that family members and physicians must make about medical care in patients with advanced disease and perceived poor quality of life, none is more heart-wrenching than the decision about artificial nutrition and hydration. The endoscopist often is placed in a precarious position when percutaneous endoscopic gastrostomy tube placement is requested in such patients. Clinical decision-making between the patient, the family and the physician should be consistent with legal and ethical principles.

The purpose of this article is to provide an evaluation of medical and ethical issues regarding the decision on placing a percutaneous endoscopic gastrostomy tube for various indications, as well as suggesting strategies to optimize the decision-making process. (*Acta gastroenterol. belg.*, 2006, 69, 317-320).

### Abbreviations

PEG : Percutaneous endoscopic gastrostomy, PVS : Persistent vegetative state.

### Introduction

PEG placement has become part of a standard training for gastroenterologists, is widely available, and is performed on a routine basis in a variety of inpatient and outpatient settings (1). Nevertheless, the overall complication rate reported for PEG-tube placement ranges from 4.9% to 10.8% (2). Complications rates are higher in patients with advanced dementia, with 30-day and 1-year mortality rates reaching, respectively, 27% and 50% (3,4). Subsequently, the decision to provide enteral access for long term nutritional support may be difficult in patients who are terminally ill or neurological impaired.

Endoscopists who place PEG tubes, particularly in geriatric and patient populations with terminal disease, need to be aware of the ethical and medicolegal aspects of performing the technique and providing artificial nutrition support in end-of -life situations.

### Ethical principles for decision making

The domain of medical ethics, particularly with regard to the provision of artificial nutritional support, involves 4 basic principles (5), that guide the decision making process between the caring physician, the endoscopist, the family, and the patient (6,7).

- Autonomy : Autonomy is self-determination or the ability to govern oneself. Autonomy entails that care cannot be delivered without informed and educated consent.
- Beneficence : Beneficence is the concept that an intervention should provide benefit for the patient.
- Nonmaleficence : Maleficence is an act by an individual in a position of trust that is unwarranted and harmful. Nonmaleficence is the deliberate avoidance of maleficence.
- Justice : Justice involves the concept of fair and equitable resources to all.

A number of conclusions may be drawn when these basic principles are applied to the provision of artificial nutritional support. A PEG tube should not be placed without informed and educated consent on the part of the patient. The decision to place the PEG tube should be based on the presumption that it will provide net benefit to the patient without causing harm, that the benefits outweigh the risk of the procedure itself, and that the patient would be offered placement of the feeding tube regardless of his socioeconomic status and financial circumstances (6,7).

Decisions about the use of artificial nutrition should be made in the same way in which decisions about other medical treatment are made (8). However, many people believe that nutrition must always be offered, just as pain management, shelter, and basic personal care must be. This view is deeply rooted in cultural and religious beliefs (9). Patients, families, and physicians are entitled to hold these beliefs, which are not easily set aside. However, to help patients and families make decisions, physicians should emphasize three key points (8).

First of all, it must be emphasized that artificial nutrition is not equivalent to feeding. It is both ethically and legally accepted that artificial nutrition and hydration is a medical therapy administered for a medical indication with the use of devices that are placed by trained personnel using specific technical procedures (8). Second,

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physicians should explain that unlike the provision of food or other forms of comfort, the procedures required for artificial nutrition and its subsequent administration are associated with uncertain benefits and considerable risks and discomfort, especially in patients who are neurologically impaired or terminally ill (3,4,10). Finally, physicians should clarify that the goal of artificial nutrition is not to increase the patient's comfort. In fact, during the administration of high-quality palliative care, symptoms of hunger or thirst generally resolve in a short time or can be managed effectively without the provision of artificial nutrition (11). Throughout the comprehensive informed-consent process for patients and families, physicians should explain the potential benefits of artificial nutrition for a patient, as well as its risks and discomfort and all relevant alternatives.

### Indications for PEG placement

It is generally agreed that indications for insertion of PEG comprise the following conditions (12,13). However, special consideration is required for patients with advanced dementia and persistent vegetative state (PVS) (13).

#### *Dysphagic stroke patients*

Up to 40% of patients develop dysphagia after an acute cerebrovascular episode (14). A recent randomized trial has shown an absolute difference in the risk of death in favour of early feeding (15). However, the improved survival was offset by an excess of survivors with a poor outcome, with worse quality of life in those allocated early tube feeding (15). Moreover, early PEG placement was associated with higher rates of death and poor outcome compared with early nasogastric tube feeding (15). These data suggest that enteral feeding via a nasogastric tube should be offered to dysphagic stroke patients within the first days of admission. PEG tube placement is indicated only if dysphagia persists 2 to 3 weeks after admission (15).

#### *Patients with cancer*

Malnutrition is common among cancer patients and is frequently referred to as cancer cachexia. PEG tubes often play a role in providing enteral nutrition in cancer patients undergoing surgical procedures or those expected to have significant side effects from chemotherapy/radiation therapy, as well as improving quality of life (16). Anticancer therapy may not only directly affect nutrition and reduce the urge to eat but may also influence the ability to chew, swallow and absorb food. This is especially true for patients with oesophageal cancer (17) and head and neck tumours (18). PEG tube placement in these patients is safe and improves their nutritional status (18-20). Enteral nutrition through a PEG tube should be considered in selected patients with malnutrition undergoing anticancer therapy with either

reasonable expectation of response, or in whom the survival is expected to be greater than 6 months (21). PEG tube placement is seldom indicated in patients with advanced cancer associated with significant deterioration of performance status or in patients with documented unresectable disease who have been unresponsive to chemotherapy and radiation therapy (21). Finally, PEG tube placement is not indicated in patients with evidence of terminal disease, severe malnutrition and a life expectancy of less than 1 month, though in cases of comfort care, this decision should be discussed with the patient, the family, and the caring physician (21).

#### *Trauma patients*

The benefits of initiating early nutrition in the management of trauma patients are widely acknowledged (22). Head and spinal injury, facial trauma, and prolonged mechanical ventilation are all common reasons for trauma patients to require external nutritional support. For most patients, the nasogastric route will suffice until they recover sufficiently to resume oral intake. For a small number of patients, however, long-term nutritional support will be required. In a recent, large retrospective series gastrostomy tubes placed via the percutaneous route had a significant lower complication rate than surgically placed tubes (23). PEG should be considered as the method of choice for gastric feeding tube placement for trauma patients.

#### *Chronic neurologic disorders resulting in dysphagia*

PEG tube feeding is a safe and effective method of providing long term enteral nutrition to patients with neurological dysphagia and offers important advantages over nasogastric tube feeding (24). In particular, PEG placement may provide a survival benefit to patients with amyotrophic lateral sclerosis suffering from dysphagia and weight loss (25,26). A recent retrospective study showed that PEG placement can even be offered in patients with low forced vital capacities (< 50%) (27). The procedure can be accomplished safely under local anaesthesia, although the low functional status in this subgroup of patients and it seems to offer extended survival (27).

#### *Patients with advanced dementia*

Patients with advanced dementia frequently develop eating difficulties and weight loss. Theoretically, enteral tube feeding is intended to prevent aspiration pneumonia, forestall malnutrition and its sequels, and provide comfort. However, two reviews of all published data revealed that tube feeding does not reduce the risk of aspiration pneumonia, improve pressure outcomes or improve functional status (3,6). Moreover, there seems to be no survival advantage with tube feeding (3). It is noteworthy that a recent retrospective study concerning patients requiring PEG feeding showed that patients with advanced dementia had a worse prognosis

compared to other subgroups, with a considerable mortality reaching 54% 1 month after PEG insertion (4). Therefore, the widespread practice of PEG insertion should be carefully reconsidered, and probably discouraged on clinical grounds for severely demented patients (3,4,28). Conservative measures considered as an alternative to placement of PEG tubes include providing adequate time and verbal queuing for the patient to eat, selecting appropriate food consistencies, temperature and taste, and offering preferred food with strong flavours (3,6).

#### Patients with PVS

The essence of the PVS is wakefulness without awareness (29). Patients with persistent vegetative state are unaware of self and environment and incapable of interaction with others. However, they have sleep-wake cycles and preserved autonomic and hypothalamic functions, meaning they can open their eyes and breath spontaneously (29). Their wakefulness misleads others to assume they are sentient, yet there is no reproducible and unequivocal evidence of awareness. The longer patients remain in PVS, the less likely they are to eventually regain awareness. The probability of recovery of awareness is very small (< 1%) after 3 months in a non-traumatic PVS or after 12 months in a traumatic PVS, underscoring the poor prognosis of this condition (30). Similarly to patients with advanced dementia, tube feeding is not associated with a better prognosis (29). However, decision making concerning withholding life-sustaining therapy, including nutrition, is harder in these cases because of the younger age of PVS patients. Most ethical analyses conclude that the choice should be guided by reliable information about how the patient would wish to be treated in this condition. Advances directives established previously by the patient, as living wills or assignment of a health care power of attorney can provide guidance about treatment preferences in the event that the patient is unable to make health care decisions for himself (6). Obviously, the patient's prognosis for functional recovery is an essential element in identifying the appropriate level of treatment (29).

#### Summary and conclusions

PEG placement for artificial nutrition and hydration is considered a medical treatment. As such, decisions for or against the treatment should be made in a shared decision model with the patient, the family or surrogate and the physician, weighing the benefits and burdens of the specific treatment. In order to satisfy the above points, we could imagine the role of a multidisciplinary nutrition team, including a gastroenterologist, a nurse, a nutritionist, and eventually representatives from other relevant specialities, like geriatrics and neurology, which could screen incoming requests for PEG tube placements, to assure that the procedure is justified and the

patient and family are well informed. The nutrition team, along with the attending physician who requested PEG tube insertion, should actively participate in informed consent, describing the procedure, identifying the potential risks, listing alternative therapy, and treatment options, and then answering questions from the patients or the family.

When artificial nutrition and hydration cannot achieve the goals of care as defined by the patient's values and what is considered appropriate medically, then this treatment need not be provided. The challenge of the decision-making process is to facilitate communication, respect the ethical principles of autonomy and beneficence, and tolerate a plurality of belief systems and cultural traditions while safeguarding the patient.

#### Research agenda

Survey with semi structured questionnaire assessing viewpoints of patients and surrogates regarding artificial nutrition with PEG concerning information provided by caring physician and endoscopist and possible impact of PEG on clinical course.

Impact of nutrition team on decision making regarding indication of PEG placement

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