

# The role of percutaneous endoscopic gastrostomy (PEG) in palliative care. What is the impact on patients and their carers?

Maria Prodea

Spitalul Clinic Județean de Urgență Sibiu

## Abstract

Percutaneous endoscopically placed gastrostomy (PEG) tubes are commonly used to provide nutritional support and are useful for long-term enteral nutrition. This systematic review discusses the practice and efficacy of PEG in terms of clinical outcomes in patients whose oral food intake is limited.

**Objectives:** To evaluate the effectiveness and safety of PEG tube feeding on quality of life of patients and to determine potential barriers to the acceptance of PEG tube feeding.

**Materials and Methods:** For the current review we used Pubmed and Google Scholar databases. We included observational and retrospective studies and systematic reviews. Our population of interest was adults over 18 years of age fed only by PEG tubes. Eligible studies evaluated quality of life and psychosocial impact on patients and their caregivers. The data collection period was 2012-2023.

**Outcomes:** Out of 18 articles, 6 relevant articles were included in the final analysis according to the inclusion criteria. Various barriers to PEG tubes feeding have been identified: inadequate competency and skills, insufficient time given, not enough information given, lack of guidelines or protocol, risk of procedure, family influences, attitudes of healthcare professionals. On the other hand, discordant results have been reported in terms of improved survival and quality of life in patients receiving PEG tube feeding.

**Conclusions:** Most articles suggest that PEG tube feeding is effective in improving quality of life of patients. Future research should focus on the development of interventions to alter the current attitudes and barriers towards PEG tubes feeding.

**Keywords:** Percutaneous endoscopic gastrostomy (PEG), enteral nutrition, palliative care, quality of life.

**Abbreviations:** percutaneous endoscopic gastrostomy (PEG), nasogastric tube (NG tubes).

## Rezumat

Tuburile de gastrostomie percutanată plasate endoscopic (PEG) sunt utilizate în mod obișnuit pentru a oferi suport nutrițional și sunt utile pentru nutriția enterală pe termen lung. Această revizie sistematică discută practica și eficacitatea PEG în ceea ce privește rezultatele clinice la pacienții al căror aport alimentar oral este limitat.

**Obiective:** Evaluarea eficacității și siguranței alimentării prin tub PEG asupra calității vieții pacienților și determinarea potențialelor bariere în calea acceptării hrănirii prin tub PEG.

**Materiale și metode:** Pentru această revizie am folosit bazele de date Pubmed și Google Scholar. Am inclus studii observaționale și retrospective și recenzii sistematice. Populația noastră de interes a fost reprezentată de adulții cu vârsta peste 18 ani alimentați doar prin tuburi PEG. Studiile eligibile au evaluat calitatea vieții și impactul psiho-social asupra pacienților și îngrijitorilor acestora. Perioada de colectare a datelor a fost 2012-2023.

**Rezultate:** Din 18 articole, 6 articole relevante au fost incluse în analiza finală conform criteriilor de includere. Au fost identificate diverse bariere legate de hrănirea prin tuburi PEG: competențe și abilități inadecvate, timp insuficient acordat, informații insuficiente, lipsa unor ghiduri medicale sau a unui protocol, riscul procedurii, influențele familiei, atitudinile profesioniștilor din domeniul sănătății. Pe de altă parte, au fost raportate rezultate discordante în ceea ce privește îmbunătățirea supraviețuirii și a calității vieții la pacienții alimentați prin tub PEG.

**Concluzii:** Majoritatea articolelor sugerează că alimentarea prin tub PEG este eficientă în îmbunătățirea calității vieții pacienților. Cercetările viitoare ar trebui să se concentreze pe dezvoltarea de intervenții pentru a modifica atitudinile și barierele actuale în ceea ce privește alimentarea prin tuburi PEG.

**Cuvinte cheie:** gastrostomie endoscopică percutanată (PEG), nutriție enterală, îngrijire paliativă, calitatea vieții.

**Abrevieri:** gastrostomie endoscopică percutanată (PEG), sondă nazogastrică (SNG).

## Introduction

Percutaneous endoscopic gastrostomy (PEG) was first introduced by Gauderer and Ponsky in 1980. A PEG tube is passed into the stomach through the abdominal wall to provide

a means of long-term enteral nutrition for patients whose oral intake is restricted.

Identifying problems before and after patient discharge, identifying the needs of caregivers of percutaneous

endoscopic gastrostomy (PEG) patients, and seeking solutions are crucial to improving quality of life for both patients and caregivers (1).

A PEG tube is placed in patients with an anticipated inability to swallow safely for more than 2-3 weeks.

Endoscopically placed percutaneous gastrostomy tubes are useful for long-term enteral nutrition; however, they are associated with lack of benefit for patients with advanced dementia, end-of-life and some stroke patients with early recovery of swallowing function. Many stroke patients regain the ability to swallow within 2-3 weeks, therefore it is preferable to initially use temporary nasogastric (NG) tubes for enteral feeding and to delay PEG placement until 14-28 days after stroke.

It is very important for physicians to discuss important topics related to PEG fitting (advantages and disadvantages) with patients and their families or caregivers, and to give them sufficient time to process the information (2,3,4).

**Materials and methods**

For this topic, the keywords used for the electronic search were: (PEG) or (enteral nutrition) and (palliative care) and (impact) and (quality of life).

For the current review we used Pubmed and Google Scholar databases.

Diagram of the selection process of relevant studies

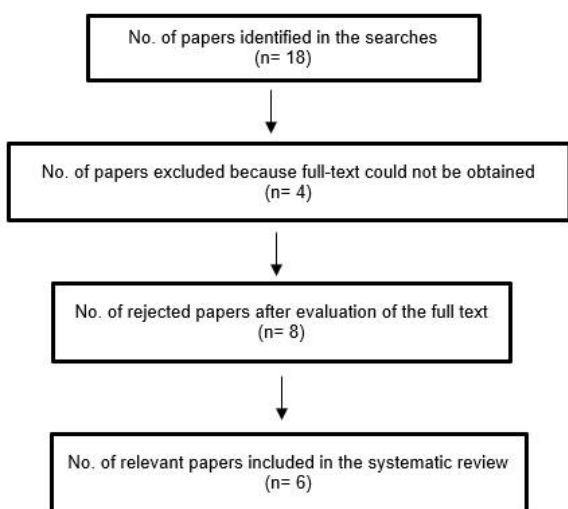
Relevant potential studies (n=18)

Studies excluded because full-text could not be obtained (n=4)

Studies excluded after full-text evaluation (n=8)

Relevant studies included in the systematic review (n=6)

PRISMA flow diagram



Inclusion criteria: age over 18 years, patients fed only by PEG, studies on quality of life and psychosocial impact on patients and their caregivers, data collection to be carried out between 2012-2023.

Exclusion criteria: patients fed parenterally or by nasogastric tube, studies without full text available and studies containing insufficient information or data.

Sezer RE et al. 2020	Observational study 21 patients and 21 caregivers;	-impact on the quality of social and professional life of carers of
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	oncological diseases, neurological diseases, swallowing disorders	patients with PEG tube feeding
Muoki DC 2020	Review; 16 articles (2008-2018) factors associated with decision making in PEG tube placement	-different patient perspectives on PEG tube placement
Jaafar MH et al. 2016	Review; 17 articles attitudes and barriers in PEG tube feeding patients	-the benefits of PEG tube feeding for long-term enteral nutrition -barriers affecting choice and PEG tube feeding
Muratori et al. 2016	Retrospective study; 438 patients with PEG (1999-2013); cancer, stroke, dementia, neurodegenerative diseases	-predictors responsible for short- and long-term mortality after PEG tube placement for enteral nutrition
Mobily M, Patel JA 2015	Review; role, goals and complications of PEG tube placement in gastrointestinal cancer patients	-the impact of PEG tube placement on the quality of life of patients and their carers
Martin L et al. 2012	Retrospective study; 270 patients with PEG; cancer, neurological diseases	-factors that may influence the experience of PEG tube-fed patients

**Results and discussion**

Tube feeding and PEG stoma care in patients involves many burdensome responsibilities for caregivers. Caregivers need to be aware of possible physical complications related to PEG in their patients, as follows: redness around the tube, infection, leakage around the tube. Caregivers should receive theoretical training with clear content and as few technical terms as possible; they should also receive repeated practical training (5,6).

Caregivers of patients with PEG had difficulties in fulfilling both household tasks and personal needs, social life and family meals are diminished or even cancelled. For single caregivers, work life may end or at best be reduced, they become physically, but also emotionally exhausted. They also suffer from fear, anxiety and a decreased quality of sleep (7).

Caregivers should be taught about feeding practices and complication prevention to ensure that patients with PEG receive optimal care.

Caregivers may also experience various gastrointestinal complications in these patients: diarrhea, constipation, nausea and vomiting, tube blockage, tube dislocation, weight loss.

Caregivers of PEG patients suffer from lack of training, they need support, validation for their actions of care, respite. These details prevent malpractice, reduce healthcare costs and improve patient outcomes (8,9).

The diagnosis of a malignant disease is often the beginning of a trajectory, cancer-associated malnutrition can occur at any time during the course of the disease due to inappetence, fatigue and metabolic disturbances (10).

If enteral nutrition is expected to be required for more than 4 weeks, a percutaneous endoscopic gastrostomy (PEG) is preferred over a nasogastric tube by many patients. However,

insertion of a PEG tube may be hindered by high peritoneal/abdominal neoplastic shedding loads or malnutrition which may require a period of enteral/parenteral nutritional stabilization prior to PEG insertion (11).

Percutaneous endoscopic gastrostomy tubes are placed when people are unable to consume an adequate quantity of food orally. This decision is multifactorial and depends on the prognosis of the disease, patients' wishes and weighing the risks against the benefits.

PEG tube placement is individualized. Uncertainty of prognosis and lack of standard recommendations can create an ambiguous situation. Patients must consider all aspects of a feeding tube before making the decision to proceed with PEG tube placement (12).

Some patients expressed dissatisfaction with PEG tube feeding in restaurants, stating that eating was a social activity for them and a way to interact with family and friends.

Older adults felt that PEG tube placement did not improve their social life or quality of life.

Other patients expressed frustration at the long duration of time they had to eat only a small portion of food while their family and friends had already finished their meal (13).

Body image is a central theme for the discussion of PEG tube placement. This issue seems to be most prevalent in female patients. Women claimed that the PEG tube was bulky and felt that others could see it, even though the PEG tube was underneath their clothes and not visible.

Many patients did not want a foreign object inserted into their body for personal reasons and cultural beliefs. Patients' personal beliefs are important because there is no definitive right or wrong decision. This can later help to ensure that patients are satisfied with their final decision (14,15).

Caregiver burden is another theme that has been associated with decisions about PEG tube placement (16).

People with dementia have difficulty eating and drinking. People with severe dementia need constant care, and it is often their families who care for them. It is difficult to decide whether or not to tube feed someone with dementia, as tube feeding can be uncomfortable or even painful and can also cause unwanted effects (17).

There are studies that have found that PEG tube feeding increases the risk of pressure ulcers compared to non-tube feeding (18).

Evidence on mortality comparing PEG with enteral feeding was inconsistent. There is no reliable evidence that PEG tube feeding has an effect on mortality compared with no enteral feeding (19).

PEG feeding is preferred versus nasogastric tube (NG) feeding for patients requiring long-term nutritional support mainly due to complications associated with NG tube placement such as dislodgement, discomfort in the nasopharyngeal area, aspiration, nasal trauma, vomiting, diarrhea and tube blockage. In addition, PEG tube feeding is associated with better outcomes in terms of mortality, complications and nutrition (20,21).

Limited information about PEG feeding among patients or their caregivers is a drawback to PEG feeding. Insufficient time indicates pressure on patients and carers to make decisions quickly. The following factors can also be added to insufficient information provided, inadequate standardized written instructions provided by professionals, restrictions in funding, insufficient human resources, limited necessary equipment, all of which negatively affect PEG tube insertion or the provision of PEG care and feeding. Some caregivers complained that

they did not receive enough training before discharge, which led to manage problems at home.

Complex patient issues must always be considered and shared. Decisions are best made when patients and carers know their choices and the impact of the choice they would face.

Regular training by health care experts through theoretical and practical courses is one method to improve the lack of knowledge and skills among medical staff involved in the care of patients requiring PEG tube feeding (22).

Nutritional medicine estimates the prevalence of malnutrition in Parkinson's patients to be between 22% and 23%. In light of these findings, the question of whether and when to start tube feeding in patients with advanced Parkinson's is important, as it is a commonly used tool in routine medical care.

Weight loss is also a major problem for patients with advanced Parkinson's (23,24). In Parkinson's patients, artificial tubes can be used not only to administer fluids or nutrition, but also for intestinal administration of levodopa-carbidopa gel.

It is vital that patient caregivers are aware of the challenge of artificial feeding through the PEG tube. Patients often do not participate in important social activities; therefore, the patient's social isolation can worsen.

Caregivers and patients should be fully trained on how to handle the artificial tube (including during hygiene tasks and before, during and after feedings) (22).

Complications in PEG can also have an effect on patients' quality of life, sometimes they cannot tolerate food and may suffer from bloating, diarrhea, constipation, nausea and vomiting; it can have a significant impact on body image. In some circumstances, patients' quality of life may be affected (26).

Percutaneous endoscopic gastrostomy is the preferred option for providing enteral nutrition, allowing improved survival and quality of life.

Predictors of poorer clinical outcomes after PEG placement for enteral nutrition are: male gender, older age, low body mass index, low albumin, high C-reactive protein (CRP) levels, and cardiovascular comorbidities (27).

Patients with severe preprocedural hypernatremia showed a significant increase in mortality at 1 month.

Identifying risk factors related to short- and long-term morbidity and mortality could save unnecessary PEG placements, preventing unnecessary morbidity and mortality.

Identifying risk factors for adverse events after PEG placement could lead to better outcomes in the management of these patients who are typically elderly and weakened.

In conclusion, new predictors responsible for short- and long-term mortality were identified: severe hypernatremia as a new independent predictor of both short- and long-term mortality after PEG placement for enteral nutrition. Furthermore, elevated C-reactive protein (CRP) levels were also significantly associated with short- and long-term mortality after PEG placement (28).

It has been found that the majority of PEG tubes are placed today more often in older adults with a variety of life-limiting chronic diseases: neurological conditions (such as stroke, multiple sclerosis, motor neuron disease and dementia associating swallowing problems and malnutrition), obstructive oropharyngeal pathology (such as patients with head and neck cancer, either as prophylactic measures or as post-radiotherapy interventions due to the effect of radiation on muscles and radiation-induced mucositis), cardiac, pulmonary, renal and oncological diseases (26, 29).

The number of PEG tube placements has increased significantly, from 15,000 in 1989 to over 216,000 in 2000. Approximately 30% of all PEG tubes are placed in patients with dementia and it is estimated that up to 10% of institutionalized geriatric patients receive artificial nutrition through a PEG tube. Despite the significant increase in the number of PEG tubes placed in patients with dementia, no studies have demonstrated their ability to improve quality or length of life.

Exploring family members' hopes, concerns and fears and then discussing the evidence related to PEG tube placement can reduce family anxiety and contribute to an overall decrease in the number of inappropriately placed tubes.

The main arguments presented in support of PEG tube placement include improved quality of life, decreased incidence of aspiration pneumonia, promotion of wound healing, and reduced frequency of pressure ulcers (30).

For patients with preserved bowel function but inadequate oral food intake, PEG enteral nutrition therapy is one of the preferred nutritional support alternatives.

With enteral nutrition support, the social role of eating disappears, removing any pleasure from mealtime. This interference with social life seems to be of greater importance than PEG-related problems.

Patients with a diagnosis of cancer report that PEG nutrition interfered with oral nutrition statistically significantly more than patients with a diagnosis of neurological disease.

PEG is often required for patients with cancer during limited oncology treatment early in the care pathway, sometimes even before enteral nutrition support is needed, and for a limited period (31).

PEG tube placement is known to have a high success rate and relatively low procedure-related morbidity and mortality.

Most caregivers and patients felt that the PEG tube helped prolong survival and aided feeding.

The real benefit in terms of quality of life is still questionable. Prolonging a poor quality of life by means of artificial nutrition is an ethical dilemma (32).

There are studies that highlight a sense of loss for many participants, including loss of ability to undertake daily activities, loss of feeling connected with others and a loss of sense of self.

Attempting to take part in previously enjoyed activities or social interactions often led to anxiety about the risk of damage to the feeding tube, as well as embarrassment about others' perceptions of the feeding tube.

Information should be tailored to the needs of both the patient and the caregiver, and both parties should have the opportunity to express their feelings and concerns.

Understanding the impact on the patient's daily life and identifying the barriers that prevent them from achieving a sense of normality can help people make the transition to establish their new normal. Educating patients on how to adjust the volume, pace or timing of their feeding regimen enables adaptation and participation in different activities, and encourages patients to regain a sense of control and freedom in their daily lives (33).

Artificial nutrition can be integrated into a palliative care programme when a positive influence on quality of life is expected and the risk of dying from malnutrition is higher than from cancer progression.

Enteral nutrition is most commonly used in palliative care patients with head and neck cancer or gastrointestinal cancer. In these patients, the main indication for starting enteral nutrition is oropharyngeal dysphagia or obstruction due to

mechanical and functional factors related to the disease, but also to side effects induced by palliative chemo- and/or radiotherapy.

Percutaneous endoscopic gastrostomy (PEG) is the gold standard in a patient with a life expectancy of weeks or months who cannot assimilate more than 60% of long-term daily energy requirements by oral intake (34).

When considering the appropriateness of a PEG tube insertion, the question to be asked is whether gastrostomy feeding would maintain or improve that patient's quality of life. This question must be answered by specialists in the context of the underlying diagnosis and prognosis, taking into account moral and ethical issues as well as respecting the patient's wishes (35).

Artificial feeding is legally considered medical treatment and requires valid consent before it can be started. For consent to be valid, the patient must have the capacity to do so voluntarily after being provided with sufficient information to guide informed choice. When a patient has the capacity to refuse treatment, his or her wishes should be respected, even if this decision may lead to death (36).

When the progression of the disease is such that the patient no longer wishes to eat or drink, then rather than inserting a gastrostomy tube, end-of-life care pathways might be considered.

The views of caregivers and nursing staff may hinder the transition to end-of-life care (37).

Future gastrostomies should aim to better delineate who will benefit most from this intervention, determine the optimal timing of this procedure, and improve understanding of how gastrostomies can improve nutritional outcomes in malnourished individuals.

## Conclusions

Feeding through a PEG tube is the desirable method for feeding patients with dysphagia or patients who cannot feed orally, but have a functional digestive system.

Home enteral feeding has a considerable physical and social impact on the quality of life of patients and their careers. Support at the time of tube placement and regular medical support can help minimize the impact on both patient and carer, allowing them to make the most of their daily activities, sleep and enjoy a better overall quality of life.

Current clinical capabilities can be used in clinical practice to provide high quality care for patients undergoing PEG. Healthcare professionals need to ensure that patients have sufficient time to make a decision that they will not regret, even if the outcome is unfavorable.

The administration of appropriate tailored and personalized care for each individual case, the adoption of preventive strategies, early identification and treatment of complications will maximize the safety and efficiency of patient outcomes and reduce stress for carers.

The decision to place a PEG tube for nutritional supplementation in terminally ill patients involves careful discussion of the potential risks and benefits in addition to understanding the patient's wishes.

In terms of reaching targets, it is not clear that terminally ill cancer patients receiving enteral feeding via the PEG tube will reach their nutritional targets.

In addition, given that the goal of palliative care is to provide comfort, it is unclear whether PEG placement for nutritional supplementation is consistent with this goal.

Some caregivers and patients felt that the PEG tube helped prolong survival, but without improving quality of life. The impact of PEG tube feeding on quality of life varied, depending on: patients' expectations, their health or disease status, socio-economic status, age, family and social support. Most feared that they might inadvertently trigger tube-related complications or feeding-related side effects. The actual benefit in terms of quality of life is still questionable and represents an ethical dilemma.

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