

# Is percutaneous endoscopic gastrostomy ethically acceptable?

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## Abstract

Percutaneous endoscopic gastrostomy has become the technique of choice. Nevertheless, because of its easy introduction, it is used for patients and under circumstances which are very questionable. Currently, what is considered ordinary and what is considered extraordinary in the care of patient has become a very common debate. Technology has evolved that can keep humans alive, who years ago would have died as a result of the natural course of their diseases. These forms of life sustained by artificial methods have been questioned and even considered unworthy because they violate basic principles of autonomy and patient benefit. With the rapid development of medicine, we need to stop and think about the ethical implications of our daily lives, even before any technical reasoning.

## Key words

Percutaneous endoscopic gastrostomy, ethics, autonomy, charity, ethical, terminally ill, futility

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## INTRODUCTION

Plato, in his magnum opus *The Republic* considers that the model society must be composed of healthy men, "And therefore our politic Asclepius may be supposed to have exhibited the power of his art only to persons who, being generally of healthy constitution and habits of life, had a definite ailment; such as these he cured by purges and operations, and bade them live as usual, herein consulting the interests of the State; but bodies which disease had penetrated through and through he would not have attempted to cure by gradual processes of evacuation and infusion:

he did not want to lengthen out good-for-nothing lives, or to have weak fathers begetting weaker sons; --if a man was not able to live in the ordinary way he had no business to cure him; for such a cure would have been of no use either to himself, or to the State" (1). This concept has become questionable in light of the advances of modern medicine because physicians are able to sustain the lives of patients almost indefinitely by artificial methods such as artificial nutrition and hydration (ANH) and percutaneous endoscopic gastrostomy (PEG).

The ethical implications for gastroenterology were publicly discussed for the first time during the X International

Congress of Gastroenterology held under the chairmanship of Professor Vince Varro in Budapest in 1976. Varro organized a session on "Ethical Issues in the care of digestive patients" (2) which was later published (3). The World Gastroenterology Organization created an Ethics Committee in 1982 (2).

In 1980 the development of PEG constituted a landmark in the history of therapeutic endoscopy (4). At present, due its many advantages, including ease of performance, low rate of complications, absence of incisions and the possibility of performing it as an outpatient procedure, PEG has become the most frequently used technique.

The main objective of PEG is to benefit the patient without causing any damage. This benefit significantly outweighs the risks of complications inherent in the procedure (5). PEG and the administration of ANH have some indications and contraindications that should be established and managed by multidisciplinary teams which provide the context in which this combination has shown the most benefit with the fewest complications (6).

Irreversible neurological states and terminal pathological conditions are difficult clinical scenarios in which the benefits that may result from performing a PEG and administering ANH are controversial. The decision to perform a PEG and to administer ANH in these situations should take into account ethical, cultural, economic and even legal issues so that we can make the most favorable decision for the patient from a holistic perspective. Nevertheless, the rapid popularization of PEG coupled with widespread ignorance about it has led to widespread use without clear justification. All of the above issues are often ignored and patients are put at risk of unnecessary morbidity and mortality. Sometimes, PEG appears to be the solution to the frustration generated among physicians, paramedical staff and family members, but it often creates false expectations in usually irreversible diseases.

Although humanity has broken all possible barriers to keep patients alive who otherwise would not survive, it is our duty as specialists in gastroenterology and endoscopy to question the indications for PEG and ANH. We must position the patient at the center of our decision making at the end of the patient's life, and we must address the ethical, legal and medical issues related to these procedures.

Along with Dr. Gauderer, the inventor of the procedure, we consider that, rather than putting technical issues at the center of the academic debate, we should put the ethical issues there. Gauderer wrote, "Because of its simplicity and low complication rate, this minimally invasive procedure also lends itself to overutilization. Therefore, as percutaneous endoscopic gastrostomy enters its third decade, much of our effort in the future needs to be directed toward the ethical aspects associated with long-term enteral feeding.

In addition to developing new procedures and devices, or to perfecting existing ones, we as physicians must continuously strive to demonstrate that our interventions truly benefit the patient (4)."

## ETHICAL ISSUES RELATED TO GASTROSTOMIES

The ethical issues regarding PEG and ANH for patients with irreversible diseases are complex. The specialist in gastroenterology and endoscopy is underestimated when a PEG is requested. In many cases, this is the result of the specialist's own behavior when she or he knows little or nothing about the case and the family and does not participate in nutritional therapy or in post treatment care of the patient. The specialist in these cases is seen as a mere technician installing the feeder. This practice has been criticized because it under rates ethical issues and reduces the patient's dignity without improving the patient's clinical status (4, 5).

Physicians should know the ethical principles that should not be violated by prescribing or performing a PEG. These principles are discussed below.

1. **Autonomy:** Autonomy means self-determination including the ability to govern oneself. Conscious adults are capable of understanding a PEG after an educational dialogue with the doctor and have the right to accept or reject its implementation without cultural, legal, economic, or medical pressures. The principle of autonomy is always higher than the principle of beneficence (5) for which reason pre-care guidelines which are defined in detail later should always be respected (7).
2. **Beneficence:** The principle of beneficence implies that any intervention should produce a gain that greatly exceeds the potential risk. The opposite is considered maleficence (7).
3. **Non-maleficence:** Maleficence involves subjecting the patient to a medical act in which the gain is not significantly higher than the potential risk. Non-maleficence is the effort by doctors to prevent maleficence and includes the concept of *first do no harm* (primum non nocere) (5, 7).
4. **Futility:** Futility means that medical intervention will have no beneficial effect on the patient (5).
5. **Justice:** Justice refers to the ability to be fair and to distribute resources equitably within a community (5, 7). This means that the investment of resources in cases with remarkable futility should be considered a violation of the principle of justice to the rest of society.

PEG the ethical principles for and against the PEG should be balanced in the process of deciding whether or not to perform the procedure. If more principles are violated than

respected, performance of PEG is not be indicated according to Esguerra who wrote, "Medical ethics cannot be seen as a list of accurate rules or conducts because the circumstances of each patient, their personal characteristics, their desires, beliefs, and environment impose conditions to which are added those related to the society in which there is a relation between the doctor, the health team, the patient and his emotional environment and family" (8).

## CONCEPTUAL EVOLUTION OF PEG AND ANH

Since the 1970s patients who would have died because the natural course of their illness made feeding impossible have been nutritionally supported. The idea that all patients, regardless of their status or clinical outcome, should receive nutritional support became popular among health care staffs. ANH came to be seen as "ordinary care," something "basic" that could not possibly be denied to a patient. It came to be considered a humanitarian act with great emotional and symbolic meaning for physicians, patients and patients' families (5).

The following concepts were used (5):

- "Providing nutrition to a patient is routine."
- "Nutrition is a basic necessity of life"
- "Providing nutrition is an undisputed medical responsibility."
- "Nurturing a patient preserves his dignity."
- "Nutrition sustains life while the disease runs its course."
- "The withdrawal of ANH results in the prolonged and painful death of the patient"

ANH under all these concepts was becoming a compulsory and unquestionable measure and its administration had no legal implications for medical personnel, caregivers or the patient's family. Any or all of these people could be seen as "inhuman" or "murderers" if ANH was not administered (5).

40 years ago, the doctor-patient relationship was different than it is today. It was paternalistic and the patient did not have the opportunity to argue with the physician (5). Currently, the core of decision is made by the patient who assumes all final decisions based on the information and education provided by the doctor.

In the past 30 years numerous cases related to patients who had terminal, irreversible diseases, or both, were presented in different courts around the world, most of them by their families who wanted to suspend ANH or other medical treatment which was already in place. They argued that their family lives had come to an end and that the support methods in place only prolonged their agony. These cases have created reflections that have resulted in a series

of legal and philosophical concepts that currently serve to guide medical decision making (5). We review them below.

### The Kathleen Quinlan Case (1976, United States)

Kathleen Quinlan was a woman who had remained in a persistent vegetative state (PVS) for 1 year after a drug overdose. Her life had been sustained by mechanical ventilation and nasogastric tube feeding. Her parents asked that mechanical ventilation be discontinued to allow the patient "the right to die." It should be noted that the families did not seek cessation of nutrition because they considered it "ordinary care" (5).

The New Jersey Supreme Court authorized the suspension of mechanical ventilation but continued nutrition. The court also held that treatments to sustain life artificially may be removed by medical personnel without legal sanctions when removal is supported by a medical ethics committee in cases without the possibility of the patient recovering consciousness (9). The patient survived nine more years, but the case led to the development of medical ethics committees in all hospitals, nursing homes and hospices. It also led to creation of "advance guidelines" that summarize a person's wishes regarding "extraordinary means" of maintaining life. It also allowed patients to appoint a health care representative empowered to make decisions for a patient when she or he loses the ability to make decisions (10).

### The Clarence Herbert Case (1983, United States)

Clarence Herbert was a man who suffered severe anoxic brain damage during the closure of an ileostomy. The patient's wife requested the withdrawal of ANH and stated that her husband had expressed his desire not to have "extraordinary" measures to sustain life before suffering brain damage. Unfortunately there were no documents expressing this desire. At Herbert's wife's request, Dr. Barber and Dr. Nedjl suspended ANH. A nurse disagreed with this decision and informed California authorities who charged the two doctors with murder. The appellate court found the doctors innocent because they were not required to provide ANH to the patient in accordance with the patient's previously stated wishes (5).

### The Elizabeth Bouvia Case (1986, United States)

Elizabeth Bouvia was a 28 year old woman who had severe cerebral palsy, was bedridden and immobile, and had constant disabling pain secondary to degenerative arthritis. The patient suffered severe nutritional impairment and PEG was performed against her will. The patient requested removal of

the PEG, which was not allowed because it was considered to be “suicide.” Finally, in an appeal, the court allowed the withdrawal of the PEG arguing that refusing to receive any kind of medical care is a fundamental right of every competent person. The patient died shortly thereafter (5).

### **The Nancy Beth Cruzan Case (1990, United States)**

Nancy Beth Cruzan was a woman who remained in PVS after a car accident with her life maintained by ANH through a PEG. Her parents requested the suspension of ANH because they believed that their daughter would not have accepted this way of life. A judge approved the suspension of the ANH, but the Missouri Supreme Court reversed this decision on the grounds that there was no hard evidence of the desire of the patient. The court’s argument that the state’s right to preserve life was superior to the wishes of incompetent patients is an argument that has given rise to much debate. The parents requested a new hearing where witnesses heard the expressed wishes of the patient. The court finally authorized the suspension of the ANH. The Cruzan case was important because it was the first time a case of this kind was discussed in the U. S. Supreme Court. That court presented three important conclusions: 1. Competent patients have the right to refuse any treatment even if such a decision leads to death. 2. Discontinuing ANH and removing the PEG is no different than suspending any other type of treatment. 3. The state can regulate the conditions under which treatment of incompetent patients can be removed to extend life, and the state can determine if there is evidence of the willingness of a patient to decide upon treatment. Although this took away power from families of incompetent patients, it is important because it imposed advance care directives (living wills) in the United States. All hospitals and chronic care centers are required to provide information when admitting patients about the patient’s right to dictate an advance care directive to determine the limits of their care (9, 11).

### **The Tony Bland Case (1993, England)**

Anthony David (“Tony”) Bland was a young man who was a victim of Hillsborough disaster in which 95 people were killed when they were crushed by the bleachers of a football stadium. Bland was diagnosed with PVS. He had remained in that state for three years at which time his parents requested the suspension of mechanical ventilation and ANH on the grounds that their son had died the day of the accident and that these treatments only prevented their son’s farewell. Upon appeal to the Judicial Committee of the House of Lords, the withdrawal of ANH requested by their families was approved. The judges argued that if

the opinion of the responsible medical staff deemed that the patient’s life would no longer be worth living, planned omissions such as suspension of ANH could be made as a benefit for the patient (10).

### **The Terry Schiavo Case (2005, United States)**

Terry Schiavo suffered a cardiac arrest which may have been the result of severe hypokalemia secondary to bulimia. She was diagnosed with PVS and her husband, her designated caregiver, promised before a judge to take care of her even if she did not improve. Nevertheless, months later, after seeing that his wife was not recovering, he began to ask that the ANH that kept her alive be withdrawn. In contrast to the Quinlan and Cruzan cases, the patient’s parents did not agree with this decision, and there was a scandalous family quarrel. Terry’s case was heard in 20 courts over 7 years. The medical report by several neurologists ruled that a PVS patient had no chance of recovery, though Schiavo’s parents never accepted this diagnosis. A judge found sufficient evidence to determine that the patient had PVS and that if she were able to express her opinion she would not agree to continue artificial nutrition. The judge authorized removal of the feeding tube. Florida Governor Jeb Bush signed “Terri’s Law” and immediately acted to require the restoration of Schiavo’s ANH. The U. S. Supreme Court quickly considered this law unconstitutional. The parents continued insistence that ANH not be suspended got the attention of Congress which passed emergency legislation to withdraw the ANH suspension order. The act was signed into law by President George W. Bush. Some of the congressmen who supported this legislation were doctors who argued that Terry did not have PVS. They believed that she should be fed indefinitely by artificial means. The seriousness of this last statement implies that they never performed the task of examining the patient. Finally the U. S. Supreme Judicial Court gave the order to suspend the ANH and refused to accept additional appeals from the patient’s parents. The patient died leaving behind a huge controversy over her case (9).

### **The Eluana Englaro Case (2009, Italy)**

Eluana Englaro remained in PVS for 17 years after a traffic accident. At the end of the first five years her father requested the withdrawal of ANH in the belief that his daughter would not have accepted this type of treatment. His request was denied on 3 occasions. Finally, after 17 years of PVS, the Italian Supreme Court authorized the suspension of food to Eluana. It argued that ANH is a medical treatment and that there was evidence that Eluana would not have accepted this treatment had she been competent. Once the order



allowing ANH to be discontinued had been issued, Prime Minister Berlusconi tried, at the last minute, to create a law would prevent suspension of ANH. This was not approved by the President. Eluana died days after the withdrawal of ANH. This case sparked interest worldwide because Italy is a country where the influence of the Catholic Church is strong. The Catholic Church does not approve of active or passive euthanasia. Besides having no ANH legislation, the Catholic Church does not recognize advance care directives and does not accepting relatives' rights to decide on treatments that must be supplied to incompetent patients. Eluana's father and the doctors and nurses who cared for her were later charged with homicide by activist groups who were against the decision of the Italian Supreme Court. They were investigated for one year until a judge of the Court of Udine decided to close the investigation (12).

These cases from the courts of the world demonstrate the increasing involvement of ethical issues in treatment with ANH and PEG. The United States has defined that ANH is comparable to other therapies such as dialysis, mechanical ventilation and chemotherapy used to sustain a patient's life and therefore should be viewed no differently than any other medical therapy (5, 13). In other words, today in the U.S.A PEG and ANH are not seen as ordinary care.

Modern concepts regarding ANH include:

- Administering ANH is not an essential part of health care and health personnel are not required to administer it (5, 13, 14).
- Distinctions between "ordinary" and "extraordinary" care are useless since today's extraordinary care can be tomorrow's ordinary care (5).
- The administration of assisted or "artificial" nutritional support is similar to dialysis therapy (5).
- The decision to suspend nutritional therapy is no different than the decision to administer it (5, 14).
- Once ANH is initiated, physicians have a duty to evaluate daily whether to continue or discontinue it as with any other treatment (14).
- The concept of autonomy requires respect for the patient's decision to refuse or accept a PEG (5, 7).
- The concept of criminality associated with the suspension of the ANH has been eliminated. Phrases such as, "if nutrition were not suspended, he would still be alive", are no longer valid (5).
- Wherever possible, the patient should have a living will which appoints a legal guardian to enforce the wishes of the patient in case the patient becomes incompetent (4, 5).
- Medical ethics committees should be involved in complex decision making for patients with irreversible or terminal diseases (4).
- The underlying disease causes a patient's death rather than absence of nutrition therapy (5, 14).
- Aggressive or futile treatment is defined by Simo as, "... delaying the advent of death by all means even by extraordinary and disproportionate means although there is no hope of cure even if it implies inflicting suffering and hardship on the parent. Aggressive treatment involves the use of useless or ineffective therapies in the relationship between risk and benefit in order to cure the patient. The features that allow identification of cruelty are futility from the therapeutic point of view, the disproportion of the means and the outcome, the penalties imposed on the patient and further suffering and humiliation of their dignity (15)."
- Advance care guidelines are defined by Simo, as, "... a written statement, signed by a person in full possession of mental faculties, in the presence of a witness and with the eventual involvement of a notary, which specifies the conditions under which that person should be treated or not treated if she or he ever were unable to decide about his own health due to an ensuing state of intellectual disability due to illness, accident or old age. This statement can be entered in a registry established for this purpose (15)."

In our opinion, ANH and PEG are generally "extraordinary" care which should be equated to endotracheal intubation or dialysis therapy. This means that if a patient is not a candidate for intubation he is a candidate for PEG. ANH and PEG are not palliative care because their indications should be based on their ability to influence the course of a potentially curable disease. They should never be part of the care of patients with poor prognoses who will die soon (5, 7).

## CONCEPTS OF THE CATHOLIC CHURCH REGARDING ANH AND PEG

In our country, where most of the patients and their families profess Catholicism, the position of faith regarding decisions about ANH and PEG is very important.

Since the sixteenth century, the Catholic Church has worked with the concepts of "ordinary" and "extraordinary" as compulsory and non-compulsory means to preserve life (16). These concepts were easy to interpret until the mid-twentieth century when it became difficult to classify the technological advances in medicine specifically regarding mechanical ventilation, dialysis, and use of ANH (16). In 1958, Father Cronin, argued in his doctoral thesis (probably the most serious study of the subject) (16) that even natural means such as eating and drinking can become optional if taking these requires great effort or if the hope of

a beneficial outcome is not present. Even ordinary means for incurable patients become extraordinary and non-mandatory (16). Father Cronin, who later became an Archbishop, reaffirmed the historical position of the Catholic Church considering life as a relative good rather than an absolute good. Life is as valuable as death which must be accepted as a path to eternal life (16). Not accepting death would lead to an extreme idolatry about life which we cannot preserve at all costs (16). Historically, these concepts have allowed the Catholic Church to consider that a human being with a terminal and irreversible illness must be treated with love, respect and dignity without being subjected to procedures which do not significantly benefit him or her (16).

Pope John Paul II's 1995 encyclical "Evangelium Vitae" reaffirmed this. In this paper, the Catholic Church accepts the suspension and final withdrawal of therapies considered futile if they are excessively burdensome, dangerous, extraordinary, or disproportionate to the benefits that could result from their use (17). In 2002, Pope John Paul II spoke at the World Congress of Gastroenterology on ANH and PEG as follows, "We certainly cannot forget that man is limited and mortal. It is necessary to approach the patient with healthy realism, preventing the sufferer of creating the illusion that medicine is omnipotent. There are humanly insurmountable limits in these cases, it is necessary to know how to accept with serenity the human condition that the believer knows how to read in the light of the divine will. This is also evident in death, the natural goal of the course of life on earth. Educating people to accept it calmly is part of your mission. The complexity of human beings also requires that when provide the necessary care do not only consider only the body but also the spirit. It would be presumptuous to count only with the technique. From this point of view, exasperated aggressive therapy, even with the best intentions, is ultimately not only be useless but also does not respect the patient who has already reached a terminal stage "(18). However, a year before his death, Pope John Paul II surprisingly said that the administration of ANH was not a medical act and that, apparently, should be provided to all patients regardless of their medical condition. He also noted that to withhold or suspend ANH leads to death by starvation and dehydration which becomes an act of euthanasia by omission (16). This view has been controversial (16, 17). Arguing that ANH and PEG are not medical acts is at least debatable since their practice and care requires training and skills that only doctors have (16). Also, the patient does not die from suspension of ANH but from the disease that prevented them from eating, drinking and hydration (16). Finally, some believe that accepting the opinion issued in 2004 by Pope John Paul II would deny the traditional position of the Church that life is a relative and not an absolute good (16).

## CURRENT STATE OF THE TOPIC IN COLOMBIA

In our country the vast majority of health professionals consider ANH to be ordinary care. Despite this, and in practical terms, nutritional support is a treatment that is initiated, suspended and removed for medical reasons.

Some doctors, nurses and nutritionists still take drastic positions against family decisions not to administer ANH for patients with terminal or irreversible illnesses. They accuse the family of "starving the patient" when the family does not accept this treatment. Every day we see with great concern and confusion that there is a remarkable lack of indications and contraindications for the use of PEG and ANH. There is also a conceptual basis about the ethical, legal, humanistic, social and economic factors that must be considered when providing ANH. In our country, most decisions about performance of PEG and administration of are results of poor analytical processes based on the emotional and circumstantial issues arising from personal opinions, religious beliefs and previous experiences by the medical and paramedical staff which prescribes these treatments in clear cases of therapeutic futility. When a gastroenterologist does not take the initiative to question the prescription of PEG and ANH, she or he is seen as a technician installing a feeding device. Nevertheless, if the gastroenterologist does question this decision, it is likely that it will not be well received by other professionals in charge of the patient.

In a country such as ours, where health system resources are so limited, it is worrying to see the constant violation of the principle of justice, with the frequent indication of expensive treatments for patients for whom benefits of therapy are absent. It is even more worrying that, for patients with irreversible neurological conditions, one or even two family members must sacrifice their work and personal life to care for these patients for whom the benefit of this type of procedure is questionable. In practice, our healthcare system is not able to provide all nursing care and to meet all the nutritional needs of patients. This becomes a constant complaint of families which often end in exhausting legal battles against the state. In our experience of asking relatives years later after they have learned the natural history of this type of disease if they would have authorized PEG and administration of ANH, the vast majority said no.

Unfortunately, in Colombia there are no clear legal definitions regarding ANH and PEG nor about other special treatments. There is a law about the rights of terminally ill patients (19) that is clear about preventing suffering and loss of dignity when using procedures and therapies that do not benefit the patient. Nevertheless, it has created a vacuum that prevents determination about whether or not administering or suspending ANH is the correct decision

in particular circumstances. Under this law, suspension could be seen as a form of euthanasia by omission with the possible legal repercussions stemming from it.

Despite this, Colombia has not been completely oblivious to the current world tendency to promote limited therapeutic efforts for patients with terminal and/or irreversible illness with the aim of preserving ethical principles, rights and dignity of the human being. Now there are medical ethics committees in all hospitals in our country which support medical staffs in the managing decisions about ANH in difficult cases. In addition, there are organizations such as the Foundation for the Right to Die with Dignity that promote expression of free will through advance care directives, and which promote respect for these documents if the patient loses the ability to decide.

In our experience, and given the legal and conceptual gaps that exist in our country regarding ANH and PEG, the best scenario is one in which the family and the doctor decide whether or not to begin ANH after carefully analyzing the true benefits and potential risks of these treatments. If necessary they should make this decision with the support of the medical ethics committees.

## **MYTHS ABOUT GASTROSTOMIES**

There are very few studies in the literature that clarify the real benefits of performance of a PEG and the administration of ANH in terms of decreased risks of choking, prevention of pressure ulcers and improvement of nutritional status and quality of life. Although the literature has not demonstrated these potential benefits, many doctors believe that ANH prevents or improves these situations. The process by which the decision to perform a PEG and administer ANH is made has been questioned since it is based on unproven expectations which are transmitted to the family. In a study conducted in 2007 by Golan et al., it was found that up to 50% of family members who were interviewed expressed dissatisfaction with the process that led them to accept a PEG. They considered that they had made the decision under pressure and without enough information about the potential benefits and complications of the procedure (20). Ironically, the same study showed 80% of physicians that indicated a PEG would not accept this procedure for a family member in similar circumstances. We will try to clarify some medical myths regarding gastrostomy.

### **1. Percutaneous endoscopic gastrostomy prevents aspiration while nasogastric tube feeding does not.**

There is little evidence about this topic. However, a meta-analysis conducted by GOMES et al. published in Cochrane in 2010 (21) evaluated nine controlled clinical trials and

found no statistically significant difference in the rate of aspiration in patients treated with PEG or nasogastric tubes. The possible reason for this finding is that both methods reduce lower esophageal sphincter pressure and therefore both may encourage aspiration (5).

### **2. PEG prevents pressure ulcers.**

A Cochrane metaanalysis published in 2009 analyzed seven prospective studies in patients with advanced dementia. No evidence was found to conclude that PEG decreases the prevalence of pressure ulcers (22). This is because patients move less due to their underlying diseases and because when receiving nutrition by PEG they are immobilized and sedated which favors pressure ulcers (5).

### **3. PEG improves nutritional status.**

It has been shown that there are no improvements in terms of muscle mass, weight gain (22), or in biochemical markers such as albumin (14) for patients receiving ANH through a PEG. We conclude that PEG feeding does not ensure that caloric goals are met (22).

### **4. PEG and the ANH decrease morbidity and mortality.**

PEG is associated with a 15% risk of minor complications such as surgical site infections, leakage and ileum). The risk of serious complications such as aspiration, obstruction, peritonitis, hemorrhaging, esophageal or gastric perforation, necrotizing fasciitis and accidental removal is 3%. The procedure has a 1% mortality rate with it (5, 23). In our opinion, these data make PEG an invasive procedure, a fact which unfortunately is usually ignored. Due to the severity of the underlying diseases requiring PEG, administration of ANH through a PEG does not reduce the mortality rate among these patients (23). In the first month after a PEG, 30% of the patients die. Within one year, 60% die (4). Some authors have even found that PEG increased mortality due to its direct or indirect complications (24).

The study by Gomes et al. showed no difference between the mortality rate among patients treated with PEG and that of patients treated with nasogastric tube feeding. They also found no differences in the rates of complications of infections, displacements, aspiration pneumonia, gastroesophageal reflux, and other complications (21).

### **5. PEG and the ANH improve the underlying disease.**

Many studies have shown that ANH changes neither the evolution nor the prognosis of the patient's underlying disease. This is particularly true in later stages of dementia

and in persistent vegetative states (14). Patients die from the underlying disease, not the lack of ANH (16).

## **6. The patients who do not receive a PEG and ANH die of starvation and dehydration.**

Although this is still a very controversial issue, many authors agree that patients do not die from lack of ANH, but, as we have stated, by following the natural course of the underlying disease (5, 13, 16).

## **7. Seriously ill patients feel hungry and thirsty, for which reason they should be fed in all cases.**

There is evidence in the literature showing that terminally ill patients do not feel hungry or thirsty (5, 13).

## **8. PEG improves life quality.**

This concept has generated great controversy, as many of the patients who are undergoing PEG are not able to perceive any improvement in their life quality. In fact, patients suffer sensory deprivation, as some go from being carefully and lovingly fed by their families to being fed through a tube. Furthermore, the need for immobilization and sedation to prevent the patient from removing a PEG violates the patient's autonomy (5).

## **INDICATIONS FOR PERFORMANCE OF PEG**

There are clear indications for performance of a PEG which are not often discussed. They include its use for potentially curable diseases and neurological injuries from which patients may recover that require nutritional support for more than 4 weeks. When the patient's mental functions are intact, other indications include severe dysphagia, pharyngeal obstruction, esophageal obstruction, generalized weakness and inability to swallow. Cancer patients for whom life expectancy is greater than six months and that will require antitumor therapy that prevents swallowing are also candidates for performance of a PEG (5, 14).

## **CONTROVERSIAL INDICATIONS FOR PEG PERFORMANCE**

Many authors agree that there are some questionable indications for performance of PEG and ANH administration. Physicians should be especially careful about whether the patient will actually benefit from the procedure or whether this constitutes a disproportionate measure (14). This should be analyzed in detail to see whether the procedure might be offered but not recommended (14).

## **Advanced states of dementia with compromised swallowing**

As noted previously, the clear benefits of administering ANH through a PEG in patients whose dementia has reached the terminal stage cannot be demonstrated (23). We have seen that these patients with ANH increase gastric secretions and have fecal and urinary incontinence with consequent increases in pressure ulcers (23). Some authors even consider that the only thing that PEG and ANH do in these cases is to prolong the dying process for the patient (4). Assisted feeding alternatives exist and must be taken into account before suggesting means of artificial feeding for these patients to their families (5, 14).

## **Persistent vegetative state**

PVS is a clinical condition with clearly established diagnostic and prognostic criteria (25, 26). PVS should be considered permanent with no chance of improvement if there are no changes in the neurological condition after 3 months in cases of hypoxic ischemic brain diseases and metabolic diseases, and after 12 months in cases of traumatic brain injuries (26). It has been shown that patients who have recovered motor and cognitive functions years later after being diagnosed with this condition had been misdiagnosed. Recovery is not a "miracle" as interpreted by many (25). Much debate about whether these patients should be fed by artificial means relates to the questions of some people about the value of life in this condition. In many cases after ANH through a PEG has been administered for some time, the frustration of families over the lack of improvement leads them to request the withdrawal of nutrition. This creates a difficult situation because removing the ANH could be interpreted as euthanasia by omission or even as murder. The worst case scenario occurs when the doctor decides to suspend the ANH, a situation that involves a medical decision as important as prescribing it, but includes emotional issues ultimately resolved in the courts (24).

Whenever ANH and PEG indications are controversial, you must obtain the support of a Medical Ethics Committee. Nevertheless, this is not often done. Morgenstern's review of 503 queries to medical ethics committees related to ANH showed that 80% of these occurred after the start of ANH and not before as should be (4).

## **CONTRAINDICATIONS FOR PEG PERFORMANCE**

- Patients with pathologies with poor short-term prognoses. Conducting a PEG for seriously ill patients for whom there is an unresolved clinical condition that threatens life does not generate a benefit and signifi-



cantly increases morbidity and mortality (27). It is common to solicit PEG and ANH for patients who are in an intensive care unit with tracheal intubation, inotropic/vasoactive support, or both. These patients' clinical situations are so serious that their lives are still in danger (4). An alternative for these patients is a nasogastric feeding tube which can be maintained for up to 8 weeks and which is useful for defining the clinical history and prognosis (14).

- Patients with severe neurological impairment and social abandonment. They are not candidates for PEG and ANH because they do not have a responsible caregiver to manage appropriate treatment (6).
- Patients who tolerate assisted nutrition and who receive a PEG and ANH to facilitate nursing work in continuing care centers (5).
- Patients with severe neurological compromises that do not have a permanent caregiver despite having a family. In these cases we must resolve the care situation before prescribing PEG since the risks of neglect exceed the potential benefits.
- Patients who have suffered major complications related to PEG due to the neglect of their families or caregivers. In these cases the decision to perform a second PEG must be accompanied by a psychosocial assessment that would ensure that the patient will receive the care needed to prevent the development of further complications.
- Competent patients who do not want the procedure despite the opinion of the health care team and family.
- Patients with terminal cancer. Inadequate food intake leads to hunger and thirst in healthy subjects, but in patients with advanced terminal illnesses whose cognitive status is intact, denial of water and food is voluntary and therefore generates no pain. Forced intake can even be uncomfortable (23).
- Patients with terminal-stage AIDS whose catabolic states are so severe that they cannot improve with nutritional support (14).

## DISCUSSION

Because of technological breakthroughs in medicine, our ability to "artificially" sustain life has increased to the point that it is increasingly difficult to decide when to terminate or suspend medical therapy. Having seen terminally ill patients suffer irreversible, long-term and ultimately futile treatment raises questions about the dignity of their lifestyle and the need for this type of treatment. Consequently, making decisions about many therapies has become increasingly difficult from an ethical and nontechnical point of view. One result of this has been the emergence of worldwide organizations which promote limitation of therapeutic

efforts for irreversible, terminal or incurable diseases because these efforts can impoverish patients' quality of life to the point that their lives lose their value and quality. These new concepts are even more complex and are subordinated to personal religious, spiritual and cultural beliefs. All of this must be taken into account when making medical decisions.

In our opinion, PEG and ANH are medical treatments that, in the absence of an advance care directive, should be reserved for patients who will significantly benefit from their use. They may be offered, but not recommended, to patients with borderline or questionable indications. In such cases the family must be given a clear explanation of the different perspectives and implications surrounding ANH for both the present and the future. After this, they must be provided with the support of a Medical Ethics Committee. Physicians should have absolute clarity about the contraindications of PEG and ANH.

This issue is not about trying to decide who is right, it is about making the best decision for each patient with the largest number of tools available. 21st century doctors, and certainly the doctors of the future, are on a thin line between "therapeutic obstinacy" and "euthanasia by omission." In this sense, the specialist in gastroenterology and endoscopy possesses the most advanced skills in ethical issues related to the administration of artificial nutrition by PEG devices.

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