



ORIGINAL ARTICLE

Exploratory study on gastrostomy in patients with neurological diseases: usefulness and impact[☆]

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Survival

Abstract

Introduction: Percutaneous endoscopic gastrostomy (PEG) is a useful intervention for patients with impaired swallowing and a functional gastrointestinal system. Neurological diseases that cause neuromotor dysphagia, brain tumors, and cerebrovascular disease are the most frequent indications; complications are rare, and morbidity and mortality rates are low.

Objective: To describe the usefulness of PEG in patients with neurological diseases, and its impact on care, survival, and costs and benefits.

Material and methods: We performed a retrospective observational study, reviewing clinical files of patients hospitalised at the National Institute of Neurology and Neurosurgery (years 2015-2017) who underwent PEG placement.

Results: The sample included 51 patients: 62.7% were women and the mean (SD) age was 54.4 (18.6) years (range, 18-86). Diagnosis was tumor in 37.3% of cases and cerebrovascular disease in 33.3%. Sixteen patients (33.3%) died and 11 presented minor complications. The PEG tube remained in place for a mean of 9.14 months; in 52.9% of patients it was removed due to lack of improvement and/or tolerated oral intake, with removal occurring after a mean of 5.1 (4.4) months. Among patients' family members, 78.4% reported a great benefit, 43.1% reported difficulty caring for the PEG, and 45.1% reported complicated care in general. The monthly cost of maintaining the PEG was €175.78 on average (range, 38.38-293.45).

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PALABRAS CLAVE

Complicaciones;
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Cuidadores;
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percutánea;
Sobrevida

Discussion and conclusions: This preliminary study reveals that PEG was well indicated in patients with neurological diseases, with survival rates similar to those reported in other studies with long follow-up periods. In patients with cerebrovascular disease, the PEG tube remained in place a mean of 9.14 months, during recovery of swallowing function; however, the cost is high for our population.

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Estudio exploratorio sobre gastrostomía en pacientes con enfermedades neurólogicas: utilidad e impacto

Resumen

Introducción: La Gastrostomía Endoscópica Percutánea (GEP) es útil para personas con problemas de la vía oral con viabilidad de la vía gástrica. Las enfermedades neurólogicas que producen disfagia neuromotora, tumores cerebrales, enfermedad vascular cerebral, son las que tienen mayor indicación; las complicaciones son escasas y baja morbimortalidad.

Objetivo: Describir la utilidad de la GEP en pacientes con enfermedades neurólogicas y el impacto en el cuidado, sobrevida y costo-beneficio.

Material y métodos: Estudio observacional retrospectivo, mediante revisión de expedientes clínicos de pacientes hospitalizados en el Instituto Nacional de Neurología y Neurocirugía (años 2015–2017) que se realizó GEP.

Resultados: Se incluyeron 51 pacientes: 62.7% mujeres, edad promedio 54.4 ± 18.6 años (Rango; 18 a 86). Diagnósticos: tumor del SNC 37.3%, y EVC 33.3%. Mortalidad 33.3% (16 pacientes): 11 presentaron complicaciones menores. Permanencia de la GEP: promedio 9.14 meses. Al 52.9% se le retiró por mejoría y/o toleró VO, con tiempo promedio 5.1 ± 4.4 meses. 78.4% de los familiares reportaron gran beneficio, 43.1% percibió difícil el cuidado de la GEP y 45.1% refirió complicado el cuidado en general. El costo de mantener la GEP mensual fue de 175.78 € en promedio (rango de 38.38 a 293.45 €).

Discusión y conclusiones: Este primer estudio revela que la GEP fue bien indicada en pacientes con patologías neurólogicas, con sobrevida similar a la reportada en otras investigaciones con seguimiento prolongado. En pacientes con EVC la permanencia de la GEP fue de 9.14 meses en promedio, por recuperación de la vía oral, sin embargo, el costo es elevado para nuestra población.

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Introduction

Percutaneous endoscopic gastrostomy (PEG), which was developed during the 1980s, has facilitated feeding of patients with oral intake difficulties but normal gastrointestinal function.¹ The procedure consist of the insertion of a feeding tube directly into the stomach through a small incision in the abdominal wall, guided by an endoscope reaching the stomach via the oesophagus. General anaesthesia is not required in the majority of cases; complications are scarce, of little clinical relevance, and easy to treat; and the procedure is relatively inexpensive.^{2,3} This has contributed to the fast development and extensive use of the technique in a great variety of situations in which swallowing is impaired, especially in patients who need enteral feeding for long periods or indefinitely.⁴

The most frequent reason for PEG (90% of cases) is impaired feeding ability, as occurs in neurological diseases causing dysphagia: cerebrovascular disease (CVD), amyotrophic lateral sclerosis (ALS), advanced stages of Alzheimer disease, multiple sclerosis, anoxic-ischaemic encephalopathy, advanced Parkinson's disease, brain tumours, and neck, larynx, and oesophageal cancer, among other diseases.⁵

PEG feeding may improve the nutritional status of patients requiring prolonged hospitalisation due to their condition, for example, patients with CVDs and oropharyngeal cancer. Up to 70% of patients with acute CVD present dysphagia; while approximately half of them sufficiently recover swallowing function, enabling them to meet their caloric requirements, the other half will present swallowing dysfunction in the long term, and their recovery is unpredictable.

PEG is of unquestionable value, as shown by several studies conducted in Spain,³ Brazil,⁶ the United States,⁷ and Mexico,⁵ where researchers observed a high survival rate, few complications associated with the procedure, and improved functional status. Furthermore, PEG is associated with less discomfort and lower risk of nasogastric bleeding or tube obstruction or dislodgement, as compared to nasogastric or nasojejunal tubes.^{6,8,9}

The use of PEG in irreversible neurological processes and terminal illnesses is debatable; placing a PEG tube may unnecessarily prolong the lives of functionally disabled individuals with a life expectancy of only a few days or weeks, while increasing patient discomfort and caregiver burden and incurring high costs. At the Instituto Nacional de Neurología y Neurocirugía Manuel Velasco

Suárez (INNN), the use of PEG is frequent; over the past 3 years, approximately 100 procedures per year were performed. However, we do not fully know which factors may have an impact on the usefulness of PEG (eg, survival time, functional status, and the socioeconomic status of the patient's family), although we aim to provide sufficient information on the procedure's risks and benefits. This study is intended to describe the usefulness of PEG, its impact on survival, and the associated complications and financial costs.

Material and methods

Population and design

We conducted an observational retrospective study by reviewing patients' clinical histories, using quota sampling. We included 70 patients hospitalised between 2015 and 2017, who underwent PEG tube placement and were discharged home. We only obtained data from 51 patients (we were unable to find an informant caregiver or patient in 19 cases). PEG was indicated due to swallowing impairment in all cases. We collected data on the following variables: patient's sociodemographic profile, diagnosis, date of PEG tube placement, functional status according to the Karnofsky Performance Status Scale, comorbidities, blood count and serum albumin data (pre- and post-PEG), socioeconomic status, and caregiver's data.

We administered a telephone survey to caregivers to determine their experience with PEG: did they know the diagnosis?, were the

benefits and risks of the procedure explained?, were they trained to provide care?, did they find it difficult to provide PEG-related care?, how long did the PEG tube remain in place?, why was the PEG tube removed?/did the patient recover swallowing ability?, how long did the patient survive with PEG?, what complications did the patient present?, and how much did it cost to feed the patient by PEG per month, including care expenses?

Statistical analysis

Data were analysed using the SPSS statistical software (version 22.0). We conducted a retrospective analysis using absolute values and percentages for categorical variables and means and standard deviations for continuous variables. We used the chi square test or the Fisher test to compare proportions when any cell presented a value below 5%. Significant differences between pre- and post-PEG values for serum albumin and blood count data were assessed with the Mann–Whitney U test.

Results

Of the 51 patients, 62.7% were women and 37.3% men; mean age (SD) was 54.4 (18.6) years (range, 18–86). The most frequent diagnoses were brain tumours, in 37.3% of patients (n = 19), CVD in 33.3% (n = 17), demyelinating disease/ALS/Guillain–Barré syndrome in 17.6% (n = 9), and other neurological disease (hydrocephalus, leukoencephalopathy, encephalopathy, metabolic myopathy, severe

Table 1 Demographic characteristics and responses to the telephone survey.

Demographic characteristics	N = 51	%
Sex		
Women	32	62.7
Men	19	37.3
Relationship		
Son/daughter	20	39.2
Spouse	10	19.6
Father/mother	7	13.7
Brother/sister	5	9.8
Uncle/nephew	1	2.0
Daughter-/son-/sister-/brother-in-law	5	9.8
Patient	3	5.9
Results of the telephone survey		
<i>Was aware of the diagnosis</i>		
Yes	47	92.2
No	4	7.8
<i>The PEG procedure was explained</i>		
Yes	47	92.2
No	4	7.8
<i>PEG risks and benefits were explained</i>		
Yes	47	92.2
No	4	7.8
<i>Complications reported by the caregiver*</i>		
Yes	11	21.6
No	40	78.4
	Mean	SD
Monthly expenditure (€)	175.78	88.33

* 11 complications were reported (8 dislodgements, one rupture, one infection, and one case of haemoperitoneum).

head trauma, pontine myelinolysis) in 11.8% (n = 6). The PEG tube generally remained in place for 9.14 months. It was removed due to improvement or tolerated oral intake in 52.9% of patients (10 patients with CVD, 9 with other neurological disease, and 7 with brain tumour), after a mean period of 5.1 (4.4) months. Functional status, as measured with the Karnofsky Performance Status Scale at the time of PEG, was a mean of 51.8 points. Regarding survival, 66.7% of patients (n = 34) were still alive at the time of the study (14 patients with CVD, 8 with brain tumour, and 12 with other neurological disease). The mortality rate amounted to 33.3% (n = 16); we should mention that of the deceased patients, 3 died within 24 hours of PEG tube placement, due to sepsis in one patient with leukoencephalopathy and due to intracranial hypertension with uncal herniation in 2 patients diagnosed with meningioma.

The comparative analysis of serum albumin results revealed no significant differences ($Z = -0.548$; $P = .548$) between pre-PEG (mean of 3.37 [0.57]) and post-PEG determinations (mean of 2.84 [1.58]). The comparative analysis of blood count results revealed no significant differences ($Z = -0.743$; $P = .458$) between pre-PEG (mean of 11.52 [2.26]) and post-PEG determinations (mean of 10.16 [5.75]). When comparing survival rates, we observed no statistically significant differences overall ($\chi^2 [12, N = 51] = 16.116$; $P = .186$). However, we did observe higher survival rates in patients with CVD (82%) as compared with other conditions: tumours (53%), demyelinating disease/ALS/Guillain–Barré syndrome (78%), and other neurological diseases (67%).

Regarding the telephone interviews with caregivers and patients, Table 1 shows the demographic characteristics and responses of the participants; 62.7% were women and primary caregivers were most frequently patients' children, in 39.2% of cases. Of all respondents, 92.2% knew the patient's diagnosis, and were informed about the procedure and its risks and benefits. Three respondents were patients (5.9%; 2 with Guillain–Barré syndrome and one with hydrocephalus), who had a PEG tube in place for a mean period of 3 months; PEG tubes were removed due to tolerance to the oral route.

Table 2 shows the perceived benefits: 78.4% reported a significant benefit; 43.1% considered care for the PEG tube to be difficult, and 52.9% considered that general care for the PEG tube was complicated/very complicated. The mean monthly cost of maintaining the PEG tube was €175.78 (range, €38.38 to €293.45).

Discussion

This first exploratory study at the INNN shows that PEG was correctly indicated in patients with neurological diseases, such as CVD and resectable brain tumours. Indication of PEG is even clearer in these cases than in other conditions with poorer prognosis, such as malignant tumours associated with short survival times and located in inaccessible areas, or advanced diseases with no possibility of functional recovery, as is the case with degenerative dementias.^{10–12} In our patients, rates of functional recovery were comparable to rates of tolerance to oral route and removal of the PEG tube. As a national reference centre, the INNN provides care to the highest number of patients from all over the country; brain tumours became the leading cause of in-hospital morbidity and mortality during the first semester of 2017. In line with these data, the most frequent disease in our series was brain tumours, in 37.3% of patients. In terms of mortality, CVD represents the third leading cause of death in the general population, and was the second cause of death in our study (33.3%); CVD is a frequent condition in the literature reviewed. A study conducted in Indiana (USA)⁷ reported a mortality rate of 41%, whereas a Brazilian study reported 39%,⁶ and research conducted at a Mexican general hospital described a rate of 48%.⁵

Table 2 Benefits of PEG as reported by respondents to the telephone survey.

	N = 51	%
<i>Difficulty in PEG care</i>		
Yes	22	43.1
No	25	49.1
No answer	4	7.8
<i>General care</i>		
Simple	20	39.2
Complicated	23	45.1
Very complicated	4	7.8
No answer	4	7.8
<i>Beneficial</i>		
Very much	40	78.4
Fairly	5	9.8
Scarcely	4	7.8
No benefit	2	3.9
<i>Survival</i>		
< 3 months	3	3.9
3-6 months	6	11.8
6 months-1 year	3	5.9
1-2 years	5	9.8
Alive (at the time of study)	34	66.7

It is important to note that patients undergoing PEG placement present few complications (tube dislodgement and migration, and local irritation or infection), which is consistent with our results. The most severe complications were one case of infection and another case of haemoperitoneum. Also, a Spanish study reported only one case of peritonitis,³ whereas the other Mexican study reviewed described 2 cases of intestinal perforation, confirming the low rate of complications associated with the procedure.

In similar studies,^{3,5–7} mortality was associated with the underlying comorbidity; however, we observed that the mortality rate was low, and directly associated with a complication unrelated to the procedure (sepsis in one patient with leukoencephalopathy and 2 patients with uncal herniation due to meningioma expansion). In terms of survival, percentages were similar: 53% in Spain, 57% in Brazil, 40% in Indiana, and 67% in our study.

PEG may facilitate the discharge of patients with neurological diseases with poor prognosis and long hospital stays due to dysphagia secondary to neuromotor disorders, as is the case with patients with brain tumours, who present impairment of the lower cranial nerves, or such upper motor neuron diseases as ALS.^{13,14} Patients with acute CVD and presenting impaired swallowing are more likely to recover if we ensure adequate feeding by PEG on a temporary basis.

None of the studies reviewed mentions the costs associated with the procedure or caregiver burden, a situation that we did analyse, as our patients have limited resources and are attended at a public hospital that is unable to provide equipment or to follow up patients outside the hospital or at their homes. Therefore, it would be beneficial to establish selection criteria such as survival time, functional status, family members' availability to care for the patients, and income level, as well as improving caregivers' training and information.

In terms of quality of life, PEG offers clear benefits, as nutrition and well-being are improved; furthermore, PEG may be even more

tolerable for patients as it avoids the need for insertion of a nasal tube, and is less likely to be accidentally removed, with subsequent re-insertion. It is also associated with higher survival rates in the short term, but not in the long term, as patients frequently die due to underlying conditions; this supports the use of the technique.^{9,15}

Despite its significant benefits, caregivers reported that care in general was complex, difficult, and costly; the technique therefore increases caregiver burden. However, this perception may be improved with proper clinical follow-up, and the consideration of the patient's financial status and support network.

In summary, we consider PEG to be useful in patients with a neurological disease affecting swallowing, whether temporarily or in the long term; however, it is important to consider clinical and prognostic status, to provide appropriate explanation of the risks and benefits to patients and their families, and to be mindful of the needs, context, and wishes of the patient.^{11,16}

Conclusions

PEG is a safe technique of great clinical relevance for long-term enteral feeding, due to the low rate of complications when proper follow-up and caregiver training are provided.

At the INNN, PEG is used frequently, and the reasons for its use are similar to those reported in the studies reviewed.^{3,5,6,9} The role of clinical follow-up of patients who are discharged home has not yet been analysed in the literature. Other factors yet to be examined include the impact of gastrostomy, at-home management, treatment planning, resource distribution, availability of services in the event of complications, and hospital readmission.

In line with the findings of Kurien et al.,¹ the decision to place a PEG tube should be made on an individual basis, considering the patient's needs, diagnosis, and life expectancy. The aim of the procedure is not only to improve patient survival and nutritional status, but also quality of life, which is not necessarily correlated with nutritional status.

The patient's social context should also be considered in any clinical intervention, as it helps to ensure that clinical practice is complete, coherent, and efficient. Our study provides a comprehensive view of the procedure, which is of practical interest to healthcare professionals who may provide care to these patients.

Conflicts of interest

The authors have no conflicts of interest to declare.

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