Percutaneous endoscopic gastrostomy: an effective strategy for gastrostomy feeding in patients with dementia

David S Sanders, Alan J Anderson and KD Bardhan

ABSTRACT – Percutaneous endoscopic gastrostomy (PEG) is an accepted technique for long-term enteral feeding. Its use has increased because of its simplicity and low complication rate. The demands for gastrostomy insertion have risen and now encompass indications where the long-term outcomes are uncertain. Dementia has become one of the commonest indications for gastrostomy feeding. This article reviews the justification for PEG feeding in dementia and suggests a practical approach for this difficult clinical situation. The clinical strategy described in this paper can be applied to other neurodegenerative diseases and provides a framework for improving a PEG service.

KEY WORDS: dementia, gastrostomy, guidelines, nutrition

Percutaneous endoscopic gastrostomy (PEG) has been the best method of long-term enteral nutrition since its introduction into clinical practice in 1980.[1] The benefit of gastrostomy insertion, with regard to morbidity and mortality, has been demonstrated in patients with cerebrovascular disease and oropharyngeal malignancy.[2–4] However, the demands for PEG insertion have risen to include conditions where the indications and long-term outcome are uncertain.[5,6]

Dementia is an ever more common reason for PEG insertion when the patient cannot or will not eat. There is an argument that gastrostomy feeding benefits the patients by improving survival, avoiding aspiration pneumonia, ensuring adequate nutrition/hydration and optimising the quality of life of the patient. This controversial debate hinges on the question of whether we as clinicians are maintaining life or prolonging death.[7–9]

What is the evidence supporting gastrostomy feeding in patients with dementia?

Survival analysis

There have been numerous reports in the literature assessing long-term survival in patients who have been given PEGs, but when dementia is the indication there is a relative paucity of survival studies, with fewer than 20 publications.[9] Survival analyses of patients with dementia who have a PEG inserted have suggested a 30-day mortality that may vary from 9.5 to 54%, and the one-year mortality has been cited as between 39 and 90%.[9] In the UK there has only been one study assessing mortality in patients with dementia, following PEG insertion.[10] We retrospectively analysed survival in a cohort of 361 patients, over a five-year period (August 1992 to July 1997 inclusive).[10] These patients were from two adjacent district general hospitals in South Yorkshire. Patients were grouped according to their diagnoses: oropharyngeal malignancy, cerebrovascular disease, miscellaneous neurodegenerative diseases (eg multiple sclerosis), and dementia. In the dementia group, metabolic and nutritional causes were excluded by a screen of blood tests. Other intracranial pathology was excluded by computerised axial tomography.

The overall mortality for the entire cohort was 28% at 1 month, 44% at 3 months, 52% at 6 months and 63% after 1 year. However, the prognosis was significantly worse in the patients with dementia (n = 103/361, 28.5% of the cohort) with a mortality of 54% at 1 month, 78% at 3 months, 81% at 6 months and 90% at 1 year (Kaplan-Meier life table analysis, log rank test p <0.0001).[10] Why should the mortality in our study be one of the poorer reported survival outcomes? It may be a reflection of different referral practices between countries. In the UK, most patients with dementia may be referred following an acute hospital admission. This group has a worse outcome than those from nursing homes, who have an elective outpatient procedure.[11] In addition, some of the lower mortality rates were reported in the initial studies and this may reflect less cautious selection in present practice.[12]

It is ethically difficult to justify a controlled study of patients with dementia who have been referred for PEG insertion with randomisation to PEG feeding or no PEG feeding. However, a recent prospective study tried to address this issue. Severely demented patients from nursing homes (n =135) who had a PEG inserted were compared with nursing home residents with a similar degree of cognitive impairment

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who were not referred for tube feeding. At 24-month follow-up, the number of survivors in each group was the same, having adjusted for independent risk factors for tube placement.[13] This observation has since been validated by other investigators.[12]

Perhaps the failure to demonstrate a significant improvement in survival reflects the fact that the loss of ability to feed oneself is associated with end-stage dementia and that neurological dysphagia is then a pre-terminal event.[14] Is this a loss of ability to feed oneself – or the loss of motivation/instinct to feed – or indeed to understand what food is? Certainly in our study these patients were significantly cognitively and functionally impaired, with Barthel scores of less than 5.[10] The Modified Barthel Index was originally used for assessing the ability of patients to perform activities of daily living following a stroke.[15] It has since been widely applied in the UK to a broad range of patients, including those with dementia. It is a pragmatic scale which tests ability in self-care including feeding without assistance. The score ranges from 0 to 20 and allows patients to be categorised into groups reflecting their degree of dependency.[16] A score of 0–5 indicates total dependence and may suggest an inability to feed oneself.

Aspiration pneumonia

PEG feeding does not reduce the risk of aspiration pneumonia in patients with neurological dysphagia.[9] It may even increase the risk of aspiration by lowering gastro-oesophageal sphincter pressures.[17]

Quality of life

This can be difficult to assess as patients with severe cognitive impairment cannot give a subjective opinion. Studies that have used activities of daily living (ADL) as a surrogate marker of quality of life have not demonstrated any improvement in functional status.[17–19] A small study on the views of carers of patients (n = 58) who were fed by PEG revealed that, at five-weeks post insertion, 81% perceived no improvement in the patients' status, or even a deterioration.[20]

Nutritional status

Observational studies have described modest improvements in the nutritional status (using serum albumin or body mass index) of individual patients with dementia, following PEG insertion. However, no significant or long-term benefit was sustained within these cohorts. The most likely explanation for this observation is the patient's catabolic state during a period of acute illness or that dementia itself is a progressive catabolic disease.[18,19,21,22]

Ethical dilemmas in PEG feeding demented patients

Despite the lack of evidence, patients with dementia are still referred for PEG and indeed have gastrostomies inserted. There may be a general misconception that feeding in these circumstances benefits the patient. However, other factors need to be considered. Some healthcare professionals (particularly nurses) believe feeding is a basic human requirement that should not be denied, irrespective of cognitive function.[22,23] By contrast, physicians experienced in the care of the elderly are less willing to favour any form of tube feeding in severely demented patients.[24]

In Canadian studies, 30% of carers who had consented to PEG insertion subsequently expressed uncertainty about whether the right decision had been made.[25,26] Factors considered to have influenced the giving of consent were emotional involvement with the patient, religious or moral convictions, lack of understanding about prognosis and a fear of death by starvation for the patient if no PEG were inserted.[26]

On occasion PEGs have been inserted to reduce the burden upon carers,[19,27] which could explain the preference for PEGs in

Table 1. Indicators of poor prognosis following PEG insertion.

Prognostic indicator	Number (n)	Observations	Reference
Age	149	>80 years, Relative risk (RR) 1.64. (95% Confidence interval (CI) 1.25–2.14)	30
	7,369	>75 years, long-term follow up 77.1% mortality, p <0.001 (subgroup comparison)	5
	1,386	>87 years, RR 1.37 with 95% CI 1.16–1.61	13
Albumin	56	Albumin <28 g/l, 62.5% mortality at 6 months, p = 0.05 (subgroup comparison).	31
	149	Albumin <25 g/l, RR 1.3 with 95% CI 1.07–1.56.	30
Dementia	361	90% 1-year mortality, p <0.0001 (subgroup comparison)	10
Aspiration	1,386	RR 1.64, 95% CI 1.08–2.51	13
Pneumonia	416	30-day mortality 29.1%. RR 3.62, 95% CI 2–6.5	32
Swallowing	149	30-day mortality 27%. One-year mortality 62%.	30
Abnormality	1,386	RR 1.33, 95% CI 1.12–1.58	13
Comorbidity	_____	Urinary tract infection, sepsis, pneumonia, influenza, underlying neoplasm and cardiac failure have all been associated with increased mortality	6, 13, 30, 32, 33

nursing home residents with dysphagia. The insertion of a PEG may reduce the length of stay in hospital and alleviate the pressure on acute medical beds,[12,18,19,27,28] but it may not then be a decision taken in the patient's best interest.[29]

Indicators of poor prognosis following PEG insertion

Given the ethical dilemma of PEG insertion in this subgroup of patients (and any other miscellaneous neurodegenerative diseases), one means of ascertaining whether someone with dementia is at high risk is to assess their negative prognostic indicators. Using multivariate analysis, these factors have been investigated in patients with gastrostomy for any reason. Advanced age, low serum albumin, accompanying comorbidity, dementia or pulmonary aspiration (as the indication for PEG referral) and a documented abnormal swallow study, have all been recognised as independent risk factors which predict a poor outcome (Table 1).[5,6,10,13,30–33]

An effective strategy for PEG insertion?

Overview

Feeding patients with dementia by PEG often poses difficult and emotive questions. Many gastroenterologists have simply adopted the role of technician, leaving the referring consultant to determine when a PEG is indicated. As the numbers of referrals increase year by year, more and more resources will have to be devoted to PEG feeding, sometimes inappropriately. A demented patient's failure to eat may reflect anorexia rather than dysphagia, and in such cases PEG insertion could be considered as equivalent to force-feeding.[14] Given the lack of evidence to support medically beneficial end-points for these patients, it is important also to confront the issue of PEG insertion for reasons of administrative and professional convenience. In addition, decisions by proxy may fail to reflect the patient's wishes as relatives/carers may be influenced by potential criticisms from other family members. Although it may appear that a patient is 'starving to death', this aspect of dementia should be viewed as part of the natural history of the disease. Although many experts have provided hypothetical guidelines for managing this clinical scenario,[7,8,17,34–37] until recently, there have been no published data to suggest that changes in practice may improve the selection of patients.

Implementing changes in local practice

Given that we had observed a high mortality in patients with dementia,[10] we adopted a pragmatic strategy to try to improve all aspects of our selection process for PEG insertion (Box 1).[38] The multidisciplinary team included both a gastroenterologist and a care of the elderly consultant. We designed a PEG referral form (Fig 1) that encompassed indications for gastrostomy insertion, the presence of comorbidity and a basic nutritional assessment. The referring medical teams were required to complete the form before consideration for PEG insertion. An endoscopy nurse would then assess whether the patient would be at high-risk for the procedure. The nurse also fulfilled an important educational role in disseminating information to patients, relatives and ward staff. The nurse had no decision-making powers in determining whether a patient could be selected or declined for a PEG. If there were any uncertainties about the appropriateness of PEG insertion, the patient would be reviewed by a gastroenterologist.

When specifically considering dementia, if this was at a significant level there would be a detailed discussion within the multidisciplinary team, taking into account the relatives' views on how the patient would have felt had s/he been able to express a view.

We did not document whether the diagnosis of dementia was Alzheimer's disease or dementia due to another cause (for example, vascular dementia). However, the diagnosis of dementia in these patients had been made previously by either the family doctor or a care of the elderly consultant. The diagnosis had not been made on the current admission. Despite this, we ensured that metabolic or nutritional causes (as previously described) were excluded. The severity of dementia was ascertained from carers who had observed the patient's mental status prior to hospitalisation. In addition, we used the Barthel's score (score of less than 5) as a surrogate marker. Both these approaches had already been validated.[10,12,16]

The gastroenterologist would advise against PEG insertion because of the high mortality evident in patients with dementia who are 'acutely ill' in hospital. This advice was based on our own UK study (30-day mortality of 54%) and on data from other investigators.[9,10] Patients were, however, never refused a PEG,

Key Points

- There is little evidence to support PEG feeding in patients with dementia and other neurodegenerate diseases
- This clinical scenario presents complex moral and ethical problems
- Dissemination of evidence to all those involved in the patient's care may improve patient selection
- A multidisciplinary approach is essential to the decision-making process

Box 1. PEG referral strategy.

1	Standardise PEG referral form including concomitant disease
2	Endoscopy nurse triage and dissemination of published evidence
3	Gastroenterological review where necessary
4	Holistic and multidisciplinary approach
5	Advise against PEG feeding in patients with dementia
6	One-week waiting list policy

especially if palliation was the goal and carers had realistic expectations about the long-term outcome. This allowed appropriate decisions to be made for each individual.

As gastrostomy insertion is not an emergency procedure, a minimum one-week waiting list policy was initiated. This provided a 'cooling off' period during which all involved in the decision could reconsider their opinion. Both hospitals involved in our previous study had the initial data presented to them at their respective general medical grand-rounds and were provided with details of the proposed new strategy. However, one of the centres chose not to implement these recommendations but to continue providing a technical service. The two centres where this study took place are homogeneous with similar referral patterns for gastrostomy insertion. They both have representation from the common referring specialities: care of the elderly, upper gastrointestinal surgeons, ear, nose and throat (ENT), and neurology. Hospital A (change in practice; Rotherham District General Hospital) serves a community of 250,000. During the 12-month study period the number of medical admissions was approximately 12,000. Hospital B (no change in practice, Doncaster Royal Infirmary) is a larger centre with a catchment area of approximately 330,000. During the same timeframe there were approximately 15,000 medical admissions. Although our initial concerns pertained to patients with dementia, our strategy for improving the PEG service could be applied to all patients referred and in particular to those with other progressive neurodegenerative diseases (where currently there are few data available supporting the use of PEG feeding).

Percutaneous endoscopic gastrostomy (PEG) referral form

Age: _____ yrs M / F

Date of admission: / / Date of referral for PEG: / /

Indications for PEG

Stroke related dysphagia	☐	Neurological dysphagia	☐
Post-trauma neurosurgical	☐	Obstructive lesion oesophagus	☐
Anorexia or cachexia	☐	Obstructive lesion GI	☐
Obstructive lesion pharynx	☐	Other systemic disease	☐
Dementia	☐	Please state: _____	
Other	☐		

CT Scan findings (if relevant)_____

Co-morbidity (tick all that apply)

Cardiovascular	☐	Respiratory	☐
Diabetes	☐	Renal	☐
Malignancy	☐	Specify site: _____	
Other	☐	Please state: _____	
Abdominal surgery	☐	Specify _____	
Abdominal aortic aneurysm	☐	INR/APTT result: _____	

Previous nutritional support Yes / No If Yes date started: / /

Naso-gastric feeding	☐	IV fluids	☐
Sub. cut. fluids	☐	Other	☐
		Please state: _____	
Unsafe swallow with all consistencies		Yes / No	
Poor prognosis for swallow		Yes / No	
Seen by dietitian		Yes / No	
Seen by speech & language therapist		Yes / No / Not applicable	
Barthel score (0–20)_____		AMT (mini-mental score 0–10) _____	

Referring doctor:_____ **Signature:** _____

Bleep No: _____

NB PEG is a surgical procedure and if any patient succumbs within 30 days, a post-mortem examination should be considered.

Please fax completed form to: Gastroenterology, Fax No: (File original in Patient Case Notes)

Fig 1. Percutaneous endoscopic gastrostomy referral form.[38]

Are there any benefits from devising a local policy for PEG insertion?

Both hospitals were prospectively assessed from June 1998 to May 1999 (with follow-up of patients till January 2001). Indications for PEG insertion and patient demographics are provided in Table 2. Statistical analysis of data was performed using Stat View 4.5, Abacus Concepts. Comparisons for mean age between the two PEG cohorts were performed using the Student's independent t-test. Comparisons for sex, annual insertion rates and indication for gastrostomy were performed using chi-squared analyses with Yates' correction. Survival was analysed by the Kaplan-Meier method and the log rank test was used to compare survival between subgroups. Data were censored at January 2001. Cox's proportional hazards analysis was used to assess whether differences between subgroups were dependent or independent of age (data were analysed with the support of the Sheffield University Statistics Unit).

The number of PEG insertions had been rising each year in both centres. After changes in practice were introduced in Hospital A, the number of procedures fell by 20, whilst in Hospital B (no change in practice), the number of PEGs inserted continued to rise from 69 to 84 during the same time frame ($p = 0.02$) (Fig 2). There was a lower mortality observed in Hospital A ($n = 31$) (at 1 month 16%, at 3 months 26%, at 6 months 39%, and 1 year 46%), than in Hospital B ($n = 84$) (at 1 month 26%, at 3 months 44%, at 6 months 58%, and 1 year 68%), although this did not achieve statistical significance (log rank test $p = 0.1$).

Table 2. Patients who had a PEG inserted between June 1998 and May 1999; numbers and demographics in both hospitals (combined total n = 115).[38]

	Hospital A	Hospital B	Statistical comparisons of demographics for 2 centres
Number	31	84	
Mean age (range): years	66.3 (20-94)	68.9 (24-94)	p = 0.5
Men/women	15/16	44/40	p = 0.9
Group 1: oropharyngeal malignancy. number (%)	4 (13%)	8 (10%)	
Group 2: Acute stroke with dysphagia	13 (42%)	34 (40%)	p = 0.9
Group 3: Dementia *	6 (19%)	18 (29%)	
Group 4: Miscellaneous	8 (26%)**	24 (21%)***	

*Specific survival outcome in individual patients with dementia in Hospital A who did have a PEG inserted: 90-year-old female, survival 499 days; 87-year-old female, survival 178 days; 82-year-old male, survival 153 days; 94-year-old female, survival 11 days; 65-year-old male, survival 109 days; 72-year-old female, survival 226 days.
**Hospital A, Group 4 (miscellaneous category) n = 8: encompassing head injury (2), motor neuron disease (3), and multiple sclerosis (3).
***Hospital B, Group 4 (miscellaneous category) n = 24: head injury (5), motor neuron disease (6), and multiple sclerosis (8), parkinsonism (2), cerebral palsy (1), Down's syndrome (1) and Huntingdon's chorea (1).

Nine patients in Hospital A were initially considered for gastrostomy insertion but did not subsequently have the procedure. All of these patients died within 21 days of referral for a PEG (Table 3).

Discussion

This is the first study to demonstrate the outcomes of adopting a pragmatic strategy towards PEG insertion. It is an observational study and so is limited by the inability to randomise patients. The reduced mortality observed in Hospital A did not achieve statistical significance (despite a reduced number of PEG insertions) when compared to Hospital B. This may be attributed to persisting inappropriate patient selection – there were still a number of patients in whom this procedure was performed where the prognosis was poor. The reduced number of PEG insertions in Hospital A may be attributable to the involvement of the endoscopy nurse. This can lead to bias; for example, discussions held with the carers of patients in Hospital A (where the guidelines were implemented) could be more persuasive than those in Hospital B. This would seem likely as the gastroenterology department in Hospital B had not changed their practice. Hospital B was still providing a predominantly technical service for PEG insertions with no involvement in the decision-making process at ward level. Although this is a limitation to the study, we are observing real clinical practice.

The one-week waiting list policy also influenced outcome; four out of nine patients died on the waiting list (Table 3).

We felt that providing evidence-based information was an important aspect of our study. The understanding that the benefits of PEG insertion (with regard to mortality and nutritional status) had only been demonstrated in patients with cerebrovascular disease or oropharyngeal malignancy[2–4] may have just as much impact as the implementation of guidelines (although we were unable to quantify this effect). The changes in referral practices within Hospital A may provide some support for this view. When considering the nine patients who did not have a PEG in Hospital A, seven were referred within three months of issuing guidelines (Table 3). Thereafter, we received fewer requests that required discussion, where opinions regarding

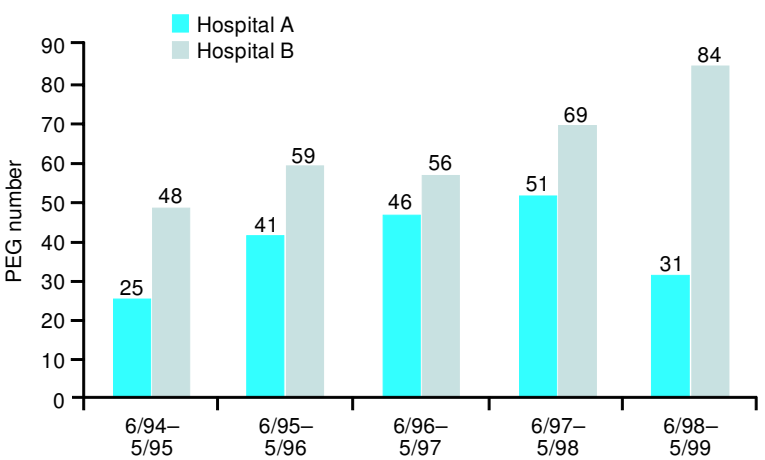

Fig 2. Number of PEGs inserted in Hospital A and Hospital B over a five-year period (changes in practice implemented in Hospital A from June 1998). Comparison between Hospital A and B before and after the new strategy (p = 0.02).[38]

Table 3. Patients in Hospital A who did not have a PEG inserted (n = 9).[38]

Age	Sex	Indication	Outcome
79	Male	CVA	Died within 24 hours of referral
84	Female	Dementia	Multidisciplinary decision against PEG insertion. Died 21 days later*
77	Female	Dementia	Died on waiting list 6 days after referral
69	Male	CVA	Died on waiting list 2 days after referral
51	Male	MS	Multidisciplinary decision against PEG insertion. Died 2 days later*
86	Male	MND	Multidisciplinary decision against PEG insertion. Died 8 days later*
92	Female	CVA	Multidisciplinary decision against PEG insertion. Died 12 days later*
82	Male	Dementia	Multidisciplinary decision against PEG insertion. Died 6 days later*
80	Male	Dementia	Died on waiting list 8 days after referral

*Patients for whom a multidisciplinary decision was made are the ones who were denied a PEG. Patients where no multidisciplinary decision is mentioned died on the waiting list.

PEG insertion were conflicting. Decisions regarding PEG insertion were more likely to be occurring at ward level, so we were no longer asked to give an opinion. The dissemination of information to patients, families, carers and nursing staff may impact on our study results but we believe that this is better than no discussion whatsoever (which had been our previous practice). As a result of these data, Hospital B has now also employed a similar strategy.

Our inability to demonstrate an improvement in survival perhaps reflects the fact that PEG insertion is not so much about prolonging survival but more about improving the quality of life. The nature and long-term implications of a decision to feed mean that carers and relatives have to come to terms with the decision.

Conclusion

PEG feeding in patients with dementia and other neurodegenerative conditions is a contentious issue with limited evidence available to support it in clinical practice. However, one has to take a pragmatic approach given the complex moral and ethical issues it raises. A pragmatic strategy and a more proactive role in the selection of patients may have modest effects on mortality and the number of PEGs inserted. This framework also allows the dissemination of evidence-based information. It is important that the common misperception that PEG feeding may improve the survival outcome of the patient is challenged.

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