



Are we providing adequate information and support to recipients of percutaneous endoscopic gastrostomy (PEG) tubes?

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ABSTRACT

Introduction

In patients with swallowing difficulties, the decision to insert a percutaneous endoscopic gastrostomy (PEG) tube is complicated, and requires a specialist multidisciplinary team. PEG recipients and their families are often under stress due to lack of continuing support.

Objectives

To describe the decision-making process for PEG insertion, and the amount of information and support provided to PEG recipients.

Methods

All PEG tube candidates over a five months period, and their carers, were interviewed before, and a month after PEG, using a questionnaire to explore the decision-making process, PEG recipients' knowledge about complications, and support measures.

Results

Twenty six PEG recipients and their carers were included (50% males) average age 71.5 years. Only 38% of

patients were able to answer questionnaires. Doctors figured highly in being seen as responsible for the PEG decision. There was a general lack of knowledge of complications amongst patients and carers. Following discharge from hospital, most patients and carers were not aware of available support measures.

Conclusions

The majority of patients requiring PEG were unable to communicate their wishes. There is a general lack of knowledge of complications, and lack of awareness of the availability of support services amongst PEG recipients and carers.

Key words: Percutaneous, endoscopic, gastrostomy, tube, information, support, patients, carers.

Introduction

Adequate nutrition is a basic requirement of life. In patients with swallowing difficulties, the decision to insert a percutaneous endoscopic gastrostomy tube

(PEG) is complex, and requires the involvement of a multidisciplinary team ⁽¹⁾. PEG is a relatively new method of enteral feeding, which was first introduced in 1980 in Cleveland, Ohio in the United States. It can be undertaken safely in patients following a recent stroke ⁽²⁾. S K Raha described the use of PEG in 161 elderly patients and found it to be a useful, well tolerated procedure in geriatric practice, but he stressed the importance of careful patient selection and evaluation in frail elderly patients ⁽³⁾.

Feeding patients with swallowing difficulties continues to present a clinical and sometimes moral dilemma in the absence of hard evidence to guide clinicians. There are no national guidelines for the timing of insertion, or further swallowing assessment in people with PEG tubes. In spite of the studies showing that those who coped best with PEG tubes were the well informed and supported patients and carers ⁽⁴⁾, we are still debating, in our local set ups, the best ways of approaching patients and carers and what information should be given.

Objectives

To describe the clinical decision-making process for PEG tube insertion by exploring patients and carers' views prior to insertion, and a month later, with special emphasis on the amount of support and information provided to them.

Study Designs

A prospective cohort qualitative study.

Setting, Patients and Methods

All patients requiring a PEG tube insertion at the manor Hospital, Walsall in the United Kingdom, over a five months period were approached. Twenty six pairs of patients and carers were personally interviewed initially at hospital, and a month later, either in person at hospital or contacted by phone if they have been discharged. Patients were the respondents unless dysphasic or cognitively impaired (MMSE <3/10). Using a questionnaire we explored the decision-making process, recipients' knowledge of existing support in case of complications, and availability of swallowing reassessment (**Appendix 1-4**).

Appendix 1

Patient questionnaire prior to PEG

1. Are you aware of going for a PEG?
2. Do you agree to have a PEG?
3. What do you know about PEG, what does it involve?
4. Why are you having a PEG?

5. Who was involved in the decision?
6. Do you know of PEG complications?
7. Who told you most about PEG?

Appendix 2

Carer questionnaire prior to PEG

1. Who discussed the decision for PEG with you?
2. Whose decision was it to insert a PEG for your relative?
3. Are you aware of any complications?

Appendix 3

Patient questionnaire post PEG

1. Are you comfortable with the outcome of the PEG?
2. Do you regret your decision to have PEG?
3. Who will you contact in case of complications?
4. Is the PEG temporary or permanent?

Appendix 4

Carer questionnaire post PEG

1. Are you comfortable with the outcome of the PEG?
2. Do you regret the decision for your relative to have PEG?
3. Have you been given printed information about PEG?
4. Who will you contact in case of complications?
5. Is the PEG temporary or permanent?

Main outcome measures

The degree of awareness, agreement and involvement in the decision-making process in patients and carers. The amount of information and support available to patients and carers.

Results

Twenty six PEG recipients were included; 13 males (50%). Their average age was 71.5 (range 32-91 and SD 14) years. 54% were stroke victims, 8% had subarachnoid haemorrhage, 12% cancer (oesophagus, larynx and tongue), 8% cerebral palsy, 4% Alzheimer's dementia, and 14% had other causes.

Their disability scores using Barthel index were as follows:

18 patients (69.2%) had Barthel score 0-5

7 patients (27%) had Barthel score 6-10

1 patient (3.8%) had Barthel score of 11

The time interval from referral for PEG till insertion was 1-7 days. Three patients were admitted from outpatients for PEG insertion, and 23 were inpatients with an average length of stay of 32.3 (range 3-86) days.

The referring consultants for PEG tubes were as follows:

Geriatricians	16 patients (61.6%)
Gastroenterologists	4 patients (15.4%)
General physicians	3 patients (11.5%)
Surgeons	3 patients (11.5%)

Regarding complications 15% of patients developed nausea, vomiting or diarrhoea, while one blocked tube had to be replaced.

Six patients (23%) died within 6 weeks:

80 year old male with paraneoplastic syndrome died within 4 days

62 year old female with a massive stroke died within 2 weeks

70 year old male with a stroke died within 2 weeks

68 year old female with Ca oesophagus died within 4 weeks

63 year old male with subarachnoid haemorrhage died within 6 weeks

69 year old male with aspiration pneumonia following a stroke died within 6 weeks

Twelve patients (46%) were discharged home, while 8 patients (31%) were discharged to nursing homes.

Interviewing patients prior to the PEG procedure:

Only ten (38.5%) patients were able to participate in answering the questions. All patients were agreeable to have the PEG, and said it was necessary because they could not swallow, and it was for their proper nutrition.

When asked who was involved in the PEG decision:

Doctors were mentioned by 8 patients

Families were mentioned by 6 patients

Nurses were mentioned by 5 patients

When asked who told them most about PEG:

Doctors were mentioned by 4 patients

Nurses were mentioned by 7 patients

When asked about possible PEG complications:

Only one patient mentioned 4 complications

Two patients mentioned two complications

Two patients mentioned one complication

Five patients mentioned none

Interviewing carers prior to the PEG procedure:

Only 24 relatives / carers discussed the PEG decision with a health care professional:

19 discussed the decision with a doctor

11 discussed the decision with a nurse

3 discussed the decision with a dietician

4 discussed the decision with a speech therapist

When asked whose decision was it to have the PEG inserted:

13 relatives mentioned it was primarily a doctor's decision

3 relatives mentioned it was mainly a doctor's and patient's decision

6 relatives mentioned it was the doctor's and their decision

2 relatives mentioned it was a joint decision between patients, doctors, nurses and themselves

When asked about possible PEG complications:

6 reported no knowledge of complications

3 reported three complications

8 reported two complications

9 reported one complication

Interviewing patients post PEG:

Only five of the original ten patients were able to participate in the later interview. The five felt comfortable with the outcome of the PEG and did not regret their decision.

In case of complications two patients would contact their general practitioner (GP), one patient would contact the endoscopy unit, one patient would contact the secretary of the hospital consultant, and one patient did not know who to contact.

Only one patient knew that the PEG was temporary and knew that his swallowing was going to be re-assessed in 2 weeks time, while the remaining four patients had no knowledge of swallowing re-assessment and thought that PEG was permanent.

Interviewing relatives post PEG:

Only 20 relatives from those who participated in the first interview were included in the late interview, of whom 12 lived with and cared for the PEG recipient.

18 relatives felt comfortable with the PEG outcome, and 2 regretted their decision.

16 relatives felt they were given enough information and 4 relatives felt they were not informed adequately.

In case of complications 10 relatives would contact GP, 3 relatives would contact district nurse, 2 relatives would contact the endoscopy unit, and 5 relatives did not know who to contact in case of complications.

17 relatives thought that PEG was permanent, while 3 relatives knew it was temporary and of these three only two knew of a date for swallowing re-assessment.

Discussion

Many studies have reported conflicting evidence about

the value of PEG feeding^(5,6). Yet few British Geriatrics units have a comprehensive swallowing assessment and feeding policy. It is true that not two patients are alike, and broad guidelines have to be considered in the clinical context of the relevant patient, which may explain the difficulty of establishing generalisable guidelines.

PEG tube feeding affects the life style of both patients and carers. It is not an easy decision to undertake because of its long term implications on self-image, independence and social interaction. Previous studies have addressed safety, nutritional and practical benefits of PEG, but few have tackled the decision-making process, or the long term views of patients and carers. Parker found that standards of care are not keeping in pace with the demand for artificial nutritional support, and recommended multidisciplinary nutritional teams to improve the care and reduce complications rate⁽¹⁾. Our study is in accordance with Callaghan⁽⁴⁾ who found that patients, families and doctors alike were all forced to make PEG decisions under tragic circumstances and without complete information, and absent alternatives.

The recurring dilemma appears to be whether patients and carers are well informed or not to make a reasonable decision. The difficulty faced by clinicians is how much should be told without being paternalistic. Too much information may overwhelm the patient and carers, and deter them from having a PEG, while it is unethical to withhold any relevant information. In addition the majority of patients needing PEG tubes are elderly with extensive strokes, or communication difficulties. Our study showed a degree of lack of information about possible complications of PEG, and the lack of knowledge about available support services once patients were discharged from hospital. Another issue was the lack of awareness about swallowing re-assessment availability. All these factors may add to the stress experienced by patients and carers. Rickman identified a significant level of depression and stress amongst PEG recipients, and highlighted the need for initial factual information as well as ongoing practical and psychological support⁽⁷⁾.

Conclusions

The majority of patients requiring PEG were very dependant and unable to communicate their wishes. The decision to insert PEG seemed inevitable to most carers. Carers were not adequately informed about PEG complications and support services available. We recommend a multidisciplinary team to help patients and carers reach an informed decision and better education and support for all PEG recipients.

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