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Mortality and Institutionalisation after Percutaneous Endoscopic Gastrostomy (PEG) in Parkinson's Disease.

Lisa Brown, Rob Skelly, Andrea Lindahl et al

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Background

- Dysphagia is common in advanced Parkinson's disease and atypical parkinsonian conditions.
- Dysphagia may lead to weight loss, reduced quality of life and aspiration pneumonia.
- PEG feeding may lead to longer survival than oral feeding in home care patients with neurological impairments (Shintani 2012)
- PEG feeding probably does not improve survival in advanced dementia (Murphy et al 2003).
- In PD, post PEG survival is estimated to be 186 days to 1.2 years, worse outcomes in fully dependent patients reported (Sarkar et al 2017,Marios et al 2017) .
- A large British study (10,952 - 591 PD) showed 14.6% 30-day mortality.
  - It did not identify Parkinson's as a risk factor for early mortality at 7 and 30 days,
  - increasing age, male gender, non-elective admission and dementia were identified as risk factors for mortality at 30 days post-PEG (Bowering et al 2014).

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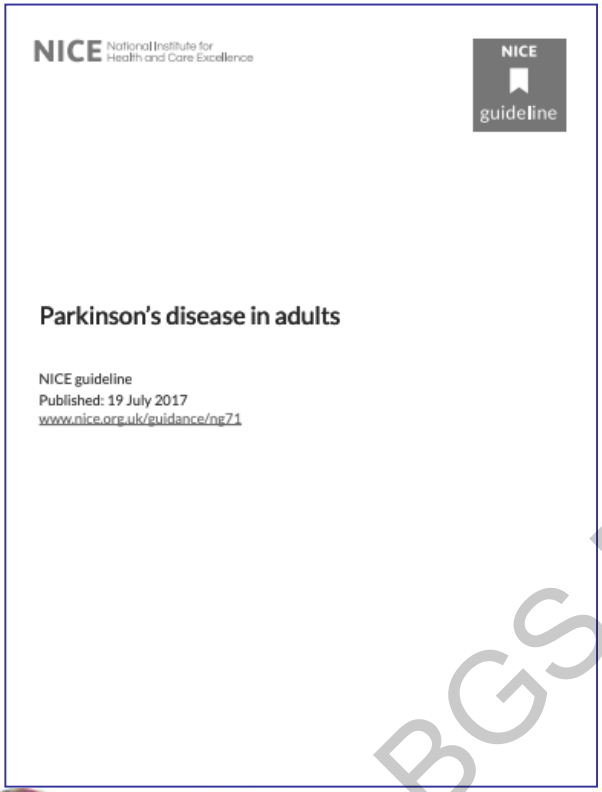
NICE National Institute for Health and Care Excellence

NICE guideline

Parkinson's disease in adults

NICE guideline
Published: 19 July 2017
www.nice.org.uk/guidance/ng71

Clinical Nutrition (2005) 24, 848–861

ELSEVIER

Clinical Nutrition
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CONSENSUS STATEMENT

ESPEN guidelines on artificial enteral nutrition—Percutaneous endoscopic gastrostomy (PEG)

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Method

- Retrospective study in 2 large university hospitals
- Cases were identified by review of a PEG registers and Searching hospital datasets for relevant diagnosis and procedure codes
- Each hospital has a catchment population of 500,000.
- Caseload of each Parkinson's services approx. 1000.
- Notes reviewed 2005-2017.
- The audit was approved by each host institution and results have been fed back locally.

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Aims

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- Estimate the rate of PEG insertion and see how this varied over time.
- Audit processes around PEG insertion:
  - planned or inserted during an emergency admission
  - involvement of SLT
  - discussion of benefits, risks and alternatives
  - organisation of community follow up.
- Audit PEG outcomes:
  - survival; complications; length of stay after PEG;
  - readmissions; place of discharge; step up in care needs

PEG placements per year

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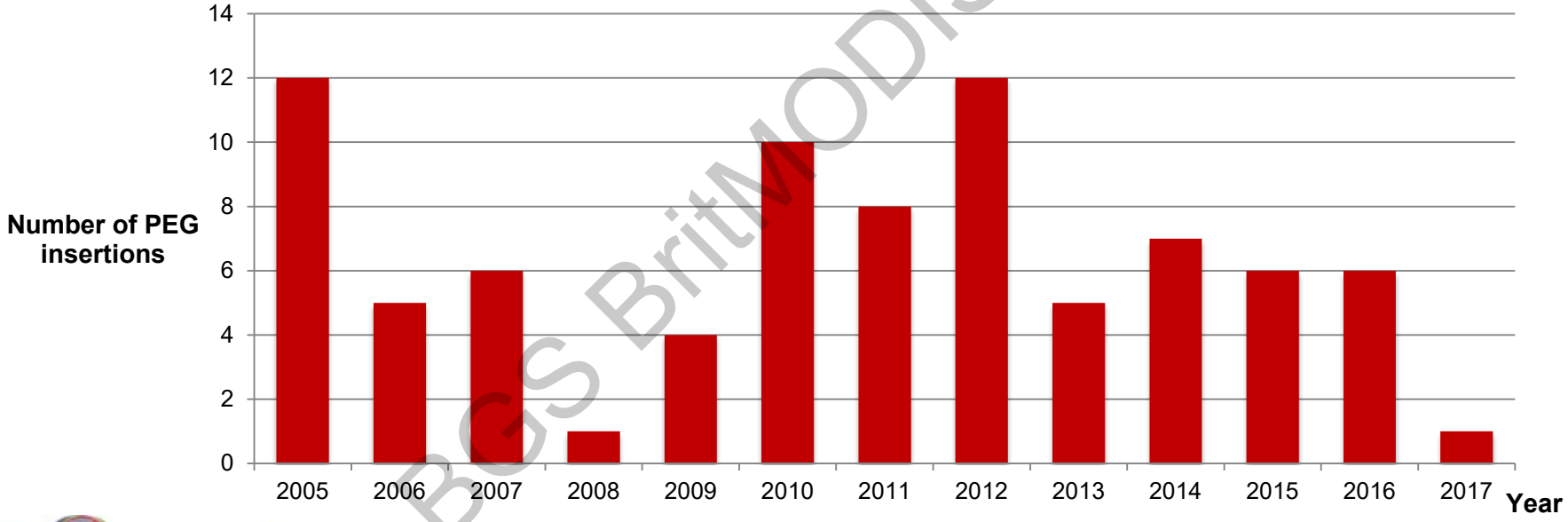
- Number of PEGs placed in PD patients in 2 large university hospitals. Each hospital has around 1000 PD patients.
- Estimated PEG placement rate: 3.2/1000 PD patients/year



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Results

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Demographics and baseline data

Number:	83
Age in years (median [range])	78 [49-97], IQR 72-82
Gender = Female	29 (35%)
Usual place of residence:	
Home alone	8 (10%)
Home not alone	53 (64%)
Residential home	9 (11%)
Nursing home	13 (16%)

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Results

Diagnosis		
Parkinson's disease	58	70%
- with Dementia	10	17%
Progressive Supranuclaer Palsy	10	12%
Multiple System Atrophy	5	6%
Dementia with Lewy Bodies	3	4%
Vascular parkinsonism	7	8%

For those with Parkinson's disease the median L-dopa dose was 400mg.

Parkinson's disease Diagnosis -Hoehn-Yahr [HY]
HY2 1 (2%),
HY3 14 (24%),
HY4 23 (40%),
HY5 (34%)..

Results

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Care Processes	
Advanced care plan in place	18 (22%)
PEG inserted during emergency admission	68(82%)
Patient made Nil by Mouth	57(69%)
NG tube used prior to PEG	64(77%)
SLT assessment	74(90%)
Documented risk benefit discussion	69(83%)
Community follow up by HEF team	40(52%)

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Outcomes

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PEG outcomes in 2 University hospitals	
Length of stay post PEG in days: median (IQR)	20 (8-30)
Cases readmitted in first year post discharge	36 (47%)
30-day mortality:	5 (6%)
Survival in days: median (IQR)	422 (93-931)

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Survival after PEG

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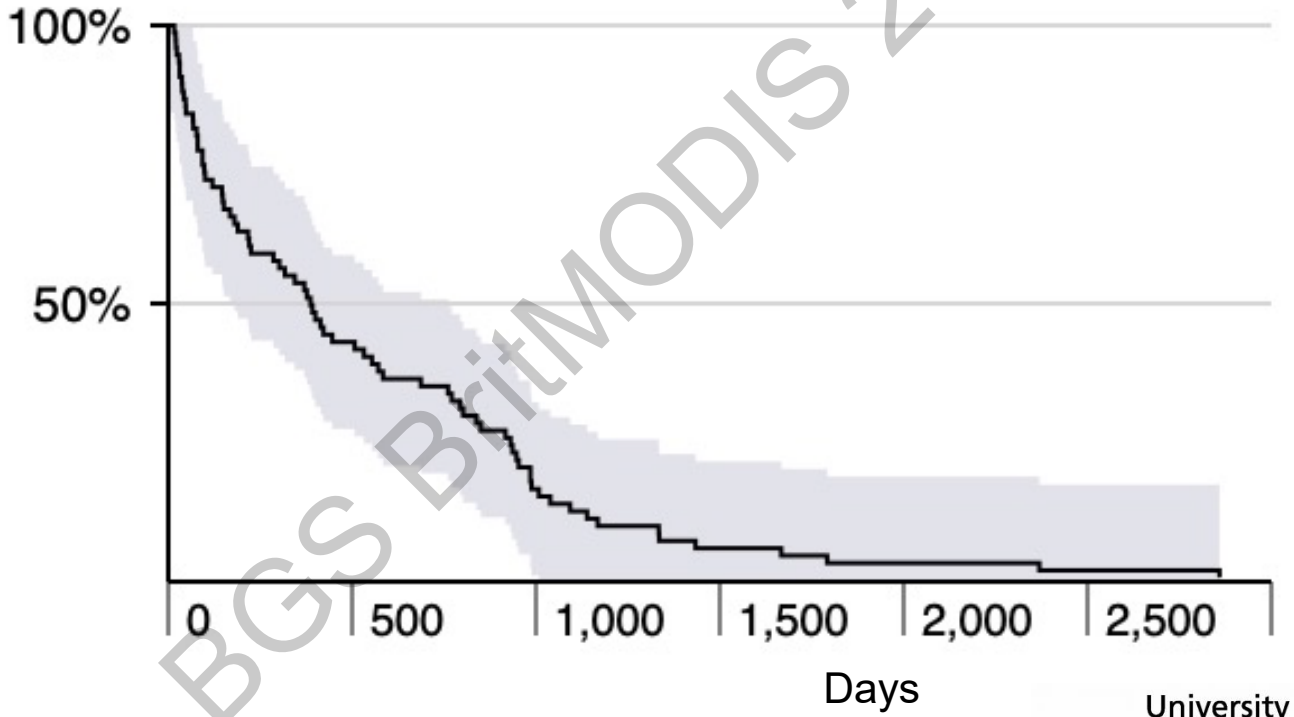

Proportion surviving (N=83)

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Baseline features	Number (%)	30-Day mortality (%)	Median survival in days (Log-rank)	Step up in care (%)
Age (years)				
<75	29 (35%)	4 (14%)	400	7 (30%)
75- 84.9	39 (47%)	1 (2.6%)	532	11 (37%)
≥85	15 (18%)	0	220 (p = 0.979)	5 (42%)
Gender				
Female	29 (35%)	2 (3.4%)	584	7 (33%)
Male	54 (65%)	3 (5.5%)	400 (p = 0.557)	16 (36%)
Diagnosis				
PD	58 (70%)	4 (6.9%)	571	19 (41%)
PSP	10 (12%)	1 (10%)	400	2 (29%)
MSA	5 (6%)	0	422	1 (25%)
DLB	3 (4%)	0	286	0
VP	7 (8%)	0	387 (p = 0.654)	1 (20%)
Hoehn-Yahr Stage				
2	1 (2%)	0	761	-
3	14 (24%)	1 (7.1%)	344	4 (50%)
4	23 (40%)	1 (4.3%)	532	6 (30%)
5	20 (34%)	2 (10%)	422 (p = 0.853)	4 (22%)

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Baseline features		Number (%)	30-Day mortality (%)	Median survival in days (Log-rank)	Step up in care (%)
Admission type					
	Elective	15 (18%)	0	771	2 (13%)
	Non-elective	68 (82%)	5 (7.4%)	392 (p = 0.672)	21 (40%)
Advanced care plan					
	Yes	19 (23%)	1 (5.3%)	771	4 (25%)
	No	64 (77%)	4 (6.3%)	387 (p = 0.717)	19 (39%)
Co-morbidity					
	0	11 (13%)	1 (9.1%)	794	4 (44%)
	1	55 (66%)	4 (7.2%)	730	16 (37%)
	2	15 (18%)	0	414	1 (10%)
	≥3	2 (2%)	0	392 (p = 0.270)	2 (100%)
Usual residence					
	Home alone	8 (9.6%)	0	985	5 (71%)
	Home not alone	53 (64%)	4 (7.5%)	571	14 (29%)
	Residential care	9 (11%)	0	370	4 (44%)
	Nursing home	13 (16%)	1 (7.7%)	168 (p = 0.634)	-
PD Dementia					
	No Dementia	48 (83%)	2 (4.2%)	584	17 (43%)
	Dementia	10 (17%)	2 (20%)	344 (p = 0.105)	2 (33%)
All		83	5 (6.0%)	422	23 (34%)

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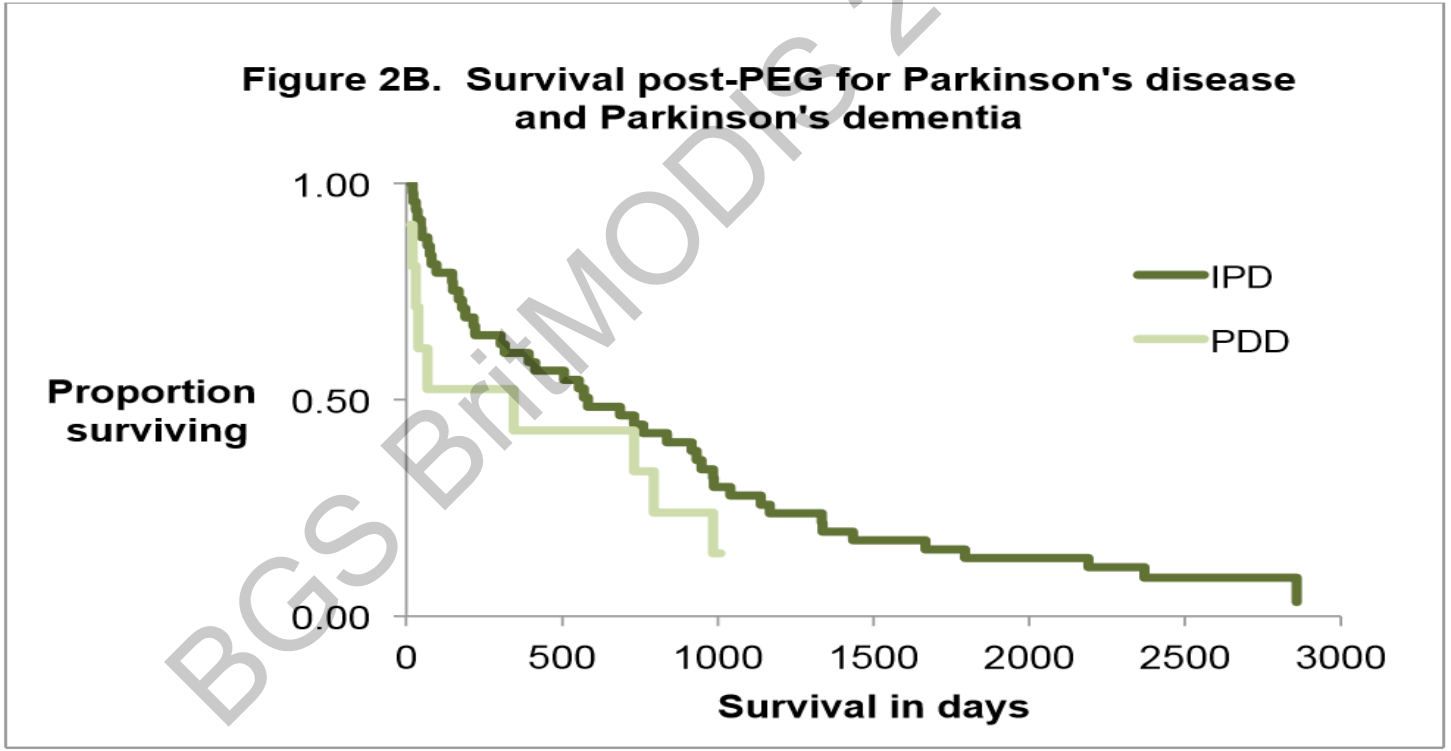
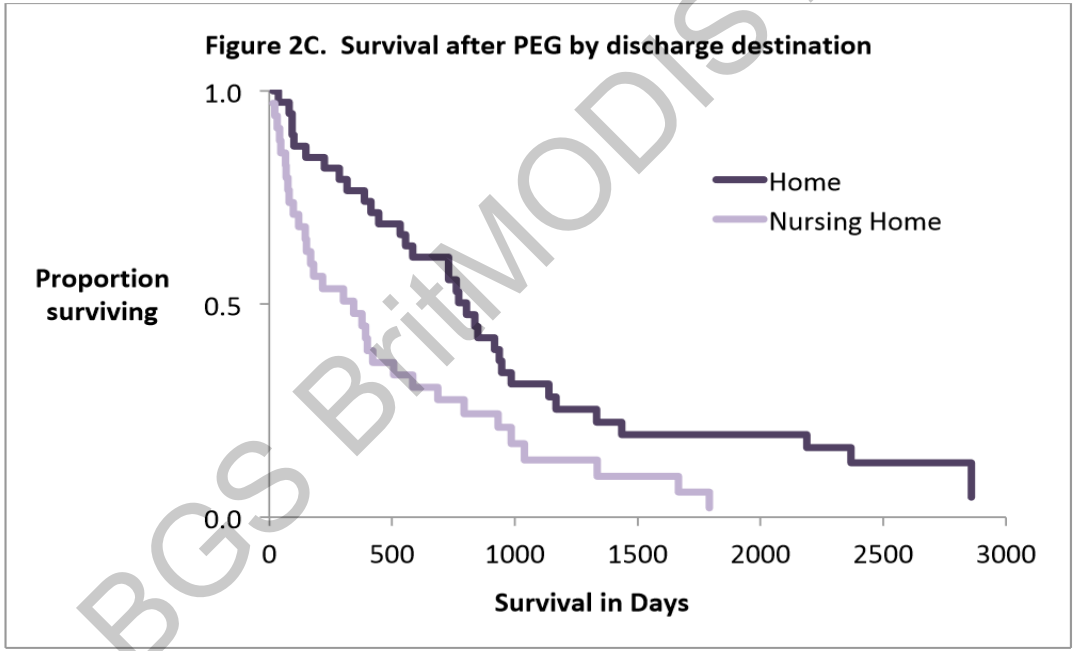
Survival plots comparing Idiopathic Parkinson's disease (IPD, n=48) and Parkinson's disease dementia (PDD, n=10); log-rank, p = 0.105.



Discharge destination

Home alone	1 (1%)
Home not alone	37 (46%)
Residential Home	6 (8%)
Nursing Home	34 (43%)
Died before discharge	5 (6%)
Step up in care on discharge	23/65 (35%)
Admitted from home, discharged to institution	18/56 (32%)
Admitted from RH, discharge to nursing home	4/9 (44%)

Survival plots comparing discharge to nursing homes (n=34, median survival 323 days) versus discharge to own home (n=38, median survival 766 days); log-rank, p = 0.005.



Complications

- Early (during admission when PEG inserted)

None	49 (59%)
Aspiration	18 (22%)
PEG site infection	7 (8.4%)
Bowel perforation	1 (1.2%)

- Complications during follow up

Buried bumper	2 (2.4%)
Accidentally removed	2 (2.4%)
Aspiration Pneumonia (admission)	14 (18%)

- Other 11 (13%)

Aspiration Pneumonia

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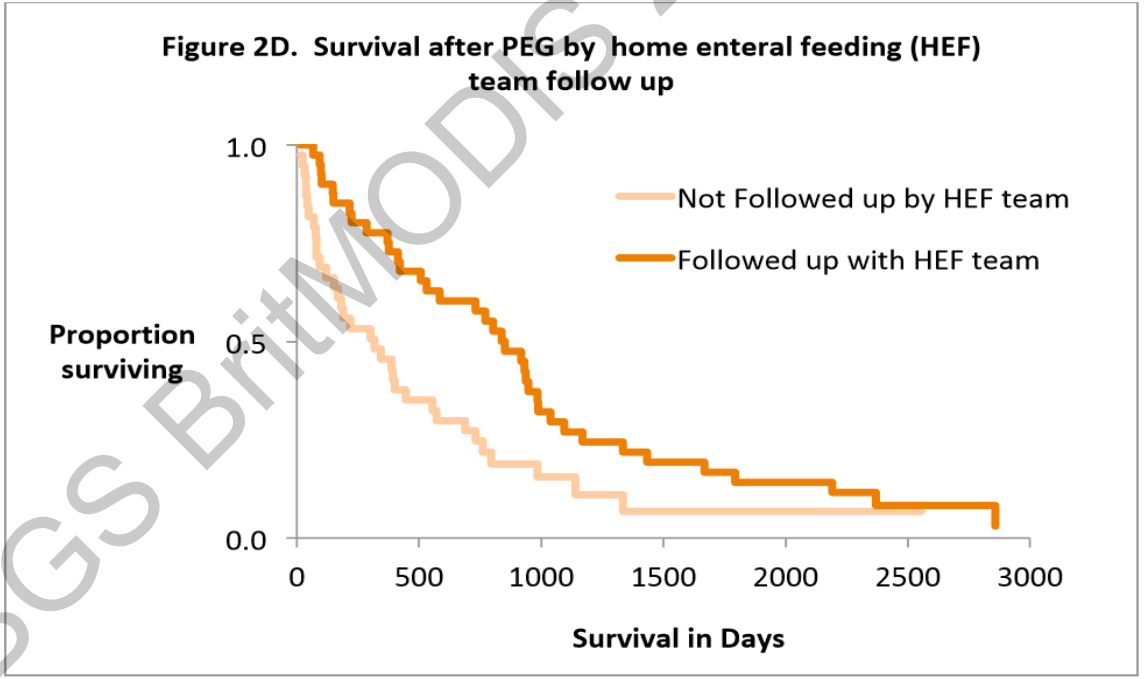
- Proportion who had aspiration at any time post PEG -34%
- (during admission plus causing re-admission)
- The rate of aspiration pneumonia in our study is consistent with other studies which report 31 – 46%
- .Are we surprised that aspiration pneumonia remains a significant problem?
  - For QOL reasons it may be that not all food is given by PEG;
  - saliva (more than 250 ml /day) can be aspirated and cause pneumonia.
  - Gastric contents can be regurgitated and aspirated.
- Aspiration might be reduced by:
  - correct feeding position: (45 degrees, not supine)
  - Prokinetic drugs

    (theoretical benefit in view of autonomic dysfunction in PD, no evidence base)

HEF team follow up

Survival plots comparing HEF team follow up (n=40, median survival 820 days) with no HEF team follow up (n=38, median survival 310); log rank, p = 0.005.

HEF team follow up by discharge destination
- Own home 66%
- Care Home 38%



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Outcomes for PEG in different time periods

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Year of PEG Insertion	Number (%)	30-Day mortality (%)	Median survival in days	Patients Readmitted in first year (%)	Step up in care
2005-2010	38 (46%)	2 (5.3%)	366	11 (33%)	14 (41%)
2011-2017	45 (54%)	3 (6.7%)	532*	25 (54%)**	9 (20%)***

*Log-rank, p = 0.298
**Chi squared test, p = 0.041
*** Chi squared test, p = 0.047

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- Strengths
  - Size compared to other studies
  - Pre and post PEG care and outcomes

- Weaknesses
  - Retrospective nature
  - Incomplete data capture
  - No comparative group of dysphagic PD patients managed without PEG
  - Long collection period
  - No patient reported QOL data

Summary of Results

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- PEG insertion in Parkinson's is infrequent: estimated 2-3 per 1000 PD patients / year, insertion rates have been fairly stable over time.
- Most patients are severely disabled (H&Y stages 4 and 5).
- Most PEGs were placed during a non-elective admission for dysphagia.
- Advanced care planning covering preferences with respect to enteral tube feeding occurred in only 22% of cases.
- 30-day mortality was 6% and median survival was 422 days.
- One third of patients admitted from home were institutionalised on discharge.
- Aspiration pneumonia occurred in a third of our patients.
- HEF team follow up was more likely in those discharged to own home (66% v 38%) and HEF team follow up was associated with longer survival

Recommendations

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1. Markers of advanced disease should prompt advanced care discussions including preference in regard to tube feeding.
2. Discussions about PEG feeding in Parkinsonian conditions should include information about
   - post-PEG survival,
   - complications including ongoing risk of aspiration pneumonia
   - risk of institutionalisation
3. HEF team follow up should include all patients discharged with a PEG
4. Research should establish the impact of PEG feeding on health related quality of life in this patient group.
5. Research should also be undertaken into strategies to reduce aspiration in PEG fed PD patients.

Aknowledgments

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references

- Shintani S. Efficacy and ethics of artificial nutrition in patients with neurologic impairments in home care. J Clin Neurosci. 2013;20(2):220-3.
- Murphy LM, Lipman TO. Percutaneous Endoscopic Gastrostomy Does Not Prolong Survival in Patients With Dementia. Arch Intern Med. 2003;163(11):1351-1353..
- Sarkar P, Cole A, Scolding NJ, Rice CM. Percutaneous Endoscopic Gastrostomy Tube Insertion in Neurodegenerative Disease: A Retrospective Study and Literature Review. Clin Endosc. 2017 May; 50(3): 270–278. doi: 10.5946/ce.2016.106
- Marois C, Del Mar Amador M, Payan C, et al. Outcome of gastrostomy in parkinsonism: A retrospective study. Parkinsonism Relat Disord 2017;43:110-113.
- Bowering K. Analysis of routine hospital administrative data (including Hospital Episode Statistics) to assess variation in process and outcomes in gastroenterology. Thesis. https://livrepository.liverpool.ac.uk/15135/1/BoweringKat_Jan2014_15135.pdf.
- National Institute of Health and Care Excellence. Parkinson's Disease in Adults. NICE Guideline [NG71]. 2017 London UK.