

Percutaneous endoscopic gastrostomy in atypical parkinsonian syndromes: survival and aspiration outcomes from a retrospective international cohort

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ABSTRACT

INTRODUCTION: Dysphagia frequently occurs in movement disorders, leading to malnutrition and aspiration. Percutaneous endoscopic gastrostomy (PEG) provides nutrition directly into the stomach, bypassing the dysfunctional swallow. However, PEG insertion is a complex decision, both clinically and ethically. Although PEG outcomes are reported in other neurological disorders, there is limited research in atypical parkinsonian syndromes such as multiple system atrophy (MSA), progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD). Insertion rates remain variable, reflecting a paucity of research and lack of consistent guidelines. Basic mortality and morbidity data would help inform practice. To our knowledge, this is the first international study of PEG insertion and its impact on survival and aspiration pneumonia in atypical parkinsonian syndromes.

METHOD: This was an international retrospective study of 72 patients with MSA, PSP or CBD. Survival was recorded from reported onset of dysphagia to death. Secondary outcomes included hospital admission rate for aspiration pneumonia.

RESULTS: Median survival was 17.4 months (95% confidence interval [CI] 14.0–24.9) in non-PEG patients versus 48.8 months (95% CI 44.8 to not reached) in PEG patients, hazard ratio (HR) 0.38 (95% CI 0.18–0.81; $p=0.013$). PEG was not associated with reduced risk of aspiration pneumonia; 0.76 versus 0.68 admissions per patient-year, incidence rate ratio (IRR) 1.41 (95% CI 0.74–2.68; $p=0.297$).

CONCLUSION: PEG insertion may improve survival in atypical parkinsonian syndromes, though we found no evidence of reduced aspiration risk. Given the rarity of these conditions, international registries may help to determine the safety and efficacy of PEG use.

Dysphagia occurs frequently in atypical parkinsonian syndromes. Subsequently, aspiration pneumonitis or pneumonia are common complications and significant causes of mortality.¹ Percutaneous endoscopic gastrostomy (PEG) tubes can be used in the setting of dysphagia to provide nutrition. In bypassing the abnormal swallow, PEG feeding was also originally thought to avoid or reduce the risk of aspiration pneumonitis or pneumonia. However, aspiration risk has proven to be more nuanced than this, with data showing no benefit or, at times, increased risk with PEG feeding.²

A number of neurodegenerative disorders have a significant evidence base to inform decision making and informed consent processes for PEG insertion.³ However, there is a paucity of research to guide decision making in movement disorders. This is particularly challenging in the atypical parkinsonian syndromes where the lower prevalence and reduced life expectancy further hamper research.

This international retrospective study analysed 72 patients with atypical parkinsonian syndromes across two regions in the United Kingdom (UK) and New Zealand. Patients with a diagnosis of multiple systems atrophy (MSA), progressive supranuclear palsy (PSP) or corticobasal degeneration (CBD) were included. The objective was firstly to determine whether PEG feeding increased life expectancy and secondly to assess whether PEG feeding reduced the risk of significant aspiration complications.

The aim is to provide clinicians and their patients with quantitative data on survival and aspiration risk to help inform and facilitate clinical decision making.

Methods

Data collection for UK patients from the York and Scarborough Teaching Hospitals NHS Foundation Trust came from two sources. The

first was a prospective register maintained by one of the authors, comprising patients reviewed by himself and one other specialist in movement disorder clinics at the Scarborough and Bridlington Hospitals (2009–2024). This register was updated according to each patient's most recent clinical diagnosis prior to death, in line with International Parkinson and Movement Disorder Society criteria. From this source, 78 deceased patients with a definitive diagnosis of MSA, PSP or CBD were identified. The second was the hospital register of patients seen throughout the hospital trust who had a clinic code of "atypical parkinsonian syndrome". This identified a further 286 deceased patients at time of search in 2024. The two lists of patients were cross-checked and duplicate patient entries were identified and eliminated.

Data collection for New Zealand patients in the Wellington Region was sourced from the hospital register for the Capital and Coast District Health Board between 2010 and 2024. This database included patients seen at Wellington Regional Hospital, Hutt Hospital and Kenepuru Community Hospital. A search was completed for patients who were deceased and had a clinic code of "multiple systems atrophy", "progressive supranuclear palsy", "degenerative disease of basal ganglia, unspecified", "extrapyramidal and movement disorder, unspecified" or "dementia with Lewy bodies". This identified 189 patients.

Patient letters were extensively reviewed and those without a diagnosis of MSA, PSP or CBD at death were excluded. Patients who were lost to follow-up or had insufficient clinical data were not included in the final analysis. Where there was no evidence of reported dysphagia, these patients were also excluded. A summary of patient identification and exclusions is shown in Figure 1.

First report of dysphagia was defined from the earliest date of any of the following: clinic letter describing episodes of aspiration or the patient noticing a problem with dysphagia, referral to speech and language therapy for swallow assessment or presentation to the emergency department or hospital admission for an aspiration event. Survival time was measured from the onset of dysphagia until death. Hospital admission for aspiration pneumonia was recorded if the discharge letter had "aspiration pneumonia" as a diagnosis, or the chest X-ray on initial assessment demonstrated a right lower lobe pneumonia. Presentations to the emergency department that did not result in admission were

not included.

Statistical analysis

All patients were deceased at database closure (31 December 2024), so follow-up times represent uncensored durations measured from the onset of dysphagia. Survival was assessed using Kaplan–Meier (KM) methods and Cox proportional-hazards regression. Median survival times with 95% confidence intervals (CIs) were estimated from KM curves. Hazard ratios (HRs) with 95% Wald CIs and p-values were obtained from Cox models.

Incidence rates for aspiration pneumonia admissions were calculated as the number of events divided by person-years of observation, with 95% CIs obtained from exact Poisson limits. To compare rates between groups, Poisson regression models were fitted with log person-time as an offset, and incidence rate ratios (IRRs) with 95% Wald CIs and p-values were reported.

For both Cox and Poisson models, age and sex were evaluated as potential confounders. Adjustment was considered meaningful if it changed the effect estimate (HR or IRR) by >10%, in which case adjusted estimates were reported as primary. Additional sensitivity analyses were applied to address outcome-specific residual biases. For survival, an age-range restriction (52–73 years) was applied to mitigate age imbalance between non-PEG and PEG groups. For aspiration outcomes, we produced a stage-matched comparison of late-stage non-PEG versus post-PEG follow-up. Late-stage non-PEG was defined as the final 37.4% of each individual's follow-up (corresponding to the median fraction of observation time to PEG insertion among PEG patients, 0.626).

All analyses were conducted in R (version 4.4.2; R Foundation for Statistical Computing, Vienna, Austria).

Ethics statement

This study was conducted as an observational retrospective analysis using fully anonymised patient data. No ethics approval was required, as per institutional and national guidelines. Patient confidentiality was strictly maintained. No identifiable information was used in data collection, analysis or reporting.

Results

The study sample characteristics are described in Table 1. In the non-PEG group (n=60), the

median age at dysphagia onset was 76.0 years (interquartile range [IQR] 69.2–80.0; range 54.0–95.0). In the PEG group (n=12), the median age was 64.0 years (IQR 60.0–69.5; range 52.0–73.0).

The full breakdown of survival outcomes is presented in Table 2. Median survival from dysphagia onset was 17.4 months (95% CI 14.0–24.9) in non-PEG patients versus 48.8 months (95% CI 44.8–upper limit not reached) in PEG patients. In Cox regression, PEG was associated with a lower risk of death (age/sex-adjusted HR 0.38, 95% CI 0.18–0.81; $p=0.013$). The crude estimate was similar (HR 0.32, 95% CI 0.16–0.65; $p=0.001$), indicating limited confounding by demographics. In a sensitivity analysis restricted to patients aged 52–73 years, the survival benefit of PEG persisted (age/sex-adjusted HR 0.34, 95% CI 0.15–0.81; $p=0.015$). Full KM survival curves are shown in Figure 2. Median time to PEG insertion was 28.3 months, and median survival following PEG insertion was 12 months.

The full breakdown of aspiration pneumonia outcomes is presented in Table 3. In the total cohort, non-PEG patients experienced 34 aspiration pneumonia admissions over 106.3 patient-years (0.32 per patient-year, 95% CI 0.22–0.45), while PEG patients experienced 24 admissions over 46.0 patient-years (0.52 per patient-year, 95% CI 0.34–0.78). The crude IRR was 1.63 (95% CI 0.96–2.74; $p=0.066$), suggesting a higher incidence among PEG patients. After adjustment for age and sex, the IRR attenuated to 1.41 (95% CI 0.74–2.68; $p=0.297$), indicating that demographic confounding accounted for much of the apparent difference.

In the stage-matched analysis, late-stage non-PEG patients had 27 aspiration pneumonia admissions over 39.8 patient-years (0.68 per patient-year, 95% CI 0.45–0.99), while post-PEG patients had 13 admissions over 17.2 patient-years (0.76 per patient-year, 95% CI 0.40–1.29). The crude IRR was 1.12 (95% CI 0.56–2.12; $p=0.744$), suggesting that disease progression also contributed to confounding of aspiration outcomes. After adjustment for age and sex, the IRR increased to 1.40 (95% CI 0.57–3.38; $p=0.452$), closely aligned with the adjusted total cohort estimate. This pattern suggests that while disease progression contributed to confounding, age and sex exerted greater influence on aspiration outcomes.

Discussion

PEG feeding presents a clinically and ethically complex decision. National Institute for Health

and Care Excellence guidance offers general recommendations for the broader population, advising PEG insertion for patients likely to require nutritional support for more than 4 weeks.⁴ International guidelines from the European Society for Clinical Nutrition and Metabolism cover the use of PEG feeding in stroke and amyotrophic lateral sclerosis (ALS).³ However, movement disorders lack robust data on enteral feeding outcomes, further complicating decision making.

The low prevalence of atypical parkinsonian syndromes significantly limits opportunities to conduct research and establish guidelines. While idiopathic Parkinson's disease is a relatively common condition, the prevalence of PSP and CBD is markedly lower, at 6.92 and 3.91 per 100,000 population respectively.⁵ As a result, despite drawing on databases from two tertiary centres dating back to 2009, our sample size remained small. This contributed to considerable heterogeneity in baseline patient characteristics.

In addition to challenges posed by low prevalence, high variability in local clinical practice presents a further obstacle to generating consistent data in this population. In our study, the PEG insertion rate for dysphagic patients was 22.9% (n=11) in the UK compared with just 4.2% (n=1) in New Zealand. Although this reduces the generalisability of our findings, it underscores the need for clearer guidance. The study is limited to just two sites and did not aim to elucidate the many patient and clinician characteristics that influence decision making. However, the observation is consistent with the variability seen in PEG placement for other conditions.

Atypical parkinsonian syndromes represent unique challenges in terms of PEG feeding decision making. Although these conditions share some clinical features with idiopathic PD, their disease trajectories—particularly with respect to dysphagia—differ markedly. Dysphagia typically emerges late in PD, whereas in MSA, PSP and CBD it appears earlier and is often more severe.^{1,6} One retrospective study reported the median latency to dysphagia as 130 months in PD, compared with 67 months in CBD, 64 months in PSP and just 42 months in MSA.⁶ Atypical parkinsonian syndrome patients also experience more rapid functional decline, partly due to poor responsiveness to dopaminergic therapy.¹ Hence, while dysphagia in PD often coincides with late-stage frailty, patients with atypical parkinsonian syndromes may require decision making regarding enteral support earlier in the disease course.

The key finding of this study is the demonstration that life expectancy increased with PEG placement. For patients and physicians wanting mortality data specifically for atypical parkinsonian syndromes this is important. However, limitations should be noted as selection bias, attrition rate and immortal time bias may have had a significant impact.

The retrospective design limited the ability to comprehensively document patient characteristics. While the results remained significant after adjusting for age, a more relevant measure would have been clinical frailty. Patients with rapidly progressive disease or advanced frailty are unlikely to be deemed suitable for PEG insertion. Consequently, survival benefit may have been exaggerated by selection bias, with fitter patients being more likely to receive PEG, and therefore more likely to survive. This is corroborated by clinic documentation showing gastrostomy was not discussed for 70% of the non-PEG group. Cognitive status was also not recorded. This is important given there is strong evidence that PEG insertion is of limited benefit in dementia patients.⁷ Although both frailty and cognition were likely taken into consideration by treating physicians in individual patient discussions, a prospective approach would enable use of a standardised clinical frailty score and cognitive assessment tools.

Beyond selection for PEG insertion, attrition also affected baseline recruitment. A significant drop-off was observed between initial patient identification and final inclusion. This largely reflected the broad clinic codes used in our searches, which captured a wide range of conditions. In the UK, many patients coded as “atypical parkinsonism” were later excluded due to overlap with other diagnoses (e.g., Lewy body dementia, vascular parkinsonism, drug-induced parkinsonism, essential tremor, chorea, myoclonus, normal pressure hydrocephalus). In New Zealand, non-specific codes such as “degenerative disease of basal ganglia” and “extrapyramidal and movement disorder, unspecified” produced similar challenges. Given the diagnostic uncertainty of atypical parkinsonian syndromes, this approach was necessary to avoid missing eligible patients. However, it meant that only a minority had a confirmed diagnosis of MSA, PSP or CBD at death. Very few patients were excluded solely for lack of dysphagia, although the exact number was not recorded.

Alongside selection and attrition, immortal time

bias represents another source of overestimation. Survival in the PEG group was calculated from the onset of dysphagia, therefore patients who survived long enough to undergo PEG insertion contributed a period of guaranteed survival before the intervention. This inherent bias may have artificially inflated the apparent survival benefit associated with PEG, and future prospective studies would require predefined entry points to mitigate these effects.

Kobylecki et al. (2024) conducted a similar UK study of patients with MSA, PSP and CBD, but restricted their cohort to individuals who had been offered PEG insertion.⁸ Outcomes were compared between those who proceeded with PEG and those who declined, with survival measured from the date of recommendation. This design reduced the impact of both selection and immortal time bias. Median survival was 24 months (95% CI 14.9–33.1) in the PEG group and 12 months (95% CI 8.2–15.8) in the non-PEG group. Their findings align with the survival advantage observed in our study, though the smaller effect size likely reflects the reduction in bias.

The second major outcome of this study is that PEG placement did not reduce aspiration pneumonia in atypical parkinsonian syndrome patients. This is consistent with previous research showing that PEG does not necessarily lower aspiration risk,¹ and it is an important consideration when discussing risks and benefits with patients. Several factors may explain this result, including confounding by disease progression, age and sex, as well as the inherent challenges of isolating the influence of PEG insertion on aspiration pneumonia.

With advanced disease progression, aspiration of oropharyngeal secretions (“silent aspiration”) remains a major risk factor even in the absence of oral intake. The stage-matched analysis was intended to mitigate this influence by aligning disease stage between groups. While the unadjusted IRR showed a smaller difference in aspiration risk, adjustment for age and sex yielded an estimate almost identical to the adjusted total cohort. This indicates that age and sex exerted greater confounding influence than disease progression in this study. Given that increasing age and male sex are established risk factors for aspiration, this finding is not unexpected. More broadly, it highlights the difficulty of assessing aspiration outcomes retrospectively, since even basic demographic factors can substantially distort results.

There are further limitations when attempting

to isolate the exact effect of PEG insertion on aspiration risk. Aspiration pneumonia is a difficult outcome to measure, as it relies on clinician judgement rather than objective criteria. The presence of a PEG tube may also bias clinicians towards attributing respiratory infections to aspiration. In addition, some enterally fed patients continue limited oral intake for comfort, further complicating assessment. This study encountered common methodological difficulties in recording aspiration data. We sought to minimise under-ascertainment by including right lower lobe pneumonia in data extraction, but this may have inadvertently captured cases of community-acquired pneumonia. While admission rates are a common method of measuring aspiration, some patients may have had conservative escalation plans, with events managed in the community rather than in hospital.

Overall, these findings suggest that retrospective analyses are limited in their ability to disentangle the influence of PEG on aspiration outcomes. Given the strong effect of basic demographic confounders and the inherent challenges of quantifying and controlling for aspiration, a substantially larger and higher-powered study would have been required to address this question definitively.

A multicentre study by Marois et al. (2017) investigated outcomes following gastrostomy in 32 patients, 78% of whom had an atypical parkinsonian syndrome.⁹ Median post-procedure survival was just 186 days, and aspiration pneumonia was the most frequent complication. Their findings are consistent with our observation that PEG insertion does not prevent aspiration in this population. However, median post-PEG survival in our cohort was substantially higher at 365 days. This variation highlights the need for larger international registries to better characterise the risks, benefits and optimal timing of PEG insertion in atypical parkinsonian syndromes.

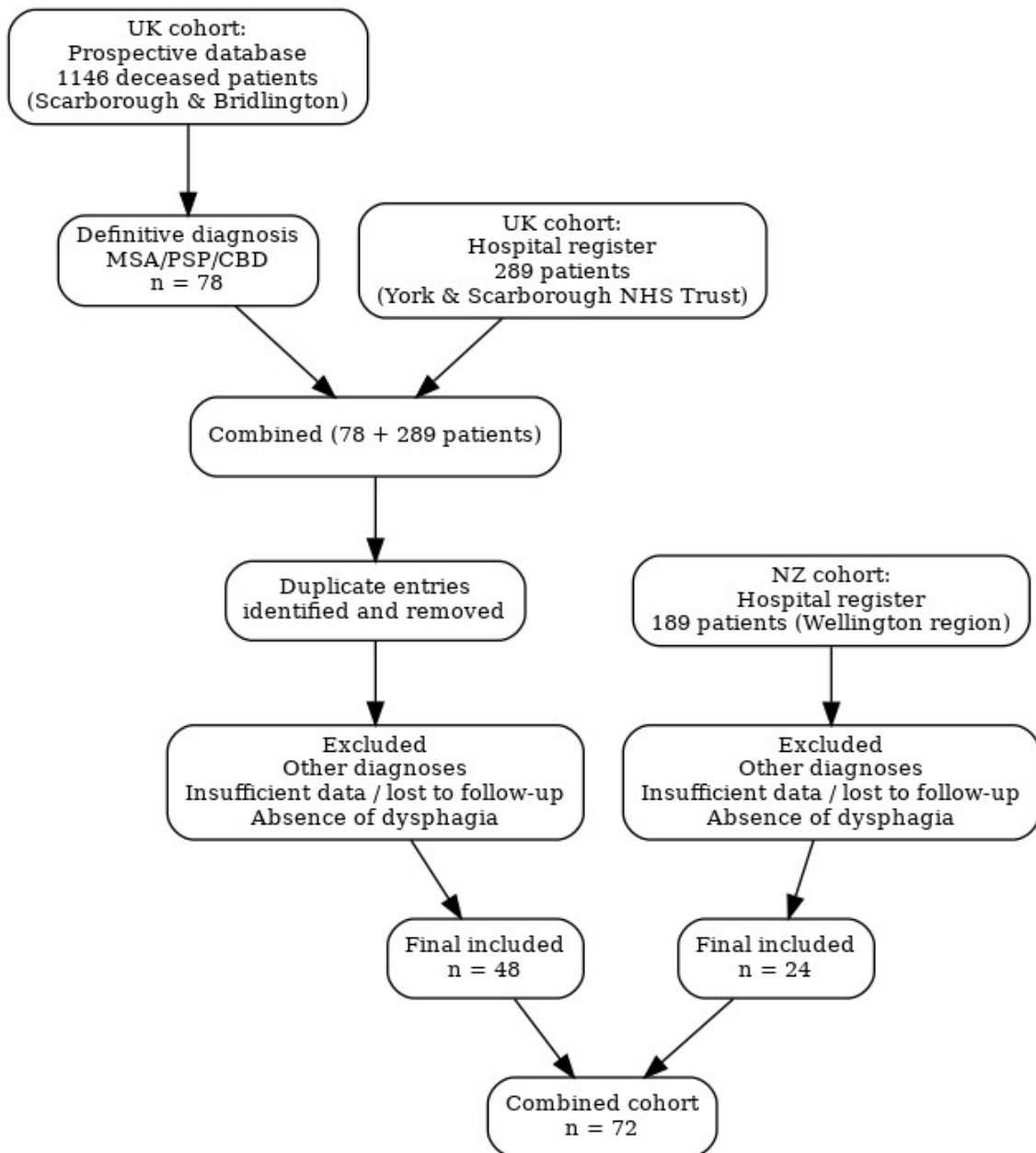
While survival data and aspiration risk can inform PEG decision making, patients and families often focus on other meaningful factors, such as quality of life (QoL) and nutrition. Existing

evidence demonstrates an association between inadequate nutrition and sarcopenia, frailty, fatigue, immunodeficiency, cognitive decline, depression and hospitalisation.¹⁰ Hence, it would be intuitive to expect enteral support to improve QoL.

Given their comparable neurological burden, studies with ALS populations may offer relevant comparators for atypical parkinsonian syndromes. In a small study of 13 ALS patients, Körner et al. (2013) found that 84.6% reported improved QoL, with 76.9% experiencing weight gain or stabilisation.¹¹ In contrast, a qualitative study by van Eenennaam et al. (2023), which explored the lived experiences of 14 ALS patients, found the relationship with PEG feeding to be more nuanced.¹² Some participants were pleased with functional improvements such as weight gain and described relief after PEG insertion alleviated the distress of mealtimes. Others expressed a loss of independence (needing help to manage feeds) and a sense of being altered by the presence of the tube. These views emphasise the importance of individualising care and recognising that clinical benefit does not always align with what patients value most.

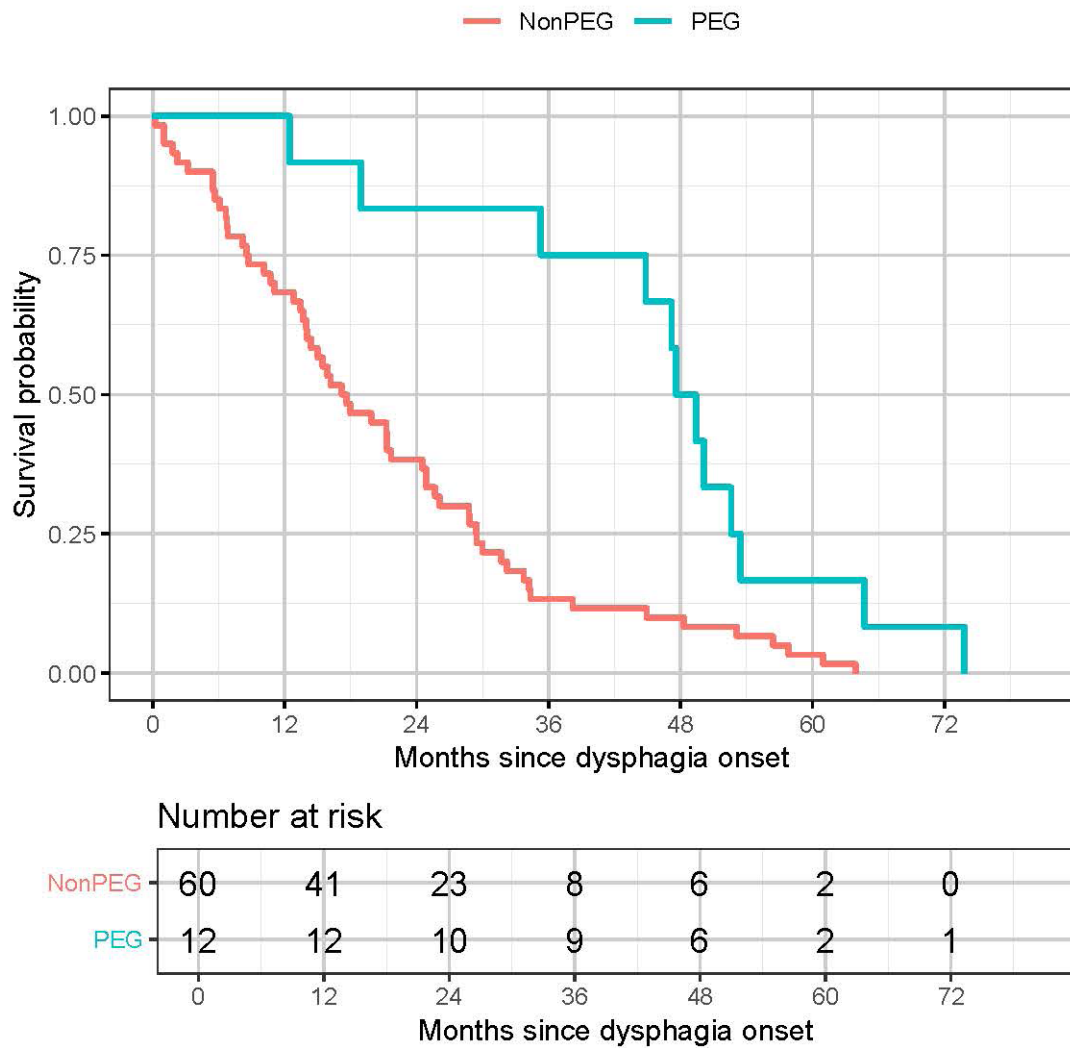
In conclusion, this study represents the first international research examining life expectancy and aspiration risk following PEG placement in a cohort of atypical parkinsonian syndrome patients. The results demonstrate that PEG insertion was associated with improved survival, with a median advantage of 27.4 months. This is broadly consistent with findings from similar populations. However, interpretation must account for substantial heterogeneity and selection bias. While aspiration pneumonia is often a key concern for patients and clinicians, we found no significant difference in hospital admission rates.

Prospective studies are needed to further evaluate the risks and benefits of PEG feeding in atypical parkinsonian syndromes, with particular attention to nutritional outcomes and QoL. Future research in this field will benefit from multicentre collaboration to enable recruitment of larger and more representative cohorts.

Figure 1: Patient selection flow diagram.

Patients identified from United Kingdom (UK) and New Zealand databases were screened for atypical parkinsonian syndromes. After removal of duplicates (UK) and exclusion for alternative diagnoses, insufficient data/lost to follow-up, or absence of dysphagia, 48 UK and 24 New Zealand patients were included, giving a combined cohort of 72.

Figure 2: Kaplan–Meier survival curves comparing percutaneous endoscopic gastrostomy (PEG) and non-PEG patients from the onset of dysphagia.



The red line represents patients who received PEG, while the blue line represents those who did not.

Table 1: Characteristics of patients with and without percutaneous endoscopic gastrostomy (PEG) insertion.

Characteristic	PEG not inserted N/60(%)	PEG inserted N/12(%)
Gender		
Female	18 (30)	3 (25)
Male	42 (70)	9 (75)
Diagnosis		
MSA (multiple system atrophy)	17 (28)	5 (42)
PSP (progressive supranuclear palsy)	31 (52)	6 (50)
CBD (corticobasal degeneration)	12 (20)	1 (8)
Country of residence		
United Kingdom	37 (62)	11 (92)
New Zealand	23 (38)	1 (8)

Patient demographics, diagnoses and country of residence are shown by PEG status. Baseline characteristics, except for age and country of residence, were broadly similar between both groups.

Table 2: Survival analysis (percutaneous endoscopic gastrostomy [PEG] versus non-PEG).

Analysis	Group	N patients	Median survival, months (95% CI)	HR (95% CI, p)	HR sex/age adjusted (95% CI, p)
Total cohort	Non-PEG	60	17.4 (14.0–24.9)	-	-
	PEG	12	48.8 (44.8–NA)	0.32 (0.16–0.65, 0.001)	0.38 (0.18–0.81, 0.013)
Sensitivity (52–73 years)	Non-PEG	25	17.9 (14.4–32.2)	-	-
	PEG	12	48.8 (44.8–NA)	0.39 (0.19–0.83, 0.015)	0.34 (0.15–0.81, 0.015)

95% CI = 95% confidence interval; HR = hazard ratio.

Median survival times and hazard ratios (HRs) from Cox regression are shown for the total cohort and for a sensitivity analysis restricted to patients aged 52–73 years. Both crude and age/sex-adjusted estimates are presented.

Table 3: Aspiration pneumonia outcomes (percutaneous endoscopic gastrostomy [PEG] versus non-PEG).

Analysis	Group	Admissions	Person-years	Rate per PY (95% CI)	IRR (95% CI, p)	IRR sex/age adjusted (95% CI, p)
Total cohort	Non-PEG	34	106.3	0.32 (0.22–0.45)	-	-
	PEG	24	46.0	0.52 (0.34–0.78)	1.63 (0.96–2.74, 0.066)	1.41 (0.74–2.68, 0.297)
Stage-matched	Late-stage non-PEG	27	39.8	0.68 (0.45–0.99)	-	-
	Post-PEG	13	17.2	0.76 (0.40–1.29)	1.12 (0.56–2.12, 0.744)	1.40 (0.57–3.38, 0.452)

PY = person-years; 95% CI = 95% confidence interval; IRR = incidence rate ratio.

Incidence rates and incidence rate ratios are shown for the total cohort and for a stage-matched analysis (late-stage non-PEG versus post-PEG). Both crude and age/sex-adjusted estimates are presented.

COMPETING INTERESTS

EJ received support from Bial Pharma UK for attending the International Movement Disorder Society Conference in Philadelphia, October 2024.

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<https://nzmj.org.nz/journal/vol-139-no-1628/percutaneous-endoscopic-gastrostomy-in-atypical-parkinsonian-syndromes-survival-and-aspiration-outcomes-from-a-retrospective-int>

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