

The Outcomes and Quality of Life in Children with Neurodevelopmental Disabilities with Percutaneous Endoscopic Gastrostomy at Queen Sirikit National Institute of Child Health

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Objective: To evaluate the quality of life (QoL) in children with neurodevelopmental disabilities after percutaneous endoscopic gastrostomy (PEG) insertion consisting of health-related problems and family satisfaction.

Materials and Methods: A cross-sectional descriptive study using a questionnaire survey was conducted. Parents of all patients performed PEG at QSNICH between 2012 and 2019 participated in the questionnaire survey. Data gathering included demographic data, health-related QoL of patients, and family satisfaction.

Results: One hundred nine cases were performed PEG at QSNICH and 60 cases had follow-ups. Of the 39 cases that completed the questionnaire, twenty cases or 51.3% were male. The median age was 103 months with a range of 30 to 178 months. Underweight, stunting, and wasting were found at 46.2%, 38.5%, and 25.6%, respectively. The most common cause of neurodevelopmental disability was spastic cerebral palsy (CP) in 32 cases (82.1%). There was no significant improvement in nutritional status after PEG insertion for six months and three years. The frequency of hospitalization caused by aspiration pneumonia in times per year; decreased significantly, at a median of 1 versus 0.5, $p < 0.001$. Additionally, 84.6% of the families reported that respiratory tract infection was decreased, and family satisfaction was 94.9%.

Conclusion: PEG insertion decreased the number of hospitalization and improved health-related problems and QoL in pediatric neurodevelopmental patients.

Keywords: Percutaneous endoscopic gastrostomy; Quality of life; Neurodevelopmental

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Children with neurodevelopmental disabilities such as spastic cerebral palsy (CP) have multiple gastrointestinal problems including oropharyngeal dysfunction, gastroesophageal reflux disease (GERD), and dysmotility of the gastrointestinal tract⁽¹⁾. Furthermore, malnutrition, and respiratory problems such as recurrent/chronic respiratory tract infections, also increase the risk of morbidity and mortality in

these children⁽²⁾. Tube feeding can prevent the risk of aspiration from oromotor dysfunction and optimize nutritional status and growth. The European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) working group recommended using a gastrostomy as the preferred way to provide intragastric access for long-term tube feeding in children with neurological impairment⁽³⁾.

Percutaneous endoscopic gastrostomy (PEG) is safe and widely accepted as a standard method to provide enteral nutrition for neurodevelopmental disabilities children. The authors' institute is a tertiary hospital, taking care of these patients with feeding problems resulting from underlying neurodevelopmental disability, with PEG insertion with the Pull technique that since 2005. The advantages of gastrostomy tube insertion over nasogastric (NG) tube placement are decreased tube displacement, reduced risk of aspiration, safer and more reliable enteral access, and optimized

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development of oral skills⁽⁴⁾.

Studies have evaluated the health-related quality of life (QoL) and satisfaction of caregivers after performing PEG. They revealed both positive and negative outcomes.

Multiple factors such as social values, beliefs, and socioeconomic status affect QoL and parental satisfaction. The goal of the present study was to evaluate the QoL of children with neurodevelopmental disabilities after PEG insertion including health-related problems and the satisfaction of their family.

Materials and Methods

The present study was a cross-sectional descriptive study. The inclusion criteria were children with neurodevelopmental disabilities that underwent PEG at the Queen Sirikit National Institute of Child Health (QSNICH) between 2012 and 2019. Parents who attended the gastrointestinal clinic at QSNICH between 2020 and 2021 were invited to participate in the questionnaire.

The case record form had two parts, the first part was data from outpatient medical records that included clinical data, weight, length, and frequency of hospitalization before and after PEG. In this part, the investigators filled all the data, with the aim to assess the aspect of health-related problems. The second part was a questionnaire about health-related QoL of patients and the satisfaction of the parents by having them use rating scores. The questionnaire was created by the researchers and presented a set of questions to parents of the patients with PEG insertion during admission from any cause. Data gathering from these parents was reviewed and developed into a questionnaire by three pediatric gastroenterologists at QSNICH. After developing the questionnaire, the authors validated it by asking five parents to read and try out the questionnaire, which all of them completely understood. The Linkert rating scale was used to evaluate satisfaction.

The children's nutritional status was assessed by inputting data from the World Health Organization (WHO) 2006 growth reference chart into INMU-NutriStat for children version 1.00 which is a program developed by the Institute of Nutrition, Mahidol University⁽⁵⁾. According to the WHO reference, the authors defined the nutritional status as follows:

1. Stunting: height-for-age Z score (HAZ) less than $-2SD$
2. Underweight: weight-for-age Z score (WAZ) less than $-2SD$
3. Wasting: weight-for-height Z score (WHZ)

less than $-2SD$

4. Overweight: WHZ more than $+2SD$

The standard protocol of PEG insertion in the present study hospital was a preoperative cefazolin prophylaxis and then followed by a postoperative for 24 hours, where the standard sterile, pull-through technique was employed. All patients received the routine postoperative betadine dressings. Oral rehydration solution (ORS) WHO formula was implemented four to six hours post-PEG insertion. Formula feeding was employed the next day. All the parents received a booklet and model demonstration that included information about caring, complications, feeding techniques, and gastrostomy tube replacement techniques before the patients were discharged.

The present project was approved by the Research Ethics Committee of QSNICH (REC 131/2563). The statistical analysis was performed by using SPSS Statistics, version 16.0 (SPSS Inc., Chicago, IL, USA). The categorical data were presented as frequency and percentage, and the continuous data were presented as median and interquartile range (IQR) values. Due to non-normal distribution of data, a non-parametric test, Wilcoxon-signed rank test was used to compare before and after PEG insertion. The p-values lower than 0.05 were considered statistically significant.

Results

One hundred nine cases of PEG were performed during the period of the study and 60 patients had been followed up at QSNICH during the COVID-19 era. Only 39 cases gave consents and fully completed the questionnaire. Among the 39 cases, 20 (51.3%) were male and 19 (48.7%) were female. The median age was 103 months with a range of 30 to 178 months old. Median WAZ, HAZ, and WHZ were -1.88 , -2.10 , and -1.72 , respectively. Underweight, stunting, and wasting were found at 46.2%, 38.5%, and 25.6%, respectively. The median duration of NG tube feeding was 12 months with a range of 1 to 68 months. Delayed PEG insertions were a result of parents needing more than one month to consider the treatment option, which accounted for 48.72% of the cases. Followed by the medical team not being properly informed accounted for 35.90% of the cases. Lastly, delayed referral accounted for 15.38% of cases. Spastic CP with epilepsy was the most common neurodevelopmental disorder found in 32 patients (82.1%). Other causes were chromosome abnormalities and genetic disorders. Nineteen patients

Table 1. Patients and parents' characteristic data

	n (%)	Median (min-max)	IQR
Patients characteristic data			
Male	20 (51.3)		
Age (month)		103 (30 to 178)	46
Duration of NG tube feeding (month)		12 (1 to 68)	20
Duration of hospitalization during PEG procedure (day)		6 (4 to 22)	6
Duration of PEG tube feeding (month)		33 (2 to 106)	35
Neurodevelopmental disease			
• Spastic CP with epilepsy	32 (82.1)		
• Down syndrome	3 (7.7)		
• Trisomy 13	1 (2.6)		
• Pseudotrismy 13	1 (2.6)		
• Aicardi syndrome	1 (2.6)		
• AADC deficiency	1 (2.6)		
Associated pulmonary disease			
• Tracheostomy tube	7 (17.9)		
• Recurrent pneumonia	5 (12.8)		
• Pharyngo/laryngo/tracheomalacia	4 (10.3)		
• Chronic lung disease	3 (7.7)		
Gastroesophageal reflux disease from 24-hour pH-impedance	6 (15.4)		
Indication for tube feeding from UGIS			
• Nasopharyngeal incoordination	24 (61.5)		
• Swallowing dysfunction	14 (35.9)		
• Tracheal aspiration	1 (2.6)		
Weight-for-age Z score (WAZ)	39	-1.88 (-8.56 to 1.59)	1.36
• WAZ < -2SD (underweight)	18 (46.2)		
Height-for-age Z score (HAZ)	28	-2.10 (-20.81 to 1.88)	2.24
• HAZ < -2SD (stunting)	15 (38.5)		
Weight for height Z score (WHZ)	28	-1.72 (-3.89 to 3.16)	2.18
• WHZ < -2SD (wasting)	10 (25.6)		
• WHZ > 2SD (overweight or obesity)	3 (7.7)		
Parents characteristic data			
Main responsible person			
• Father/mother	32 (82.1)		
• Grandfather/grandmother	5 (12.8)		
• Others	2 (5.1)		
Education of caregiver			
• High school	30 (76.9)		
• Undergraduate	9 (23.1)		
Income of family/month (THB)			
• No income	1 (2.6)		
• <5,000	1 (2.6)		
• 5,000 to 10,000	10 (25.6)		
• 10,000 to 15,000	11 (28.2)		
• 15,000 to 20,000	10 (25.6)		
• >20,000	6 (15.4)		
Parents can replace gastrostomy tubes by themself			
• Yes	36 (92.3)		
• No	3 (7.7)		

AADC=aromatic L-amino acid decarboxylase deficiency; CP=cerebral palsy; IQR=interquartile range; NG=nasogastric; PEG=percutaneous endoscopic gastrostomy; UGIS=upper gastrointestinal studies

Table 2. Early and late complications of percutaneous endoscopic gastrostomy

Complications	No. cases (39); n (%)
Early (within 14 days)	
No complication	21 (53.8)
Infected wound	4 (10.3)
Hypersecretion	1 (2.6)
Pneumonia	11 (28.2)
Others	2 (5.1)
Late (more than 14 days)	
No complication	14 (35.9)
Infected wound	8 (20.5)
Tube obstruction	9 (23.1)
Granulation	6 (15.4)
Buried bumper	1 (2.6)
Others	1 (2.6)

had pulmonary-associated disease with chronic respiratory problems, while seven remaining had tracheostomy tubes. GERD deduced by 24-hour pH Impedance was found in six patients (15.4%). Upper gastrointestinal studies (UGIS) were performed in all patients before PEG insertion. Swallowing problems were defined by the UGIS result. Nasopharyngeal incoordination is a nasal regurgitation of barium as a result of incoordination of pharyngeal contractions or insufficient closure of the nasopharyngeal area. Swallowing dysfunction is an abnormal oral phase of swallowing due to poor sucking reflex or pooling of barium in the pharynx due to delay or difficulty to swallow. Tracheal aspiration was also employed while barium was aspirated into the trachea during UGIS. Nasopharyngeal incoordination was the main indication in 24 patients (61.5%). The patient's and parents' characteristic details are shown in Table 1.

Early complications within 14 days after PEG placement, were respiratory problems found in 12 cases (30.8%), while the major late complication was gastrostomy tube obstruction found in nine cases (23.1%) (Table 2).

The key person who took responsibility was the father or mother accounting for 82.1%. Ninety-two-point-three percent of parents were able to replace the gastrostomy tube by themselves. Regarding their education, thirty parents (76.9%) graduated from high school, most of them earned an income less than 20,000 THB per month (84.6%), or approximately 667 US dollars. Eighty-four percent of parents got information at least 80% to 100% before having their child undergo PEG, and 35.9% immediately decided on the treatment. When compared with NG,

Table 3. Satisfaction of gastrostomy tube when compared with NG tube feeding

When compared with NG tube feeding	n (%)
Gastrostomy tube feeding technique	
Easier	33 (84.6)
Comparable	5 (12.8)
More difficult	1 (2.6)
Expenses of gastrostomy tube caring	
Cheaper	8 (20.5)
Comparable	12 (30.8)
More expensive	18 (46.2)
Missing data	1 (2.6)
Changing gastrostomy tube	
Easier	37 (94.9)
Comparable	1 (2.6)
More difficult	1 (2.6)
Respiratory tract infection	
Decreased	33 (84.6)
As before	5 (12.8)
Increased	1 (2.6)
Respiratory tract secretion	
Decreased	19 (48.7)
As before	19 (48.7)
Increased	1 (2.6)
Easy to physical therapy	
Easier	17 (43.6)
As before	15 (38.5)
More difficult	7 (17.9)
Accidental pull gastrostomy tube	
Never	17 (43.6)
Decreased	16 (41.0)
Comparable	5 (12.8)
Increased	1 (2.6)
Frequency of hospitalization	
Decreased	34 (87.2)
As before	4 (10.3)
Increased	1 (2.6)

NG=nasogastric

gastrostomy tube feeding technique and replacement were easier.

After PEG insertion, patients had significantly decreased frequency of hospitalization caused by aspiration pneumonia, counted by the number of times per year, to median 1 and a range of 0 to 5 (IQR 1) versus 0.5 with a range of 0 to 3 (IQR 1) ($p < 0.001$). Parents also reported lower percentage of respiratory tract infection, secretion, and frequency of admission by 84.6%, 48.7%, and 87.2%, respectively (Table 3).

According to the Likert rating scale, 94.9% of parents reported satisfaction in the overall aspect

Table 4. Satisfaction of parents after gastrostomy tube insertion

Rate satisfaction	1 : Worst n (%)	2: Unsatisfied n (%)	3: Fair n (%)	4: Satisfied n (%)	5: Very satisfied n (%)	Likert rating scale mean±SD
Overall satisfaction	0 (0.0)	0 (0.0)	2 (5.1)	6 (15.4)	31 (79.5)	4.74±0.55
Ease of gastrostomy tube care	0 (0.0)	0 (0.0)	11 (28.2)	6 (15.4)	22 (56.4)	4.28±0.89
Call for help from GI doctors and nurses team	0 (0.0)	0 (0.0)	0 (0.0)	8 (20.5)	31 (79.5)	4.79±0.41
Improving nutritional status after PEG performing	0 (0.0)	0 (0.0)	0 (0.0)	7 (17.9)	32 (82.1)	4.82±0.39
Overall quality of life of patient and caregivers	0 (0.0)	0 (0.0)	2 (5.1)	9 (23.1)	28 (71.8)	4.67±0.58
Satisfaction of doctor	0 (0.0)	0 (0.0)	0 (0.0)	3 (7.7)	36 (92.3)	4.92±0.27
Satisfaction of nurse	0 (0.0)	0 (0.0)	0 (0.0)	5 (12.8)	34 (87.2)	4.87±0.34
Get information about gastrostomy tube caring	0 (0.0)	0 (0.0)	0 (0.0)	6 (15.4)	33 (84.6)	4.85±0.37

PEG=percutaneous endoscopic gastrostomy; SD=standard deviation

Likert rating scale: 4.51 to 5.00 very satisfied, 3.51 to 4.50 satisfied, 2.15 to 3.50 fair, 1.51 to 2.50 unsatisfied, 1 to 1.50 worst

Table 5. Comparison of nutritional status of patients before and after PEG insertion at 6 months and 3 years

Z score (n)	Before PEG insertion		After PEG insertion for 6 months			After PEG insertion for 3 years		
	Median (min-max)	IQR	Median (min-max)	IQR	p-value*	Median (min-max)	IQR	p-value#
WAZ (39)	-1.88 (-8.56 to 1.59)	1.36	-1.73 (-8.33 to 1.18)	1.78	0.41	-1.96 (-3.25 to 0.46)	1.64	0.76
HAZ (28)	-2.10 (-20.81 to 1.88)	2.24	-2.64 (-23.52 to -0.20)	3.94	0.22	-1.93 (-2.23 to -0.79)	1.13	0.07
WHZ (28)	-1.72 (-3.89 to 3.16)	2.18	-0.15 (-2.69 to 4.21)	3.65	0.31	0.13 (-2.80 to 2.26)	4.03	0.27

HAZ=height-for-age Z score; WAZ=weight-for-age Z score; WHZ=weight-for-height Z score; PEG=percutaneous endoscopic gastrostomy; IQR=interquartile range

* Comparison between before PEG and after PEG insertion for 6 months, # Comparison between before PEG and after PEG insertion for 3 years

after PEG insertion. Seventy-one-point-eight percent of parents felt it was convenient to take care of the gastrostomy tube. It had been shown that parents were able to manage PEG problems and satisfied doctors and nurses as they were informed with sufficient information to take care of their kids. In addition, 95% of parents stated that overall QoL had been improved. Seven out of eight topics of satisfaction after PEG insertion showed more than 4.51 in the Likert rating scale, which meant very satisfied (Table 4).

Table 5 shows a comparison of the nutritional status of the patients before and after PEG insertion at six months and three years. There was no significant improvement in WAZ, HAZ, and WHZ.

Discussion

The present study was a cross-sectional descriptive study in neurodevelopmental disability children that underwent PEG at QSNICH between 2012 and 2019. The present study describes the clinical data of 39 neurodevelopmental disability patients that underwent PEG. The predominant indication for PEG is CP in 82.1%, which is higher than the studies of Townsend et al.⁽⁶⁾ at 41% and Alsaggaf et al.⁽⁷⁾ at 77%. The median duration of NG tube feeding before PEG was 12 months with a range

of 1 to 68 months (IQR 20). This finding is longer than the recent guideline from ESPGHAN 2021 that states that PEG is indicated when non-oral nutritional support is anticipated to be required for a period of longer than three to six weeks or when trans-nasal tube feeding is unsafe. One of the causes of delayed insertion of a gastrostomy tube were that 48.7% of the parents usually need more than a month to consider the procedure, followed by the medical team not being properly informed, and delayed referral. Early complication within 14 days after PEG insertion in the present study was pneumonia at 28.2%, followed by an infected wound at 10.3%. When identifying the postoperative pneumonia group, which was 11 cases, the authors found 81.8% had no tracheostomy tube, 45.5% were underweight, 71.4% were stunted, and 42.9% were wasting. These may imply that if a patient had no tracheostomy tube, they may not be able to clear secretions after the PEG procedure under general anesthesia, resulting in accumulation of secretion in CP patients. Poor nutritional status may affect the immune system and cause pneumonia. Although preoperative antibiotic prophylaxis, cefazolin was administered to all patients before PEG, and continued postoperatively for 24 hours, standard sterile, pull-through technique, and all patients

received the routine postoperative betadine-dressings after the insertion, patients still had infected wound defined as peristomal skin redness or discharge from gastrostomy up to 10.3%, which similar to 12.1% of Duarte et al. study⁽⁸⁾. All of these patients received intravenous cloxacillin and gentamicin, which treat the skin infections successfully.

After PEG, 30.8% of the patients had co-respiratory problems and 46.2% were underweight, which led to a prolonged course of hospitalization by median six days with a range of four to 22 days, compared to three days of Fortunato et al. study⁽⁹⁾. Late complications were tube obstruction in 23.1%, infected wound in 20.5%, and granulation tissue in 15.4%, compared to Goldberg et al. in 2009⁽¹⁰⁾ where these were seen more prevalent in granulation tissue at 68%. Thirty to thirty-two percent^(11,12) of patients had minor complications such as granuloma, local skin infection, and leakage.

Parents reported that PEG was easier than NG tube in terms of feeding technique at 84.6% and tube replacement at 94.9%. It also diminished the rate of respiratory tract infection at 84.6% and the number of hospitalizations at 87.2%. However, the drawback was the gastrostomy tube was 46.2% more expensive compared to NG tube. The frequency of admission times per year decreased from median 1 with a range of 0 to 5 (IQR 1) to 0.5 with a range of 0 to 3 (IQR 1) times per year ($p < 0.001$). The finding is similar to that of Sullivan et al. study⁽¹³⁾ that showed a significant decrease in the number of admissions from 0.5 to 0.09 times per year.

Before PEG insertion, 46.2% of patients were underweight. There is no significant improvement in the nutritional status of the patient after PEG insertion at six months and three years. Studies by Civan et al.⁽¹⁴⁾, Franco Neto et al.⁽¹⁵⁾, and Park et al.⁽¹⁶⁾ found that there was a significant improvement in both height, weight, and BMI after PEG. Di Leo et al.⁽¹⁷⁾ found that 64.4% of patients had a progressive improvement in %WA, so if the patient had a negative deviation of body weight, and height Z-score, early placement of gastrostomy tube feeding should be considered⁽¹⁸⁾. The nutrition status of patients in the present study did not improve after PEG insertion could be attributed to low-income families. Data from the National Statistical Office, Ministry of Digital Economy and Society in 2021 found that the mean income for families was 28,454 THB per month or about 950 US dollars, while only 15.4% of families in the present study had income of more than 20,000 THB per month. This is a probable reason as to why

the quality of feeding in the present study patients caused a negative effect on their nutritional status.

In the present study, 95% of parents reported an increase in overall satisfaction and QoL, similar to the study of Sumritsopak et al.⁽¹⁹⁾, which was done in Thailand. Therefore, it can be assumed that the baseline culture, belief, and socioeconomic background would share many similarities. The study demonstrated that 88% of children and parents had improved QoL. In contrast, the study by Franken et al.⁽²⁰⁾ found that health-related QoL in neurological impaired children after gastrostomy was significantly lower than in neurologically normal children.

A limitation of the present study is that while 60 cases have been followed up at QSNICH during the COVID-19 era, only 39 cases consented and fully completed the questionnaire, so the results must be interpreted with caution because of the small sample sizes and inadequate power to detect the differences. An additional limitation is recall bias from parents about subjective data such as frequency of hospitalization. In the present study, the authors did not use a standard structured questionnaire (such as SAGA-8) that had adequate internal consistency and appropriate sensibility. A new questionnaire should be created to get more information about outcomes and QoL.

Conclusion

PEG is an effective option to enhance the QoL for both children with neurodevelopmental disabilities and their parents. It also decreased the frequency of hospitalization.

What is already known on this topic?

Most children with neurodevelopmental disabilities have oropharyngeal incoordination leading to respiratory complications and malnutrition. Gastrostomy tube feeding is a standard recommendation for long-term tube feeding in this group of patients.

What this study adds?

Long-term gastrostomy tube feeding in children with neurodevelopmental disabilities decreases the frequency of hospitalization and improves their QoL.

Conflicts of interest

The authors declare no conflict of interest.

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