



# Percutaneous Endoscopic Gastrostomy in Children: Caregivers' Perspectives

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We aimed to study caregivers' perspectives on percutaneous endoscopic gastrostomy (PEG). We interviewed the caregivers of 33 children who were fed via PEG and that, of these caregivers, those who believed that they received adequate information prior to and after PEG insertion had a better quality of life. Furthermore, 65% would proceed for an earlier PEG insertion which was associated with several factors including lower educational level, lower household income, and longer traveling time from their residence to our institution. Data from our study may help improve understanding caregivers' perspectives and concerns in children who already or will have PEG.

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GASTROSTOMY TUBE FEEDING is an alternative method of enteral feeding which is performed in patients who are unable to tolerate an appropriate oral intake, or safely feed self orally.

Percutaneous endoscopic gastrostomy (PEG), as compared to a traditional open surgical gastrostomy, is a less invasive surgical procedure that requires a shorter hospital stay and enables a faster recovery. Advantages of gastrostomy tube feeding include improved nutritional status, improved quality of life (QoL) not only in the child but also in the caregiver and family (Sullivan, Juszczak, Bachlet, et al., 2004). However, some caregivers may still hesitate to proceed with PEG even after providing information regarding advantages and disadvantages of the procedure (Craig, Scambler, & Spitz, 2003; Guerriere, McKeever, Llewellyn-Thomas, et al., 2003). A prior study found that caregivers would make an earlier decision to proceed with PEG insertion if they understand that gastrostomy tube feeding would be clearly beneficial for their child (Martinez-Costa, Borraz, Benlloch, et al., 2011).

Our team consists of pediatric gastroenterologists, registered nurses, and home health care specialists. We provide information and answered questions regarding PEG prior to the procedure and give advice on feeding tube management, enteral feeding, and potential tube complications after the PEG insertion on an individual basis. We also provide pamphlets prior to a discharge from the hospital and contact information in case that further concerns and questions are raised. However, studies on caregivers' satisfaction and perspectives on PEG are limited in children residing in developing countries. Most studies have been performed in industrialized countries, hence the results maybe different due to diverse socioeconomic status and cultural backgrounds. We aimed to study 1) caregiver's satisfaction and opinions before PEG including barriers to proceed with the procedure and 2) caregiver's satisfaction and opinions after PEG including postoperative complications.

## Methods

We included children who underwent PEG insertion between January 2010 and December 2012 (3-year period) and still remained on gastrostomy tube feeding at a tertiary and referral center. Caregiver of the child was interviewed

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via telephone or during follow-up visits in the pediatric gastroenterology outpatient setting with a 37-item questionnaire. The questionnaire included demographic and baseline information (i.e., gender, child's and caregiver's age, caregiver's education level, household incomes, location of residence, travelling time from the caregiver's residence to our institution), child's underlying disease, satisfactions and opinions before and after the PEG insertion up to the interview date. We also gathered information regarding postoperative complications. The interview process lasted for approximately 30 minutes. Agreements were graded on a 5-level scale (5: mostly satisfied or strongly agreed, and 1: least satisfied or strongly disagreed). Before the formal data collection, we cross-checked the questionnaire with ten caregivers by two independent investigators (RS, NB), and the responses matched more than 90%. The study was approved by the ethics committee at our institution.

We performed all analyses using SPSS version 18 for Windows. Data were expressed as mean (standard deviation), median (interquartile range [IQR]), and proportions. Comparisons of discrete variables across different groups (using mostly satisfied or strongly agreed [level 5] compared to other levels [level 1–4]) were assessed using chi-square test or Fisher exact test. A two-tailed  $p$  less than .05 was considered statistically significant.

## Results

During the 3-year period, we performed PEG in 59 children, but 26 children were excluded from the study for various reasons (PEG was removed due to improved clinical status [ $n = 12$ ], death due to the child's underlying disease [ $n = 8$ ], institutionalized children [ $n = 4$ ], and unable to reach [ $n = 2$ ]). Therefore, we interviewed the caregivers of 33 children who were fed via gastrostomy tube feeding. Most (76%) caregivers were mothers, 39% aged less than 35 years upon the calendar year, and 55% lived in the country's capital. Approximately one-third had household incomes less than the national average. Traveling time from the caregiver's residence to our institution was approximately 1 hour for caregivers residing in the country's capital, and almost 5 hours for caregivers residing in other provinces. Demographic data and baseline information are shown in Table 1. Median child's age was 2.4 years (IQR, 0.9–5.2), and duration from the PEG insertion to the interview date was 1.6 years (IQR, 1.2–2.8). Main indications for PEG include cerebral palsy ( $n = 10$ ), other neurologic disorders ( $n = 13$ ), genetic disorders ( $n = 5$ ) [maple syrup urine disease [2], Prader–Willi syndrome [1], Apert's syndrome [1], Rubinstein–Taybi syndrome [1]], pinealoblastoma ( $n = 2$ ).

### Before PEG and Caregiver's Concerns

Pre-gastrostomy data were available in 31 patients (94%) because two children were not currently living with the

**Table 1** Demographic data of the 33 study children who underwent percutaneous endoscopic gastrostomy.

Characteristic	Results
Primary caregiver	
Mother (n, %)	25 (76)
Father (n, %)	5 (15)
Other (n, %)	3 (9)
Age of the primary caregiver (years)	38 ± 9 (range 18–65)
<35 years (n, %)	13 (39)
Highest education: less than vocational level (n, %)	18 (55)
Household income: below national average (n, %)	11 (33)
Residing in the capitol (n, %)	18 (55)
Traveling time from the residence to hospital (minutes)	180 ± 186 (range 30–780)
Residing in the capital	58 ± 24 (range 30–90)
Residing in the provinces	281 ± 201 (range 30–780)

caregiver who initially made the decision to proceed for PEG. Table 2 demonstrated data regarding opinions before PEG insertion. Most caregivers ( $n = 28$ , 90%) strongly/somewhat agreed that they received adequate information, though 12 caregivers (39%) still had a difficult time making a final decision to undergo PEG insertion. The most concerned reason was the child's pain ( $n = 17$ , 55%). Moreover, 20 caregivers (65%) would proceed for an earlier PEG insertion.

### After PEG and Complications

Again, more than 90% strongly/somewhat agreed that they received adequate information after the procedure ( $n = 30$ ), felt comfortable cleaning the gastrostomy wound site ( $n = 32$ ), mostly/somewhat satisfied with improved nutritional status ( $n = 31$ ) and overall health ( $n = 30$ ) of their child, while caregivers less than 80% strongly/somewhat agreed that they spent less time on feeding via PEG when compared to the pre-PEG period ( $n = 24$ ) (Table 3). Caregivers agreed that granulation tissue was most frequently observed ( $n = 7$ , 21%). Redness around the PEG site was not frequently observed ( $n = 2$ , 6% strongly/somewhat agreed) but seemed to be of their concern (Table 4).

### Associations Between Variables

Several significant associations (comparing mostly satisfied or strongly agreed [level 5] vs. other levels [level 1–4]) between variables were found, as shown in Table 5. We found that younger caregivers (aged less than 35 years) were more likely to worry about the child's pain as compared to the older individuals. Postoperatively, improved child's overall health was associated with improved child's QoL and improved family's QoL, while improved caregiver's QoL was associated with satisfaction with the received

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