

# Percutaneous endoscopic gastrostomy tube placement in children with neurodevelopmental disabilities

## Parents' perspectives

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### ABSTRACT

**الأهداف:** دراسة انطباعات وآراء أهالي هؤلاء الأطفال بخصوص عملية تركيب واستخدام أنبوب التغذية عن طريق المنظار والعوامل المؤدية الى الانطباعات السلبية.

**الطريقة:** تم إدراج 30 عائلة بطريقة مرجعية من خلال مراجعات وحدة المناظير بمستشفى جامعة الملك عبد العزيز الجامعي، جدة، المملكة العربية السعودية خلال الفترة من 15 يناير إلى 15 يوليو لعام 2012م. وقد تم إعداد استبانة متضمنة 25 سؤالاً لتقييم انطباعات وخبرة الوالدين بخصوص عملية تركيب واستخدام أنبوب التغذية عن طريق المنظار.

**النتائج:** تراوحت أعمار الأطفال المدرجين بين 3-19 عام (معدل 10.2) وكان معظمهم (77%) يعانون من شلل دماغي شديد. وقد تمت عملية تركيب أنبوب التغذية عن طريق المنظار منذ 2-144 شهراً (معدل 39) قبل بدء هذه الدراسة. وقد ذكر 43% من الوالدين فقط أن لديهم معلومات كافية عن العملية ومعظمهم (73%) كان لديهم تحفظات وتخوف منها نتج عنها تأخير في إجرائها ( $p=0.016$ ). وبعد إجراء العملية وجد معظمهم (67%) أن الخبرة كانت أفضل مما توقعوا وقد ارتبط ذلك بنسبة معلوماتهم السابقة عن العملية ( $p=0.03$ ). وقد أحس معظم الوالدين (80%) بالندم على عدم إجراء هذه العملية منذ وقت مبكر مما ارتبط أيضاً بنسبة معلوماتهم السابقة عن العملية ( $p=0.008$ ).

**خاتمة:** معظم أهالي الأطفال لم يتم إعلامهم وتثقيفهم جيداً عن عملية تركيب أنبوب التغذية عن طريق المنظار ومعظمهم اعتبروا أن خبرتهم كانت أفضل مما توقعوا وبالتالي ندموا على عدم إجراء هذه العملية منذ وقت مبكر.

**Objectives:** To study the attitudes of parents toward percutaneous endoscopic gastrostomy (PEG) tube placement and identify contributing factors to their negative attitudes.

**Methods:** Thirty consecutive parents were included retrospectively through a single endoscopy unit at the King Abdulaziz University Hospital, Jeddah, Kingdom of Saudi Arabia from January to July 2012. A structured 25-item questionnaire was designed to examine their demographics, attitudes, and experience with the PEG procedure.

**Results:** Patients' ages were 3-19 years (mean: 10.2), mostly with severe cerebral palsy (77%). Their PEG tubes were inserted 2-144 months (mean: 39) prior to the encounter. Only 43% of the parents felt informed and most (73%) had negative attitudes toward the procedure, which was associated with significant delays ( $p=0.016$ ). After the procedure, most parents (67%) reported a better-than-expected experience, which was associated with their information levels ( $p=0.03$ ). Most parents (80%) regretted not having the PEG tube placed earlier. This depended on their information level, as those who were not informed were more likely to have strong regrets when compared to those informed (82% versus 42%,  $p=0.008$ ).

**Conclusion:** Most parents are not well-informed regarding the PEG procedure, which affects their expectations and experiences. Most parents found the experience better than what they expected and regretted not having carried it out earlier.

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Children with severe cerebral palsy and other chronic neurodevelopmental disabilities often have serious feeding problems as a result of swallowing dysfunction and dysmotility.<sup>1,2</sup> This frequently results in recurrent aspiration, chronic malnutrition, and growth failure. Tube feeding is, therefore, a common intervention to permit safe delivery of nutrition.<sup>3</sup> Longer term gastrostomy feeding has been used successfully to alleviate the distress and frustration associated with feeding and constitutes a patient-friendly alternative to the nasogastric tube.<sup>4</sup> Percutaneous endoscopic gastrostomy (PEG) is widely used for this purpose and seem to be associated with a lesser complication rate when compared to surgical gastrostomy.<sup>5,6</sup> Studies have documented that PEG feeding has a positive impact on growth of neuro developmentally disabled children, and on the quality of life of both children and their parents.<sup>7,8</sup> The frequency of vomiting and recurrent chest infections decreased and the general nutritional condition improved. The parents of neurologically disabled children are often faced with the decision of having their child undergo PEG tube placement. They frequently resist the idea and have difficulties in making the decision resulting in significant delays.<sup>9</sup> There are often differences in the perceptions between parents and healthcare professionals throughout the decision making process and in the provision of subsequent care.<sup>10</sup> Parent's attitudes toward the placement of PEG tube in children with neurodevelopmental disabilities have received limited study in Saudi Arabia. Parents in our region may have unsubstantiated misconceptions and apprehensions regarding this procedure. Contributing factors to negative attitudes could result from personal, socioeconomic, and educational factors. Our objectives are to study the attitudes of parents of children with neurodevelopmental disabilities toward PEG tube placement and identify possible contributing factors to their negative attitudes. We also aim to examine their experiences and impressions after PEG tube placement.

**Methods.** Thirty consecutive parents were included retrospectively through the pediatric gastroenterology and neurology referrals to the Endoscopy Unit of King Abdulaziz University Hospital, Jeddah, Kingdom of Saudi Arabia. The study sample was collected from

15 January 2012 until 15 July 2012. Only families of children with chronic neurodevelopmental disabilities, such as cerebral palsy, were included. Children with life threatening, progressive, or terminal disorders were excluded. Children admitted for PEG re-insertion were excluded, as well. All procedures were performed by one certified pediatric gastroenterologist. Chart review was conducted to collect disease related variables. A structured 25-item questionnaire was designed to examine the parents' demographics and attitudes toward PEG placement and study the contributing factors to their negative attitudes. Likert scale items were used to assess their prior knowledge and attitudes, and subsequent experience and impressions after the procedure. The study design and questionnaire were approved by King Abdulaziz University Hospital Ethics Committee. An assigned coauthor conducted all the interviews after obtaining informed consent, and individually assisted both parents to complete the questionnaire with follow-up phone interviews.

The data were collected in Excel sheets and statistical analysis was performed using Statistical Package for Social Sciences version 17 (SPSS Inc, Chicago, IL, USA). Descriptive analyses were performed and the variables were examined using chi-square test and 2x2 tables were used to assess significant associations. Statistical significance was defined as  $p < 0.05$ .

**Results.** Thirty families completed the questionnaires during the study period. Most families (83%) were from the Jeddah area and 73% were of Saudi nationality. The patients' ages ranged from 3-19 years (mean: 10.2; standard deviation [SD] - 4.3), with 50% being males. The parent's socioeconomic details are summarized in Table 1. Most of our patients (77%) were diagnosed with cerebral palsy with a mean duration of diagnosis of 9.6 years. Most patients had severe physical and mental handicap (97%). Their PEG tubes were inserted by one certified gastroenterologist 2-144 months (mean: 39; SD: 33) prior to our encounter. The most common indication was severe pseudobulbar palsy in 22 (73%) with poor oral intake, recurrent choking, and/or chest infections in all the patients. The parents' responses to some of our key knowledge and experience questions are summarized in Table 2. Only 43% of the families reported having some knowledge regarding PEG tube feeding before it was introduced and recommended by their physicians. The level of their knowledge and information regarding the procedure was weak on the Likert scale, with only 10% being very well informed (Table 2). Many had many negative attitudes toward the PEG procedure, and up to 50% resisted having it carried

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**Table 1** - The socioeconomic details of families included in a study at King Abdulaziz University Hospital, Jeddah, Kingdom of Saudi Arabia (n=30).

Variables	Mother (%)	Father (%)
Age	21-59 years (mean: 38; SD: 9)	32-64 years (mean: 46; SD: 8.9)
<i>Educational level</i>		
None	7 (23.0)	1 (3.0)
Primary	5 (17.0)	3 (10.0)
Secondary	3 (10.0)	12 (40.0)
High school	11 (37.0)	6 (20.0)
College or university	4 (13.0)	8 (27.0)
<i>Occupation</i>		
None	27 (90.0)	1 (3.0)
Governmental	3 (10.0)	15 (50.0)
Private	0	7 (23.5)
Self-employed	0	7 (23.5)
<i>Monthly income</i>		
<2000 SR (500 USD)		6 (20.0)
2000-5000 SR (>500-1300 USD)		10 (33.0)
>5000-10,000 SR (>1300-2600 USD)		8 (27.0)
>10,000 SR (>2600 USD)		6 (20.0)
SD - standard deviation, SR - Saudi Riyal, USD - US dollar		

**Table 2** - Parent's responses to the Likert scale items examining their knowledge and experience regarding percutaneous endoscopic gastrostomy (PEG) tube placement (n=30).

Likert scale item	n	(%)	95% CI
<i>How do you assess your level of information about PEG tubes?</i>			
Very well-informed	3	(10)	0.0-21
Moderately informed	2	(6)	0.0-16
Somewhat informed	8	(27)	11-42
Not informed	17	(57)	39-74
<i>Did you have prior negative feelings about PEG insertion?</i>			
Very much so	3	(10)	0.0-21
Moderately	11	(36)	19-54
Somewhat	8	(27)	11-42
None	8	(27)	11-42
<i>Did you resist doing it when it was offered initially?</i>			
Very much so	2	(7)	0.0-16
Moderately resisted	10	(33)	16-50
Somewhat resisted	3	(10)	0.0-21
No resistance	15	(50)	32-68
<i>How do you rate your experience with PEG tube placement?</i>			
Worse than expected	4	(13)	1-25
As expected	6	(20)	6-34
Better than expected	6	(20)	6-34
Much better than expected	14	(47)	29-65

out. Those with negative feelings were more likely to resist having it done ( $\chi^2 - 12$ ; degrees of freedom [df] - 3;  $p=0.007$ ). A common misconception (33% of cases) was the thinking that once the PEG tube is placed, the child would not be able to take oral feeding. These concerns resulted in significant resistance and delays in performing the procedure ( $\chi^2 - 10$ ; df - 1;  $p=0.001$ ), which reached 2 years in 27% of patients. Parents' information level and attitudes toward PEG tube placement were independent ( $\chi^2 - 0.9$ ; df - 3;  $p=0.82$ ). Other socio-demographic or economic variables and attitudes to PEG tube placement were also independent (Table 3). After the procedure, most parents reported an overall experience that was better than what they expected (Table 2). The PEG experience depended on their information levels as those who felt informed were more likely to have an as-expected experience ( $\chi^2 - 17.9$ ; df - 9;  $p=0.03$ ). Only 13% of the parents felt that the whole experience was worse than they expected. This was mainly related to recurrent local complications. Most parents (80%) regretted not having the PEG tube inserted earlier. This is associated with their information level as those who were not informed were more likely to have strong regrets when compared to those with more knowledge ( $\chi^2 - 22.3$ ; df - 9;  $p=0.008$ ).

**Discussion.** There is evidence that there are increasing numbers of children who are being fed enterally at home.<sup>11</sup> This early initiation of tube feeding may have a strong positive impact on both the child and the family. Patient management, family dynamics, and growth rates improved significantly when PEG was placed earlier in life.<sup>12</sup> For this purpose, PEG tube placement is often considered in children with severe neurodevelopmental disabilities.<sup>12</sup> It results in significant reduction in feeding times, increased ease of drug administration, and reduced concern regarding the child's nutritional status.<sup>13</sup> Therefore, adequate information, communication, and support are needed for these families in order to get PEG tube placed early.<sup>14</sup> The diverse influences of the underlying neurodevelopmental disability and the interventions should be addressed in the delivery of such health service.<sup>15</sup>

Our study confirms that many families in our region are not well informed about the PEG tube placement. Thus, many of them have misconceptions and negative attitudes resulting in significant delays. Therefore, proper information and clarification of any misconceptions are important to prevent such delays. Other authors agree that a delay in acceptance of the procedure by parents is the main issue of concern in

**Table 3 -** Association of parent's attitudes with their socio-demographics and economics of families included in a study at King Abdulaziz University Hospital, Jeddah, Kingdom of Saudi Arabia (n=30).

Variables	Did you resist inserting the PEG tube				Total	$\chi^2$	df	P-value
	Very much resisted	Moderately resisted	Somewhat resisted	No resistance				
<i>Gender</i>						0.40	3	0.94
Male	1	5	2	7	15			
Female	1	5	1	8	15			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			
<i>City</i>						2.1	3	0.54
Jeddah	1	9	2	13	25			
Outside	1	1	1	2	5			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			
<i>Nationality</i>						3.9	3	0.26
Saudi	2	6	3	11	1			
Other	0	4	0	4	3			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>				
<i>Father's education</i>						14.1	15	0.513
None	0	1	0	0	1			
Primary	0	0	0	3	3			
Intermediate	1	4	1	6	12			
High school	0	2	1	3	6			
College	1	3	0	3	7			
Others	0	0	1	0	1			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			
<i>Father's employment</i>						9.3	9	0.4
Government	1	5	2	7	15			
Private company	0	3	0	4	7			
Own business	0	2	1	4	7			
Jobless	1	0	0	0	1			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			
<i>Mother's education</i>						9.5	1.5	0.84
None	1	1	1	4	7			
Primary	0	2	0	3	5			
Intermediate	0	2	0	1	3			
High school	1	3	2	5	11			
College	0	2	0	1	3			
Others	0	0	0	1	1			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			
<i>Mother's employment</i>						2.1	3	0.54
Government	0	2	0	1	3			
Jobless	2	8	3	14	27			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			
<i>Total income</i>						7.09	9	0.627
<2000 SR	1	1	1	3	6			
2000-5000 SR	0	4	1	5	10			
>5000-10,000 SR	1	2	0	5	8			
>10,000 SR	0	3	1	2	6			
<b>Total</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>30</b>			

PEG - percutaneous endoscopic gastrostomy, df - degrees of freedom, SR - Saudi Riyal

this situation.<sup>12</sup> Some of our parents thought that once the PEG tube is placed, the child will not be able to take oral feeding. This finding is similar to the results published by other authors who found that concerns about the loss of oral feeding, which was regarded as having a range of psychosocial effects for the child and family, was frequently raised by parents.<sup>16</sup> This can be

easily clarified by adequate education including the biomedical emphasis on health and quality of life. However, health care professionals need to consider, more comprehensively, the implications of the underlying neurodevelopmental disability and the potential effects of the intervention on issues other than physical well-being, such as weight.<sup>17</sup>



Most of our parents had an excellent experience that was better than they expected and the majority regretted not having the PEG tube placed earlier. Other authors found similar high satisfaction rate that reached 90% in one study.<sup>12</sup> Most parents recognized that they would have accepted an earlier placement of the PEG tube had they anticipated the outcome.<sup>12</sup> This result is similar to the findings of other authors who found that most parents would recommend PEG to families of children with neurodevelopmental disabilities and would elect it again if they were given the chance.<sup>18</sup> The experience of our parents depended on their information levels as those informed were more likely to have an as-expected PEG experience. This suggests that the better-than-expected experience was related to the parent's poor knowledge and misconceptions about the PEG procedure. It appears that they realized that it was better than they anticipated. This is also supported by the finding that those who were not informed were more likely to have strong regrets for not having had the PEG tube placed earlier. Some of our families (13%) encountered a worse-than-expected experience as a result of recurrent local complications. Commonly reported problems in the literature include vomiting, diarrhea, infection of the PEG site and leakage.<sup>19</sup> Previous qualitative studies have also found problems related to social isolation, access to medical care, and demanding daily care among experiences in families of children with neurodevelopmental disabilities who were fed through a PEG tube.<sup>20,21</sup>

There are some limitations to our study. Our sample was not large; however, it was representative of children with neurodevelopmental disabilities coming for PEG placement with variable ages and socio-demographic backgrounds. No association was found with the parent's demographics or socio-economic variables. This is likely to be a result of our study sample. Parent's reporting bias may have affected the results since the questions on their knowledge and perceptions, as well as their tolerance levels are predisposed to subjective judgments. We tried to overcome this shortcoming by assigning one coauthor to personally assist all parents in completing the questionnaires. Finally, the questionnaire is self-structured and therefore has not been used or validated in other studies.

In conclusion, most parents are not informed well regarding the PEG procedure, which affects their expectations and experiences. Some parents had significant misconceptions; however, most of them found the PEG experience better than what they expected and regretted not having it done earlier. Therefore, parents who are faced with this decision may find our findings

encouraging. Several other areas for targeted education were identified. This will hopefully assist in delivering effective care and in improving parents' perceptions regarding PEG procedures, keeping in mind that parents of children with neurodevelopmental disabilities have a greater need for practical and emotional support.

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