

Parental experiences of the decision-making process regarding percutaneous endoscopic gastrostomy tube insertion and its post-management in children with developmental disabilities accessing a university clinic in Sri Lanka.

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Background: Feeding difficulties are common in children with developmental disabilities and the Percutaneous Endoscopic Gastrostomy tube is the most common long-term alternative feeding method used among them. Anecdotally in the Sri Lankan context, there appears to be a reluctance to go through a PEG insertion. There is a need to undertake a research study on the parental decision-making process and the post-management of PEG to understand how speech and language therapist can better support parents.

Objective/s: The main purpose of this study was to explore the parental experiences on the decision-making process regarding PEG insertion and its post-management in children with developmental disabilities accessing a university clinic in Sri Lanka.

Methods: This was a qualitative study using a phenomenological approach. Ten parents who have a child with a developmental disability, aged between one to eight years with one to three years of PEG experience with their children were the participants of this study. Semi-structured interviews were conducted using an interview guide which consisted of 10 questions. The qualitative data were analyzed using a simple thematic analysis.

Results: The study results indicate the lack of awareness and miscommunication with professionals throughout the decision-making process of PEG and the lack of parental satisfaction with it. However, they were satisfied with the speech and language therapist's involvement in both decision-making and the monitoring process in the post-management of the PEG procedure. Also, negative societal views made the parents reluctant to consider a PEG and it affected post-PEG management as well by limiting societal participation in meal times due to visibility. The parents also described the strengths and challenges of post-PEG management. All the parents were satisfied with the decision that they made to go through with a PEG for their children with developmental disabilities due to the lack of complications on the PEG procedure and as a long-term alternative feeding method.

Conclusion/s: Parental awareness on the PEG procedure supports the decision-making process. Professional involvement is important in providing adequate information with a key role for the speech and language therapist.

Key words: *Decision making, Post management, PEG, Speech and language therapist*