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Challenges of home percutaneous endoscopic gastrostomy feeding of children for mothers with chronic illnesses and their coping mechanisms: A qualitative study

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ABSTRACT

Introduction: This paper investigated what challenges mothers with chronic illnesses experienced when feeding their children through PEG tubes and what coping strategies they implemented when those challenges presented themselves.

Materials and Methods: This was a qualitative study that adopted phenomenology as a research design. The sample consisted of nine mothers. Data were collected through focus group interviews and were analyzed using Colaizzi's content analysis. Intercoder reliability was calculated using the formula proposed by Miles and Huberman.

Results: Participants had a mean age of 31.2±4 years. The data were grouped under three categories, five main themes, and 14 subthemes. Participants expressed concern about the uncertainty of their situation and were afraid of losing their children. They also stated fear that there would be no one there for their children if something happened to them. PEG-related complications were infection, catheter dislodgement/ blockage, and hypergranulation.

Conclusion: Participants used to go to the hospital when faced with problems in the early days, but then they came up with solutions. At first, they did not know anything about how to insert and use the PEG tube. They learned everything from their friends or the internet. We can state that women are more concerned about their children because of their own chronic diseases.

Keywords: Care, children, chronic diseases, parent, percutaneous endoscopic gastrostomy

Introduction

Chronic diseases are serious health problems with both personal and social consequences. The World Health Organization[1] places particular emphasis on the top four or five chronic diseases with tangible and intangible consequences. Chronic diseases affect parents and children. Being a caregiver parent with a chronic disease poses more challenges because it adversely affects how the parent and his/her child feel and look at things.[2,3] Parents with chronic

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illnesses are less likely to be involved in their children's lives because they have to deal with their own conditions.[4]

An adequate and balanced diet is of utmost importance for children. Malnutrition caused by a lack of essential nutrients is the leading cause of child deaths (60%), especially in the developing countries.[5] There is no large-scale study reporting the incidence of malnutrition in children in Turkey. However, small-scale studies indicate that three out of 10 children are malnourished, which is higher among children with chronic illnesses and hospitalized children.[6] Percutaneous endoscopic gastrostomy (PEG) feeding is an effective way of preventing malnutrition.[7]

Children with PEG have more care needs at home because they need the support of family members or other caregivers to lead their lives.[7] Caring for children with PEG puts an extra physical, psychological, emotional, and socioeconomic burden on caregivers' shoulders.[8,9] Providing care poses physical, psychosocial, and financial stressors for caregivers who are mostly parents.[10] According to the European Society of Clinical Nutrition and Metabolism (ESPEN), parents trained on PEG experience fewer major and minor complications (infection, leakage, bleeding, blockage, fistula, etc.) and have less care burden.[7,11,12] Especially mothers of children with PEG have to deal with increased care burden, and therefore, experience too much stress and anxiety and feel overwhelmed and undersupported.[13,14] Therefore, health-care professionals should train caregivers and propose solutions to their problems.[15] This paper focused on the experiences of mothers with chronic illnesses who took care of their children with PEG. The research questions were developed based on SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, and Research).[16]

Research Questions

1. What challenges do mothers with chronic illnesses face when feeding their children with PEG?
2. How do they overcome those challenges?
3. Under what circumstances do they need help from nurses?
4. Why do they need nurses?

Materials and Methods

This was a qualitative study that adopted a phenomenological approach.

Participants

The study population consisted of 60 mothers of children with PEG monitored at the pediatric gastroenterology unit of a university hospital. Nine mothers who volunteered were included in the sample. The inclusion criteria were (1) caring for a child with PEG, (2) being able to use the Internet, and (3) having a chronic illness. The exclusion criteria were (1) having lost a child with PEG before and (2) having the child with PEG hospitalized.

Data Collection and Procedure

The researchers contacted the mothers who met the inclusion criteria and asked them whether they would like to participate in the study. Nine mothers agreed to participate. Before focus group interviews, the researchers sent each participant a consent form and the data collection forms and asked her to fill them out. Afterward, they interviewed her. Each participant was interviewed once, and each interview lasted about 90 min. The researchers (one as a moderator and the other as a reporter) continued to interview more participants until data saturation. They used a semi-structured interview questionnaire, which was revised by experts. Audio recordings of the interviews with the participants were taken.The reporter took notes during the interviews. They put the audio recordings and notes together within the first 72 h after each interview. They assigned numbers to participants to ensure confidentiality and anonymity.

Interviews

The interviews were conducted between February 3, 2021, and March 20, 2021. The data were collected using a demographic characteristics questionnaire and a semi-structured interview questionnaire. The demographic characteristics questionnaire consisted of 23 items (13 for mother and 10 for child). The semi-structured interview questionnaire consisted of nine open-ended questions:

1. What did you feel when your child underwent a PEG insertion?
2. How long have you been using PEG for?
3. Have you been trained on PEG use and care?
4. Who trained you on PEG use and care?/How did you learn how to use PEG?
5. Have you ever needed help from a nurse? If so, when?

6. Have you ever had any problems with PEG?
7. How did you solve those problems?
8. What scares you the most?
9. What are your recommendations to nurses about PEG?

Quality Guarantee

Consistency and confirmability were ensured for reliability, and credibility and transferability were ensured for validity.[17] The researchers continued interviewing participants until data were saturated.[18] They used a semi-structured interview questionnaire to achieve consistency. For credibility, participants were interviewed at their convenience, and doctors and nurses they knew were also present in the interviews. The moderator briefly repeated participants' responses for verification. As for transferability, although results cannot be generalized, they can be adapted to different situations.[17] Therefore, the researchers compared the results with those of earlier studies.

Data Analysis

The data were analyzed using Colaizzi's phenomenological interpretation method.[19] Intercoder reliability was calculated using the formula proposed by Miles and Huberman. It was found to be 0.85.[20] The researchers consulted an expert in qualitative research to clarify some of the concepts for data reduction. Table 1 shows the steps of analysis. Table 2 shows the themes.

Table 1. Steps of Colaizzi's phenomenological interpretation method

1. Collecting data*
2. Identifying important statements**
3. Making sense of statements**
4. Clustering themes**
5. Developing themes and defining details**
6. Stating the phenomenon clearly
7. Verifying the fundamental structure***

*The researchers brought together and read the reporter texts within the first 72 h after each interview to avoid missing data. **Miles and Huberman model (Baltaci, 2017). ***Participants verified the points on which the researchers disagreed.

Ethical Consideration

The study was approved by the Ethics Committee of the Faculty of Health Sciences of Necmettin Erbakan University (Date: February 03, 2021, Meeting No: 7, Decision No: 12 and Date: April 07, 2021, Meeting No: 9, Decision No: 14). Written consent was obtained from all participants. Their consent was also obtained to audio record the interviews. The researchers saved and encrypted all records. The Standards for Reporting Qualitative Research was

Table 2. Themes

Categories	Main themes	Subthemes	No	
Problems	Fear	Fear of the unknown	17	
		Hurting/fear of losing the child	8	
		Fear that no one will be there for the child	8	33
	Complications	Infection (redness, leakage, microorganisms, etc.)	9	
		Catheter dislodgement	7	
		Hypergranulation	4	
		Catheter blockage	4	24
Solutions	Ways of solution	Going to a hospital	7	
		Solving a problem when presented a 2nd time	2	9
	Source of information for solutions	Friends, the internet, etc.	6	
		Nurse	4	
		Doctor	2	12
Suggestions	Training	Doctors should provide training	1	
		Nurses should provide training	8	9
Total	5*	14*		87

*One participant has more than 1 statement used to analyze and report the data.[21] The research was conducted according to the ethical principles outlined by the Declaration of Helsinki.

Findings

Demographic characteristics

The sample consisted of nine mothers. They had a mean age of 31.2±4 years. They had a primary school (n=3), middle school (n=2), or bachelor's degree (n=4). Only one participant was employed. One family had no social security. Six participants had a neutral income (income = expenses), while the remaining had a negative income (income < expenses). Seven participants lived in cities and the others in towns. Participants had hypertension (n=3), rheumatism (n=2), migraine (n=2), asthma (n=1), or diabetes mellitus (n=1). Children had a mean age of 23.5±22 years, body height of 96.2±10 cm, and body weight of 16.5±8 kg. Children had had PEG for 14.4±13 months. Two were always fed through PEG tubes, five were fed through PEG tubes intermittently, and two preferred pump feeding. Children had cystic fibrosis (n=1), hypoxic ischemic encephalopathy (n=1), muscular atrophy (n=1), chronic lung failure (n=1), hypotonic epilepsy (n=1), SMA type 1 (n=2), or unknown diagnosis (n=1). Participants were assigned codes (P1, P2, P3...) to protect their anonymity.

Themes

Fears

Fear of the unknown

Participants stated that they were afraid when they had no support. Some noted that they were scared so much that they stopped feeding their children for a while. They experienced more fear when they did not know what to do.

"*I had no idea about PEG care; we had a lot of problems, I even had to stop feeding my kid for a while. I just couldn't give him any food. I wish I'd known better back then! P7*"

Hurting the child/fear of losing the child

Children with catheters looked strange to participants because they were not accustomed to seeing such a thing. Therefore, they were worried about doing something wrong and hurting their children. Some noted that they avoided touching their children:

"It seemed so hard. I mean, I couldn't provide any care to my kid. I couldn't even touch her. I was like, what if I do something wrong, what if the tube comes out loose..." P3

Fear that no one will be there for the child

Participants feared death because of their chronic diseases. They were also afraid that no one would be there to take care of their children if they died.

"I sometimes think about it. I'm sick, so who would take care of my kid if I died. That's what I'm most scared of." P9

"There is no one to help me; so, there is no one to take care of my kid if something bad happens to me. My life revolves around my kid; she is my everything. I'm worried, like what would she do without me?" P6

Complications

Catheter blockage

Participants experienced catheter blockage because they did not know how to handle it:

"We had tons of problems...leakage, redness, blockage, and whatnot. I was supposed to give water and formula, but no one told me that, so I had no idea. I use water now..." P7

Catheter dislodgement

Another problem participants faced was PEG dislodgement, mostly because of the balloon:

"Apparently, the PEG balloon burst, but I had no idea. I mean, the balloon burst, and the catheter was displaced. I didn't realize it; I didn't know that there was a balloon there. I was like, why would it burst anyway? So, they said the balloon was burst, and so the formula was not going in. I just couldn't do it..." P2

Hypergranulation

Another PEG-related complication was hypergranulation tissue. Participants stated that they were afraid of hypergranulation the most.

"We had tons of problems, leakage, extra tissue, infection... That flesh had freaked me out, the wound site, and the catheter is there, besides something grew up there, something huge, like a wound...The doctor burnt it away with a caustic pencil. I do the same thing now" P5

Infection (redness and leakage)

Participants also faced PEG-related infections that started with leakage.

"We had blockage, redness, and leakage after the PEG was inserted. That leakage would just not stop; we were fed up with it. We tried very hard to stop it. On top of that, there was also redness around PEG. I just didn't know what to do..." P3

Ways of Solution

Going to the hospital

Participants went to the hospital or called 112 when they needed help.

"I get really scared, but now I know what to do. We either go to the hospital or call 112; they show up right away" P9

Solving a problem when presented a 2nd time

Participants turned to health care institutions for help when they encountered a problem for the 1st time. However, they tried to make use of different sources to come up with their own solutions when problems presented themselves a 2nd time.

"At first, I was afraid. I took my kid to a hospital each time PEG came out loose, but we couldn't just go to a hospital every time it happened. So, I learned about it; I learned how to replace it by myself. I can also inflate the balloon with water. A nurse taught me how to burn the extra flesh with a caustic pencil. I burn it away when extra flesh bulges out" P5

Source of Information for Solutions

Friends/Internet, etc.

Most participants turned to friends or the internet to learn what to do for PEG care.

"I spent the night in the unit when they inserted PEG for the 1st time. I didn't get to learn much though; so, I learned everything from the Internet; everything is there and I asked other mothers for advice.." P7

Nurses

Two participants noted that they learned from nurses.

"We stayed at the hospital for 10 days after PEG was inserted. We spent a lot of time with nurses. In fact, they were always there for us, so I didn't have any problems. Aspiration, dressing, caring... We learn a lot from nurses. We always get support from nurses in difficult times." P4

"... I wish there was a nurse who taught us about PEG when it was first inserted. We wouldn't have so many problems if it'd been the case..." P5

"My child has a PEG; she is a teenager now and I think I will need help from nurses" P8

"I feel my child is not growing like his peers, I will need nurses"P3

Doctors

A participant who regularly visited the same center stated that she got information from her own doctor about every problem she encountered.

"I'm grateful for my doctor for explaining everything to us. We learned everything from him. Besides, he was always there for us." P1

Training

Nurses should provide training

Participants had no difficulty communicating with nurses and felt closer to them. Therefore, they wanted nurses to give them training on PEG.

"The nurses are very friendly, I can ask them anything, and they explain everything in a way we can understand; so, I would like to learn about PEG from nurses. They've told us about everything, they would never keep things to themselves." P9

Doctors should provide training

The participant who regularly visited the same center remarked that she preferred if the doctor provided training on PEG care and justified her reason as follows:

"I'm grateful for my doctor for explaining everything to us. We learned everything from him. Besides, he was always there for us." P1

Discussion

Anxiety is a common problem for people who care for PEG patients. They feel nervous because they do not know how to provide care, worry about hurting their patients, or fear that there would be no one there for their patients if something happened to them.[14,22-24] Mothers of children with special needs experience fear (56.4%), anxiety (54%), and hopelessness (5.4%) because they are afraid of losing their children or worried about what will become of them in the future.[25] Some caregiver parents are afraid of losing their children or dying and leaving them all alone.[26] Caregiver parents with chronic illnesses experience more anxiety, depression, and stress and suffer from poor quality of life and have low life satisfaction and self-esteem.[3] Our participants were also afraid of being dependent on others or dying before their children and leaving them all alone. Moreover, they feared making mistakes during PEG use/care and hurting their children. Therefore, we should assess caregiver mothers' anxiety and fear levels and provide them with psychological support.

Caregivers who do not know much about PEG use and care are likely to experience more anxiety and face more complications.[15] The most common complications are mechanical problems, such as tube blockage, tube dislodgement, dislocation, and hypergranulation.[12,15,24,27] The most common complications associated with PEG are tube occlusion and tube displacement.[7,12,27-29] Our seven participants also experienced PEG dislodgement. Training PEG users on its care are an effective way to prevent dislocation.

People who are trained on PEG care are likely to face fewer or no complications. Pars and Soyer (2020) found that the majority of mothers knew little about tube location (90%), tube hygiene (66.7%), stoma care (63.3%), and mechanic complications (76.7%). Sumritsopak et al. (2015) according to the most common complications faced by PEG caregivers (n=33) are the formation of granulation tissue, redness around the gastrostomy area, leakage, and fracture/deformation of the feeding tube.[23] Four of our participants reported hypergranulation. They stated that they did not know how to treat hypergranulation tissue and tried to treat it by burning the proud flesh with a silver nitrate stick or caustic pencil. Tube blockage was another PEG-related complication due to insufficient care, ASPEN and ESPEN have evidence level A and B recommendations.[7,28,30] PEG caregivers inject water into the tube, draw fluid from it, roll it, or push a piece of wire through it to break up clogs.[11,24,29] Pars and Soyer (2020) reported a 73% reduction in the prevalence of PEG-related complications 3 months after training on blockage prevention. Using the wrong methods to open a clogged tube may cause it to break or dislodge.[29] Our participants reported catheter displacement (n = 4) and tube blockage (n = 7). We think that training caregivers on PEG care can help prevent tube blockage, granulation, and tube dislodgement due to wrong interventions.

Wrong intervention causes infections at the PEG insertion site (wound site). The prevalence of PEG-related infections ranges from 0.8%[31] to 42.9%.[24] Proper care prevents infections. Although mothers are considered competent, they are actually partially competent (36.7%) or completely incompetent (66.3%) in stoma care.[14] All our participants reported infections, indicating that caregiver mothers know little about PEG care.

Health-care professionals, including nurses, are regarded as the right source of information on PEG care.[12,14] Most mothers can get information about PEG care from family members (91.9%), books (18.4%), or family physicians,[32] information resources; nurses (63%), midwives (53%), and doctors (31%)[25] sometimes they turn to the internet (22.5%).[33] Our participants reported 24 complications. It can be thought that mothers do not feel close to ask questions to health personnel.

Communication is a key to training. According to Başol (2018), patients prefer to talk to nurses because they hesitate to ask questions or say something to doctors. Esenay et al. (2016)[22] reported that parents would like to be trained by doctors (90%), clinical nurses (70%), or firm nurses (2%). Family members of PEG patients state that they can learn about PEG care from nurses because they can communicate better with them.[35] Our participants also noted that nurses were easier to talk to. Therefore, we can state that parents can manage PEG care much more effectively if they receive training from nurses.

PEG children and their parents need nurses throughout the entire process.[7,27] A critical component of PEG care is ensuring that the caregiver acquires the necessary knowledge and skills.[24] Another ideal nursing intervention for PEG children and their parents would be to implement follow-up programs encompassing developmental stages.[14] Eight of our participants stated that nurses should be responsible for providing training on PEG care. However, six of them noted that they learned about PEG care either from friends or the Internet. Therefore, we can state that nurses should play a more active role in PEG care training.

Limitations

The study had one limitation. The data were collected online due to the COVID-19 pandemic.

Conclusion

Having a child with PEG poses more challenges for parents with chronic illnesses. Such parents generally know little about how to apply PEG feeding properly. Moreover, they worry about losing their children or fear that they will die because of their chronic conditions and that no one will be there taking care of their children. Infection, catheter dislodgement/blockage, and hypergranulation are the most common PEG-related complications. In the early days of PEG insertion, they went to the hospital when they encountered a problem, but now they develop their own solutions. Again, in the early days, most mothers knew little about PEG use, and therefore, turned to friends and the internet to learn about it. Only a few mothers consulted their doctors and nurses. Mothers need help and support from nurses throughout the whole process, especially about PEG care/use and the development of their children.

Implications for Practice

Health-care professionals should provide education on PEG feeding and care. Education should start from day 1 and be continuous. A standard training program should be developed for this. “Adaptation rooms” for PEG care should be established in hospitals. Nurses should be responsible for providing PEG training, as patients and family members find it easier to talk to them.

Disclosures

Ethichs Committee Approval: The study was approved by the Faculty of Health Sciences of Necmettin Erbakan University Scientific Research Ethics Committee (Date: 03/02/2021, No: 12).

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