Percutaneous endoscopic gastrostomy placement: Caregiver decision making in Taiwan

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Background/Purpose: To explore Taiwanese caregivers’ decision making experiences of accepting a percutaneous endoscopic gastrostomy tube for their family member.

Methods: A phenomenological approach was used for the interview and analysis. Semi-structured, in-depth interviews were conducted with a purposive sample of 26 caregivers of patients who had percutaneous endoscopic gastrostomy tube in southern Taiwan.

Results: Five themes were recognized to reflect caregivers’ decision making experiences with a percutaneous endoscopic gastrostomy: awareness of suffering, awareness of options, uncertainty, opportunity, and contentment with the decision.

Conclusion: Caregivers’ decisions to proceed with a percutaneous endoscopic gastrostomy procedure were mediated by desires to relieve patients’ suffering. To empower caregivers to make enteral feeding decisions, nurses must provide sufficient information about percutaneous gastrostomy tubes and their care, support decision making and help to identify an opportunity for gastrostomy tube placement.

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Introduction

Nasogastric tubes (NGTs) and percutaneous endoscopic gastrostomy (PEG) tubes are critical for individuals who are unable to swallow and require enteral nutrition, fluids, and medications. During long-term nutritional support, PEG tubes improve patients’ comfort, promote nutritional status, and improve cosmetic appearance compared with NGTs.1,2

PEG tubes have been adopted and are widely used in Western society since 1980.3,4 It has been estimated that nearly 10% of institutionalized geriatric patients receive enteral nutrition via a PEG tube in the USA and Canada.3,5 In 1994, PEG technique was introduced to Taiwan and advocated by professionals from a variety of healthcare disciplines.6 However, the prevalence of PEG tube use among Taiwanese long-term care residents has shown little change from 0.1% in 2002 to 2.8% in 2007.7,8 Yet, positive outcomes related to PEG tube feedings in Taiwan have included improvement of nutritional status, as indicated by hemoglobin and albumin values,9 low procedure-related mortality rate,10 and a 70% patient satisfaction rate.11

The low PEG adoption in Taiwan can partly be explained by cultural barriers, inadequate access to information on PEG tubes, financial constraints, and a lack of available medical resources.6 PEG tube placement decisions are also complicated by moral dilemmas and prevailing political, economic, social, and cultural factors.12 Ethnicity and embedded cultural values play a significant role in healthcare-related decisions and attitudes toward end-of-life care, including PEG tube placement decisions. Braun and associates13 analyzed the 10-year national trend for PEG tube use among dementia patients in the USA and reported that African-Americans chose more aggressive care and opted to use PEG tubes more often than Caucasian Americans. A comparative, cross-sectional survey of Jewish patients indicated a significant difference in tube-feeding prevalence between Canada (11%) and Israel (52.9%).14 Recent studies on decision making regarding the use of PEG tubes conducted in non-Asian countries have examined patient and family concerns and experiences15–17 in Asian cultures, most medical decisions are made by family caregivers. The oldest son usually assumes the duty of gaining family consent and making the final decision regarding treatment and healthcare options.18,19

There is a dearth of research on PEG tube placement and feeding decision making in Chinese society. In a culture where the long-term use of NGTs prevails despite the known advantages of PEG tubes, it is important to understand the decision-making experience of caregivers. The purpose of this study was to understand Taiwanese caregivers’ experiences in making a decision about accepting a PEG tube for their family member.

Methods

Design

Phenomenology is a branch of philosophy and a research method that seeks to understand the essence of experiences.20,21 According to Husserl,22 reality can only be understood through subjective experience. The decision to accept a PEG tube within the Chinese culture is a subjective experience, and therefore phenomenology was an appropriate framework for this qualitative study. Caregivers or family members of a patient with a PEG tube were asked to reflect on their experiences from the time at which PEG tube placement was considered to the time of the interview in 2008.

Participant caregivers

After obtaining Institutional Review Board approval, a purposive sample of 33 caregivers was identified by six nursing agencies in southern Taiwan that provided home-care services for adult patients with PEG tubes. Caregivers were invited through phone calls, and 26 of them (79%) agreed to participate and provided informed consent. Each caregiver was interviewed, who provided demographic data. Caregivers were predominately female (n = 20, 77%), with a mean age of 52.5 years (SD = 11.0, range = 29–84 years). Eighteen (69%) had a high school education or higher. Caregivers included seven wives, six sons, six daughters, five daughters-in-law, one mother, and an attendant. Most patients with PEG tubes were male (n = 19, 73%), with a mean age of 74 years (SD = 15.6, range = 20–91 years). All patients experienced NGTs prior to PEG tube placement, with six patients (23%) having an NGT over a year. At the time of PEG tube placement, 13 (50%) patients were alert, while 13 had altered states of consciousness including comatose (7 patients). Twelve patients (46%) required physical restraints during their NGT experience, while only one required restraints after obtaining a PEG tube. Twenty (77%) patients had lived with a PEG tube for over a year, with a mean PEG tube duration of 45.7 months (SD = 40.3, range = 3–192 months).

Procedure

Interviews were conducted at the caregiver’s home or the facility housing the patient. Each interview, conducted in Mandarin and lasted 60–90 minutes, was tape recorded. Field notes were compiled after each interview, and interviews were transcribed. The following prompts were used to elicit caregivers’ experiences: (1) tell me about the circumstances surrounding the decision to use a PEG tube for your parent (spouse or child) and (2) if you had to make the decision again, would you do anything different?

Data analysis

Existential phenomenological interpretation is a process of relating parts to the whole narrative. To understand the meaning of the phenomenon itself, the transcripts were reviewed line by line following Giorgi’s23 phenomenological analysis guide: (1) read the entire set of protocols to get a sense of the whole; (2) discriminate units from participants’ description of the phenomenon being studied; (3) express the psychological insight into each of the meaning units; and (4) synthesize all the transformed meaning units into a consistent statement regarding
participants’ experiences. Two researchers (YL and CSY) independently analyzed each text by reading and writing an interpretive note reflecting the interview. Themes reflecting participants’ experiences were generated through an iterative process. Disagreements over the meanings of data were discussed and resolved, and a consensus was achieved. Finally, a description was written to reflect the essence of the participants’ experiences.

Methodological rigor

The trustworthiness of the data analysis was confirmed by Lincoln and Guba’s criteria of credibility, dependability, confirmability, and transferability. Credibility was supported by the fact that the researchers (YL, CSY, and CCH) have been engaged in long-term care practice in Taiwan for over 10 years. The identified themes were reviewed by three caregivers; feedback through member checking enhanced credibility of the analysis. An audit trail to document clearly the decisions made regarding the analysis maintained dependability. Confirmability was accomplished by maintaining a reflective journal and an audit trail. Efforts to meet the criterion of transferability included communicating the interpretation in a clear and meaningful way to allow the reader to transfer the results to their context.

Results

From the 26 interviews, five themes reflecting caregivers’ decision-making experiences regarding the use of PEG tubes were identified: awareness of suffering, awareness of options, uncertainty, opportunity, and contentment with the decision. Awareness of suffering refers to caregivers’ recognition and desire to change the patient’s life after prolonged NGT use. The discomfort and suffering from the NGT use decreased both the patient’s and the caregiver’s quality of life. After becoming aware of the suffering, caregivers identified a PEG tube as an alternative feeding method. However, the PEG option created additional uncertainty and anxiety as PEG tube placement and feedings are not without risk, particularly for frail elderly patients. Opportunity describes caregivers’ actions related to identifying and taking advantage of an appropriate time or circumstance for the PEG tube placement. Contentment refers to caregivers’ satisfaction as they reflected on their decision to use PEG tubes.

Awareness of suffering

Caregivers found out that prolonged NGT use caused physical problems and pain. They described patient suffering across the range of consciousness, as evidenced by verbal and nonverbal behaviors. They recounted patients’ painful experiences with gastrointestinal bleeding and physical restraints to illustrate the suffering, which created further frustration in the caregiving role. Caregivers said:

“It really hurts; my mother would cry loudly … just looking at her face… you could feel how much pain the NGT has caused.” (Participant mimicked the sound and facial expressions.)

“For bleeding problems, I had to send my father back to the hospital 17 times in a year.”

“To restrain my Mom broke my heart. To see her hands become rigid (by restraints) made me so sad…. ”

Use of NGTs not only resulted in physical suffering but also impacted the patient’s psychosocial health. In an alert and awake patient, the unappealing cosmetic appearance of an NGT prevented social interactions. A caregiver said:

“Having the elephant’s nose (NGT), my father did not want to see any friends or go out…”

As they became cognizant of the suffering that long-term NGT placement caused, caregivers developed a conscious awareness about the need to change the situation and a desire to decrease the suffering of the patient and the caregiver.

Awareness of options

Availability of an alternative option, PEG tubes, provided hope to diminish the suffering caused by NGTs. Caregivers clearly identified the individuals as well as the situation surrounding their newfound awareness of the PEG alternative. Caregivers were informed of PEG tubes by healthcare professionals including the attending physician and homecare nurses. Some caregivers reported actively seeking an alternative solution to NGTs because they were aware of the patients’ suffering. Others, by chance, had seen residents in the same facility who were equipped with a PEG tube, and then inquired about the PEG option. Caregivers said:

“It was in hospital to treat the bleeding, the GI doctor suggested a PEG …”

“My Mom suffered …, I asked my friend who worked in hospital and got PEG information…”

“I was surprised to see a PEG resident living near my father. …His condition encouraged me to ask about a PEG…”

Caregivers appreciated learning about the PEG tube and regretted not having the information earlier so they might have been able to shorten the suffering. Caregivers felt that healthcare professionals should actively provide information on PEG tubes to those who might benefit from their use. A caregiver said:

“Why didn’t they (Dr.) tell us earlier …? It should be the physician’s job to let us know the PEG option…”

Uncertainty

An awareness of the suffering and NGT alternatives led to development of uncertainty among caregivers.
and risks of PEG use were not specified, leaving caregivers with numerous concerns. Caregivers sought answers to the following questions, which reflected their uncertainty in decision making: Could the patient tolerate the PEG insertion? Would they recover their swallowing ability? How long would they live? What was the cost of maintaining a PEG? Could they take care of the PEG stoma? Despite the uncertainty, caregivers had a strong desire to seek the comfort that a PEG tube promised. Caregivers replied:

"Although she is not clear...She is my Mom, she deserves no pain..."

"We imagined the benefits of PEG ...we certainly are not sure ...but we decided to take it."

Consensus for the PEG tube placement decision among family members was needed to resolve the uncertainty about the advantages and disadvantages of using a PEG tube.

"Although I take care of my Mon, I cannot decide it (to accept a PEG) alone...."

"I can't take on all the responsibility...I have four siblings, they live in different cities...we had to talk about the whole situation and decide together ...It takes time...."

It took several months for family members to reach a consensus and accept a PEG tube. In this study, the longest time from awareness of suffering to placement of a PEG tube was 9 months. Each caregiver had individual concerns and uncertainties. A caregiver said:

"I had to be sure that he could tolerate the technique...his condition was stable ...and I could handle the stoma care."

When the uncertainty was resolved, caregivers took advantage of the opportunity that an unrelated hospitalization offered to act on their PEG decision.

Opportunity

In Taiwan, the placement of a PEG tube mandates a hospital admission and a 2–3-day stay. Many patients were frail and totally dependent, and it was difficult to transfer them from a home or long-term care facility to the hospital. Therefore, it was not surprising to find that the majority of caregivers had taken advantage of an unplanned, unrelated hospitalization to have a PEG tube placed. According to caregivers, the best time to have a PEG inserted was soon after they obtained agreement from the family and while the patient was still hospitalized. A caregiver said:

"...it's so difficult to move him out of the house....since he was in the hospital, we (family) decided to have it (PEG)."

Contentment with the decision

Any remaining caregiver uncertainties related to the PEG decision resolved after the PEG tube was placed and feeding began. Caregivers compared their quality of life prior to and after the use of the PEG tube, and were satisfied. They said:

"After using PEG, she never bled."

"There was no need for rehospitalization."

"He can get along with the PEG quite well, no pain shows on his face."

"She does not refuse to go out."

"He doesn't need to be restrained...no suffering. We both have a good life."

Caregivers recognized and confirmed that the use of PEG tubes had positively impacted their life. Caregivers noted:

"PEG use improved my father's and my life...a lot of relief from the care burden."

"It felt right to have PEG...I would make the same decision again...."

However, the use of a PEG tube was not problem free. Although caregivers experienced minor complications, such as stoma infection and difficulty cleaning and maintaining tube patency, they concluded that these problems were manageable and preventable with experience. A caregiver said:

"During five years of PEG feedings, my Mom has experienced a stoma infection and leakage...We know how to deal with these....now we know how to prevent these from happening...."

The comfort of using PEG tubes helped caregivers overcome minor complications. The caregivers in this study were unanimous that they would make the same decision again. They expressed their desire and willingness to share their PEG tube experience with other caregivers.

Discussion

Five themes emerged from the data: awareness of suffering, awareness of options, uncertainty, opportunity, and contentment with the decision, which portray the decision-making process of 26 caregivers on PEG tube placement for their loved ones. The results of our study indicated that comprehensive information about PEG tubes, including their analyzed risks and benefits, and patients' stories significantly influenced caregivers' decisions. Caregivers, after witnessing patients suffering from gastrointestinal bleeding, physical restraints, and distorted body image with the prolonged NGT use, yearned for a change that provides patients with a better quality of life. The introduction of PEG offers both the patient and the caregiver a solution to enhance their quality of life. Although apprehensive initially, caregivers generally felt benefited and contented with the PEG tube placement. Improved patient outcomes and quality of life following the placement of PEG tubes relieved caregivers' apprehension on the PEG decision.
A developing awareness of patient suffering signaled the need for a change in their situation and required effective problem solving and decision making by caregivers. Sources of information on the availability and utility of the PEG tube as an option varied significantly. Some caregivers in this study became proactive and actively sought out information about PEG tubes as a solution to diminish patients’ pain and suffering. All decision-making options contain an element of risk; selecting an option has been compared to gambling. Sufficient information is critical for the decision maker to select an option that offers the most attractive payoff.

Similar to previous studies in England and Israel, caregivers in our study expressed dissatisfaction with PEG decision making due to the lack of adequate information. Many caregivers who participated in the current study reported having to struggle and actively seek information on PEG tubes from healthcare professionals. The finding in our study echoes two themes identified in Brotherton and Abbott’s study about difficulty in PEG decision-making: “inadequate knowledge to make an informed decision combined with the paternalistic and prescriptive attitude of health care professionals”. Delay in providing PEG tubes as an alternative to NGTs for patients due to healthcare providers’ ignorance or incompetence creates needless pain and torment for patients and caregivers. Professional accountability related to care of patients with PEG tubes needs to be strengthened, as indicated by Taiwanese accountability related to care of patients with PEG tubes.

Despite the various characteristics of the patient and the caregiver, the process of PEG decision was very similar. Caregivers in this study went through a very complex process to decide PEG tube placement for the patients. Filial piety embedded in Confucianism and Chinese culture was the central philosophical value for caregivers in this study. The participants upheld similar culture background and were willing to provide the best care for their family, and no apparent cultural difference was observed among them. Most caregivers, seeing and feeling the suffering of patients, felt obligated to improve the patients’ quality of life, thereby fulfilling their own duty of filial piety. Patients’ functions and state of consciousness were not the priorities in caregivers’ decisional hierarchy. Angus and Burakoff suggested that patients in a vegetative or near-vegetative state are not suitable referrals for a PEG tube placement because such patients are unable to experience changes in quality of life and have a high probability of prolonged death. The caregivers in the present study challenged this recommendation. They opined that comfort, a basic human need, should not be discounted based on the state of consciousness. Research has also indicated that both competent and noncompetent patients have an improvement in nutritional state and aspects of quality of life with PEG interventions. Furthermore, experts have articulated the need to treat pain and suffering in all persons with altered states of consciousness. More empirical research on the needs and outcomes of PEG intervention is needed to provide evidence for clinicians and caregivers to make a better decision. Despite the burden of PEG treatment, positive perceptions toward PEG tubes have been reported globally. Caregivers in this study were satisfied and content with their decision. Preferences of patients and caregivers must be taken into account in evaluating the outcomes of PEG intervention and formulating clinical guidelines.

Policies and practices concerning end-of-life decision making that emphasizes rational, individual, and legal biases reflect a Western culture. Such biases ignore the influence of family members and larger social network. In Asian cultures, illness is considered a family event rather than a personal concern. Family-based medical decisions are a function of filial piety, creating an orientation toward the extended family as opposed to individual patient self-interest. Achieving family consensus to place a PEG tube was perceived as a requirement by the caregivers in this study. Although family consensus building took time, it was an integral cultural component of the decision-making process. Family meetings offered the multidisciplinary team a valuable opportunity to discuss fully with family members about the pros and cons of PEG tube placement in patients. Voices of the family could be listened to, their uncertainty with treatment could be discussed, and conflicts could be resolved. Family meetings should be held based on the family’s needs in the PEG decision-making process.

**Limitations**

Small sample size and qualitative method limit the generalizability of the findings. The ability of participants to recall their decision-making experience may have changed over time; moreover, caregivers’ experiences of patients with PEG tubes who had died may be different. About three-fourths of patients in our study were male, while the majority of the caregivers were female. The extent to which gender contributes to the decision-making process is unknown and needs to be explored further. Experiences of caregivers who decided against PEG tube placement were not included; they would provide a valuable comparison group for future study.

**Implications**

As the first study to explore Chinese caregivers’ account of their experiences in making PEG tube placement decisions, the study findings are important to healthcare providers. While making a decision about PEG tube placement is difficult for Chinese caregivers, PEG information promotes decision making. Findings of this study support the development of “decision aids” to provide PEG information. A culturally appropriate clinical guideline on PEG tube must be developed to help healthcare providers care for patients in need of PEG tubes from assessment, management, and evaluation. It is important for healthcare providers to assess patients’ physical and nutritional status as well as value, preference, and cultural and spiritual concerns in the family. Educational materials can integrate patients’ stories along with useful information to empower patients, caregivers, and healthcare providers. Additional study is needed to understand the long-term experiences of caregivers after PEG tube placement.

**Conclusion**

A phenomenological study revealed that caregivers’ decision making concerning the use of PEG tubes was
reflected in five themes occurring sequentially as a process initiated by an proactive awareness of patient suffering and options to relieve the suffering. Decision-making uncertainty was shared with family members. Caregivers struggled with decision implementation but took advantage of unplanned opportunities. As patient’s and caregiver’s quality of life improved, caregivers were content with the PEG decision.

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