

THE DECISION-MAKING EXPERIENCES OF CAREGIVERS REGARDING
FEEDING TUBE PLACEMENT IN COMMUNITY DWELLING ADULTS

A DISSERTATION

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DEDICATION

For my husband, Allan Muoki, and my children, Alana, Grayson, and Lexi thank you for your unconditional love and support. For my parents, Delton and Shelia Smith, thank you for your patience and guidance.

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ABSTRACT

DELTRA MUOKI

THE DECISION-MAKING EXPERIENCES OF CAREGIVERS REGARDING FEEDING TUBE PLACEMENT IN COMMUNITY DWELLING ADULTS

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Despite the increase in feeding tube placement as people live longer with chronic illness, the research is scarce regarding how to care for the caregiver of individuals with chronic illnesses especially with percutaneous endoscopic gastrostomy feeding tubes (PEG). This study aims to explore the caregiver's experience regarding decision-making for PEG feeding tube placement in community dwelling adults. PEG feeding tubes are placed when individuals are unable to orally consume adequate nutrition. PEG feeding tubes ensure that individuals are able to meet their nutritional needs, but they can be accompanied by complications and other challenges that may affect daily living. Subsequently, caregivers may be involved in order to help manage care, which could lead to caregiver burden if there is lack of support. The National Institute of Nursing Research's recent movement towards relieving caregiver burden and enhancing quality of life support the importance of this study.

A descriptive phenomenological study was conducted at six post-acute care rehabilitation and skilled nursing facilities (The Medical Resort at Bay Area, The Medical Resort at Sugar Land, The Medical Resort at Willowbrook, The Resort at Texas

City, The Medical Resort at Pearland, and The Medical Resort at the Woodlands) in Houston, Texas and the surrounding areas. Caregivers had some role in the decision-making for PEG feeding tube placement and intended to spend at least 4 hours per day providing direct care. Purposive sampling, data collection, and data analysis using Colaizzi's method was conducted simultaneously. The transcripts were read and re-read with significant themes and meanings placed into a word document. They were then categorized into subthemes and placed in an excel spreadsheet for identification of overlapping themes.

Although all participants expressed there was no regret in the decision to place a PEG feeding tube because it was a necessity and best for the patient, they expressed concerns about lack of education that was provided before and after PEG feeding tube placement as well as concerns about the complications. The findings suggest the need for support and adequate preparation from nurses in order to relieve caregiver burden and improve care.

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CHAPTER 1

INTRODUCTION

Focus of Inquiry

The role of the caregiver and their involvement in the patient's care and shared decision-making process has been a central focus in the paradigm shift of patient and caregiver-centered care. The National Institute of Nursing Research's (NINR) Strategic Plan: Advancing Science, Improving Lives specifically focuses on enhancing quality of life and relieving caregiver burden for patients with chronic conditions (NINR, 2011). Approximately 50% of adults in the United States have one or more chronic illnesses (NINR, 2011). The symptoms and complications from the chronic illness can contribute to diminished quality of life, strain on community resources, and caregiver burden (NINR, 2011). Although the culture of healthcare continues to push evidence-based practice for individualized care and shared decision-making, there are several other confounding factors such as personal beliefs, fear, anxiety, and lack of or inadequate information that may present as barriers (Muoki, in press). Without fully understanding the caregiver's perspective and experience, the analysis and implementation of the evidence is limited.

Percutaneous endoscopic gastrostomy (PEG) tube placement was first performed in 1980 by Dr. Michael Gauderer as a new method to place a feeding tube and provide long term nutrition instead of surgically placing the feeding tube (Gauderer, Ponsky, &

Izant, 1980). The PEG feeding tube is placed into the left upper quadrant of the stomach via the use of a long flexible tube known as an endoscope. The endoscope is placed into the mouth and moved down into the stomach. The light on the tip of the endoscope transilluminates the abdominal wall to identify a safe location for placement. A needle is then placed into the stomach and visualized within the cavity of the stomach to verify the identified placement site. The needle is removed and an incision is made. A plastic sheath is inserted into the incision and a guide wire is passed through the sheath. The guide wire is grasped with a lasso. The endoscope is removed from the mouth, which allows the guide wire to exit the mouth. The PEG feeding tube is tied in a knot to the guide wire and pulled back down the mouth, esophagus, and into the stomach and out of the incision until it hits the internal stopper. This stopper holds the PEG feeding tube in place inside the stomach and then the external stopper is attached on the outside of the PEG feeding tube against the abdominal wall. This method is less invasive than surgical placement of a PEG feeding tube (Yuan, Zhao, Xie, & Hu, 2016).

PEG tubes are placed when individuals are unable to orally consume nutrition to meet their daily requirements leading to malnutrition. Cerebral vascular accidents, dementia, head and neck cancer, muscular dystrophy, and paralysis are some of the illness that may result in PEG placement (Muoki, in press). According to the most recent statistics from the National Centers for Health Statistics, approximately 245,000 patients received tube feedings (Centers for Disease Control and Prevention, 2018). Jaafar, Mahadeva, Morgan, and Tan (2016) stated that PEG tube placement is common practice in long term care and community settings, but the attitudes and acceptance of PEG tubes

vary based on several factors such as personal beliefs, prognosis, cultural values, and individualized healthcare goals. The decision-making experience is complicated by a lack of definitive standards of care for PEG tube placement in various chronic conditions (Mayre-Chilton, Talwar, & Goff, 2011). Individuals must consider the possibility of complications, alternations in daily life, and psychosocial adjustments such as body image (Muoki, in press).

These changes may affect the patient as well as the caregiver who may also be involved in the decision-making process. Caregiver involvement will only continue to increase as people continue to live with multiple chronic conditions. By 2020, it is projected that 81 million Americans will be living with multiple comorbidities (National Health Council, 2014). In a study conducted by the Center for Medicare and Medicaid Services (CMS), 66% of participants had two or more chronic diseases and 14% had six or more chronic diseases (CMS, 2012). Caregivers will be tasked with the role of helping these individuals to make decisions and manage their care including their nutrition. Merrick and Farrell (2012) noted that patients felt that having a PEG tube placed was a burden to their family and friends. This feeling of concern stemmed from the patients' perceptions regarding lack of community resources for individuals with PEG tubes (Mayre-Chilton et al., 2011).

Statement of Purpose

The purpose of this study is to gain a better understanding of the caregiver's experience regarding decision-making for PEG feeding tube placement in community dwelling adults. A better understanding of these experiences will provide information to

nurses to help alleviate caregiver burden, establish standards of care in clinical practice, and support additional research in this area.

Significance to Nursing

A review of the literature, as thoroughly noted in Chapter II, revealed that the majority of published studies focused only on PEG placement in geriatric patients with dementia or the patient's perspective of PEG placement. Some of the studies focused on the specific aspects of caring for a PEG and administering the tube feedings after the PEG tube had been placed. The studies that included the caregiver utilized the patient and caregiver as a dyad for the sample. There is a lack of information and understanding of the caregiver's experience with the process of handling declining nutrition in a community setting and their role in ultimately deciding to place a PEG tube. This study aimed to address this gap.

With the shift towards individualized patient centered care, healthcare cannot forget about those who provide care and support to the patient. If nursing is charged with administering holistic care to patients, then it must extend that care to the network of individuals that accompany the patient. This includes the caregiver, family, and friends. Holistic care does not just include support services for the patient but also for those who care for the patient. If support is not extended to the caregiver, then the caregiver may not be able to fully provide care to the patient after discharge. This may result in readmissions or physical and psychosocial issues for the patient.

Caregivers play an important role in healthcare and help to ensure that patients receive physical and emotional care especially in the absence of healthcare professionals.

In order learn how to best provide care to the caregiver, the nursing profession must engage in rich conversation with those individuals experiencing the phenomenon. This study serves as the foundation to seek the perspectives of other caregivers who have experienced decision-making regarding feeding tube placement. This information can be analyzed and nursing can then educate themselves and others. The information that is provided to subsequent caregivers experiencing the same phenomenon is based on their predecessors. This significantly contributes to evidence-based practice. Caregivers are provided with material that is applicable and practical to the decision-making experience for PEG feeding tubes.

Researcher's Relationship to the Topic

The researcher's interest in this topic emerged in 2016 while beginning a new role as a nurse practitioner at a large academic institution. The researcher was offered an opportunity to start a new clinic at the institution that was solely focused on PEG feeding tubes. There were previous challenges with getting patients into clinic in a timely and efficient manner to discuss options for declining nutrition such as PEG feeding tube placement as well as addressing complications with existing PEG feeding tubes.

The researcher was able to successfully start the nurse practitioner operated clinic but quickly realized that there were several issues and concerns addressed by the patient and caregiver during the clinic visits and via telephone calls. Caregivers voiced concerns and frustration about lack of support and education post PEG feeding tube placement. Some of the caregivers even voiced concerns regarding tension between the patient and caregiver. Some of the statements and questions included "There is no support for

families after they place the PEG feeding tube.” “Who do I call when I have problems with the tube or the formula?” “How do I take care of the PEG feeding tube?” “He does not want to look at the PEG feeding tube because it makes him depressed? What do I do?” “I am still trying to work and take care of the feedings. This is hard.”

If caregivers voiced these concerns in the presence of the patient, then what concerns would they voice when interviewed alone? The researcher was curious to understand the decision-making experience for the caregiver who often takes care of these individuals post PEG feeding tube placement. Education is usually so patient-focused that nurses forget that the caregivers are often heavily involved in providing care for these individuals once they are discharged. The researcher wanted to know how to better prepare not only the individual receiving the PEG feeding tube but also the caregiver who will accompany the patient post PEG feeding tube placement and likely through the course of their treatment plan. As a practicing nurse practitioner and sole provider in the PEG feeding tube clinic, the researcher is interested in providing holistic care and relieving caregiver burden. Consequently, this study was developed with the intention of addressing this gap in clinical practice.

Philosophical Underpinnings

This descriptive phenomenological study utilized the philosophical underpinnings of Edmund Husserl to describe the experiences of caregivers regarding decision-making for PEG feeding tube placement in community dwelling adults. Edmund Husserl Gustav Albrecht (1859–1938) was a German philosopher and mathematician who is well known for his work in descriptive phenomenology (Welch, 1939). Phenomenology is defined as

the ability to describe human experiences without utilizing theoretical frameworks (Welch, 1939). Descriptive phenomenology, in particular, allows the researcher to describe the lived experience of others based on their own understanding. Husserl's underpinnings assumed that the lived experiences were not described based on a generalized theory (Husserl, 1973). He moved away from naturalism and suggested that it was the study of consciousness that gave meaning to the experience and the foundation of knowledge and understanding (Husserl, 1973). Naturalism is a theory that assumes all beings and events are of the natural world (products of the earth such as plants, animals, air, and water) and split between the natural and supernatural realm. Husserl believed that the researcher could then determine what was fundamental to those experiences.

He believed that the source of all knowledge was derived from the subjective meanings of one's experience (Reiners, 2012). Husserl stated that there is no way of knowing if an object or experience has a different meaning other than the meaning humans assign to it (Husserl, 1973). Humans reflect on their lived experience and then assign meaning to those experiences (Husserl, 1973). Husserl termed this concept *intentionality*. Intentionality assigns meaning to all human experience that give rise to a phenomenon (Husserl, 1973; Welch, 1939).

Husserl's fundamental principle was *phenomenological reduction* (Reiners, 2012). Phenomenological reduction allows the researcher to fully perceive and understanding the experience without external bias (Husserl, 1973; Welch, 1939). Husserl termed this process transcendental subjectivity. The researcher is able to obtain the true meaning or essence of the experience. In order to enact phenomenological

reduction, humans must “bracket” or set aside preconceived ideas and beliefs, which Husserl referred to as the “natural attitude” (Reiners, 2012). The act of “bracketing” the “natural attitude” is known as epoché (Husserl, 1973; Welch, 1939). The researchers must first identify their bias and preconceived ideas in order to have awareness so that they can be removed from the consciousness (Husserl, 1973; Reiners, 2012; Welch, 1939). This may be accomplished with the use of journaling. Those biases are set aside so the researcher can transcend their personal beliefs and opinions to understand the beliefs and opinions of others.

Eidetic reduction occurs once the researcher tries to analyze the phenomenon of the participants in order to understand the essence or “pure” consciousness of their experiences (Husserl, 1973; Welch, 1939). The researcher examines the experiences, which are often described via interviews and then attempts to draw various inferences from those experiences. The researcher must then determine the essential elements of that experience which cannot be eliminated. If eliminated, those elements would completely change the participant’s experiences as they described it. This allows the researcher to truly describe an experience as perceived and understood from the perspective of the others and not from their own perspective.

After identifying those essential elements or the essence of the experience, the researcher participates in phenomenological proper also known as reduction proper (Husserl, 1973; Welch, 1939). During phenomenological proper, the researcher describes the essence of the lived experience of the participants (Husserl, 1973; Welch, 1939). This essence is deemed likely to be true for all who experience the same lived experience or

phenomenon (Husserl, 1973; Welch, 1939). This also helps to ensure the generalizability of the study.

This research method seeks to describe how an individual perceives their experiences of the phenomenon being study. Descriptive phenomenology was a good choice for this study because it allowed the researcher to bracket preconceived ideas and beliefs in order to actively listen to the decision-making experiences of caregivers of adults with PEG feeding tubes. The research method allowed the researcher to describe a phenomenon that can improve the delivery of care, patient outcomes, and quality of life.

Assumptions

Assumptions of this study included:

1. Caregivers are able to honestly disclose and relate their experiences and role of decision-making regarding PEG feeding tube placement in community dwelling adults.
2. Caregivers are genuinely interested in sharing their experiences for the enhancement of evidence-based practice.
3. Purposive sampling will allow the researcher to have access to rich and detailed experiences of caregivers who have experienced decision-making regarding PEG feeding tube placement in community dwelling adults.
4. Caregivers provide data that informs the research question.
5. Understanding the decision-making experiences of caregivers regarding PEG feeding tube placement will lead to the development of new strategies to relieve caregiver burden and potentially affect standards of care in clinical practice.

Research Question

A descriptive qualitative study was proposed to investigate the research question:
What are the decision-making experiences of caregivers regarding PEG feeding tube placement for community dwelling adults?

Summary

Individuals are living longer with the progression of advanced medical technology and new discoveries in medicine. Subsequently, the population is getting older and is living with more co-morbidities and chronic illnesses. Declining nutrition resulting in PEG feeding tube placement may be one of the long-term effects of chronic illness such as a cerebral vascular accident, paralysis, and muscular to dystrophy. The literature findings suggest that patients and their caregivers are both affected by PEG feeding tube placement. The gap in the literature is the lack of information about the caregiver's role and experience with decision-making for PEG feeding tube placement and how they were affected. A descriptive phenomenological study is proposed to describe the experiences of caregivers regarding decision-making for PEG feeding tube placement in community dwelling adults. The findings of this study may contribute to the relief of caregiver burden as it relates to PEG feeding tube placement and support further nursing research.

CHAPTER II

DECISIONAL CONFLICT IN PERCUTANEOUS GASTROSTOMY TUBE PLACEMENT IN ADULTS: AN INTEGRATIVE REVIEW OF THE LITERATURE

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Abstract

Percutaneous endoscopic gastrostomy tubes are placed when individuals are unable to orally consume adequate nutrition and require an alternative method to meet their daily nutritional needs. This decision is multi-factorial and depends on the prognosis of the illness, the patients' wishes, and weighing risks versus benefits. The recent movement towards patient-centered care supports open communication and shared decision-making, which has the potential to mitigate decisional conflict. The aim of this literature review was to identify factors associated with the decision-making process for gastrostomy tube placement for adults. Three quantitative, four qualitative, and one Q-methodology studies were analyzed. Social life, body image and intimacy, uncertainty and fear, complications, and burden to caregiver were central factors that influenced decision-making. Social life and body image associated with intimacy were found to be the most prevalent themes in the review. This review indicates that decision-making for gastrostomy tube placement is highly individualized. Patients need adequate information to make informed decisions

that are congruent with their healthcare goals. Nurses should act as patient advocates and must have candid discussions to ensure that patients have received thorough and adequate information regarding gastrostomy placement and management.

Introduction

The decision to place a feeding tube when death is not imminent can be a daunting topic and task for the patient and family. Chronic illnesses such as motor neuron disorders, cerebral vascular accident, cognitive impairment, paralysis, and head and neck cancer have been identified as situations that may require PEG tube placement. Declining nutrition can be a symptom of chronic diseases. According to the most recent statistics from the National Centers for Health Statistics, approximately 245,000 patients received tube feedings (Centers for Disease Control and Prevention, 2018).

PEG tube placement was first performed in 1980 as a new method to place a feeding tube and provide long-term nutrition instead of surgically placing the feeding tube (Gauderer et al., 1980). Endoscopic placement allows a PEG tube to be placed using a less invasive method other than surgery (Yuan et al., 2016). However, the studies have shown that the literature is conflicting and the recommendation for PEG tube placement in other chronic illness is inconsistent in clinical practice (Gieniusz et al., 2018; Mayre-Chilton et al., 2011; Merrick & Farrell, 2012; Stavroulakis et al., 2014). In these situations, decisional conflict may be even more prevalent because treatment planning decisions are formulated even when the course of their disease may not be clear (Hamilton et al., 2013). The presence of a PEG tube may prolong the patient's life but may not enhance the quality of their life (Peck, Cohen, & Mulvihill, 1990). PEG tube

placement may also be accompanied by complications such as leakage, infection, discomfort, and body image issues. PEG tube placement may also conflict with the patient's personal healthcare goals and beliefs.

Decisional conflict is conceptually defined as uncertainty about a course of action that involves unknown outcomes or risks resulting in potential significant consequences, high probability of regret, or the potential to compromise values when selecting a choice (O'Connor, 1995). O'Connor (1995) conducted a concept analysis where she explained that decisional conflict is exhibited via assessing personal beliefs, weighing all potential options, signs and symptoms of stress, and avoiding decision-making. The contributing factors to this phenomenon have been the focus of many studies, yet individuals are still faced with decisional conflict especially in healthcare where the outcomes may not be guaranteed.

Gieniusz et al. (2018) stated that the decision to receive enteral nutrition should be approached from an individualized perspective with the patient's wishes being thoroughly discussed and incorporated into the decision. The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) supports this statement by adding that nurses should present evidence-based literature to the patient to assist with decision-making (Barrocas et al., 2010). In addition to encouraging patients to actively participate in the decision-making process, patients need to have access to the evidence with a strong understanding of the literature to make informed decisions (Gieniusz et al., 2018; Hanson et al., 2011; Yeh et al., 2013). However, the literature and expert opinion are not always clear and definite. This combination of factors can lead to an ambiguous situation for

treatment planning and decision-making. The literature highlights feeding tube placement as a common procedure in healthcare. Patients need to be aware of all factors prior to making a decision.

Background

PEG tube placement was first performed in 1980 as a new method to place a feeding tube and provide nutrition instead of surgically placing the feeding tube (Gauderer et al., 1980). Endoscopic placement allows a PEG tube to be placed using a less invasive method other than surgery (Yuan et al., 2016). The terms PEG tube, feeding tube, and enteral nutrition is used interchangeably and simultaneously in clinical practice. For this integrative literature review, the term PEG tube will be used.

According to Barrocas et al. (2010), there are no definitive practice guidelines for who should and should not receive a PEG tube. The available evidence, patient preferences, and clinical judgment should be considered when making this decision. If the patients' healthcare goals are not acknowledged and respected, there is the chance that the patient may regret their decision if the outcome is not as they anticipated. Patients should be able to make a decision that they can accept even if the outcome is unfavorable or different from anticipated. The meaning of the concept of a favorable outcome is individualized. Some patients may value quantity of life versus quality of life and vice versa. These personal philosophies and worldviews must be explored with the patient. Nurses have their own personal philosophies that guide their practice and research interests. It is important that nurses do not allow their own personal worldviews about feeding tube placement and artificial nutrition to affect the education that is provided to

the patient. Nurses are morally obligated to allow patients to maintain their autonomy if they are mentally competent (Barrocas et al., 2010). Decisions are highly individualized, and patients need to consider all aspects of a feeding tube prior to making the decision to proceed with PEG tube placement. Ultimately, the patient will have to be content with the outcome of the decision.

The Review

Aims

The aim of this integrative literature review is to gain a better understanding of the factors associated with decisional making in percutaneous gastrostomy tube placement. This review utilizes an integrative methodology as guided by Whittemore and Knafl (2005), which consist of five elements: problem identification, literature search or methods, data evaluation, data analysis or results, and presentation or conclusion. The variables of interest are decisional conflict and feeding tube placement in the context of adult patients. The sampling frame was directed at review of primary research studies addressing decision-making in feeding tube placement for adult patients. The selected articles identified key factors that affect decision-making in feeding tube placement.

Methods

A search of the databases Cumulative Index of Nursing and Allied Health Literature (CINAHL), Embase, MEDLINE, and PubMed was conducted using the keywords “decisional conflict,” “decision-making,” “enteral nutrition,” “feeding tube,” and “percutaneous endoscopic gastrostomy tube.” These combinations of search terms were identified by the literature as well as terms and phrases that are often used in clinical

practice. The date range was selected from 2008–2018 to identify the most recent and relevant literature. A hand search was also conducted which yielded 26 articles. The database search yielded 1,482 articles with 660 articles remaining after duplicates were removed. Inclusion criteria included (a) the English language; (b) decision-making and ambiguity in the context of nursing; and (c) full text articles. Exclusion criteria included (a) languages other than English, (b) lack of relevance, (c) grey literature, and (d) abstracts. Grey literature was excluded because the focus was to examine primary research on this topic. These criteria were determined based on gaps identified in the literature, and the author's desire to enhance nursing practice and patient outcomes.

Whittemore and Knafl (2005) encouraged disclosure of the limitations of the selected studies via quality assessment using an instrument or scoring system. The data was evaluated using the John Hopkins Evidence-Based Practice Evidence Level and Quality Guide (JHNEBP). The goal of this tool is to ensure quality appraisal of the most recent literature and incorporation of that literature into clinical practice (Dang & Dearholt, 2017). This tool has also been used in various studies by novice and expert researchers and nurses (Buccheri & Sharifi, 2017). This evaluation tool focuses on appraising the study for evidence grades with specific definitions of quality for Levels I-III, Level IV, and Level V. The eight selected studies for the integrative literature review were all Level III evidence with three non-experimental studies, four qualitative studies, and one Q-methodology study. The key themes and patterns were appropriately identified and translated to clinical implications and ideas for future research. The

recommendations in the studies were strongly supported by review of the literature and thorough and logical data synthesis.

Search Outcomes

The Preferred Reporting System for Systematic Reviews and Meta-analyses (PRISMA) was used to retrieve articles relevant to this integrative review (see Figure 1; Moher, Liberati, Tetzlaff, & Altman, 2009). The titles and abstracts of the literature were reviewed for relevance to the topic, which yielded 161 articles. Ninety-three articles were excluded because they focused more on clinical decision-making of the providers, included grey literature, or focused on the technical skills of PEG tube placement. This resulted in 68 articles. Of those articles, 60 articles were excluded because they did not specifically focus on decisional conflict in PEG tube placement from the patients' perspectives. As a result, three quantitative, four qualitative, and one Q-methodology studies were selected for data analysis.

Data Abstraction and Synthesis

There were 726 patients that participated in the eight studies utilized for this review. The age range was from 32–91 years old. There were 351 male patients and 359 female patients. Brotherton and Abbott (2009) did not overtly disclose the characteristics of their 16 patients. The diagnoses for the review consisted of head and neck cancer (36 patients), unspecified cancer diagnosis (58 patients), motor neuron disease (11 patients), multiple sclerosis (4 patients), cognitive impairment (172 patients), and stroke (330 patients). There was no diagnosis provided for 114 patients. One patient had progressive pharyngeal scarring.

Whittemore and Knafl (2005) recommended a constant comparison method to help identify themes, patterns, and relationships. Data reduction is the first phase of data analysis and includes identifying a classification system for the data being reviewed (Whittemore & Knafl, 2005). The information was arranged in ascending alphabetical. Next, the following categories were identified for data extraction: author and year, country, title of study, study design, sample size, and main outcomes. These categories were constantly reviewed and revised throughout data analysis to ensure that all pertinent data was captured. Whittemore and Knafl (2005) stated that the second phase in data reduction is to organize the data in a logical and manageable method. The information was then entered into a data extraction matrix (see Table 2.1). This allows for easy identification and visualization of the themes, patterns, and relations of the primary research studies (Whittemore & Knafl, 2005). The following paragraphs describe the themes, patterns, and relationships that were identified in the primary research studies selected for this integrative literature review.

Results

Description of Included Studies

A total of eight primary research studies that met the criteria were selected for review. Two of the studies identified decisional conflict as an outcome of PEG tube placement and sought to identify the contributing factors (Stavroulakis et al., 2014; Vesey, Leslie, & Exley, 2008). Four phenomenological studies aimed to describe the patients' journeys and experiences with decision-making for PEG tube placement (Brotherton & Abbott, 2009; Kwong et al., 2014; Vesey et al., 2008; Mayre-Chilton et

al., 2011). Chow Yeow et al. (2012) conducted a correlational study between various variables and decision-making regarding PEG tube placement.

One Q-methodology study (Merrick & Farrell, 2012) offered a dynamic approach to clarify ideas and concepts before systematically analyzing those concepts. All of the studies described the PEG tube decision-making process and uncertainty associated with the process from the patients' perspectives. Five of the studies were conducted in the outpatient clinic or community setting. Two of the studies were in a hospital setting. One study recruited participants from both outpatient and inpatient settings. The geographic locations included North America, Europe, and Asia.

Whittemore and Knafl (2005) stated that data evaluation is determined based on the sampling frame and a quality appraisal tool such as JHNEBP. Therefore, all of the above studies were included as long as they met the inclusions and exclusion criteria. The aim was to identify those factors that contribute to decisional conflict and highlight the common themes in the context of PEG tube placement. These factors were included in the overall data analysis and practice implications. Several of the studies also identified the gaps in the literature and possible options for future research to decrease decisional conflict.

Main Findings

Social life. Issues with modifications to patients' social lives were found to be a key factor in the decision-making of PEG tube placement. Patients expressed concern that the inability or limited ability to orally consume nutrition would alter their social relationships with friends and family especially in public places. Mayre-Chilton et al.

(2011) found that some of the patients expressed concern over watching other people orally consume and enjoy their meal while they used tube feeding formula as their source of nutrition. Other patients stated that they could orally consume small amounts of food but used the PEG tube as a supplemental source of nutrition. Patients also expressed distress with tube feeding in public restaurants so they would arrange to feed before or after their outing (Kwong et al., 2014). One patient even stated that he had to use his car more for transportation because that was his “mobile dining room” (Mayre-Chilton et al., 2011). The majority (66%) of older adults believed that PEG placement did not enhance their social life or quality of life (Chow Yeow et al., 2012).

Some patients expressed frustration with the length of time it took them to eat only a small portion of their food while their family and friends had already completed their meal (Mayre-Chilton et al., 2011). Stavroulakis et al. (2014) found that some patients were hesitant about PEG tube placement because they did not want to give up the pleasures of oral nutrition. These patients stated that eating was a social activity for them and a way for them to interact with their family and friends (Stavroulakis et al., 2014). Brotherton and Abbott (2009) explained that patients actually felt frustrated that nurses had not thoroughly explained the intricate details that would significantly affect the patients’ social life. Kwong et al. (2014), however, found that patients often eventually adapted to the PEG tube. For some of the patients, they felt that people were often supportive and understanding once they were open and honest about their nutritional condition.

Body image and intimacy. Body image is a central theme for the discussion surrounding PEG tube placement. Lin, Li, and Watson (2011) found that many patients did not want a foreign object inserted into their body because of personal and cultural beliefs. The issue of body image seemed to be the most prevalent in female patients. Vesey et al. (2008) found that all seven of their female participants reported issues with body image. The women commented that the PEG tube was bulky and felt like others could see it although the PEG tube was under their clothes and not overly visible (Vesey et al., 2008). One of the women specifically explained that she would walk around and not exhale because she was trying to hide the PEG tube (Vesey et al., 2008).

Merrick and Farrell (2012) identified cognitive-affective dissonance as a factor in decision-making for PEG tube placement. One of the patients referred to the tube as an “alien” and vocalized that she could not wait to have it removed. She explained that she started to obsess that others might see the PEG tube. Intimacy and sexual intercourse were also found to be key themes associated with body image. Mayre-Chilton et al. (2011) discussed the obstacles that PEG tube placement could present as it relates to sexual intercourse. Patients expressed concerns with starting new relationships and knowing that they may not feel comfortable enough to be naked and intimate with their partner (Mayre-Chilton et al., 2011).

Uncertainty, fear, and anxiety. Fear of the unknown was identified as a key factor in the literature. Patients expressed concern over the technical aspects of PEG tube placement and voiced concern about having to undergo a procedure (Kwong et al., 2014; Lin et al., 2011; Merrick & Farrell, 2012; Stavroulakis et al., 2014). Patients

identified that the fear of the unknown regarding the course of their disease and prognosis caused them to be reluctant to make a decision regarding PEG tube placement (Stavroulakis et al., 2014). One patient explained that anyone would be hesitant if they were getting a “hole in their stomach” (Kwong et al., 2014, p. 529). Patients also identified that nurses failed to provide adequate information and were perceived to have a nonchalant attitude when discussing PEG tube placement with the patients (Brotherton & Abbott, 2009). One patient stated that the provider seemed to forget that he knew nothing about a PEG tube (Brotherton & Abbott, 2009). These factors contributed to patients’ uncertainty regarding PEG tube placement. Kwong et al. (2014) found that patients were satisfied with the decision once they decided to proceed with PEG tube placement even if they initially experienced anxiety.

Complications. Patients voiced concerns that the complications of PEG tube placement were not thoroughly discussed prior to insertion although they deemed most complications to be minor and more of a nuisance (Lin et al, 2011). Approximately 121 of the 607 patients experienced PEG tube infection or leakage and expressed distress over lack of information regarding how to manage these complications (Lin et al., 2011). In the study by Brotherton and Abbott (2009), 10 of the 16 patients stated that they did not receive enough or appropriate information about the PEG tube. The patients stated that the information was more focused on the rationale and technical skills for PEG tube placement and not on the complications and daily routine of life with a PEG tube (Brotherton & Abbott, 2009).

Caregiver burden. Caregiver burden was another theme that was associated with decision-making regarding PEG tube placement. Merrick and Farrell (2012) noted that patients felt that having a PEG tube placed was a burden to their family and friends. Patients were concerned about burdening their family and friends with the expenses required for the purchase of tube feeding formula and supplies (Mayre-Chilton et al., 2011). This feeling of concern stemmed from the patients' perceptions regarding lack of community resources for individuals with PEG tubes (Mayre-Chilton et al., 2011). The patients specifically vocalized a concern about the lack of psychological, emotional, and social support in the community once they were discharged from the hospital (Mayre-Chilton et al., 2011). They felt that this resulted in emotional and psychological strain on their family and friends. Kwong et al. (2014) noted that patients still expressed feeling supported by their family and friends although they were concerned that PEG tube placement would be a burden.

Discussion

This integrative literature review describes some of the factors that contribute to decisional conflict in PEG tube placement for patients. The literature is conflicting and some of the studies selected for review described different perspectives of the patients regarding PEG tube placement. While several key themes were identified in the studies, it is clear that there are no universal deciding factors in the decision-making process for PEG tube placement. PEG tube placement is individualized. The uncertainty of the prognosis and lack of standard recommendations can create an ambiguous situation. The literature highlights that the recommendation for PEG tube placement varies depending

on the illness, prognosis, nurses, and patients' wishes. There is no general consensus because there are numerous reasons why a PEG tube is placed, and patients have different health goals and lived experiences that influence their decision. The findings implicate that exploration of the patient's personal values and beliefs is important because there is no definitive right or wrong decision. This can subsequently help ensure that patients are content with their ultimate decision.

Nurses can specifically affect the decision by providing all possible information regarding PEG tube placement in order to ensure that patients are making informed decisions and are able to weigh the risks and benefits themselves. This also helps to ensure that the decision to place a PEG tube is congruent with patients' expectations for their care and treatment plan. Also, patients are able to address any issues of uncertainty, anxiety, and fear if they are allotted time to receive information, ask questions, and process the content. Analysis of the literature and findings suggest that information and open communication are central to the decision-making process for PEG tube placement. PEG tube placement alters patients' personal and social lives. The outcome is perceived as negative or positive based on the individual interpretations of PEG tube placement and its alignment with their personal worldviews.

This integrative literature review has some limitation. Some of the selected studies had a relatively small sample size and recruited participants from only one site. As a result, the generalizability of the findings may be limited. In addition, some of the studies used self-reporting that is subjective and draws upon memory recall during the decision-making process for PEG tube placement.

Conclusion

This integrative literature review aimed to address the following main question. What are the factors associated with decisional conflict in gastrostomy tube placement in adults? Whittemore and Knafl guided the data analysis, and themes were identified in the studies. The findings suggest that patient education combined with the exploration of personal healthcare goals is important to alleviate decisional conflict regarding PEG tube placement in adults. Nurses are in a unique position that allows the delivery of direct patient care in addition to addressing psychosocial needs and questions. The studies suggest that nurses should ensure that patients have ample time to make a decision that they will not regret even if the outcome is unfavorable. Some studies identified that some adults were pleased with their decision to place the PEG tube although they experienced complications with the PEG tube (Kwong et al., 2014; Mayre-Chilton et al., 2011). Some other studies, however, suggested that adults expressed regret with PEG tube placement although they did not experience complications (Mayre-Chilton et al., 2011; Merrick & Farrell, 2012). It can be concluded that this decision is multifactorial, and there is no universal answer. By empowering patients to participate in treatment decisions, healthcare continues to move towards a holistic approach.

This integrative literature review contributes to nursing practice by exploring a phenomenon and understanding the existing literature, while identifying areas for further research (Whittemore & Knafl, 2005). Based on the findings of this integrative literature review, there is an identified need for critical evaluation and reasoning to enhance patient outcomes. The data is conflicting, and patients are expected to make treatment decisions

in the face of uncertainty and emotional distress. Nurses are in a position to act as patient advocates and help identify factors that contribute to decisional conflict in PEG tube placement especially as healthcare moves toward a more patient-centered approach. This also increases patient satisfaction. Not every patient has the same needs or personal healthcare goals.

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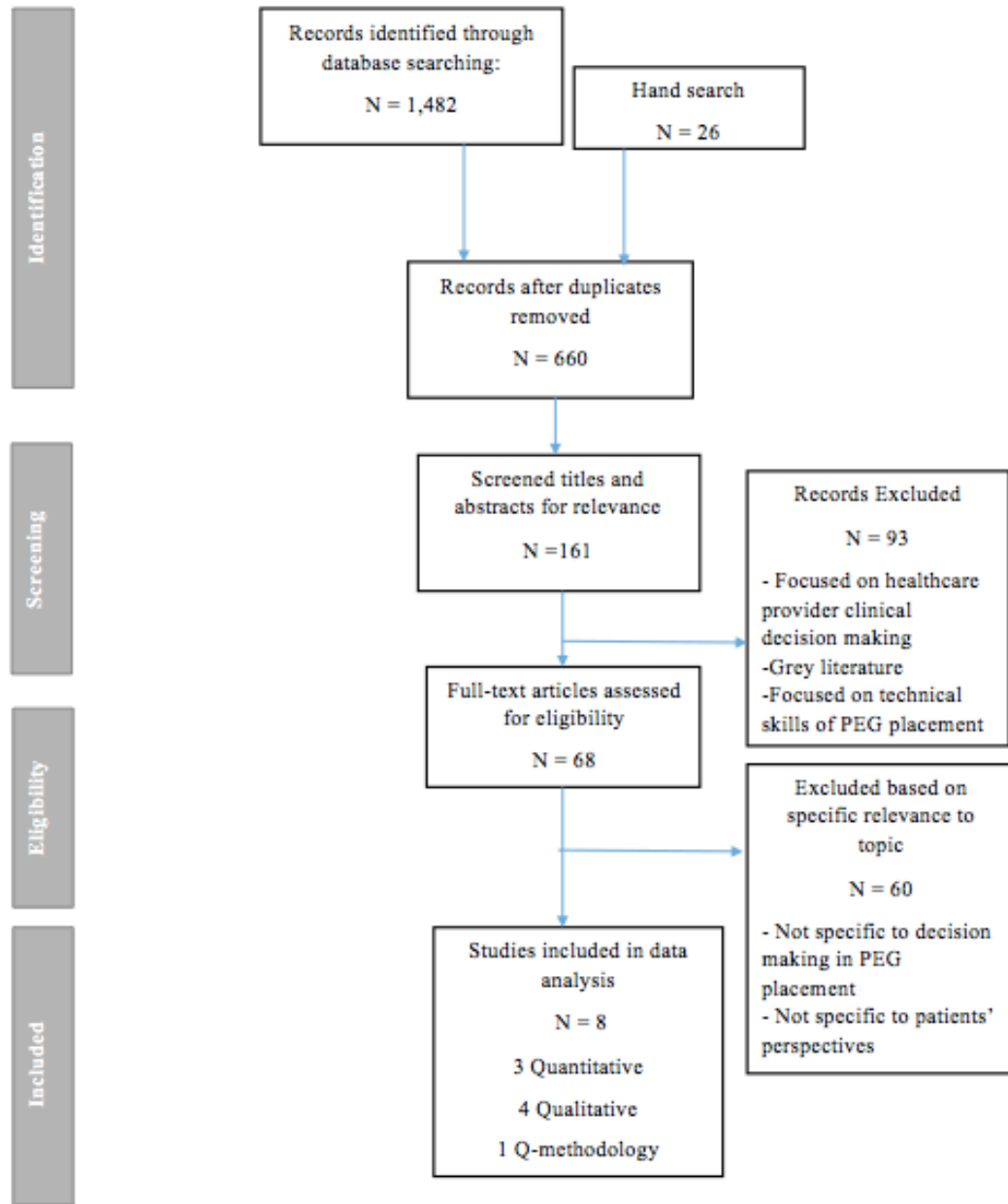
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Author, year, country	Title of study	Study design	Sample size	Main outcomes
Vesey et al. (2008) UK	A pilot study exploring the factors that influence the decision to have PEG feeding in patients with progressive conditions	Phenomenology	n = 7 patients	No alternatives provided and felt the decision would save their lives; All female patients reported issues with body image; 5 out of 7 patients expressed a lack of time and information to make decision
Brotherton & Abbott (2009) UK	Clinical decision making and the provision of information in percutaneous endoscopic gastrostomy (PEG) tube feeding: An exploration of patients and their carers' perceptions	Phenomenology	n = 16 patients n = 27 caregivers	Poor communication, lack of information and inappropriate information, paternalistic attitudes of HCPs, and feeling excluded from the decision-making process
Lin et al. (2011) Taiwan	A survey of the reasons patients do not choose PEG tube as a route for long-term feeding	Cross sectional	n = 607 patients	Most common reasons patients refused PEG tube: cultural beliefs, belief that they were "too old" for an operation, worried about complications, and body image
Mayre-Chilton et al. (2011) UK	Different experiences and perspectives between head and neck cancer patients and their care-givers on their daily impact of a gastrostomy tube	Grounded theory	n = 6 head and neck cancer patients	Conflicting advice and the omission of information; Patients worried about caregiver burden especially with finances; Negative impact on social and personal aspects of life especially intimacy
Chow et al. (2012) Singapore	Research in brief: Perception of tube-feeding among older adults with mild cognitive impairment and their family surrogates	Correlational	n = 50 older adults and family surrogates	66% of older adults and 60% of family surrogates perceived poor quality of life with PEG; 62% of family surrogates were comfortable with PEG decision making but only 26% were aware of the older adults' preferences; Differences in perception regarding PEG placement
Merrick & Farrell (2012) UK	Head and neck cancer patients' experiences of percutaneous endoscopic gastrostomy feeding: A Q-methodology study	Conventional Q-methodology	n = 15 head and neck cancer patients	Reported fear and anxiety with PEG tube placement; 6 out of 15 participants did not recognize medical benefits of PEG tube
Kwong et al. (2014) Canada	The experiences of patients with advanced head and neck cancer with a percutaneous endoscopic gastrostomy tube: A qualitative descriptive study	Phenomenology	n = 15 patients head and neck cancer patients	Initial concerns with PEG placement: Altered social life, uncertainty, and caregiver burden. After adaptation to life with a PEG tube, the patient stated that the tube became a normal part of their routine
Stavroulakis et al. (2014) UK	Factors influencing decision making in relation to timing of gastrostomy insertion in patients with motor neuron disease	Retrospective	n = 10 patients with motor neuron disease	Factors delaying feeding tube placement: reluctance to give up oral consumption of food, uncertainty, negative perception, not fully understanding the benefits
† PEG: Percutaneous endoscopic gastrostomy				
‡ HCP: Healthcare provider				

Figure 1: PRISMA Flow Diagram



(Moher et al., 2009)

Figure 1

PRISMA Flow Diagram

CHAPTER III

METHODOLOGY

Procedure for the Collection and Treatment of Data

A descriptive phenomenological study was used to gain a better understanding of the caregiver's experience regarding decision-making for PEG feeding tube placement in community dwelling adults. This study was guided by the philosophical underpinnings of Edmund Husserl's descriptive phenomenology and Colaizzi's method of data analysis. The study focused on understanding the true and pure decision-making experiences of caregivers regarding PEG feeding tube placement. The researcher set aside her personal biases and prejudices to transcend beyond the "natural attitude" with the aim of describing and understanding the experience solely from the caregiver's perspective. Husserl argued that this is the only way to gain knowledge and assign meaning to individual experiences that shape the human being and perceptions. This chapter presents information on the study setting, participants, protection of human subjects, data collection and analysis, and qualitative rigor.

Setting

The setting of this study was six post-acute care rehabilitation and skilled nursing facilities (The Medical Resort at Bay Area, The Medical Resort at Sugar Land, The Medical Resort at Willowbrook, The Resort at Texas City, The Medical Resort at Pearland, and The Medical Resort at the Woodlands) in Houston, Texas and the

surrounding areas. Senior Care Excellence owns all of these facilities. Each facility has approximately 100 beds with the average length of stay being 30 days. These facilities provide physical therapy services, occupational services, speech pathology services, dialysis services, hospice, ventilator services, and Alzheimer services. There is a team of physicians from different specialties who provide care to patients in the facility to ensure the highest quality and continuity of care. The vice president of operations provided a letter of support to the Texas Woman's University Institutional Review Board for this study (see Appendix A).

Participants

Purposive sampling was used to recruit participants. Polit and Beck (2012) stated purposive sampling is often used to select participants who are likely typical of the population being studied or who are knowledgeable about the issues under study. The sample will consist of participants who are English speaking, 18 years of age and older, role in the decision-making, and intending to provide care for at least 4 hours per day (see Appendix B). The caregiver must be an adult over the age of 18 in order to legally make decisions/provide consent. They must have had some role in the decision-making in order to share their experience regarding the phenomenon. They must intend to provide care in order to be deemed a caregiver. The gastrostomy tube must have been placed in the last 7 days, and the ultimate goal must be for the patient to be discharged to a private home. Recall of emotions and feelings is significant to this study so the researcher wanted to capture those feelings as close to the time of the experience as possible. Exclusion

criteria were ultimate discharge to a long-term care facility or a caregiver who was not involved in the decision-making or daily care for the patient.

There were two daughters (a fulltime employee and a homemaker) and one sister (retired) selected for the pilot study. They represented Asian, African American, and non-Hispanic Caucasian ethnicities. The age range was from 30s–70s. The sample size for the pilot study was 10% of the projected sample size for the dissertation (Polit & Beck, 2012). The sample size for the dissertation study is 35 or until data saturation. Data saturation occurs when there is no new data, no new themes, no new coding, and the ability to replicate the study is evident (Fusch & Ness, 2015; Guest, Bunce, & Johnson, 2006; O'Reilly & Parker, 2012; Walker, 2012). The main goal of achieving an adequate sample size is to ensure that there is rich data to help answer the research question (Fusch & Ness, 2015).

Protection of Human Subjects

After obtaining a letter of support from Senior Care Excellence and receiving human subjects' approval from the Texas Woman's University Institutional Review Board, the researcher posted recruitment announcements in the post-acute care rehabilitation and skilled nursing facilities' foyers, cafeterias, and day rooms (see Appendix C & Appendix D). The Vice President of Operations also provided the researcher with a list of all of the patients who have had a gastrostomy tube placed in the last 7 days, and the researcher left a flyer at the bedside of those patients. The researcher also reached out to the caregivers of these patients who met the inclusion criteria in person, by telephone, or by email and provided them with an introduction, description of

the study, and invitation to contact the researcher with any questions (see Appendix E & Appendix F). The researcher sent a follow-up recruitment email if she had not received a response within 48 hours (see Appendix G).

Potential participants who were interested in participating in the study had the option to contact the researcher by telephone, text, or e-mail. Once a caregiver contacted the researcher and expressed interest in the study, the researcher contacted the individual and further discussed the purpose of the study, the inclusion criteria, the time commitment, and the data collection methods of the study. The researcher answered any of the potential participant's questions. Once the participant agreed to an interview, individual interviews took place in person, via FaceTime or Skype, according to the participant's preference. The researcher made email and/or telephone/text reminders confirming the interview 24-48 hours prior to the scheduled time.

If the participant chose to be interviewed via telephone, FaceTime, or Skype, the researcher e-mailed or mailed the informed consent in advance of the interview. Before commencing the interview, the participant was re-informed of the study purpose, potential risks, and the anticipated time commitment. The researcher stressed that participation was strictly voluntary and that he or she could withdraw from the study at any time without repercussions. All questions were answered and consent was signed prior to collecting any data (see Appendix H). For the pilot study, all three participants chose in person interviews that were conducted in a secure and private location at the approved facility.

Potential Risks

A potential risk in this study was loss of confidentiality. Confidentiality was protected to the extent that is allowed by law. The interview was held at a private location that the participant and the researcher agreed upon. No one but the researcher knew the full name of the participant. The audio recording and the written interview are stored in the locked fireproof safe at the researcher's home office and only accessible to the researcher. All identifying information was deleted from the transcript. The audio recordings will be deleted by August 1, 2021. There was a potential risk of loss of confidentiality in all email, downloading, and Internet transactions. The results of the study may be reported in scientific magazines or journals but the participant's name or any other identifying information will not be included.

Another potential risk in this study was loss of time. The anticipated total time commitment for the interview and potential follow-up activities (i.e., clarification, member checking, discussing the findings) was approximately two hours. The participants were instructed to let the researcher know if they were unable to accommodate this time commitment.

Another potential risk in this study was fatigue. During the interview, the participant was informed that they could stop and take breaks at any point during the interview. They were free to stop study participation at any time without consequence.

Another potential risk in this study was emotional upset. The participants were informed that they could stop and take breaks at any point during the interview, or stop the interview completely without repercussions. The following resources were provided

to the participants if they needed to seek help: Jewish Family Services and National Alliance of Mental Illness Greater Houston. The contact information was provided to the participants upon request.

The researcher tried to prevent any problem that could happen because of this research. The participants were instructed to let the researcher know at once if there was a problem. However, Texas Woman's University does not provide medical services or financial assistance for injuries that might happen because they took part in this research.

Potential Benefits

The participants were informed that their involvement in this study was voluntary and they could withdraw from the study at any time. Following the completion of the study, they received a \$20 gift card for their participation. If they are asked to discuss findings of the study, they will receive an additional \$10 gift card. Participants who choose to participate in the interview via phone, Skype, or FaceTime, received Target electronic gift card via e-mail. If they wanted to know the results of this study, they were informed that the researcher would mail or email them to the participant.

Data Collection

Instruments

A demographic data collection form was used to capture the participants' relationship to the patient, sex, ethnicity, education level, marital status, employment status, and information regarding care provided to the patient. The demographic data form was coded for confidentiality but was treated as identifiable data due to the anticipated small sample size. The prepared semi-structured interview guide steered the

interview (see Appendix I). The interview guide posed questions to the participant regarding their experience, particularly related to how they became aware of the possibility of feeding tube placement, the people involved in the discussion, the information that was provided to them, their role in the decision-making for PEG tube placement, barriers and factors contributing to the decision. The researcher also asked the participants to describe how information for PEG feeding tube placement and management can be explained to caregivers more clearly and effectively.

Data Collection Procedures

The researcher reviewed study details (i.e., purpose, inclusion criteria, data collection, and time commitment) and reviewed the informed consent form before the study procedures began. Consent was obtained from each participant prior to collecting any data. Demographic data was collected using a demographic data collection form, which was coded for confidentiality (see Appendix J). The demographic data collection form and the document that links the participants' names to the code number remained in a locked fireproof safe in the home of the researcher and only accessible to the researcher.

Each interview was audio recorded. The participant was addressed by a code name of their choice to maintain anonymity during the interview. The participant was reminded of this prior to beginning the interview. The prepared semi-structured interview guide directed the interview. All recorded interviews remained in a locked safe in the home of the researcher. All interview questions were asked and answered. The participant was thanked and the recording stopped. All participant questions were addressed and the

participant was reminded that they might be contacted again for verification of transcription, interview responses, or additional questions. A professional transcriptionist with human subjects training transcribed recordings (see Appendix K). Recordings and transcriptions were coded for confidentiality and identified by a code name that the participant chose prior to beginning the interview to maintain anonymity. If there was identifying information in the audio recording, that information was not transcribed. Audio recordings are stored as password-encrypted files on an external hard drive stored in a locked fireproof safe at the researcher's home and only accessible to the researcher. If there are any questions or concerns related to the recordings or demographic data collection forms, the researcher may contact the participant via telephone or email to clarify unclear content or inaudible sections of the recording. Member-checking was also utilized to ensure that the participants' own meanings and perspective are represented and not those of the PI (Birt, Scott, Cavers, Campbell, & Walter, 2016). Participant recruitment and data collection continued until data saturation occurs. The external hard drive(s) and all identifiable information will be destroyed no later than 8/1/2021.

Data Analysis

Colaizzi's method of data analysis was used for this study and occurred concurrently with data collection. This data analysis method is congruent with descriptive phenomenology and thus enhances the rigor of the study. The first step in Colaizzi's method is to read and re-read the data in order to acquire a general understanding (Colaizzi, 1978). Second, the researcher should identify significant statements that are directly correlated with the phenomenon being studied (Colaizzi, 1978). This can be

achieved by using short direct quotes that are the significant statements. Third, the researcher should formulate meanings based on the data and significant statements that have been extracted (Colaizzi, 1978). There may be several other unidentified meanings and concepts that are discovered during data collection and analysis (Munhall, 2007). Fourth, these discovered meanings are categorized into themes that are experienced by all participants (Colaizzi, 1978). These themes eventually were described to generate a model or framework for the phenomenon (Colaizzi, 1978). The last two steps encompass member checking and revisions, if needed, based on participants' feedback (Colaizzi, 1978). This method of data analysis helps to ensure that the researcher has systematically analyzed the data in order to provide valid findings and disseminate evidence.

Colaizzi's method of data analysis was applied in the following manner. Prior to beginning each interview, the researcher recorded her preconceived ideas and thoughts in a reflective journal. Immediately after the interview, the researcher wrote down notes, observations, and thoughts on the semi-structured interview guide which were stored in the locked fireproof safe at the researcher's home office. A professional transcriptionist transcribed each audio recording shortly after each interview. The researcher read and re-read the transcripts to identify significant statements. Notes regarding potential meanings were written in the margin of the transcripts. This information was extracted into a word document where the meanings, direct quotes, and initial impressions were categorized together. As subsequent interviews were conducted, this process was repeated. The themes were extracted into an excel spreadsheet. The overlapping themes for all three participants were then highlighted. The researcher re-read and reviewed the transcripts,

notes, and reflective journal again to ensure that all significant information had been extracted from the transcripts and categorized for thematic analysis.

Qualitative Rigor

Lincoln and Guba's framework for trustworthiness utilized four criteria to enhance qualitative studies: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). This framework was utilized to enhance the trustworthiness of this pilot study. Credibility is obtained by ensuring that the study findings are a true reflection of the participant's experience (Lincoln & Guba, 1985). The researcher utilized reflective journals to bracket preconceived ideas so that the results of the study were a true reflection of the participants of the study, which increased credibility. The researcher was consistently re-reading the transcriptions and comparing significant statements and findings as data collection continued. Member checking is also important to ensure credibility because the researcher validates her findings with the source of the information.

An audit trail enhances dependability of the study because it can be followed and reviewed by an external reviewer (Lincoln & Guba, 1985; Marrow, 2005). This also helps to ensure that the study can be replicated, which is important for dependability (Marrow, 2005; Polit & Beck, 2012). The researcher explicitly explained the data collection process, data analysis, and how the philosophical underpinnings of Edmund Husserl supported the methodology. Future researchers should be able to replicate this study because the methodology has been clearly described in detail.

Confirmability is described as having the study findings corroborated by other individuals (Lincoln & Guba, 1985; Marrow, 2005). The researcher used a reflective journal, clarifying questions during interviewing, and member checking to enhance confirmability. These steps ensure that the findings are those of the participants and that the researcher has bracketed her thoughts and preconceived ideas so that they do not influence the study. An audit trail also contributes to confirmability because it is objective evidence that a process was methodically followed to arrive at the results (Anney, 2014).

Transferability means that the study findings and methodology can be replicated in another group or setting (Lincoln & Guba, 1985). The researcher was able to collect thick, descriptive data during interviewing to assist with transferability of the study. Thick descriptions allow the researcher to obtain meaning and understanding from experiences that can be transferred from one context to another (Loh, 2013). Transferability is also evaluated by ensuring there is a heterogeneous sample that is reflective of the population. The researcher also thoroughly disclosed the inclusion and exclusion criteria as well as the demographic characteristics of the sample.

CHAPTER IV

THE DECISION-MAKING EXPERIENCES OF CAREGIVERS REGARDING FEEDING TUBE PLACEMENT IN COMMUNITY DWELLING ADULTS: A DESCRIPTIVE PHENOMENOLOGICAL STUDY

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Abstract

PEG feeding tube placement is multifactorial and is considered a life-saving mechanism, which leads to a host of thoughts and feelings that affect the decision-making experience. As people live longer and the population ages, these decisions often involve the caregivers who have their own experience, which has the potential to result in caregiver burden and anxiety. A descriptive phenomenological study was conducted to describe and understand the caregiver's decision-making experience regarding PEG feeding tube placement in community dwelling adults. Edmund Husserl's philosophical underpinnings were utilized in conjunction with Colaizzi's (1978) method of data analysis to maintain the rigor of the study. Sixteen adult caregivers of patients from six rehab and skilled nursing facilities were interviewed using a semi-structured interview guide. The audio-recorded interviews were transcribed and thematic analysis was conducted. The study results yield four main themes: "Survival...that was the determining factor;" "The doctor decided;" "More education...just make sure they

understand;” and “It makes me very scared.” Implications for practice, policy, and future research are thoroughly discussed.

Introduction

According to Mundi et al. (2017), an estimated 248,846 adults in the United States have PEG feeding tubes. PEG feeding tubes are placed when an individual cannot orally consume adequate nutrition. This number is expected to increase as life expectancy increases with advancements in medical science and technology. There are over 300 conditions in which PEG feeding tubes are placed such as neurologic, genetic, respiratory, gastrointestinal, and cardiology (The Feeding Tube Awareness Foundation, 2019). PEG feeding tube placement is often a new experience for both patients and their family members. The burden of caregiving may affect these individuals. Caregivers develop their own experiences, which tend to be overshadowed by the needs of the patient. Caregivers may experience feelings of anxiety, fear, or uncertainty as they navigate the responsibilities of caring for another individual as well as meeting the demands of their own life (Muoki, in press). This is especially true when they become immersed in the decision-making for medical treatment of a loved one.

The Coalition to Transform Advanced Care (C-TAC) in collaboration with the Cigna Foundation recently completed an ethnographic study with 6,700 caregivers in the United States to discuss caring for loved ones. The key findings of the study suggest a need for additional support and community resources for caregivers (C-TAC, 2017). One of the main issues for caregivers is that they struggle with the demands of caregiving and their lack of knowledge about the disease process and management (C-TAC, 2017). An

overwhelming 70% of caregivers felt that caregiving had a negative impact on the state of mind, and 41% of caregivers expressed feeling like there was a lack of support (C-TAC, 2017). The experiences of the caregiver can directly affect the care they are able to provide to their loved ones if they are emotionally and physically drained.

The role and importance of caring in the nursing profession continues to be an area of focus for improvement. The National Institute of Nursing Research's (NINR) Strategic Plan: Advancing Science, Improving Lives specifically focuses on enhancing quality of life and relieving caregiver burden for patients with chronic conditions (NINR, 2011). In order to help mitigate the feeling of being overwhelmed and burdened, nursing must first identify the stressors and problem areas that plague the decision-making experience of caregivers regarding PEG feeding tube placement (Muoki, in press). Once the areas have been identified, they can then be interpreted for meaning. The meanings of these experiences provide resolutions to caregiver burden. These resolutions have the potential to significantly influence policies, guidelines, and programs for patients and families who receive a PEG feeding tube.

Caregiver burden has the potential to be mitigated or even prevented. Caregivers should be provided with the tools, knowledge, and resources they need to successfully provide care for their loved ones while still balancing their own lives. This descriptive phenomenological study was conducted to describe the decision-making experiences of caregivers regarding PEG feeding tube placement in community dwelling adults.

Methods

Setting and Participants

The setting of this study was six post-acute care rehabilitation and skilled nursing facilities in Houston, Texas and the surrounding areas. The same corporation owns all the facilities. The vice president of operations provided a letter of support to the Texas Woman's University Institutional Review Board for this study. Texas Woman's University provided final IRB approval.

The majority of the caregivers (62.5%) were the adult children of the individuals with PEG feeding tubes and 25% were the spouses (see Table 4.1). Over half (56.25%) of the caregivers were black and 68.75% were female. Most caregivers (87.5%) ranged in age from 35-75 years old. Over half (56.25%) of them were married. About thirty-one percent of the caregivers were divorced. Approximately 63% of caregivers had a high school diploma, GED, or some college but no degree.

Purposive sampling was used to recruit caregivers. Polit and Beck (2012) stated purposive sampling is often used to select participants who are typical of the population being studied or who are knowledgeable about the issues under study. The sample consisted of caregivers who were English speaking, 18 years of age and older, had a role in the decision-making, and intended to provide care for at least 4 hours per day. The caregivers had to be adults over the age of 18 in order to legally make decisions/provide consent. They had some role in the decision-making in order to share their experience regarding the phenomenon. They intended to provide care in order to be deemed a caregiver. The gastrostomy tube had been placed in the last 7 days, and the ultimate goal

was for the patient to be discharged to a private home. Recall of emotions and feelings was significant to this study so the researcher wanted to capture those feelings as close to the time of the experience as possible. Exclusion criteria were ultimate discharge to a long-term care facility or a caregiver who was not involved in the decision-making or daily care for the patient.

The final sample size was $N = 16$ after it was determined that data saturation was reached. In the final 3-4 interviews, no new information or themes were identified during analysis and coding. The data completely answered the identified research question for this descriptive phenomenological study.

Data Collection Instruments

A demographic data collection form was used to capture the caregivers' relationship to the patient, sex, ethnicity, education level, marital status, employment status, and information regarding care provided to the patient. The demographic data form was coded for confidentiality but was treated as identifiable data due to the anticipated small sample size. The prepared semi-structured interview questions served as a guide for the interview. The interview guide posed questions to the participant regarding their experience, particularly related to how they became aware of the possibility of PEG feeding tube placement, the people involved in the discussion, the information that was provided to them, their role in the decision-making for PEG tube placement, barriers and factors contributing to the decision. The researcher also asked the caregivers to describe how information for PEG feeding tube placement and management can be explained to caregivers more clearly and effectively.

Data Collection Procedures

The researcher reviewed study details (i.e., purpose, inclusion criteria, data collection, and time commitment) and reviewed the informed consent form before the study procedures began. Consent was obtained from each participant prior to collecting any data. Demographic data was collected using a demographic data collection form, which was coded for confidentiality. The demographic data collection form and the document that links the caregivers' names to the code number remained in a locked fireproof safe in the home of the researcher and only accessible to the researcher.

Each interview was audio recorded. The participant was addressed by a code name of their choice to maintain anonymity during the interview. The participant was reminded of this prior to beginning the interview. The prepared semi-structured interview guide directed the interview. All recorded interviews remained in a locked safe in the home of the researcher. All interview questions were asked and answered. The participant was thanked and the recording stopped. Following the completion of the study, participants received a \$20 gift card for their participation. All participant questions were addressed and participants were reminded that they might be contacted again for verification of transcription, interview responses, or additional questions.

A professional transcriptionist with human subjects training transcribed the recordings. Recordings and transcriptions were coded for confidentiality and identified by a code name that the participant chose prior to beginning the interview to maintain anonymity. If there was identifying information in the audio recording, that information was not transcribed. Audio recordings were stored as password-encrypted files on an

external hard drive stored in a locked fireproof safe at the researcher's home and only accessible to the researcher. If there were any questions or concerns related to the recordings or demographic data collection forms, the researcher contacted the participant via telephone or email to clarify unclear content or inaudible sections of the recording. Member-checking was also utilized to ensure that the caregivers' own meanings and perspective were represented and not those of the PI (Birt, Scott, Cavers, Campbell, & Walter, 2016). Participant recruitment and data collection continued until data saturation was reached.

Data Analysis

Colaizzi's (1978) method of data analysis was used for this study and occurred concurrently with data collection. This data analysis method is congruent with descriptive phenomenology and thus enhances the rigor of the study. This method of data analysis helps to ensure that the researcher has systematically analyzed the data in order to provide valid findings and disseminate evidence.

Colaizzi's method of data analysis was applied in the following manner. Prior to beginning each interview, the researcher recorded her preconceived ideas and thoughts in a reflective journal. Immediately after the interview, the researcher wrote down notes, observations, and thoughts on the semi-structured interview guide that was stored in the locked fireproof safe at the researcher's home office. A professional transcriptionist transcribed each audio recording shortly after each interview. The researcher read and re-read the transcripts to identify significant statements. Notes regarding potential meanings were written in the margin of the transcripts. This information was extracted into a word

document where the meanings, direct quotes, and initial impressions were categorized together. As subsequent interviews were conducted, this process was repeated. The themes were extracted into an excel spreadsheet. The overlapping themes for the caregivers were then highlighted. The researcher re-read and reviewed the transcripts, notes, and reflective journal again to ensure that all significant information had been extracted from the transcripts and categorized for thematic analysis.

Qualitative Rigor

Qualitative rigor was maintained throughout this study via the use of reflective journals for bracketing preconceived ideas, which increased credibility. The researcher explicitly explained the congruency of the data collection process, data analysis, and the philosophical underpinnings of Edmund Husserl to enhance dependability and the ability to replicate the study. Clarifying questions during interviewing and member checking were utilized to enhance confirmability. Also, thick, descriptive data was captured during interviews to assist with transferability of the study. Exact quotations with rich descriptions were provided to support the identified themes and spotlight the voices of the caregivers.

Results

This descriptive phenomenological study explored the lived experience of caregivers regarding decision-making for PEG feeding tube placement in community dwelling adults. Data collection via semi-structured interviews produced rich, descriptive accounts of the caregivers' experiences. The theme and subthemes were categorized to provide a thorough understanding of the caregivers' experiences (see Table 4.2). The four

categories are (a) survival, (b) authoritative decision-making, (c) lack of education, and (d) fear and anxiety. The meanings of these themes are highlighted in Table 4.3. Data analysis using Colaizzi's method yielded one overarching theme, four themes, and 12 subthemes, which are described in detail in the following sections.

Overarching Theme: “We had no choice because he needed it...but didn’t know anything about it”

Analysis of the data revealed that caregivers felt that there really was no choice but to have the PEG feeding tube placed although they had various feelings and concerns about the management of the tube. The caregivers felt like the situation was “dire” and a matter of “life and death” by the time the doctor mentioned PEG feeding tube placement. This left the caregivers with “no choice.” One of the caregivers, a patient’s daughter, was quite upset with how the discussion occurred regarding PEG feeding tube placement. She expressed the following sentiments:

You know...give us some warning prior to when you see that nutrition is becoming an issue. Tell us then. Don't wait until it's dire because then you put us in a position where we don't feel like we have a choice. You're telling us this is a life or death matter, and we need to make this decision right now. I feel like this is a progressive choice and decision that healthcare workers know.

Another participant, a patient’s wife, stated, “I felt desperate at that point that I was going to lose my husband, so it was just hope for the best.” Some of the caregivers were just eager to have their loved ones return to their prior state of independence. A

caregiver in his 70s voiced similar concerns of desperation. He stated, “Whatever it took to get her back to her normal self where she could start eating solid foods on her own.”

Although the caregivers agreed to PEG feeding tube placement out of desperation, they voiced concerns about lacking education about the PEG feeding tube and being scared. One of the caregivers said, “It is nerve-wracking, taking somebody home that you don’t know if you’re going to be able to take care of.” Ultimately, the caregivers’ main focus was on the well-being of the patient and making sure they received nutrition. They often ended up just “agreeing with authorities” although they had concerns and unanswered questions.

Theme One: Surviving...that was the determining factor

This theme spotlights the fight or flight response that the caregivers experienced when making the decision to place the PEG feeding tube for survival. Survival was the driving force for PEG feeding tube placement for all sixteen caregivers. The caregivers associated the PEG feeding tube to the prevention of death. They were so concerned with trying not to “lose” their loved ones. As a result, they all “just agreed” because the decision was perceived as being an emergency, and the PEG feeding tube was the bridge to survival. One of the caregivers, a patient’s daughter, explained how urgent the situation became.

When they put it [the PEG feeding tube] in, she was at sixty-five pounds and was going down below that. He [the doctor] said that everything’s going to start shutting down, so we’re going to have to do something. I said then by all means, let’s do it. I really didn’t want her to have one. I don’t want anything to happen to

her so it's got to be done. I just said "Okay" and went from there. It's your mother and you don't want to lose her.

The caregivers were deeply affected by the malnourishment and physical condition of their loved one, which pushed them into the mind frame of "I'll do anything to keep him alive." One caregiver, a patient's wife, vividly described the physical appearance of her husband.

He just looked like skin over bones, and then I could see the ribs on the front and the ribs on the back. I told people he looked like a Holocaust survivor. That's exactly the way I thought about him, and seeing that just about tore me up. I think they could've told me anything, and I'd have done it at that point. I'll do anything to keep him alive.

There are four subthemes under Theme One, which are clearly identified and thoroughly discussed in the following paragraphs.

He could not live without food. The PEG feeding tube was placed for many different reasons including weight loss, difficulty swallowing, and loss of the ability or will to eat. Some of their loved ones had become extremely malnourished. The caregivers voiced the necessity of PEG feeding tube placement for nutrition and hydration. The stepson and caregiver of one of the patients explained, "It was just only a matter of time before he would dwindle away and eventually die because of not being able to eat." Another caregiver, a patient's daughter, said, "I just wanted my dad to live, and I knew he could not live without food. We did not want him to starve." Malnutrition may worsen other medical conditions and can have a detrimental effect on one's health even if it does

not lead to death. This caregiver, a patient's daughter and a registered nurse, explained, "The primary doctor said she's so malnourished. She's losing weight. It's making all her other symptoms worse. Your body can't heal without nutrition."

It's one of the most wonderful tools to keep a person alive. Some of the caregivers viewed the PEG feeding tube as simply a "tool," a means to an end. Their perception was that the PEG feeding tube was a piece of "equipment" that was used to prevent a potentially devastating consequence of malnutrition. Several of the caregivers utilized key phrases such as "a gift to the patient," "a blessing," "helps her not to get too sick," "keeping her alive," and "keep nutrition in the body."

One patient's brother stated, "In my opinion, I think that's one of the most wonderful tools and equipment there is to keep a person alive." Another caregiver, a patient's sister, detailed her thoughts.

It's a gift to the patient because the patients need the nourishment, and without the feeding tube, he wouldn't eat. How would he eat? So it's a blessing. I think medical science has advanced. I remember way back when my uncles had problems eating. They didn't have this. I remember they would always try to feed them pureed food, very pureed or some liquid they could take down. But now, with the feeding tube, it's great. You don't have to try to get their food down like a baby. I remember my grandmother had pureed food or something liquid with a straw. This feeding tube is a blessing.

Another caregiver mentioned, "I have no problem with it because it would help her not get too sick like she used to get."

There was no choice if I wanted to keep him alive. Caregivers felt like there really was no decision. They felt that there was no choice. The choice was made for them if they wanted to keep their loved one alive. One patient's son and caregiver said, "It's a no-brainer...it's common sense...the feeding tube is helping them, you know, saving them." Another patient's son stated, "She had no other choice. There's really nothing that she could do. That was beyond her chance to choose."

She needed it to prevent her from having pneumonia. Approximately one-third of the caregivers mentioned issues with "choking," "aspirating," and "pneumonia" regarding the decision to place the PEG feeding tube and enhance the chance of survival. The caregivers realized that the occurrence of any of the above-named events could increase the chances of death, which is exactly what they were trying to prevent by placing the PEG feeding tube. One of the caregivers, a patient's brother, described his experience.

They were saying that she was aspirating and they wanted to do this gastro tube to start feeding her. It was reluctance on my part but you hate to see a family member go through this. Man, that's tough. There was a little bit of apprehension, but I guess on the other hand, you kind of want to make sure they don't get pneumonia. So it was down to having her get a feeding tube versus maybe getting pneumonia. If she develops pneumonia, the survival rate is not that good.

A different caregiver, the patient's daughter, said, "They noticed that he's starting throwing up and choking. He could get an infection or he could get pneumonia."

Theme Two: The doctor decided

This theme describes the strong influence the doctors had on making the decision to place a PEG feeding tube. Caregivers felt there were very few choices and no collaboration with the doctors during decision-making. Several of the caregivers felt that the “doctor decided” to place the PEG feeding tube. One of the caregivers, a patient’s sister, explained, “I took the word of the doctors and nurses there...so I agreed with it.” Another caregiver said, “The doctors decided to go ahead and put the feeding tube in.” A patient’s mother stated, “The doctor decided to give her a feeding tube. The decision was based on what the doctor told me would be better.” The caregivers expressed that there really was no decision to be made since the doctor just “told” them it had to be done. There are two subthemes under Theme Two, which are clearly identified and thoroughly discussed in the following paragraphs.

We just agreed with the authorities. The perspective that doctors have authority was a significant factor that influenced the decision-making experience for caregivers. The caregivers believed that the doctors “knew what was needed” because they were “not a doctor or nurse.” A patient’s son expressed his thoughts.

I guess in the society we live in and the day we live in, we just kind of go with what the authorities say, and I’m no different. The authorities on the subject say this and that and we say okay. I am obviously not a doctor by any stretch of the imagination. Okay, I’ll just have to believe what you guys are telling me. Another caregiver, a patient’s brother, shared similar feelings regarding his decision-making experience. He stated, “It was based purely on a recommendation by the doctor.

It doesn't have anything to do with spiritual or religious beliefs. So we made decisions based on what the professionals are telling us."

There was no collaboration at all. Some of the caregivers voiced concerns about the lack of shared decision-making with the doctors. One caregiver, a patient's daughter, thoroughly described her experience. Her feelings of anger were evident via her tone of voice.

It wasn't really a suggestion. She's getting a feeding tube. There was no collaboration at all. You know, it wasn't—well, here are your options. It was—she needs nutrients and this is the only way to get them there. There was no collaboration at all. I wasn't okay with any of it. I felt very out of the loop.

She goes on to provide recommendations regarding how family should be included in the decision-making for PEG feeding tube placement.

They need to include the family, and say, "Okay, if they're not eating by this time, this is what's going to happen, or this is how much food they need to be able to eat otherwise you're going to be looking at this." Give the family an opportunity to work with the patient to say, "Hey, look, you don't really want this feeding tube, so you got to eat." Maybe it works, and maybe it doesn't. When you come on the phone like, "Hey, you know, you got to do this right now," it doesn't feel like collaboration.

Theme Three: More education...just make sure they understand

This theme refers to the importance of caregivers possessing knowledge about the details, care, and management of the PEG feeding tube. Several caregivers expressed

concerns about feeling “ignorant,” “not knowing anything,” and not receiving “adequate training.” Caregivers also felt that the staff needed adequate training about the PEG feeding tube. Many of the caregivers felt that they never received specific details about the PEG feeding tube and were only told it was “going to be put in.” One of the caregivers described her experience with the lack of PEG feeding tube education.

I felt very out of the loop. Don't tell people you're not going to tell them how to use it until discharge. Show them how to use it when they get there. When they first get there, make sure that somebody is there. Schedule a time with them to show them. Don't tell them that you will show them upon discharge so you don't send them home ignorant. Include them in the process so that they know because I don't know anything. I still don't know anything.

Another caregiver voiced similar feelings. She stated, “I wish I would have known more about it so I could understand what was going on first, but they didn't tell me anything.” There are three subthemes under Theme Three, which are clearly identified and thoroughly discussed in the following paragraphs.

I don't remember anybody telling me any side effects. Although caregivers felt like they had no choice from a survival standpoint, they still voiced the need and desire to be well educated about the PEG feeding tube. A patient's wife shared her experience that was simply due to lack of education.

I'm finding out things that I did not find out about such as every other day, I try to shave him. Today is a shaving day, and I lower the bed. Well, no one told me that I was supposed to turn off the feeding tube if I lower it down too low. Then the

nurse came in, fortunately, not long after I'd done it and said, "Oh, no, you have to turn that thing off or either raise him up." I don't know if that caused him problems or if we caught it in time. They could've avoided that by just simply telling me, "Make sure that his head is always at this particular angle or higher." Now I know that. I could've already damaged my husband. Fortunately, he didn't do any coughing. It wasn't long before the nurse came in, but that could've been avoided.

Another caregiver stated, "I think then the doctor said something about, 'Well, you do know about the feeding tube?' I said yeah, and then that was about it. As far as side effects or problems, I was not told any of those."

They didn't tell me what other options were out there. Some of the caregivers voiced concerns about the doctor not providing them with information about other options or alternatives that could improve the nutritional status of their loved ones. Some caregivers made comments such as "I wasn't given any options." One of the caregivers, a patient's wife, stated, "I knew that they said the feeding tube would be the next step, but they didn't tell me what other options were out there." Another caregiver mentioned, "There are no other alternatives that I know of."

I didn't get a course on the feeding tube. Many of the caregivers felt like they should have received a training course on PEG feeding tube management to prepare them for taking care of their loved one at home. One of the caregivers explained, "Well, they didn't give me the whole nine yards. I didn't get a course on the feeding tube thing. I

don't know." Another caregiver, a patient's brother, provided an explanation of his experience and thoughts.

Somebody needs to do some training and provide instructions on how to properly flush and maintain. Make sure they are receiving adequate training.

Now, I know that's a two-way street. You have to be able to want to provide it and then whoever's going to be taking care of the individual has to want to receive it.

But like from your side, I'd like for you to be sure and make sure that it is offered. If at some point in time they want to revisit, you know, just to make sure they're doing this right, make that happen as well.

Theme Four: It makes me very scared

Theme Four identifies the various circumstances associated with PEG feeding tube placement that evoked feelings of distress. The etiology of fear and anxiety was multifactorial. The caregivers used key phrases such "scared of losing her," "scared cause I'm not a nurse," "scary to go home," "scared to choke," and "scared to death." One of the caregivers explained, "Make sure that the family is educated all along the journey so they're not in fear about what's happening." Another caregiver, a patient's daughter explained her experience.

Some of the family was scared and some accepted it. I think some were scared because they didn't really know a lot about it. Some of us had already heard about it before, but we all wanted what was best for dad.

One caregiver said, "I was always thinking, are we making the right decisions? Are we cleaning it the right way? What about if I do it wrong? What about if I'm not doing it

correctly?” There are three subthemes under theme four, which are clearly identified and thoroughly discussed in the following paragraphs.

I am not a nurse. The caregivers expressed a sense of fear associated with managing the PEG feeding tube because they did not view themselves as professionals or having “adequate training.” One patient’s daughter explained that her mother feared her daughter did not have the ability to provide care because she “wasn’t a nurse.”

I would look at the nurses, and they were showing me how they were doing it. Of course, all of them had different ways to do things. She [mom] was scared about the feeding tube and who was going to take care of it. I told her, ‘Well, they already showed me. I’ll take care of you’. She was still scared because I’m not a nurse. It’s scary to go home with something that you’re not used to...I’m not a nurse.

Very concerned that he may pull the feeding tube out. The caregivers were fearful and concerned about the complications that may accompany PEG feeding tube placement. They were concerned that the feeding tube may accidentally be “pulled out” or get “clogged.” One of the caregivers, a patient’s daughter, shared her concerns about the PEG feeding tube.

Well we are very concerned that he may pull the feeding tube out of his stomach. So it may be helpful to tell the caregiver that is a possibility. I didn’t know that we had to keep an eye on him. If he pulled it out, it might be bleeding, and then he would need to be transported back to the hospital so they can redo it over there. So that’s the only thing that we need to be aware of.

Another caregiver shared her thoughts about the fear and anxiety that surfaced when she noticed drainage from the PEG feeding tube. She stated, “I always wonder like, ‘My God, what did I do wrong? Did I mess something up? Did I pull the tube out or something?’”

Another of the caregivers, a patient’s daughter, explained the anxiety that accompanied having a clogged PEG feeding tube.

He clogged the feeding tube. My head was pounding because I was like, “What do I do now? What do I do?” All along I was thinking what the doctor and surgeon told us since the very beginning. “Be careful with clogging that tube.” I was like, “My God, it cannot be happening now.” He didn’t take any medications or any feeding since 7 o’clock at night, and it was like 7 o’clock in the morning.

It means that she is losing her independence. Most caregivers voiced sentiments about feeling that the decision to place a PEG feeding tube represented “loss of independence and control” for their loved one and “not being prepared for that.” One patient’s daughter said, “She’s always been active. So, for her, now not to be able to do that on her own...that took a lot on her.” Another caregiver stated, “It means that she’s really losing her independence. She’s got to go around with that thing all the time and she just can’t move hardly.”

Some of the caregivers struggled with the decision to place a PEG feeding tube. They felt that they were losing or giving up control of something as basic as the oral consumption of food and water. One patient’s daughter said, “He has been an independent person his entire life. There’s no way I think he would want a feeding tube. I

think it makes him feel awful. It's absolutely horrible." Another caregiver said, "We're not prepared for that. She was very independent when she got here, and now they are sending her back home with this feeding tube."

Discussion

PEG feeding tube placement is a dynamic issue that encompasses an array of feelings and emotions. Caregivers stressed that survival was the driving force for decision-making, which usually occurred in an urgent situation. PEG feeding tube placement was not viewed as an elective procedure but rather one performed out of necessity to prevent death. As a result, they felt that the decision was often authoritative in nature and made by the doctor. Since the decision was usually made in a very short time frame, feelings of fear and anxiety were evoked by the lack of advanced warning. The caregivers often felt underprepared to care for the PEG feeding tube, which also elicited feelings of fear and anxiety. Despite these obstacles and concerns, the caregivers still agreed to PEG feeding tube placement to save their loved ones' lives. The results highlight that caregivers still wanted to be well-educated and experience shared-decision making with the healthcare team although they ultimately knew there was no choice in the matter if they wanted to keep their loved ones alive.

Implications

The study results spotlight significant room for improvement in order to enhance decision-making and relieve caregiver burden and anxiety. Strategies must be implemented to enhance the communication amongst caregivers, patients, and the healthcare team. Poor communication and collaboration can lead to feelings of fear and

anxiety that can directly affect the caregiver's life and the ability to provide effective care to their loved one. Steps should be taken to provide detailed education about the care, management, and possible complications of the PEG feeding tube. Instructions should also be provided about how to handle those complications in order to decrease the caregiver's anxiety if they were to experience those complications. This information should be provided prior to PEG feeding tube placement so caregivers are not alarmed after the tube is placed.

It is important to remember that caregivers have varying views about PEG feeding tube placement. Some may not like the idea of a PEG feeding tube, and the PEG feeding tube placement may be a sensitive topic. They may have just agreed because they did not want their loved one to die. Nurses should show compassion and understanding by providing education and allowing time for open discussion. Caregivers should be encouraged to ask questions and openly communicate their concerns. This allows the caregiver to actively participate in the decision-making process and feel prepared once the PEG feeding tube is placed. These implications are congruent with the NINR's Strategic Plan: Advancing Science, Improving Lives, which specifically focuses on enhancing quality of life and relieving caregiver burden for patients with chronic conditions (NINR, 2011).

Further research is needed to investigate the caregiver's lived experience of caring for a PEG feeding tube at home after discharge from the rehab and skilled nursing facility. This qualitative study could provide additional information about caregivers' experiences with PEG feeding tubes and areas of concern that need to be addressed. The

results gained from those qualitative studies could then provide the foundation for quantitative studies to test the implementation of an intervention.

Strengths and Limitations

The strength of this study was that the setting occurred in the community where resources may have been more limited than if the study was conducted in a large institution. As a result, the researcher was able to capitalize on real issues that affect caregivers when resources are not conveniently and readily available. Another strength of the study was that the patients had PEG feeding tubes placed for different reasons. As a result, the caregivers may have had broader experiences, which increase the transferability of the study results. Another strength of this study was that caregivers provided rich, detailed descriptions of their experience. A limitation of this study was that the methodology required the caregivers to recall events. This recall bias may have resulted in caregivers inaccurately reporting information, which can directly affect the study results.

Conclusion

Although they felt like they had no choice regarding PEG feeding tube placement if they wanted their loved ones to survive, the caregivers voiced concerns about their lack of knowledge and input regarding decision-making for PEG feeding tube placement. They utilized key phrases such as “no choice,” “the doctor decided,” “keep her alive,” “scared,” “nerve-wracking,” and “didn’t get a lot of information.” One of the caregivers, a patient’s son, provided the following advice for nurses to aid caregivers with the decision-making for PEG feeding tube placement.

Give words of encouragement and hope. Give them all the avenues that are possible so they can take to try to remedy a situation as best they can. Being nice really helps, it does. It goes a long way. When you make people feel that you care, they soften up. They begin to trust a little more. It comforts them and soothes them. It will help them to deal with it a little better. Just keep it real. That's the other thing. Just be down to earth and not sensationalizing or make it a hyper situation. It is, I think, the best approach.

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Table 4.1

Participant Demographics (N = 16)

Demographics	Values (%)
Caregiver's Relationship to the Patient	
Spouse	4 (25%)
Sibling	1 (6.25%)
Parent	1 (6.25%)
Child	10 (62.5%)
Age Range	
24-34 years old	1 (6.25%)
35-60 years old	7 (43.75%)
61-75 years old	7 (43.75%)
76+ years old	1 (6.25%)
Sex	
Male	5 (31.25%)
Female	11 (68.75%)
Ethnicity	
Black	9 (56.25%)
White – Non Hispanic	3 (18.75%)
Hispanic	3 (18.75%)
Asian/Pacific Islander	1 (6.25%)
Highest Level of Education Completed	
Some High School, No Diploma	1 (6.25%)

High School Graduate or GED	3 (18.75%)
Some College, No Degree	7 (43.75%)
Associate Degree	2 (12.5%)
Bachelor's Degree	1 (6.25%)
Graduate Degree	2 (12.5%)
Marital Status	
Single, Never Married	2 (12.5%)
Married or Domestic Relationship	9 (56.25%)
Divorced	5 (31.25%)
Employment Status	
Full-time	7 (43.75%)
Retired	5 (31.25%)
Unemployment	1 (6.25%)
Homemaker	1 (6.25%)
Self-employed	2 (12.5%)
Hours of Care Prior to Feeding Tube	
0-5 hours	4 (25%)
6-11 hours	2 (12.5%)
12-17 hours	3 (18.75%)
18-24 hours	7 (43.75%)
Hours of Care Prior After Feeding Tube	
6-11 hours	3 (18.75%)
12-17 hours	6 (37.5%)

18-24 hours	7 (43.75%)
Length of Time Providing Care	
0-3 months	1 (6.25%)
4-7 months	2 (12.5%)
8-12 months	5 (31.25%)
12 + months	8 (50%)

Table 4.2

Theme and Subthemes by Category

Overarching Theme: "We had no choice because he needed it...but didn't know anything about it"		
Categories	Themes	Subthemes
Survival	Surviving...that was the determining factor	<p>He could not live without food.</p> <p>It's one of the most wonderful tools to keep a person alive.</p> <p>There was no choice if I wanted to keep him alive.</p> <p>She needed it to prevent her from having a pneumonia.</p>
Authoritative Decision Making	The doctor decided	<p>We just agreed with the authorities.</p> <p>There was no collaboration at all.</p>
Lack of Education	More education...just make sure they understand	<p>I don't remember anybody telling me any side effects.</p> <p>They didn't tell me what other options were out there.</p> <p>I didn't get a course on the feeding tube.</p>
Fear and Anxiety	It makes me very scared	<p>I am not a nurse.</p> <p>Very concerned that he may pull the feeding tube out.</p> <p>It means that she is losing her independence.</p>

Table 4.3

Themes and Meanings

Themes	Meanings
Surviving...that was the determining factor	Spotlights the fight or flight response that the caregiver experiences when making the decision to place the feeding tube to keep the patient alive
The doctor decided	Describes the strong influence of doctors making the decision to place a PEG feeding tube
More education...just make sure they understand	Refers to the importance of caregivers having knowledge about the details, care, and management of the PEG feeding tube
It makes me very scared	Identifies the various circumstances associated with feeding tube placement that evokes feelings of distress in the stakeholders from the caregivers' perspectives

CHAPTER V

SUMMARY OF THE STUDY

There is a shift in nursing towards patient-centered care with caregiver and family involvement. Family and friends are often involved in the decision-making for PEG feeding tube placement for their loved ones since they will likely provide care upon discharge when the patient returns home (Ladas et al., 2002). However, the literature often focuses on the patient's perspective or the patient and caregiver as a dyad. Caregiving can result in anxiety and burnout (Bevans & Sternberg, 2012). There is a lack of information and understanding of the caregiver's experience regarding declining nutrition in a community setting and their role in ultimately deciding to place a PEG feeding tube (Muoki, in press). This study aimed to address this gap.

This descriptive phenomenological study utilized the philosophical underpinnings of Edmund Husserl to describe the experiences of caregivers regarding decision-making for PEG feeding tube placement in community dwelling adults. Husserl proposed that phenomenology is based on the meaning of one's experience (Reiners, 2012). Individuals described everyday experiences while "bracketing" or setting aside preconceived ideas and beliefs (Reiners, 2012). Husserl's main focus was what individuals know, also known as "intentionality" (Reiners, 2012). This included thought, perception, emotion, memory, and imagination (Reiners, 2012). This research method described how an individual perceives their experiences of the phenomenon being study. The research

method allowed the researcher to describe a phenomenon that can improve the delivery of care, patient outcomes, and quality of life.

Sixteen caregivers were recruited via purposive sampling from six post-acute care rehabilitation and skilled nursing facilities in Houston, Texas and the surrounding areas, which are all owned and operated by the same corporation. The demographic tool collected information about the caregiver's relationship to the patient, age range, sex, ethnicity, highest level of education completed, marital status, employment status, and the hours and length of time the caregiver provided care. This information was reported via the use of frequencies and percentages. All caregivers were interviewed using a semi-structured interview guide. A professional transcriptionist with human subjects training transcribed these audio-recorded interviews. The transcripts were analyzed using Colaizzi's method of data analysis and provided exhaustive, rich descriptions of their experiences. The following paragraphs summarize and discuss the study results. The conclusions, implications for nursing practice, and recommendations for future studies are also discussed below.

Summary of Findings

Data analysis yielded one overarching theme, four main themes, and 12 subthemes. The overarching theme was "We had no choice because he needed it...but didn't know anything about it." The four main themes are as follows: (a) "Surviving...that was the determining factor," (b) "The doctor decided," (c) "More education...just make sure they understand," (d) "It makes me very scared." These findings represent the essence of the caregivers' decision-making experiences regarding

PEG feeding tube placement in community dwelling adults. The following paragraphs are organized by the major themes and discuss the findings of this study.

Discussion of the Findings

The findings are significant because they provide first-hand accounts of a phenomenon. This detailed information allows others to grasp the true meaning of the experience, and can be utilized to create policies and programs that may benefit other caregivers.

Theme One: Surviving...that was the determining factor

Caregivers entered survival mode when faced with the decision to place a PEG feeding tube. The conversation was often initiated when the patient was no longer able to swallow, eat, or was at risk for aspiration. Some of the patients lost so much weight that one of the caregivers said, “he looked like a Holocaust survivor.” She stated that she was “desperate” by the time the PEG feeding tube was discussed. Some called the PEG feeding tube a “tool and equipment” that prevent death and “extended his stay.” The PEG feeding tube was also regarded as “serving a purpose to keep him alive.” Although the caregivers had various personal concerns regarding the PEG feeding tube, they all ultimately wanted to keep their loved one alive.

Theme Two: The doctor decided

Caregivers stated that the decision to place a PEG feeding tube was made by the doctor, and they just agreed. They believed that the doctor was an “authority” figure. Another caregiver stated that the decision was “based purely on a recommendation from the doctor.” In a society where the healthcare paradigm is shifting towards shared

decision-making, some of the caregivers felt like there was “no collaboration” between the caregiver and doctor. The caregivers even stated that the doctor “told” them it was time for it to be done and “that was that.”

Theme Three: More education...just make sure they understand

There was a lack of education regarding PEG feeding tube indications, management, and care. Caregivers felt that they were “not prepared” to manage the PEG feeding tube after discharge from the rehab and skilled nursing facility. They described feeling “out of the loop” and “ignorant.” The results indicated that the caregivers had not been given information about the “side effects” or “other options.” Some of the caregivers even voiced concerns about not receiving “the whole nine yards” of PEG feeding tubes or “a course on feeding tubes.”

Theme Four: It makes me very scared

The etiology of fear and anxiety was multi-factorial. Caregivers voiced concerns about feeling scared that their loved one experienced “loss of independence and control” with PEG feeding tube placement. The placement of the PEG feeding tube removed the ability to “choose” their nutrition. The PEG feeding tube also incited fear for caregivers because they were concerned about their ability to care for the PEG feeding tube. Some of the patients were even concerned about the caregivers’ abilities to care for the PEG feeding tube since they were “not a nurse.” Some of the caregivers felt like they did not have “adequate training” prior to discharge. Also, the caregivers expressed fear of complications such as “pulling the tube out of the stomach” and a “clogged tube” resulting in their loved one “not being able to feed or take medication.”

The findings of this study accentuate the importance of the paradigm shift in nursing towards patient and family centered care by understanding the caregivers' perspectives and identifying areas for improvement to relieve caregiver burden. Caregivers need and deserve the same attention as the patient because the demands of caregiving place them at a high risk for injury or adverse events (Reinhard, Given, Petlick, & Bemis, 2008). Reinhard et al. (2008) also explained that caregivers are unpaid but are obligated to learn new skills. This obligation coupled with the stress of making a "life or death" decision concerning the feeding tube about which they know nothing can be overwhelming. This is especially true when caregivers are expected to properly maintain and use the PEG feeding tube to prevent complications and keep their loved one alive. This can be a daunting task for the caregiver. The findings indicate that caregivers still desired collaboration and education when deciding to proceed with PEG feeding tube placement although they felt like there was really "no choice." Placement of the feeding tube creates feeling of uncertainty and anxiety because it involves risks like all other procedures (Yeh et al., 2013).

Caregivers voiced feeling "desperate" and "hoping for the best" as they "just agreed" to have the PEG feeding tube placed because they wanted to "keep him/her alive." The sense of desperation allows little time to process the situation if doctors "wait until it's dire." This also incites feelings of fear and anxiety. This fear and anxiety is compounded when the caregiver is not presented with adequate information. These events can also lead caregivers to perceive that the doctor is making the decision because they do not have enough time and information to make an informed decision. The patient

and family will ultimately have to deal with the consequences of the decision (Charles, Gafni, & Whelan, 1999). These issues are all interrelated and should each be addressed in order to relieve caregiver burden and create an environment conducive to shared and informed decision-making.

Philosophical Underpinning

This study was congruent with Husserl's descriptive phenomenology as it allowed the researcher to explore and understand the phenomenon of caregivers' decision-making experiences via rich, detailed descriptions. The researcher was able to bracket her pre-conceived ideas and beliefs by keeping a reflective journal and therefore achieved phenomenological reduction. The researcher then analyzed the data to achieve the essence of caregivers' decision-making experiences regarding PEG feeding tube placement for community-dwelling adults. This resulted in Husserl's eidetic reduction. The essences are thoroughly described. The researcher discussed implications for the essences, which are deemed likely to be true for all who experience the same lived experience or phenomenon (Husserl, 1973; Welch, 1939).

Assumptions

The following paragraph reviews the initial study assumptions and provides supporting evidence for each assumption.

1. Caregivers are able to honestly disclose and relate their experiences and role of decision-making regarding PEG feeding tube placement in community dwelling adults. Caregivers candidly disclosed feelings of fear and anxiety that affected their decision.

2. Caregivers are genuinely interested in sharing their experiences for the enhancement of evidence-based practice. Sixteen caregivers enthusiastically participated in data collection.
3. Purposive sampling will allow the researcher to have access to rich and detailed experiences of caregivers who have experienced decision-making regarding PEG feeding tube placement in community dwelling adults. As thoroughly discussed via direct quotations, the caregivers provided rich, detailed descriptions of their experiences, which allowed the researcher to identify the essences of the phenomenon.
4. Caregivers provide data that informs the research question. There were four main themes and 12 subthemes that were clearly identified and discussed based on the study results.
5. Understanding the decision-making experiences of caregivers regarding PEG feeding tube placement will lead to the development of new strategies to relieve caregiver burden and potentially affect standards of care in clinical practice. The implications are completely described below based on the identified themes.

Conclusions

The following conclusions are provided below based on the study findings:

1. The decision to place a PEG feeding tube placement is often made out of necessity. Caregivers feel like they have no choice if they want to keep their loved one alive. They are often agreeable to PEG feeding tube placement based on that factor alone.

2. Caregivers may feel ambiguity regarding the decision to place a PEG feeding tube. The tube is often placed when malnutrition has become urgent, and there is little time to make a decision. They may be given little to no information and are required to make an uneducated decision. However, they are desperate for their loved ones to receive nutrition and avoid death.
3. Caregivers experience fear and anxiety from different etiologies. They are fearful of losing their loved one. They are also fearful of the unknown and making a decision without receiving proper education. They are also fearful because PEG feeding tube care and management is a new experience.
4. Although caregivers feel like they have no choice, they still want to be educated on the indications and management of the PEG feeding tube. They feel underprepared and are even interested in training courses to recognize complications and learn how to prevent them.
5. Caregivers perceive that their loved ones experience a loss of independence by having a PEG feeding tube placed because it removes their ability to completely control their diet.

Implications for Practice and Policy

The following recommendations are provided based on the study results:

1. Implement plans to enhance the communication among caregivers, patients, and the healthcare team. Poor communication and collaboration can lead to feelings of fear and anxiety that can directly affect the caregiver's life and the ability to provide effective care to their loved one.

2. Provide detailed education prior to PEG feeding tube placement about the care, management, and possible complications of the PEG feeding tube. Instructions should also be provided about how to handle those complications in order to decrease the caregiver's anxiety if they were to experience complications.
3. Show compassion and understanding by providing education and allowing time for open discussion. Every caregiver has different feelings and perceptions about the PEG feeding tube. Caregivers should be encouraged to ask questions and openly communicate their concerns.
4. Official training courses for caregivers are strongly recommended prior to PEG feeding tube placement. The courses serve multiple purposes and allow for a safe, open forum for caregivers to address their concerns, learn about the management of the PEG feeding tube, and receive answers to their questions.
5. The training course should then be offered again after PEG feeding tube placement to address concerns that may have arisen after discharge.
6. Implement a policy that hires and trains nurses specifically for PEG feeding tube care and management. These nurses with expertise in PEG feeding tubes can train other nursing staff as well as the caregivers.
7. Implement tactile education for caregivers via simulation with PEG feeding tubes and mannequins.
8. Discuss the possibility of PEG feeding tube placement when the patient initially starts to exhibit signs and symptoms of malnutrition instead of waiting until the PEG feeding tube is urgently needed for survival.

Recommendations for Future Studies

Recommendations for future studies are presented based on the study findings:

1. Conduct a qualitative study to investigate the caregiver's lived experience of caring for a PEG feeding tube at home after discharge from the rehab and skilled nursing facility.
2. Conduct a qualitative study to describe the caregiver's decision-making experience of those who chose not to have the PEG feeding tube placed.
3. Develop and test a standardized training course for caregivers regarding PEG feeding tube. This study would determine the effectiveness of the training program.
4. Replicate this study in a different city and state to compare the research findings.

Summary

The decision to place a PEG feeding tube is complex and can elicit a host of feelings. The caregivers' decision-making experiences regarding PEG feeding tube placement in community dwelling adults was thoroughly explored and described in this study. The study methodology was congruent with Edmund Husserl's philosophical underpinnings. Therefore, the rigor of this study was fully maintained. The data were analyzed using Colaizzi's method of data analysis and resulted in one overarching theme, four main themes, and 12 subthemes. The study results emphasized that survival was a driving force for PEG feeding tube placement. Caregivers often felt that they had no choice in the decision-making process and perceived that ultimately the doctor made the decision. Discussion and decisions were often only initiated when the situation was

urgent and had become a matter of life and death. As a result, there was a lack of education regarding PEG feeding tube indications and management, which left caregivers feeling underprepared to care for the PEG feeding tube. These experiences resulted in feelings of fear and anxiety for the caregiver. Implications for practice, policy, and future studies were provided based on these study results.

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APPENDIX A
Letter of Support

Letter of Support



June 25, 2018

Deltra Muoki
2331 Alberton Lane
Pearland, Texas 77584

Re: Letter of Support

Dear Mrs. Deltra Muoki:

Senior Care Excellence is delighted to offer you full access to the patients and their families/caregivers at all six of our facilities which include The Medical Resort at Bay Area, The Medical Resort at Sugar Land, The Medical Resort at Willowbrook, The Resort at Texas City, The Medical Resort at Pearland, and The Medical Resort at the Woodlands.

We value evidence-based practice and the advancement of nursing care as this directly affects our patients and their families. We are excited to be part of a research study that we feel will enhance patient outcomes and learning opportunities for our nursing staff.

If you have any questions, please feel free to contact Senior Care Excellence's Vice President of Operations, Oscar Osundwa, RN at 832-561-1561 or oosundwa@scexcellence.com.

Sincerely,

A handwritten signature in black ink, appearing to read "Oscar Osundwa", written in a cursive style.

Oscar Osundwa, RN
Senior Care Excellence
Vice President of Operations

APPENDIX B

Participant Eligibility Criteria Screening Form

Participant Eligibility Criteria Screening Form

Instructions: All potential participants require screening and must meet inclusion criteria prior to participating in this study. Please select “yes” or “no” for the following questions. Each potential participant must mark “yes” to all inclusion criteria and “no” to all exclusion criteria to participate in this study.

INCLUSION CRITERIA

1. Is the potential participant/caregiver 18 years of age or older?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

2. Is the participant a caregiver to a patient at The Medical Resort at Bay Area, The Medical Resort at Sugar Land, The Medical Resort at Willowbrook, The Resort at Texas City, The Medical Resort at Pearland, or The Medical Resort at the Woodlands?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

3. Did this caregiver have some role in the decision-making for PEG tube placement?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

4. Will this caregiver provide a minimum of 4 hours of direct care per day to the patient?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

5. Has the patient who is associated with the potential participant/caregiver had a PEG tube placed in the last 7 days?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

6. Is the potential participant English speaking?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

7. Is the intent that the patient who is associated with the potential
participant/caregiver will ultimately be discharged to a private home?

☐ Yes (1) ☐ No (2) If the answer is no, exclude from the study

APPENDIX C

Institutional Review Board Approved Letters

Institutional Review Board Approved Letters



Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
irb-houston@twu.edu
<https://www.twu.edu/institutional-review-board-irb/>

DATE: August 23, 2018

TO: Ms. Deltra Muoki
Nursing - Houston

FROM: Institutional Review Board (IRB) - Houston

Re: Approval for Caregivers' Experiences with Decision-Making Feeding Tube Placement for Declining Nutrition in the Community (Protocol #: 20198)

The above referenced study has been reviewed and approved by the Houston IRB (operating under FWA00000178) on 8/22/2018 using an expedited review procedure. This approval is valid for one year and expires on 8/22/2019. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Ainslie Nibert, Nursing - Houston
Dr. Sandra Cesario, Nursing - Houston
Graduate School



Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
irb-houston@twu.edu
<https://www.twu.edu/institutional-review-board-irb/>

DATE: July 26, 2019

TO: Ms. Deltra Muoki
Nursing - Houston

FROM: Institutional Review Board (IRB) - Houston

Re: *Extension for Caregivers' Experiences with Decision-Making Feeding Tube Placement for Declining Nutrition in the Community (Protocol #: 20198)*

The request for an extension of the IRB approval for the above referenced study has been reviewed by the TWU IRB (operating under FWA00000178). This study was originally approved on August 22, 2018 and has been renewed. Approval for this study expires on August 21, 2020.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Ainslie Nibert, Nursing - Houston
Dr. Sandra Cesario, Nursing - Houston

APPENDIX D

Recruitment Announcement

Recruitment Announcement

Are you a caregiver of an adult with a feeding tube placed in the last 7 days?



Purpose: Gain an in-depth understanding of your experiences

Eligibility

Caregivers of individuals who have had a gastrostomy feeding tube (PEG) placed in the last 7 days, had some role in the decision making for PEG tube placement, and provide a minimum of 4 hours of direct care per day once the individual is discharged to a private home

***This study involves an interview and potentially additional interviews for follow-up and discussion. A gift card will be provided upon completion.**

If you are interested in participating, please contact Deltra Muoki at dsmith25@twu.edu or call/text me at 281.723.0523. Thank you!

APPENDIX E
Recruitment Script

Recruitment Script

Hi Mr. /Mrs. (potential participant's name).

My name is Deltra Muoki, and I am a PhD student in the College of Nursing at Texas Woman's University. I am the principal investigator on this study with a research interest in the experience of caregivers of individuals with PEG tubes. I am extending an invitation for you to participate in my dissertation research. I am conducting a study entitled The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults. The information acquired from this study may enhance nursing practice, patient outcomes, and future research. The TWU human subjects review board has approved the study.

The purpose of this study is to gain an in-depth understanding of the caregiver's experience with the process of handling declining nutrition and their role in ultimately deciding to place a PEG tube. The contribution of the caregiver's experience may enhance nursing practice and understanding regarding the challenges that caregivers face when handling declining nutrition and PEG tube placement for patients in the community.

I am seeking caregivers of adults who have had a PEG tube placed in the last 7 days and had some role in the decision-making for PEG tube placement. You must be intending to provide a minimum of 4 hours of direct care per day once the individual is discharged to a private home. If you agree to participate in this study, the interview will be scheduled at a time and location that is convenient for you. The interview may be conducted in-person, via telephone, or via FaceTime or Skype. You will be asked to participate in a one-hour interview regarding your experience with the decision-making process for PEG tube placement.

Are you interested in participating in this study? If you need additional time to consider participating or have questions in the future, please feel contact me at dsmith25@twu.edu or 281.723.0523. Sandra Cesario RN, PhD is the supervising faculty for this study. Thank you for your time.

Deltra Muoki RN, MS
Texas Woman's University

Sandra Cesario RN, PhD
Professor, College of Nursing, Texas Woman's University

APPENDIX F

Recruitment E-mail

Recruitment E-mail

To caregivers of residents with a PEG tube,

My name is Deltra Muoki, and I am a PhD student in the College of Nursing at Texas Woman's University. I am the principal investigator on this study with a research interest in the experience of caregivers of individuals with PEG tubes. I am extending an invitation for you to participate in my dissertation research. I am conducting a study entitled The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults. The information acquired from this study may enhance nursing practice, patient outcomes, and future research. The TWU human subjects review board has approved the study.

The purpose of this study is to gain an in-depth understanding of the caregiver's experience with the process of handling declining nutrition and their role in ultimately deciding to place a PEG tube. The contribution of the caregiver's experience may enhance nursing practice and understanding regarding the challenges that caregivers face when handling declining nutrition and PEG tube placement for patients in the community.

I am seeking caregivers of adults who have had a PEG tube placed in the last 7 days and had some role in the decision-making for PEG tube placement. You must be intending to provide a minimum of 4 hours of direct care per day once the individual is discharged to a private home. If you agree to participate in this study, the interview will be scheduled at a time and location that is convenient for you. The interview may be conducted in-person, via telephone, or via FaceTime or Skype. You will be asked to participate in a one-hour interview regarding your experience with the decision-making process for PEG tube placement.

If you are interested in participating in the study or have questions, please feel contact me at dsmith25@twu.edu or call or text me at 281.723.0523. Sandra Cesario RN, PhD is the supervising faculty for this study. Thank you for your time.

Thank you in advance,

Deltra Muoki RN, MS
Texas Woman's University

Sandra Cesario RN, PhD
Professor, College of Nursing, Texas Woman's University

APPENDIX G

Follow Up Recruitment E-mail

Follow Up Recruitment E-mail

To caregivers of residents with a PEG tube,

I am following up on a request I recently sent you regarding participation in a research study. My name is Deltra Muoki, and I am a PhD student in the College of Nursing at Texas Woman's University. I am the principal investigator on this study with a research interest in the experience of caregivers of individuals with PEG tubes. I am extending an invitation for you to participate in my dissertation research. I am conducting a study entitled The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults. The information acquired from this study may enhance nursing practice, patient outcomes, and future research. The TWU human subjects review board has approved the study.

The purpose of this study is to gain an in-depth understanding of the caregiver's experience with the process of handling declining nutrition and their role in ultimately deciding to place a PEG tube. The contribution of the caregiver's experience may enhance nursing practice and understanding regarding the challenges that caregivers face when handling declining nutrition and PEG tube placement for patients in the community.

I am seeking caregivers of adults who have had a PEG tube placed in the last 7 days and had some role in the decision-making for PEG tube placement. You must be intending to provide a minimum of 4 hours of direct care per day once the individual is discharged to a private home. If you agree to participate in this study, the interview will be scheduled at a time and location that is convenient for you. The interview may be conducted in-person, via telephone, or via FaceTime or Skype. You will be asked to participate in a one-hour interview regarding your experience with the decisional making process for percutaneous PEG tube placement.

If you are interested in participating in the study or have questions, please feel contact me at dsmith25@twu.edu or call or text me at 281.723.0523. Sandra Cesario RN, PhD is the supervising faculty for this study. Thank you for your time.

Thank you in advance,

Deltra Muoki RN, MS
Texas Woman's University

Sandra Cesario RN, PhD
Professor, College of Nursing, Texas Woman's University

APPENDIX H

Study Consent Form

Study Consent Form

TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Title: The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults

Investigator: Deltra Muoki, RN, MS.....dsmith25@twu.edu 281.723.0523
Advisor: Sandra Cesario, RN, PhDscesario@twu.edu 713.794.2110

Explanation and Purpose of the Research

You are being asked to participate in a research study for Ms. Muoki's dissertation at Texas Woman's University. The purpose of this study is to gain an in-depth understanding of the caregiver's experience regarding managing malnutrition and their role in ultimately deciding to place a percutaneous endoscopic gastrostomy (PEG) feeding tube. You are eligible for participation if you had some role in the decision making for PEG tube placement, will be providing at least 4 hours of direct care per day for an adult with a PEG tube placement in the last 7 days, and the adult will be ultimately discharged to a private home.

Description of Procedures

As a participant in this study you will be asked to spend approximately one hour of your time in an in-person, FaceTime/Skype, or telephone interview with the principal investigator (PI). The PI will ask you questions about your experience, particularly around decision making for PEG tube placement in an adult with declining nutrition. You and the PI will decide together on a private location and time for the interview. All interviews will be audio recorded and then transcribed professional transcriptionist with human subjects training who has signed waiver of confidentiality. In order to be a participant in this study, you must be at least 18 years of age or older and be a caregiver who had some role in the decision making for PEG tube placement and intends to spend at least 4 hours per day providing direct care for adults with PEG tube.

After transcription of the initial interview the PI may communicate with you via telephone or email to confirm or clarify answers to interview questions. This will require approximately 30 minutes of your time.

The PI will ask you questions about your experience, particularly related to how you became aware of the possibility of feeding tube placement, the people involved in the discussion, the information that was provided to you, your role in the decision making for PEG tube placement, barriers and factors contributing to the decision. The PI will also ask you questions about your experience of living with the decision to place a feeding tube, struggles, and feelings since the PEG tube was placed. The PI will also ask you to describe how information for PEG tube placement and management can be explained to caregivers more clearly and effectively.

Approved by the
Texas Woman's University
Institutional Review Board
Approved: August 22, 2018

Initials
Page 1 of 3

After the PI has reviewed the transcripts, you may be contacted for member checking to ensure the descriptions correlate with the participant's experiences and to discuss the emerging findings. If you agree, a second interview via phone will be scheduled and audio recorded lasting a maximum of 30 minutes.

Potential Risks

A potential risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a private location that you and the PI have agreed upon. No one but the PI will know your full name. The audio recording and the written interview will be stored in the locked fireproof safe at the PI's home office and only accessible to the PI. All identifying information will be deleted from the transcript. The audio recordings will be deleted by August 1, 2021. There is a potential risk of loss of confidentiality in all email, downloading, and Internet transactions. The results of the study may be reported in scientific magazines or journals but your name or any other identifying information will not be included.

Another potential risk in this study is loss of time. The anticipated total time commitment for the interview and potential follow-up activities (i.e.: clarification, member checking, discussing the findings) is approximately two hours. Please let the PI know if you are unable to accommodate this time commitment.

Another potential risk in this study is fatigue. During the interview, you will be able to stop and take breaks at any point during the interview. You are free to stop study participation at any time without consequence.

Another potential risk in this study is emotional upset. You can stop and take breaks at any point during the interview, or stop the interview completely without repercussions. (6) The following resources will be available where you can seek help if needed: Jewish Family Services and National Alliance of Mental Illness Greater Houston. The contact information will be provided to you upon request.

The PI will try to prevent any problem that could happen because of this research. You should let the PI know at once if there is a problem and she will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study you will receive a \$20 gift card for your participation. If you are asked to discuss findings of the study, you will receive an additional \$10 gift card. Participants who choose to participate in the interview via phone, Skype, or FaceTime, will receive Target eGift card via e-mail. If you would like to know the results of this study we will mail or email them to you.

Approved by the
Texas Woman's University
Institutional Review Board
Approved: August 22, 2018

Initials
Page 2 of 3

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the PI and/or faculty advisor; the phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2480 or via e-mail at IRB@twu.edu.

Your participation in the interview indicates your consent to participate in this study.

Signature of Participant

Date

*If you would like to know the results of this study tell us where you want them to be sent:

Email: _____

or

Address:

Approved by the
Texas Woman's University
Institutional Review Board
Approved: August 22, 2018

Page 3 of 3

APPENDIX I

Semi-Structured Interview Guide

Semi-Structured Interview Guide

Title: The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults

Date _____ **Participant ID** _____

Location _____

1. How was the decision made to place a PEG feeding tube?

Probing Questions:

- a. When/how did you know? What happened?
- b. What were your initial thoughts when the PEG feeding tube was first suggested?
- c. Please explain who told you about feeding tube placement. Who else was present?
- d. What did people do and say in the conversation?
- e. Please explain if the presented information addressed your concerns or questions. Why or why not?

2. What was challenging about making the decision to place a PEG feeding tube?

Probing Questions:

- a. What barriers were present when considering feeding tube placement?
- b. What was the most significant factor that influenced the decision?
- c. What were your feelings when the decision was being made?

- d. How did your personal beliefs influence your feelings about the feeding tube
- e. How did your personal beliefs influence your feelings about the feeding tube?

3. What do you think the patient's experience was with the decision to place a PEG feeding tube?

- a. What were the patient's feelings and thoughts about the decision?
- b. How did he/she react when during the decision-making experience?
- c. What do you think having a feeding tube means to the patient?
- d. What do you think is his/her biggest struggle with the feeding tube?

4. What were advantages of placing a PEG feeding tube?

5. What were the disadvantages of placing a PEG feeding tube?

6. What does the caregiver recommend for an effective and positive decision-making experience regarding PEG feeding tube placement?

Probing Questions:

- a. What helped in this process?
- b. What and didn't help in this process?
- c. What should nurses tell caregivers about the PEG feeding tube prior to placement?
- d. How can nurses provide better support and care to caregivers during the decision-making process?

7. What else, if anything, do you think I should know about the decision to have a PEG feeding tube?

- a. What would you like others to know about the decision for feeding tube placement?
- b. What else do you think I should know about the decision?

PI Notes:

Post Interview Comments/Reflections:

APPENDIX J

Demographic Data Collection Form

Demographic Data Collection Form

Title: The Decision-Making Experiences of Caregivers Regarding Feeding Tube

Placement in Community Dwelling Adults

Primary Diagnosis of Patient Associated with the Caregiver _____

Participant ID _____ **Name** _____

Email Address _____ **Phone** _____

Would you like to receive the study results via email? ☐ Yes (1) ☐ No

(2)

Caregiver's Relationship to the Patient

☐ Spouse or Partner ☐ Sibling (Sister or brother) ☐ Parent

☐ Child (son, daughter, step child, daughter in law, etc.)

☐ Other familial relative (Aunt, uncle, cousin, grandchild)

☐ Non-familial relationship (friend, neighbor, etc.)

☐ Other: Please Describe _____

Age Range

☐ 18-23 years old (1) ☐ 24-34 years old (2) ☐ 35-60 years old (3)

☐ 61-75 years old (4) ☐ 76+ years old (5)

Sex

☐ Male (1) ☐ Female (2) ☐ Other (3)

Ethnicity: Check all that apply

☐ Black (1) ☐ White – Non Hispanic (2) ☐ Hispanic (3)

☐ American Indian/Alaskan Native (4) ☐ Asian/Pacific Islander (5) ☐ Other (6)

Highest Level of Education Completed

- ☐ No Schooling completed (1) ☐ Grades 1 through Grade 8 (2)
- ☐ Some high school, no diploma (3) ☐ High school graduate or GED (4)
- ☐ Some college, no degree (5) ☐ Technical/trade training (6)
- ☐ Associate Degree (7) ☐ Bachelor's Degree (8) ☐ Graduate degree

(9)

Marital Status

- ☐ Single, never married (1) ☐ Married or domestic relationship (2)
- ☐ Widowed (3) ☐ Divorced (4) ☐ Separated (5)

Employment Status

- ☐ Full-time (1) ☐ Part-time (2) ☐ Student (3) ☐ Retired (4)
- ☐ Unemployed (5) ☐ Disabled (6) ☐ Homemaker (7) ☐ Self-Employed (8)

Relationship between Patient and Caregiver

How many hours per day had you provided care for the patient prior to PEG placement?

- ☐ 0-5 hours (1) ☐ 6-11 hours (2) ☐ 12-17 years old (3)
- ☐ 18-24 hours (4)

How many hours per day do you think you will provide care for the patient after PEG placement?

- ☐ 0-5 hours (1) ☐ 6-11 hours (2) ☐ 12-17 years old (3)
- ☐ 18-24 hours (4)

How long have you been providing care to the patient?

☐ 0-3 months (1)

☐ 4-7 months (2)

☐ 8-12 months (3)

☐ More than 12 months (4)

APPENDIX K

Adept Word Management, Inc. Confidentiality Agreement and Certificates

Adept Word Management, Inc. Confidentiality Agreement and Certificates



AGREEMENT OF CONFIDENTIALITY
ADEPT WORD MANAGEMENT, INC

I, MEMLAUGHlinforAdeptWordManagement, the undersigned, am an independent contractor who has agreed to contract transcription services with Adept Word Management, Inc. By signing this Confidentiality Statement, I indicate my understanding that:

With my acceptance of any Adept-related project, I agree that the project is to be kept strictly confidential. I will not share the contents of this project with anyone outside the employ of Adept, or my own independent contract service. If information regarding proprietary concepts or any other confidential issues - about products or individuals - are used or disclosed inappropriately, our clients and or affiliates may suffer a loss or injury and could seek legal action to recover damages from the person who used or disclosed the information. Specific violations of confidentiality resulting in economic loss may be punishable by law.

I agree that I will not at any time disclose services or information about Adept, its clients or affiliates. Nor will I allow anyone else to examine or copy any records or documents having to do with any Adept related project.

I agree not to disclose any of the material obtained through Adept Word Management, Inc., including the names of all clients and their clientele, and hold this information strictly confidential. I agree to indemnify and hold harmless Adept from any and all actions, causes of action and claims for damages, including attorneys fees, arising out of an Adept related project or this agreement.

MEMLAUGHlinforAdeptWordManagement
INDEPENDENT CONTRACTOR

3/28/13
DATE

Address: ADEPT WORD MANAGEMENT

Phone: 281-495-7995

Date: _____

SSN: TIN: 76-0457402



Study Title: The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults

Principal Investigator (PI): Deltra Muoki

Adept Word Management™ Inc., and all staff members, hereby agree to the following conditions of confidentiality concerning all information that may be supplied to me by members of the study research team.

- We agree to keep strictly confidential all information that may be communicated to me verbally, in written form, or in any other form.
- We agree to take all precautions necessary to prevent knowledge of this information from reaching any unauthorized parties. We clearly understand that authorized persons are only those persons who are approved members of the research team.
- We will not use any information provided for any purpose other than that required by the PI/research team.
- We will not keep any copies, summaries, or transcripts of the confidential documents provided in any form and will return all such documents to the PI/research team upon completion of our duties.

Name: M E McLaughlin

M E McLaughlin
Signature

August 13, 2018
Date

Deltra Muoki
Principal Investigator Signature

August 2, 2018
Date



**AGREEMENT OF CONFIDENTIALITY
ADEPT WORD MANAGEMENT, INC**

Adept Word Management, Inc. has agreed to provide transcription services for. By signing this Confidentiality Statement, I indicate my understanding that:

I agree that the project is to be kept strictly confidential. I will not share the contents of this project with anyone outside the employ of Adept or independent contractors of Adept. If information regarding proprietary concepts or any other confidential issues - about products or individuals - are used or disclosed inappropriately, our clients and or affiliates may suffer a loss or injury and could seek legal action to recover damages from the person who used or disclosed the information. Specific violations of confidentiality resulting in economic loss may be punishable by law.

I agree that I will not at any time disclose services or information about Adept, its clients or affiliates. Nor will I allow anyone else to examine or copy any records or documents having to do with any Adept related project.

I agree not to disclose any of the material obtained through Adept Word Management, Inc., including the names of all clients and their clientele, and hold this information strictly confidential. I agree to indemnify and hold harmless Adept from any and all actions, causes of action and claims for damages, including attorneys fees, arising out of an Adept related project or this agreement.

Deltra Muoki
Type or Print Name

M E McLaughlin for Adept Word Management, Inc.
Type or Print Name

Deltra muoki
Signature

M E McLaughlin
Signature

August 2, 2018
DATE

October 19, 2017
DATE

APPENDIX L

Human Subjects Training Certificates

Human Subjects Training Certificates

NIH NINR Developing Nurse Scientist Course Certificate of Completion

Certificate of Successful Completion of

An Approved Continuing Nursing Education Activity

Name: Deltra Muoki

Email: deltramuoki@yahoo.com

Successfully Completed

Title: Developing Nurse Scientist Course

4 Contact Hours

Code Number: 9633

Presentation Date: 2/16/2017

Web based presentation

Name/Address of Provider:

The National Institute of Nursing Research

31 Center Drive

Bethesda, Maryland 20892



RESEARCH

This continuing nursing education activity was approved by the Maryland Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation
MNA Code Number LN12-09-531-529





Completion Date 20-Feb-2017
Expiration Date N/A
Record ID 22363754

This is to certify that:

Deltra Muoki

Has completed the following CITI Program course:

Social and Behavioral Responsible Conduct of Research (Curriculum Group)
Social and Behavioral Responsible Conduct of Research (Course Learner Group)
1 - RCR (Stage)

Under requirements set by:

Texas Woman's University

CITI

Verify at www.citiprogram.org/verify/?wcb821c70-7e90-4bd6-b190-7da88fe828ba-22363754

APPENDIX M

Acceptance E-mail Manuscript GNJ-18-90R1

Acceptance E-mail Manuscript GNJ-18-90R1

RE: GNJ-18-90R1, entitled "Decisional conflict in percutaneous gastrostomy tube placement in adults: An integrative review of the literature"

Dear Mrs. Muoki,

I am pleased to inform you that your work has now been accepted for publication in Gastroenterology Nursing. All manuscript materials will be forwarded immediately to the production staff for placement in issue 43(5) (Sept/Oct) of 2020.

OPEN ACCESS

If you indicated in the revision stage that you would like your submission, if accepted, to be made open access, please go directly to step 2. If you have not yet indicated that you would like your accepted article to be open access, please follow the steps below to complete the process:

1. Notify the journal office via email that you would like this article to be available open access. Please send your Email to kathy.baker@tcu.edu. Please include your article title and manuscript number.
2. A License to Publish (LTP) form must be completed for your submission to be made available open access. Please download the form from <http://links.lww.com/LWW-ES/A49>, sign it, and Email the completed form to the journal office.
3. **Within 48 hours of receiving this e-mail:** Go to <http://wolterskluwer.qconnect.com> to pay for open access. If you have not previously used this site to place an order, you will need to register for an account (your login will be different from your Editorial Manager

login). When placing your order, you will be asked for the following information. Please enter exactly as shown:

a. Article Title - Decisional conflict in percutaneous gastrostomy tube placement in adults: An integrative review of the literature

b. Manuscript Number - GNJ-18-90R1

Thank you for submitting your interesting and important work to the journal.

With Kind Regards,

Dr. Kathy A. Baker

Editor

Gastroenterology Nursing

APPENDIX N

Manuscript Submission GNJ-19-132

Manuscript Submission GNJ-19-132

Dear Mrs. Muoki,

Your submission entitled "The decision-making experiences of caregivers regarding feeding tube placement in community dwelling adults: A descriptive phenomenological study" has been assigned the following manuscript number: GNJ-19-132.

You may check on the progress of your paper at any time by logging on to Editorial Manager as an author.

<https://www.editorialmanager.com/gnj/>

Thank you for submitting your work to Gastroenterology Nursing.

Kind Regards,

Jonathan Kemmerer-Scovner



Managing Editor

Gastroenterology Nursing

Submissions Being Processed for Author Deltra Muoki, MS, APRN, AGNP-C, CMSRN

Page: 1 of 1 (1 total submissions)

Display results per page.

 Action 	Manuscript Number ▲▼	Title ▲▼	Initial Date Submitted ▲▼	Status Date ▲▼	Current Status ▲▼
Action Links	GNJ-19-132	The decision-making experiences of caregivers regarding feeding tube placement in community dwelling adults: A descriptive phenomenological study	Sep 15, 2019	Oct 07, 2019	Under Review

Page: 1 of 1 (1 total submissions)

Display results per page.

APPENDIX O

Gastroenterology Nursing Publication Release Letter

Gastroenterology Nursing Publication Release Letter

From: ["JRP - Journal Permissions" <journalpermissions@lww.com>](mailto:JRP - Journal Permissions)
To: [Zeranque, Amanda](#)
Subject: RE: Article ReUse in Dissertation [Case # 01273764] [ref:_00Dd0dxc_5000V1CuzGS:ref]
Date: Wednesday, July 25, 2018 10:20:00 AM

Hello Amanda,

If the students are authors of published Wolters Kluwer articles, they are permitted to use the **final peer reviewed manuscript** (*post peer-review and acceptance for publication, but prior to publisher's copyediting and formatting*) in their thesis/dissertation.

If their thesis/dissertation is being posted to an institutional repository, please ensure the following as per below:

- Post only the final peer reviewed manuscript after the embargo period has elapsed (**12 months after publication**)
- A link to the final article with the proper citation is included along with the following disclaimer: This is a non-final version of an article published in final form in (full journal citation) *ex: Thomson, Imogen Do Good Medical Students Really Make Good Doctors, Academic Medicine, Volume 92, Issue 6, June 2017, http://journals.lww.com/academicmedicine/Fulltext/2017/06000/Do_Good_Medical_Students_Really_Make_Good.22.aspx*
- Please remember that we do not permit articles to be posted on open access websites, such as Research Gate.

For additional information, please review the [Author's Permission Document](#)

In regards to the student who's requesting to publish with Gastroenterology Nursing, are they requesting to reuse an already published article?

Does the above answer your question in regards to thesis use?

If you have any further questions, please let us know.

Thank You,
Chandreyi

Wolters Kluwer Permissions Team
Health Learning, Research & Practice
permissions@lww.com



Final Defense

Date of final defense: September 25, 2019

Student: Deltra Catrece Muoki

Student ID#: 0704443

We, the undersigned are submitting herewith a ☐ Thesis ☒ Dissertation, entitled:
The Decision-Making Experiences of Caregivers Regarding Feeding Tube Placement in Community Dwelling Adults

written by the aforementioned student. We affirm that we have examined this document
for form and content and recommend that it be accepted in partial fulfillment of the
requirements for the degree of: Doctor of Philosophy in Nursing Science

with a minor in: N/A

Handwritten signature of Sandra Cesario in black ink.

Major Professor/Committee Chair

Handwritten signature of Peggy Lander in black ink.

Committee Member

Handwritten signature of Anna J. Hitt in black ink.

Committee Member

Committee Member

Committee Member

Handwritten signature of Charlie M. Hitt in black ink.

Department Chair (or appropriate title for Departmental Administrator)

Extra signature lines have been provided.

The Graduate School

P.O. Box 425649 | Denton, TX 76204 | 940 898 3415 | gradschool@twu.edu