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Pondering PEG Tube Placement: Ethical Considerations in Advanced Dementia

Nursing 6033: Ethical Dimensions in Nursing

Ethics Paper

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Introduction

Summary of the Case Study

Inez Martin is an 84 year old white female with history of Alzheimer's dementia. She is a resident of Pilgrim Rest Nursing Center in Bossier City, Louisiana. Mrs. Martin's cognitive status has declined over the past year resulting in functional limitations and dependence in management of with activities of daily living (ADL). She demonstrates a decrease in dietary intake over the past two months, consuming less than 25 percent of her meals. Over the past week, intake consisted only of sips of Ensure and water with medications. Mrs. Martin is widowed with no living children and her nephew, Gary Martin, serves as her surrogate. However, although she does not have a living will or durable power of attorney.

When Mrs. Martin is admitted to the hospital with dehydration, nutritional status continues to decline and consultation with speech therapy is obtained to evaluate swallowing. Video esophagram reveals a delayed swallowing reflex with no evidence of aspiration. On Day 3 of her admit, Gastrointestinal Specialist is consulted for percutanous endoscopic gastrostomy (PEG) placement for nutritional support due to malnutrition. The Doctor of Nursing Practice (DNP) prepared Nurse Practitioner arrives to the geriatric unit for the consultation (Appendix A). She discusses the risks and benefits of placing a PEG tube with Mrs. Martin's nephew and he responds by stating, "I want what is best for my aunt".

General Ethical Dilemma

In Mrs. Martin's case, malnutrition is related to pharyngeal-phase dysphagia as evidence by delayed swallowing reflex on video esophagram. Her attending physician believes that PEG tube placement will improve her nutritional status and chance of survival, however, this belief is

controversial and research does not confirm these assumptions (Kuo, Rhodes, Mitchell, Mor & Teno, 2009).

The ethical dilemma in this case is: Should the PEG tube be placed or not? Will it be a benefit or burden for Mrs. Martin? This paper analyzes the ethical and legal aspects of PEG tube placement in patients with advanced dementia. The ethical principles of beneficence, non-malficience, justice and autonomy are evaluated. Arguments for and against are presented followed by a discussion of the DNP student's personal decision. Case consultation worksheets that highlight relevant information (Appendix B) are included.

Ethical Considerations

Clarification and Expansion of Ethical Dilemma

PEG placement is considered gold standard in providing long-term enteral nutrition for dysphagia associated with neurological diseases, dementia and malignancies (Detweiler, Kim & Bass, 2006). Data regarding the prevalence of PEG tubes with advanced dementia is lacking, however existing research documents rates ranging from 18 to 34 percent in this population (Kuo et al., 2009). A study by Kuo et al. (2009) determined that the incidence of PEG placement was 53.6 per 1000 nationally in nursing home residents with advanced dementia. According to Cervo, Bryan & Farber (2006) this relatively high incidence can be attributed to the uncomplicated nature of the procedure and low risk for procedure related complications. Rare complications include bleeding, perforation, respiratory complications and infection at insertion site (Roche, 2003). PEG placement takes approximately 30 minutes and is completed with conscious sedation. It may be performed on an out-patient basis, but generally is performed in the acute care setting (Kuo et al., 2009).

Many patients with advanced dementia suffer from malnutrition during the final stages of the disease process (Cervo, Bryan & Farber, 2006). Poor intake can be related to failure to recognize food, loss of appetite, early satiety, or dysphagia (Candy, Sampson & Jones, 2009). Dysphagia can range from the inability to manage food bolus in the mouth to gross aspiration (Finaucane, Christmas & Travis, 1999). Swallowing difficulties and malnutrition seen in advanced dementia are indicators for making a decision to place a PEG tube. The American Gastroenterological Association (1994) practice guidelines support PEG tube placement in patients "who cannot or will not eat, for patients who have a functional gut, and for whom a safe method of access is possible" (p. 1). Health care providers and family members often believe that tube feedings will improve chance of survival, nutritional status, and further complications such as impaired skin integrity in patients with advanced dementia, but PEG placement benefits are controversial (Kuo et al., 2009).

Existing Research Evidence

Fincucane, Christmas & Travis (1999) conducted a search for evidence comparing effectiveness of tube feeding with oral feeding in patients with advanced dementia. The search of MEDLINE from 1966 to 1999 revealed no randomized clinical trials. Therefore, the authors provided a systematic review of clinical evidence relating tube feedings to comfort, reduction in skin breakdown, prevention of aspiration, consequences of malnutrition and increased survival rate in patients with advanced dementia concluding that PEG tube risks outweigh benefits. A non-randomized prospective study by Feinburg, Knebl & Tully (1996), confirmed that episodes of aspiration were significant less in orally fed patients with oro-pharnygeal transfer dysphagia than patients feed by feeding tubes (as cited in Fincucane et al.). Henderson, Trumbore, Mobarhan, Benya, & Miles (1992) analyzed the nutritional status and clinical

outcomes of 40 patients receiving tube feedings in a long-term care setting. The results of this study showed that these patients continued to exhibit signs of malnutrition despite adequate protein and calorie intake (as cited in Fincucane et al.). Fincucane et al. retrieved no articles that associated tube feedings with improved mortality rates in patients with dementia. In addition, no evidence that tube feedings reduced the development of infections or skin breakdown was identified (Fincucane et al.). DeLegge (2009) commended Fincucane et al. for this article, recognizing it as a pivotal paper launching a change in clinical practice.

A quasi-experimental study conducted by Meier, Ahronhein, Morris, Baskin-Lyons & Morrison (2001), followed a cohort of patients with advanced dementia in order to determine the influence of tube feedings on survival. Ninety-nine subjects were enrolled in the study and were followed after their index hospitalization. Of the 99 subjects, 17 (17.2%) had a feeding tube on admission, 51 (51.5%) had a feeding tube placed during the index hospitalization and 31 (31.3%) were discharged without a feeding tube. The median survival for those that had a feeding tube placed during the index hospitalization was 195 days compared to 189 days for those that did not have a feeding tube placed. Meier et al. concluded that tube feeding was not associated with survival among these patients.

Kuo, Rhodes, Mitchell, Mor & Teno (2009) conducted a retrospective analysis of Medicare claims in order to determine the incidence, indications for and complications of feeding tubes. They utilized the 2000 Minimum Data Set (MDS) that includes information on nursing home residents that live in facilities who are certified by Medicare or Medicaid. A sample of 5209 subjects with advanced dementia who had a feeding tube placed within one year of their initial MDS assessment was studied. The researchers found that 64.1 percent of the subjects died within one year following insertion of a feeding tube with a median survival rate of

165 days. Twenty percent (1 in 5) of the subjects developed a feeding tube complication requiring replacement, repositioning, or removal of the tube. A correlation between the lack of advanced directives and feeding-tube placement was identified. Based on these findings, Kuo et al. recommend decision-making guidelines in order to decrease the utilization of feeding tubes in nursing home residents with advanced dementia.

Arguments For and Against PEG Placement

Authors of existing research argue that positive clinical outcomes are not supported by tube feeding in patients with advanced dementia (Fincucane et al., 1999; Meier et al., 2001; Kuo et al., 2009), although its use continues to escalate in clinical practice. Dennehy (2006) asserts that "there is no right or wrong answer" for any case (p. 20). The nurses responsibility to utilize a holistic approach when assessing the needs of individuals and their families. The American Nurses Association (ANA) Code of Ethics for Nurses (2001) states that:

> Nurses actively participate in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted or unwanted treatment and patient suffering. The acceptability and importance of carefully considered decisions regarding resuscitation status, withholding and withdrawing life-sustaining therapies, forgoing medically provided nutrition and hydration, aggressive pain and symptom management and advanced directives are increasingly evident. (p. 8)

Byrd (2004) states that nurses must acknowledge their personal values and beliefs and recognize preconceptions regarding the use of feeding tubes before guiding patients and family through the decision-making process. The ethical principles of autonomy, nonmaleficence, beneficence and justice (Beauchamp & Childress, 2009) facilitate decision-making by the health care provider. Autonomy refers to *self rule* and freedom to make personal decisions. This

concept is the underpinning of informed consent. Beneficence is described as obligatory actions that are intended to benefit others. The ethical principle of nonmaleficence is defined as "intentionally refraining from actions that cause harm" (Beauchamp & Childress, p. 151). Justice in regards to principles of health care ethics is described as "fair, equitable and appropriate treatment" regardless of what an individual is owed (Beauchamp & Childress, p. 241). These principles as related to PEG tube placement in patient with advanced dementia are addressed.

Autonomy. Respecting patient's autonomy and supporting the health care decisions made are paramount (Beauchamp & Childress, 2009). Capacity for autonomous choice is lacking in patients with dementia, therefore surrogates serve as decision-makers on their behalf. Like health care providers, surrogates should not inflict their own values in the decision making process but respect the patient's values and beliefs (Lo, 2009). In addition, advanced directives should be given the same respect as a competent patient's right to autonomy. This respect recognizes that the patient was once able to make his own decisions and it fulfills their health care wishes (Dennehy, 2006).

Beneficence. Health care providers and family members may feel obligated to provide tube feedings to patients who cannot or will not eat, believing that it will be beneficial. The ultimate decision to place a PEG tube may be based on cultural norms rather than research evidence, that does not offer promising outcomes in patients with dementia (Fincucane et al., 1999; Meier et al., 2001; Kuo et al., 2009). Many families view feeding as an essential element of caring, whereas others feel that it is futile (Gillick & Volandes, 2008). Slomka (1995) argues that "tube feeding has nothing to do with apple pie and motherhood" and therefore, the physiological need rather than cultural need should be assessed (as cited in Gillick & Volandes,

2008, p. 366). Health care providers acknowledge the symbolic value of feedings by using an alternative such as hand feeding, if applicable (Gillick & Volandes). Compared to tube feeding, hand feeding provides comfort to the patient with dementia through personal contact as well as stimulation of the taste buds (Dennehy, 2006).

Nonmaleficence. The concept of nonmaleficence overlaps with beneficence in the consideration of PEG tube placement in patients with dementia. The health care provider considers PEG tube placement as a means for providing nutrition, understanding that there is a potential for harm, such as post-procedure complications of local infection, tube occlusion, leaking and colocutaneous fistulas (Dennehy, 2006; Roche, 2003; Finucane et al., 1999). The *doctrine of double effect* is a dilemma that adds complexity when an intervention has two possible outcomes, one good and one bad (Beauchamp & Childress, 2009).

Justice. The health care providers recommendation for PEG placement in the demented patient may be predicted on the belief this is "best care" and the patient deserves best care. A counter perspective, is that according to Finicane et al. (1999) is that tube feeding patients are deprived of the pleasure of eating or made experience discomfort caused by friction from the bumper of the PEG and mobility restriction when the tube is connected to a feeding pump for continuous feedings. In addition, the patient may inadvertently pull at the PEG tube requiring an abdominal binder or wrist restraints be used. Dennehy (2006) describes the use of restraints in patients with dementia as "unjust and unsavory" practices (p. 19). Dennehy also argues that it is unfair to use valuable resources that are known to be futile. Lo (2009) describes tube feeding as *impersonal*, pointing out that caregivers may be more focused on technical issues related to PEG tube management and subsequently neglect to comfort the patient.

Incorporating ethical principles. Cervo, Bryan & Farber (2006) stress that family meetings allow focus be shifted from unrealistic expectation of full recovery to provision of comfort for these patients. Topics for discussion should include risk and benefits of PEG placement including procedure related and local complications, alternatives to tube feedings such as hand feedings, and the potential need for restraints after PEG placement (Roche, 2003; Cervo, Bryan & Farber, 2006). Veracity, a moral virtue, is vital in health care ethics and should be identified as an independent principle along with beneficence, nonmaleficence, justice and autonomy (Warnock, 1971 as cited in Beauchamp & Childress, 2009). Veracity is defined as the accurate and truthful communication of health care information in manner that is understood by the patient or family (Beauchamp & Childress). Aspects of this virtue should be respected during all interaction with the family, especially during the family meeting.

Legal Considerations

Legal standards as well as ethical principles guide the decision making process for PEG tube placement in patients with advanced dementia. Health care providers must consider informed consent, advanced directives and reimbursement laws. Informed consent serves both to protect the physician from malpractice and to enhance the well being of the patient (Lo, 2009). In addition, failure to obtain informed consent or providing inadequate information may be led to malpractice charges for the health care provider (Lo). It ensures that pertinent information was discussed and the patient or surrogate agree to the procedure (Lo). A dilemma can occur because the document does not verify the degree in which the patient or surrogate understands the procedure which can led to misconceptions and potential legal reactions. This reiterates the importance of the family meeting to provide information and clarify understanding of all possible outcomes (Cervo, Bryan & Farber, 2006).

Advanced directives are critical elements in the decision making process, especially for patients with dementia. These documents indicate who would act as surrogate and what interventions the patient would accept or refuse if decision making capacity is lost (Lo, 2009). It is imperative that health care providers discuss advanced directives at routine office visits although sometimes they wait until it is too late (Cervo, Bryan & Farber, 2006). It is helpful if the appointed surrogate participates in these discussions as it ensures their understanding of the patient's wishes and facilitates preservation of patient autonomy when the time arrives (Lo, 2009). In many cases, health care providers rely on oral directives from family members and friends when written documents are not available. Only eleven states, including Louisiana, permit the use oral directives (Sabatino, 2005). Several states forbid the use of oral advanced directives unless they mention a specific intervention and clinical situation, such as feeding tube in advanced dementia (Lo).

In some cases, patients must have a PEG placed before transferring from the acute care to long term care facilities or nursing homes (Ganzini, 2006). There are financial incentives for institutions that care for patients with feeding tubes. According to Mitchell, Buchanan & Littlehale (2003) reimbursement cost from Medicare are more for patients that are tube feed even though hand feeing utilizes more time and resources (as cited in Ganzini). Health care providers may therefore feel legally obligated to place a PEG tube in patients that need to be transferred. As another issue, some families may pressure a physician into performing the procedure in a patient who cannot or will not eat. The physician may agree to the procedure in order to avoid legal action, even though he feels that it futile (Lo, 2009).

Personal Decision

I believe that each decision for PEG placement should be contextually appropriate giving consideration to the needs of the patient with advanced dementia. I agree with Dennehy (2006) that there is not a right or wrong answer for placing PEG tubes in patients with advanced dementia. Using the ethical principles of beneficence, nonmaleficence and justice the decision to insert a PEG tube should ultimately be based on physiological findings. PEG tubes should not be considered if death is imminent (Byrd, 2004). In addition, hand feedings should be encouraged especially if the patient does not exhibit signs of aspiration. Cultural and religious beliefs contribute to decision-making and should be respected as a person's value system frames their advanced directives. Health care providers and surrogates alike should uphold the advanced directive preserving patient autonomy.

It is the health care providers responsibility to conduct a family meeting. Information regarding the risk and benefits should be presented to the family in a logical manner and at the surrogates level of understanding. Presenting this information in a veracious and genuine manner will allow the family to make the best decision for their loved one. The health care provider should support the family's final decision regardless of his personal beliefs.

Summary

Health care providers must be knowledgeable about ethical and legal principles to successfully guide the decision making process.

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Appendix A

Case consultation

Patient: Inez Martin
DOB: 8/22/1925

CONSULTATION- 11/3/2009

HPI: Inez Martin is an 84 year old white female with history of Alzheimer's dementia who presents in consultation today for evaluation for PEG tube placement. She was admitted to the hospital on 11/1/2009 with dehydration. Her cognitive status has declined over the past year resulting in functional limitations and dependence with ADLs. She has had a decrease in dietary intake over the past two months, consuming less than 25 percent of her meals. Over the past week, intake has consisted of sips of Ensure and water with medications. She has had a 30 pound weight loss over the past 2 months. Weight on admit 95 pounds.

She was evaluated by speech therapy 11/2/09 and had a video esophagram completed that revealed a delayed swallowing reflex with no evidence of aspiration.

PMH: Alzheimer's dementia, Osteoarthritis, colon polyps and diverticular disease

PSH: Appendectomy

MEDICATIONS: Aricept, Namenda, Megace, ASA, MVI, Metamucil

ALLERGIES: NKDA

SH: Widow, 1 child (deceased- MVA). Resident of Pilgrim Rest Nursing Center. Gary Martin (nephew) and his wife Charlotte served as caregivers prior to nursing home. She does not have a living will or durable power of attorney.

FH: Mother died at age 75 with metastatic colon cancer. Father died at 90 with MI, he also had dementia. 1 sibling- sister had a stroke and died at age 75.

ROS: Difficult to obtain from patient due to lethargy. No reports of abdominal pain, vomiting, diarrhea, constipation, melena or hematochezia according to her nurse. No documented fever.

PE: VS: BP 106/65, HR 85, RR 18, Temp 98.9. General: 84 year old elderly, thin white female. Neuro: Lethargic, opens eyes to verbal stimuli, Speech somewhat difficult to understand. Oriented to person and recognizes nephew. PERRL. Lungs: Clear to auscultation bilat. Heart: S1S2 with regular rate and rhythm. Abdomen: Scaphoid, non-tender, bowel sounds present in all four quadrants. Ext: No cyanosis or edema. Skin: Stage 2 decubitus ulcer noted on coccyx.

LAB: 11/1/09 (Admit): Na 150, BUN 55, Creat 1.9, Hgb 13, HCT 39
11/3/09: Na 145, BUN 22, Creat 1.1, Hgb 9.8, HCT 29. Prealbumin 10 mg/dl

Impression: Pharyngeal phase dysphagia secondary to the end stages of Alzheimer's dementia.
Malnutrition secondary to # 1

Plan: Had a long discussed with Mrs. Martin's nephew regarding the risks and benefits of placing a PEG tube. Explained that existing research literature does not show promising outcomes for feeding tubes in patient with dementia. He responded by stating "I want what is best for my aunt" and elected to forego PEG placement as he believes she "would not have not wanted a feeding tube". Will continue hand feedings with pureed foods and nutritional supplements.

Appendix B

Case Consultation Worksheets

Worksheet A

Step 1: Personal Response

I believe that every cases is different and there is not a right or wrong answer for placing a PEG tube in patients with dementia.

I am opposed to placing a PEG tube when death is imminent.

Step 2: Facts of the case

Mrs. Martin's prognosis is poor, however death is not imminent.

She interacts minimally within her environment but recognizes her nephew

Dependent in ADLs

No evidence of aspiration- Lungs clear- Video esophagram does not reveal aspiration

Step 3a: Clinical/Psychological Issues Influencing Decision

Existing research does not show that PEG are beneficial for patients with dementia

Mrs. Martin is able to swallow without evidence of aspiration

Step 3b: Initial Plan

Conduct a family meeting- discuss risk and benefits of PEG tube

Step 4: Policies & Ethical Code Directive

AGA position statement & ANA Code of Ethics

Step 5: Ethical Principles Analysis

Autonomy- Respect and support decisions made by the surrogate

Beneficence- doing of good. Research does not support PEG placement in patients with dementia- risks outweigh the benefits

Nonmaleficence- prevent harm. There is a potential for harm with PEG tubes. Doctrine of double effect complicates this intervention

Justice-fairness. PEG can cause discomfort and restrict mobility. May require restraints.

Step 6: Possible Legal Issues

Informed consent, advanced directives and reimbursement laws

Worksheet B

Plan & Implementation Strategy

Family meeting- Nephew elected to forego PEG placement

Continue hand feedings and comfort care

Support the decision made by the family

Write down how your plan:

Advances Clinical/Psychological Interests:

Quality of life will be maintained with plan of care

Adheres to agency policies and professional ethics codes:

ANA Code of Ethics- incorporated into decision-making process

Minimizes harm and maximizes other ethical principles to the extent possible for the client and relevant others:

Autonomy- Decision made by the family is respected

Beneficence- Hand feeding will be more comforting than PEG feedings

Nonmaleficence- Potential complications of PEG will not be an issue in this case

Justice- Dignity will be respected. Caregivers can focus on caring for Mrs. Martin rather than the PEG tube.

Allows you to operate within the law:

Yes. In the state of Louisiana it is permitted to use oral directives from family members