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From Means to Ends: Artificial Nutrition and Hydration

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KEYWORDS

• Ethics • Artificial nutrition • Hydration
• Decision-making • Reasoning

The withdrawal, withholding, or implementation of life-sustaining treatments such as artificial nutrition and hydration challenge nurses on a daily basis. To meet these challenges, nurses need the composite skills of moral and ethical discernment, practical wisdom and a knowledge base that justifies reasoning and actions that support patient and family decision making. Nurses' moral knowledge develops through experiential learning, didactic learning, and deliberation of ethical principles that merge with moral intuition, ethical codes, and moral theories. Only when a nurse becomes skilled and confident in gathering empiric and ethical knowledge can he or she fully act as a moral agent in assisting families faced with making highly emotional decisions regarding the provision, withholding, or withdrawal of artificial nutrition and hydration.

NURSING KNOWLEDGE

There are ways of "knowing" that underpin how nurses reason and act concerning the use and effectiveness of artificial nutrition and hydration (ANH). Among these reasons are those that nurse theorist Barbara Carper suggested in her seminal work published in 1978 entitled "Fundamental Ways of Knowing in Nursing," in which she suggests a typology of nursing knowledge using 4 patterns: empirics, ethics, personal, and esthetic.[1] Two of these patterns are particularly relevant and support the notion that moral reasoning and action cannot occur in the absence of empiric knowledge combined with ethics education. These ways of knowing are implicated in the daily decisions that challenge nurses regarding ANH.

Empiric Knowledge

Empiric knowledge represents the science of nursing, providing verifiable factual and descriptive information that can be applied to a clinical situation. ANH is the delivery of

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nutrients via the gastrointestinal tract, the vascular system, or subcutaneously for hydration alone. This life-sustaining treatment nourishes patients in varying degrees and with greater or lesser success in a variety of clinical states, including persistent vegetative state (PVS), advanced progressive dementia, and other terminal illnesses, and in several temporary or chronic conditions. ANH in the form of enteral nutrition is commonly administered through the gastrointestinal tract either through a temporary or permanent enteral tube. According to reports from the *National Hospital Discharge Survey,* approximately 279 000 permanent enteral tubes were placed in 2005,[2] a 3-fold increase over the past 20 years.[3] Some of this increase may be attributed to improved technology in the development of the percutaneous endoscopic gastrostomy in 1980, which requires no major surgery or general anesthesia.[4]

ANH is an effective and viable therapy for temporary or chronic conditions that affect the ingestion of food and fluids. Some literature demonstrates that ANH prolongs life, improves survival and nutritional status, and improves quality of life in limited instances. Such situations include nourishment for individuals with a temporary inability to use the gastrointestinal tract because of a nonterminal illness or the need for a time trial to examine a patient's chance for recovery. In those instances, ANH is clearly not only physiologically useful but qualitatively beneficial.[5,6] Its advantage in many clinical settings is questionable and may reflect knowledge differences about the goals of care.[7]

For patients in a terminal state or others who are severely ill, there is large body of evidence regarding ANH's lack of efficacy to prolong life or reduce symptom burden. Evidence is conflicting or fails to show that ANH affects the survival rate of severely ill patients,[8] patients receiving chemotherapy,[7,9–11] or the complication rates after cancer surgery.[12–14] Results are also mixed when examining the literature on hydration alone. Hydration of terminally ill patients resulted in poorer nutritional status and the lack of a strong association between clinical signs of dehydration and fluid balance.[15] This finding compares to a more positive outcome from hydration of cancer patients, in which they describe a lower symptom burden.[16] Unlike these conflicting reports, a significant body of knowledge seems to support a lack of evidence to show improved survival in patients with dementia.[17–22]

Support for ANH use in other disease states is mixed. In postoperative patients with upper gastrointestinal neoplasms and patients receiving radiation therapy for advanced head and neck cancers, ANH was shown to decrease morbidity and improve nutritional status.[12,23,24] ANH also may prolong life in patients with bulbar amyotrophic lateral sclerosis,[25,26] acute stroke with dysphagia or head injury,[27,28] short-term critical care status,[29] and extreme short-bowel syndrome.[30] PVS poses special considerations for many, but there is little evidence to support that ANH contributes to an improvement in quality of life.[31] The physiologic response of persons in vegetative states to ANH may differ from those who are actively dying and may not appear as burdensome. The lack of a clear pathology in PVS further compounds the issue.[32] ANH may prolong life in PVS, leaving patients in this state of unawareness for years.[31,33] Given the inconsistent evidence concerning the impact of ANH, some might assume that it may be helpful but cannot be harmful. Despite this assumption, most nurses are well aware of the considerable risks associated with ANH, including aspiration pneumonia, diarrhea, catheter and tube site infections, mobility limitations during infusion, and self-extubation.[19,34–36]

Finally, clarification of empiric knowledge related to the effect of the absence of nutrition, hydration, or both treatments simultaneously is necessary. Unfortunately, there is little evidence to support or refute the presence or lack of distressing symptoms as a result of removal of ANH or hydration. Physiologically, starvation can be

described as the ''depletion of food stores in the body tissues.''[37] The main effect of starvation is the depletion of protein and fat stores caused by limited carbohydrate stores in the body; patients eventually succumb to a loss of body protein.[38] Symptomatically, patients exhibit the primary result of acidosis—central nervous system depression manifested by disorientation and eventual coma.[37] In addition to acidosis, some postulate that starvation may be accompanied by an increase in endorphin release, thereby creating a sense of elation,[39] which some believe is the basis for claims of analgesia or anesthesia in terminally ill patients who refuse food.[40]

Data regarding symptoms that result from dehydration are controversial. Some argue that this phenomenon is painless and not distressing,[20,41,42] whereas others found that dehydration resulted in thirst, agitated delirium, neuromuscular irritability, and nausea.[43–46] The experience of caregivers supports the notion that dehydration is an acceptable and comfortable manner in which to die.[47] Evidence suggests a connection between the more experienced caregiver and a higher level of acceptance.[48] Despite the findings of ''The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research''[49] in 1983, which found no moral or ethical distinction between artificial nutrition and other life-sustaining treatments, there seems to be a societal disconnect in categorizing ANH as either a life-sustaining treatment or a basic ordinary need. It is also possible that ANH may be classified as a medical intervention in patients with a terminal illness but as basic nursing or ancillary care in patients with chronic nonfatal conditions.[33]

Ethical Knowledge

Carper writes that ethical knowing examines the intersection between knowledge and reasoning, which ultimately directs action in terms of nurses' duties, obligations, and moral imperatives.[1] Professional ethics codes, then, can serve as the end result and the framework for ethical knowledge and ethical reflection.

Ethical codes

Knowledge of ANH treatment, benefits, and burdens provides a basis for application of ethics and morality. In general, the term ''ethics'' is used broadly to define the evaluation and understanding of the moral life.[50] Concomitantly, morality addresses social norms concerning personal conduct: right versus wrong, behaviors, character, and motives.[50] For professionals, guideposts for morality in health care are codified through ethical codes. In nursing, the beginning stages of an ethical code date to more than a century ago.[51] This was followed by development of the International Council of Nurses (ICN) code of ethics in the mid-1950s.[52] Although different in specific focus, these codes reflect the same basic principles highlighting the profession's expected standards of behavior and conduct.

The ''Code of Ethics for Nurses with Interpretive Statements''[53] does not specifically address ANH or any other particular life-sustaining therapies. It does, however, use a variety of ethical theories and addresses the 4 basic principles in biomedical ethics (autonomy, beneficence, nonmaleficence, and justice) to assist nurses in deliberating ethical dilemmas and outlining broad ethical postures.[53]

Ethical theories and principles

In any discussion of ethics, it is useful to refer to philosophy and standard theories of morality that provide a basis for moral reasoning and action. According to renowned philosophers Tom Beauchamp and James Childress,[50] ethics describes how society understands and examines the moral life in terms of decision making. Nurses may develop an awareness of an evolving ethical conflict that may be characterized by

the dichotomy of following orders for order's sake or creating good for most patients. Following orders is an example of a deontologic perspective. This theory focuses on duties. A proponent of deontologic ethics views moral action as one in which the moral agent (the nurse) acts based on perception of duty, de-emphasizing individual feelings and societal consequences.[54] Correct actions then come from a sense of knowing what is right and not to avoid or promote other consequences. In other words, morality and doing ''good'' are not predicated on producing happiness or other perceived positive consequences but are intrinsically valuable.[55]

Utilitarianism, in contrast, is the ethical theory of utility. Goodness is equated with happiness or pleasure with a goal of providing the most good for the greatest number of individuals. Right and wrong acts are evaluated based on whether they cause happiness. Unlike deontology, utilitarianism accepts the adage that the end may justify the means.[54,56]

Although comprehensive ethical theories provide an underpinning for decision making, additional knowledge in the form of the 4 basic principles is necessary. In Western medical ethics, these principles have historically informed ethical discussions and include autonomy, beneficence, nonmaleficence, and justice. Autonomy is self-rule that is free both controlling interference by others and inadequate understanding that prevents meaningful choice. Consequently, it is the basis of informed consent. Respect for patients flows from the principle of autonomy. Discussions and concerns about patient competence are informed by this principle of respect for autonomy.

The principle of autonomy was codified with the passage of the Patient Self-Determination Act (PSDA) in 1990. The PSDA requires health care institutions that receive federal funding in the form of Medicare or Medicaid payments to ask patients if they have or would like to complete an advance directive. The advance directive provides patients with the opportunity to make their health care wishes known when they no longer are able to effectively communicate these wishes to health care providers. Despite the well-intentioned nature of this legislation and the use of advance directive, some feel this has been less than successful in promoting the autonomy of patients and has proven to fail frequently.[57,58]

Beneficence is a moral obligation to act for the benefit of others and implies acts of mercy, kindness, and charity. Some acts of beneficence are obligatory and some are not. Although one is always required never to do harm, one is not always required to do good. Relationships, either personal or professional, require different responsibilities in performing acts of beneficence. Utilitarianism is based on beneficence. It includes protecting the rights of others, preventing harm from occurring to others, removing conditions that cause harm to others, and rescuing persons in danger.[59]

The principle of nonmaleficence is the obligation not to inflict harm on others. Broadly, it means not depriving others of the goods of life. More specifically, rules that emanate from this principle focus on avoiding the infliction of pain or suffering on others.[59] Although beneficence and nonmaleficence may seem like two sides of a coin, obligations not to harm others are frequently more stringent than obligations to help them.[59] The principle of justice includes notions of fairness and equality for all and may be applied to health care situations in terms of fair distribution of resources, whether scarce or plentiful. This is potentially important to the nurse when organizational ethics conflict with the care of an individual.

REASONING

Reason defined as a ''statement offered in explanation or justification'' is ''the power of comprehending, inferring, or thinking, especially in orderly rational ways.''[60]

Reasoning may be seen in this context as the exercise of decision making. Up to this point, the nurse has gathered empiric knowledge in the form of scientific evidence and applied moral knowledge from professional codes of ethics, ethical theories, and principles. Dealing with value differences that result in ethical dilemmas involving the use, withdrawal, or withholding of ANH may be examined within the framework of the previously described ethical theories and principles. Classification of ANH as a medical treatment or basic care and the degree to which burdens or benefits of this treatment are addressed frequently frame the discussion of this intervention.

Ethically, no distinction is made between ANH and other life-sustaining treatments,[49] and there is no moral difference between the withdrawal of ANH and the withholding of ANH.[59,61] Despite this, many practitioners report feeling a visceral difference in withdrawing treatment because it is more "active" and seems to be the sole cause of the patient's eventual demise. Some states have placed different or higher standards on the withdrawal of ANH, further complicating this issue for many nurses.[62] Ideally, nurses can reason through the dilemmas associated with the provision, withholding, or withdrawal of ANH by using an ethical decision-making process. Although there are many models for decision making, most include 4 steps similar to the nursing process. Bosek and Savage include the following 4 actions: (1) identify the ethical problem, (2) identify and consider alternatives, (3) implement a choice, and (4) evaluate the decision-making process and its outcome.[56] Nurses' lack of confidence and knowledge of this process and the ethical components at work can create confusion and uncertainty resulting in exacerbation of already established ethical dilemmas.[63]

Evidence suggests that nursing students analyze ethical dilemmas from a personal moral posture, whereas experienced nurses eventually acquiesce to institutional goals and ethical frameworks, which may be at odds with professional and personal ethics. Consequently, continuing education is necessary for nurses to participate meaningfully as moral agents.[63] Evaluating nursing students' responses to ethical vignettes in the clinical setting at the beginning of nursing education and then at the end of a 4-year program, Nolan and Marker[64] found that nursing students did not consider their clinical experiences as influential in their ethical development as much as ethics coursework. This finding further supports the argument that nurses require increased exposure to ethics education. The lack of sound reasoning may be attributed to the lack of empiric and ethical knowledge consequently impeding a rational and orderly process in ethical decision making.

Because of the pace which with nurses are required to work, ethical education training and the development of sound ethical reasoning and beliefs are worth the effort. Engaging in activities that create time and space for serious ethical deliberation can help create effective ethical decision making when there is no time to engage in lengthy discourse. In this way, the practice of sound ethical analysis may become routine. Allmark[65] suggested that excellence in practice is based on the development of good habits.

In nursing education, evidence indicates that ethical development and the ability to discern ethical dilemmas rely more on deciding that behaviors or actions are "right" rather than on being able to analyze an issue.[66] The ability to think critically about an ethical argument is necessary and is about more than providing a solution to a problem. Exemplifying practical wisdom, ethical judgments need to be supported by good reasons, the absence of which renders any ethical analysis weak. As clinical knowledge increases, the nurse is able to understand how theory can inform practice. Dreyfus and Dreyfus[67] agreed and observed that beginner nurses follow rules but expert nurses trust intuition, knowing that nursing is a place where "theory and

practice intertwine in a mutually supportive bootstrapping process as a nurse develop(s) his or her skill.'' They conclude that both need to be cultivated.[68]

Not uncommonly, when end-of-life decisions are being made, nurses experience moral distress, which is defined as ''pain or suffering affecting the body, a bodily part, or the mind.''[69] The experience of ''moral distress'' is explained as a result of nurses having to live with another's decision versus being the one who is the decision-maker, hence distress. An increased sense of moral agency through formal ethics education assists nurses in ameliorating these effects and allows a more open dialog.[70]

The Symbolism of Food

Adding to the ANH dilemma, some assume that ANH and food are synonymous and, as such, find the issue of withdrawal or withholding of this life-sustaining treatment a difficult and highly emotional topic. The meaning of food is thoroughly discussed in anthropologic and sociologic literature in terms of the social, religious, and personal significance for behaviors attributed to food and eating.[71] In particular, personal meanings of food are based on social and emotional needs,[72–74] particularly those experienced early in life.[75] In this context, food represents a social norm and a significant symbol of life.[73,74,76,77] The imbalance of literature between anthropology, sociology, and health care on this topic may account for the continued confusion as to the placement of ANH into life-sustaining treatments or symbolic and basic care.[78] Nurses must reason through personal, professional, and institutional values, acknowledging the reality of this emotive issue.

TO ACT

Nurses act in different ways based on their level of experience and variety of clinical exposures. Noting the novice-to-expert theory, Benner[68] described nursing as a clinical practice in which theory becomes relevant as nurses progress along the continuum. Assuming this process may be applied to the development of ethical skill and sensitivity, it is plausible to suggest that nurses with basic knowledge of ethical theories and principles are at the beginning of the continuum. This knowledge, along with continued ethics education, may only be evident and useful as nurses mature in their professional life. Others argue that development of clinical skills is different from ethical skills in that nurses arrive at undergraduate education already equipped with a moral sense.[67] At issue, then, is whether this moral sense is a personal one with roots in a particular religious or cultural background and requires further professional maturation.

Using the decision-making process, the nurse reasons through all aspects of the ANH dilemma and arrives at a conclusion that is intellectually and internally consistent, morally sound, and provides a rationale for the intended actions. Through this process the nurse addresses the conflicts among caregivers, family, and patients as to whether ANH is an appropriate treatment for a patient. Evidence suggests that ethics education has a positive influence on moral action in nurses.[79] The combination of personal moral postures and basic and continuing ethics education provides a foundation for professional maturation. As a result, nurses may develop increased clinical understanding that creates new possibilities for moral agency, defined as the ability to act.[68,80] The degree to which nurses understand and subsequently act on their own moral agency is determined by the depth and skill of their ethical analysis. A strong sense of moral agency, supported by ethics education, is vital to the nurse's ability to act confidently.

SUMMARY

To achieve meaningful ends to the controversies that arise in the provision of ANH, various measures have been used. Each measure entails requisite skills of knowing, justifying, and acting with empiric and ethical perspectives. Given the preponderance of controversial issues associated with the provision, withholding, and withdrawal of ANH, there is an obligation to strike a balance between those who may benefit and those who do not. This balance should be based on scientific evidence as to the burdens and benefits of ANH.[7,81] This risk/benefit analysis includes the need for expert clinical and ethical skills as ANH and its inherent symbolic meanings evoke highly emotional responses.

Nurses' obligations also require a clear understanding of the foundational ethical principles of autonomy, beneficence, justice, and nonmaleficence. Knowledge of ethical theories helps nurses justify their ethical stance. Understanding the empiric evidence related to the benefits and burdens of ANH helps nurses serve patients and families when offering clinical advice and mediating ethical discussions. Decisions regarding the appropriate use of ANH necessitate the interplay of empiric knowledge, personal moral sense, and application of ethical theories and principles and are the means by which nurses support those ends important to patients and families.

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