Communication and Education for Families Dealing with End-of-Life Decisions

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Clinical and consultant dietetics practitioners are frequently faced with ethical issues surrounding end-of-life care. In 1978, as a volunteer clinical dietitian in a hospice, I quickly realized that I had ventured into a practice setting that had limited evidence-based practice guidelines and few dietetics colleagues. The Academy of Nutrition and Dietetics (Academy)/Commission on Dietetic Registration Code of Ethics for the Profession of Dietetics (1) was then, and continues to be, an invaluable aid in professional practice and conduct. This article demonstrates how several ethical principles in the Code address the values and obligations of the dietetics practitioner when communicating with and educating families as they deal with end-of-life decisions.

DILEMMA EXAMPLE 1

A patient with pancreatic cancer requests advice on use of pangamic acid and megadoses of vitamin C because other conventional treatments have been tried and failed. The practitioner gave the patient and family the opportunity to make an autonomous decision about what course of action they would choose, and also gave the patient and family hope that perhaps the treatment might benefit the patient psychologically and physically. Scientific evidence may emerge in time that could change the dietetics practitioner’s statements. As Principle 14 states, it is incumbent upon the practitioner to continually strive “to increase professional knowledge and skills and apply them to practice.”

DILEMMA EXAMPLE 2

Much has been written in recent years in the Journal about the ethical dilemma of withholding/withdrawing medically assisted nutrition and hydration (2,3). Much less is written on the situation when health care professionals are asked by a patient or family to institute or continue nutrition and hydration when medically inadvisable or futile. This request is not unusual for the dietetics practitioner in the practice of palliative medicine or end-of-life care. It may be counter to the practitioner’s religious or cultural beliefs, and can be complicated by an exorbitant financial cost, which can impact the care given to other clients.

Although nonfutile medical treatment need not be offered, it is sometimes requested. The moral principles of beneficence (doing good by alleviating suffering), nonmalefice (do no harm), and justice (provide a quality of care that the patient is entitled to with a fair allocation of resources) assist health care professionals in making ethical decisions. These principles, however, may be counter to the ethical decision-making process.

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overriding but not absolute principle of autonomy (self determination) that allows a patient to decide what level of medical care, if any, he or she would want instituted or withdrawn.

When a patient and/or family request the dietetics practitioner to advocate for them, and the dietetics practitioner’s values and beliefs are in conflict with those of the patient and/or family, several ethical questions arise. The principles of the Academy’s Code of Ethics can help the practitioner.

Principle 5 states: “The dietetics practitioner provides professional services with objectivity and with respect for the unique needs and values of individuals” (1). The principle is further explained that the dietetics practitioner does not, in professional practice, discriminate against others on the basis of race, ethnicity, creed, religion, disability, sex, age, gender identity, sexual orientation, national origin, economic status, or any other legally protected category; also that the dietetics practitioner provides services in a manner that is sensitive to cultural differences (1). The dietetics practitioner in this case would provide the evidence-based guidelines on the benefits and burdens of nutrition and hydration in terms that are understandable to the patient and family and address their values in a culturally-sensitive manner. This can be a very difficult principle to fulfill if the practitioner is not knowledgeable of cultures or belief systems that are different than one’s own. To be uninformed of these matters, however, is as unacceptable as being insensitive.

Principle 9 states: “The dietetics practitioner treats clients and patients with respect and consideration” (1). To do so requires that the dietetics practitioner not only provide sufficient information to enable clients and others to make their own informed decisions, but that they also respect the client’s right to make decisions regarding the recommended plan of care, including consent, modification, or refusal (1). This principle necessitates that the dietetics practitioner recognize and exercise professional judgment within the limits of his or her qualifications and collaborate with others, seek counsel, or make referrals as appropriate, as stated in Principle 8 of the Code (1).

Depending on the knowledge, values, and beliefs of the dietetics practitioner, these Principles in the Code can help determine the practitioner’s professional conduct in the ethical dilemma of whether or not to advocate for institution or refusal of medical nutritional therapy and how to communicate and educate the patient and family. Study courses in moral reasoning, ethical decision making, and health care law, service on institutional ethics committees, and the thoughtful consideration of one’s own wishes under these and other circumstances are some of many ways to enhance the dietetic practitioner’s ability to discern and decide ethical dilemmas.

References