Seminars in Oncology Nursing, Vol 30, No 4 (November), 2014: pp 287-295

ETHICAL AND LEGAL ISSUES IN PALLIATIVE CARE

MARY S. MCCABE AND NESSA COYLE

OBJECTIVES: *To provide foundational knowledge about approaches to ethical decision-making that arise as part of palliative care of cancer patients and their families.*

DATA SOURCE: *Journal articles, research reports, state and federal regulations, professional codes of ethics and state of the science papers.*

CONCLUSION: *More and more, cancer deaths occur after a long progressive illness, requiring ongoing goals of care discussion and a focus on joint decision-making. No matter how diverse the community or how advanced the healthcare setting, the needs, preferences, and values of the patient and family will continue to be at the core of palliative care.*

IMPLICATIONS FOR NURSING PRACTICE: *The increasingly complex healthcare environment makes it essential that nurses have an understanding of medical ethics and relevant federal and state laws so that this knowledge can be applied to the many issues arising in palliative and end-of-life care.*

KEY WORDS: *Palliative care, bioethics, end-of-life conflict, nursing codes of ethics*

A basic knowledge of ethics, relevant federal and state law, and how these intersect with palliative care and end-of-life care provides a necessary framework for oncology nurses working in an increasingly complex healthcare environment. The National Consensus Project for Quality Palliative Care emphasizes this aspect of care in Domain 8: Ethical and Legal Aspects of Care, where it states in Guideline 8.1 "The patient or surrogate's goals, preferences, and choices are respected within the limits of applicable state and federal law and within current accepted standards of medical care and professional standards of practice. These goals, preferences, and choices form the basis for the plan of care."[1]

In the United States, as well as other technologically advanced countries, the majority of cancer deaths occur after a long and progressively debilitating illness. Co-morbidities are common and symptoms with suffering tend to be cumulative. Sudden deaths, although they do occur, are much less frequent. The combination of advances

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Mary S. McCabe, RN, MA: *Director, Survivorship Program, Chair, Ethics Committee, Memorial Sloan Kettering Cancer Center, New York, NY.* Nessa Coyle, ACHPN, PhD, FAAN: *Consultant in Palliative Care and Bioethics, Memorial Sloan Kettering Cancer Center, New York, NY.*

Address correspondence to Mary S. McCabe, RN, MA, Memorial Sloan Kettering Cancer Center, 1275 York Ave., Room 2101J, New York, NY 10065. e-mail: mccabem@mskcc.org

0749-2081/3004-$36.00/0.
http://dx.doi.org/10.1016/j.soncn.2014.08.011

in science and medical technology, concerns about paternalism, emphasis on patient autonomy, and reluctance to offer a clinical judgment in guiding the decisions of patients and their families have complicated the picture. Healthcare providers have the means to prolong life, but also the means to prolong the dying process. This double-edge sword has led to both benefits and challenges for society and an implicit responsibility to provide care that is clinically and ethically appropriate.[2] Clinical judgment and effective communication are essential ingredients in the ethics of care. Illness with a long trajectory provides both the opportunity and the obligation for nurses and other healthcare professionals to have ongoing conversations with patients and their families about their desire for present and future healthcare interventions that align with their values, beliefs, and goals. Presenting the patient and or family with the opportunity to have these conversations (for example, at key points in a disease trajectory, such as at time of initial diagnosis or when the disease has progressed and goals of care need to be revisited) is an ethical obligation. The need to have these conversations becomes even more urgent when the patient presents with advanced disease.[2-4]

CASE

An 88-year-old orthodox Jewish man presents with recently diagnosed thyroid cancer and extensive pulmonary metastases. He is not a candidate for chemotherapy or surgery, but radiation therapy is being considered for palliation. The patient, who is alert but confused, is admitted to the hospital for dyspnea. He has a devoted, extended family that communicates well with each other. His wife is deceased and his two daughters are his healthcare agents. They both defer, however, to one of the patient's sons-in-law (who is a Rabbi) for decisions about care. An ethics consult is called by the primary care team for assistance in addressing the patient's code status, as well as to answer the family's questions about the institutions policy regarding Jewish Law around end-of-life care. After meeting with the clinical team, the ethics consultant speaks with the daughters and one son-in-law and then meets with the son-in-law who is the Rabbi. A very extensive discussion is held regarding what needs to be done to fulfill Jewish law and how this could be done without causing the patient any additional suffering. From the Rabbi's perspective, DNR may be appropriate, but nutrition, hydration, and oxygen need to be provided to the patient. The consultant discusses what can be done to fulfill the spirit of these requirements. It is explained that the patient is at risk for aspiration pneumonia and that oral feeding may no longer be safe. The risks associated with tube feedings are also explained. The Rabbi does not question this clinical judgment and agrees that the nutrition and hydration requirements can be fulfilled with intravenous fluids, if needed. The question of intubation without cardiac resuscitation is raised. It is explained that intubation is uncomfortable and that the patient would in all likelihood need to be sedated afterwards. The Rabbi states that he does not want his father-in-law to suffer and that the patient himself had expressed that wish. After extensive discussion, he states that if the patient stops breathing or his heart stops, "it will be God's wish and the clinical staff should not interfere." The family is in agreement. The patient's condition deteriorates over the next few days and he dies peacefully with his family at the bedside.

Comment – respect for the family, their values, and traditions, identifying the decision-maker, and accommodations on both sides facilitated this man's peaceful death.

CONTEXT AND CULTURE MAKE A DIFFERENCE

Although the tenets of bioethics–doing good, avoiding harm, respecting people and their communities, and justice–are of concern to every culture and society, how they are conceptualized is grounded in the moral traditions and philosophy of a particular society and culture, as reflected in the above case. For example, many cultures do not share the primacy of the value of individualism and individual autonomy.[5,6] The family as a whole, rather than the individual, or a religious leader, as