CE Ethics Series

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Ethical Issues Experienced by Hospice and Palliative Nurses

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Nurses encounter ethical dilemmas in their clinical practice especially those associated with palliative and end-of-life care. The Hospice and Palliative Nurses Association (HPNA) members were asked to participate in an ethics survey. The survey aimed to identify ethical issues experienced by hospice and palliative nurses, identify resources available to them and barriers if any to their use, and to identify how HPNA can be of support to hospice and palliative nurses. One hundred twenty-nine (n = 129) HPNA members completed the online survey. The information from each of the surveys was carefully reviewed, and responses were collapsed into 6 themes. The ethical dilemmas included inadequate communication, provision of nonbeneficial care, patient autonomy usurped/threatened, issues with symptom management and the use of opioids, issues related to decision making, and issues related to discontinuing life-prolonging therapies. Approximately two-thirds of the nurses used resources in an attempt to resolve the ethical issues, including a formal ethics consultation, involvement of the palliative/hospice team, consulting with other professionals, and use of educational resources. One-third of the nurses said there were institutional or personal barriers that prevented the ethical dilemma from being resolved. Participants suggested ways that HPNA could help them to effectively manage ethical dilemmas.

KEY WORDS

ethical dilemmas, ethics, hospice care, nurses, palliative care

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Nurses frequently confront ethical dilemmas in their clinical practice especially those associated with end-of-life (EOL) care. These dilemmas have become more common in the face of advances in science and medical technology. Health care providers now have the means to prolong life and in some cases prolong the dying process.[1,2] Implicit is a responsibility to provide care that is clinically and ethically appropriate. Many nurses, who are in the frontline of providing compassionate and skilled EOL care, feel ill prepared to address ethical issues when they occur,[1,2] and yet the nurse is more likely to be involved in EOL care and be present at the time of death than are any other health professionals.[3] Nurses are uniquely positioned to have conversations with patients and families about present and future health care interventions and how they align with their values, beliefs, and goals.[4,5] The American Nurses Association's position statement, *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life*, supports nursing in advocating on behalf of patients regarding identification of health care preferences.[6] The position statement asserts that it is nurses' responsibility to facilitate the process of informed health care decision making for patients.[6] The close relationship between hospice and palliative nurses with their patients and families provides a natural setting for these conversations to occur.[4,5] In acknowledgment of this reality, the Institute of Medicine's report, *The Future of Nursing: Leading Change Advancing Health Care*, states that although physicians have traditionally been responsible for these difficult EOL conversations, nurses are now taking the lead.[7]

SURVEY PURPOSE AND AIMS

1. To identify ethical issues commonly experienced by hospice and palliative nurses
2. To identify resources available to the nurses and barriers if any to their use
3. To identify how the Hospice and Palliative Nurses Association (HPNA) can be of support to hospice and palliative nurses in addressing ethical issues

METHODS

The Survey

An open-ended survey was developed that consisted of exploratory questions. It was developed using the

SurveyMonkey online Web site. The survey consisted of 3 main questions asking the respondents to (1) describe the most recent ethical dilemma they had encountered, (2) identify what resources were available to help resolve the dilemma, and (3) describe how the HPNA could be of support to them in resolving ethical dilemmas (Table 1). Follow-up questions included how frequently such dilemmas arose; whether the dilemma was resolved, if not why not; if barriers existed to resolving dilemmas; and what resources the nurses used for resolving ethical dilemmas.

PARTICIPANTS

Several methods were used in an effort to encourage HPNA member completion of the survey. A link to the survey was (1) sent to the HPNA Bioethics Special Interest Group (SIG) members, (2) sent to the 2013 Clinical Practice Forum attendees, (3) included in the HPNA September 30, 2013, e-newsletter, (4) posted on the HPNA announcement page, and (5) included in the September/October 2013 End-of-Life Nursing Consortium e-newsletter. A total of 129 nurses completed the survey.

TABLE 1 Basic Survey Structure

1. Please describe the most recent ethical dilemma that you have encountered.
a. Was the situation resolved?
Yes
No
b. If yes how?
c. If no, why do you think that was?
d. How frequently have you encountered similar or other ethical dilemmas?
This is the first time
Daily
Weekly
Monthly
2. What resources are available to you to help resolve ethical dilemmas?
a. Are there personal or institutional barriers that prevent you from utilizing these resources?
Yes
No
3. How can HPNA be of support to you in resolving ethical dilemmas

Analysis

The responses to each of the survey questions were reviewed and placed in tables by the lead author. The tables were then independently reviewed by 3 of the authors. For the 3 main questions, significant statements were extracted and then clustered into themes and subthemes. The 3 authors then held several teleconference meetings to review the themes and subthemes and reach concordance. Not all responses were able to be collapsed into a theme.

RESULTS

Question 1: "Please Describe the Most Recent Ethical Dilemma That You Have Encountered"

There were 128 responses to this question yielding the following 6 themes: inadequate communication, provision of nonbeneficial care, patient autonomy usurped/threatened, issues with symptom management and the use of opioids, issues with decision making, and discontinuing life-prolonging therapies at the EOL. Table 2 summarizes the themes and subthemes with examples of supporting quotes and comments.

Nurses described ethical issues related to inadequate communication that occurred when patients and/or surrogates were given conflicting information or when goals of care were not addressed. As 1 nurse described, "The provider offers unrealistic goals at the end of life, continues to treat, often saying it is the family's wishes (when the family does not have all the information to help make a realistic choice)." In addition, nurses identified situations where patients and surrogates were given conflicting information especially when multiple providers were involved in the patient's care, thus further complicating their ability to make decisions in the best interest of the patient. One nurse described a situation where "After a discharge had been developed and approved by the primary care provider and patient/family, a specialist walked into the room and told the patient that he preferred another plan and offered dialysis (which was inappropriate in an 89-year-old with multisystem failure and dementia)." The nurse was then placed in the position of having to advise the patient and family on how best to proceed.

Several examples were shared by nurses of care given to patients that they perceived as nonbeneficial or futile. One nurse described a "family requesting that 'everything is done' despite no clinical improvement with treatments." The nurses were the ones who often asked, "What are we doing here?" Some nurses struggled with determining what care is most appropriate for the oldest of the old. As 1 nurse described, "Full code status on a 98-year-old…."Another nurse described, "Continuation of futile care in a neonate who had multiorgan failure and no chance of intact survival because no one would stop escalating care."

TABLE 2 The Most Recent Ethical Dilemma You Have Encountered

Themes and Subthemes	Supporting Quotes and Comments
1. Inadequate communication	
a. Lack of goals of care discussions b. Patients/surrogates given conflicting information	''The provider offers unrealistic goals at end of life, and continues treatment, often saying it is the family's wishes, when the family does not have all of the information to make a realistic choice.'' ''After a discharge had been developed and approved by the primary care provider and patient/family, a specialist walked into the room and told the patient that he preferred another plan and offered dialysis.''
2. Provision of nonbeneficial care	
a. Health professionals offering nonbeneficial treatment b. Continuing nonbeneficial treatment c. Families asking for nonbeneficial treatment	''A patient was clearly end of life, and the physician continued aggressive therapy and did not prepare the family for end-of-life.'' ''Continuing aggressive care in the face of medical futility when the family asks that 'everything' be done.'' ''Families demanding nonbeneficial care for the oldest old.'' ''Family requesting that 'everything is done' despite no clinical improvement with treatments.'' ''Physicians struggle so with setting appropriate limits to care.'' ''Continuation of futile care in a neonate who had multiorgan failure and no chance of intact survival because no one would stop escalating care.''
3. Patient autonomy usurped/threatened	
a. Family want information kept from the patient b. Family not in agreement with the patient's wishes c. Medical team not in agreement with the patient's wishes	''Frequently the patient is not part of the final decision'' ''We have had several families who don't want the patient to know their diagnosis or prognosis or that they are in hospice.'' ''The family didn't want to honor the patient's advance directives.'' ''The patient requested no further treatment, and yet treatment was continued.'' ''Family overruled patient request for 'do not resuscitate' (DNR).'' ''The health care directive names an agent and also gives clear instructions about treatment preferences, but the agent is requesting treatments in conflict with the written instructions.'' ''Patient requested to discontinue gastric feeding tube but family not in agreement.'' ''Physicians abdicate to family members rather than advocating for the patient and good medicine.'' ''Patient expressed wishes to stop all treatments and have DNR status. Liver team did not agree with patient's decision and met with patient numerous times to reevaluate his decision.''
4. Concerns about managing distressing symptoms and the use of opioids	
a. Undermedication b. Overmedication c. Disagreement as to whether the patient is experiencing pain d. Appropriate limits the use of opioids	''A chronically ill patient consistently complained a pain rating of 25 on 0- to 10-point scale with a history of chemical abuse and the health care provider refused to further address the pain issue as the patient was already on large doses of opioids and adjunct medications.'' ''Patient in the intensive care unit recently was extubated and had morphine drip 20 mg/h. I thought this dose way over good symptom control especially with bradypnea and suggested decreasing the opioid. The intensivist disagreed and said she is dying anyway… I agreed but we in no way should hasten it.'' ''A family member refused me to give the patient morphine that the patient had asked for.'' ''A hospice patient who had to be kept overly sedated in order for him to breathe, but by overly sedating him, he wasn't able to eat. Ultimately I feel we hastened his death, but had he not been sedated, he would not have been comfortable.''

(continues)

TABLE 2 The Most Recent Ethical Dilemma You Have Encountered, Continued

Themes and Subthemes	Supporting Quotes and Comments
5. Decision making	
a. Unsure if patient has decision-making capacity b. Surrogate decision making c. No decision maker	''The patient had end-stage dementia and critical aortic valve stenosis as well as other comorbidities. He had no health care surrogate or involved family members. The patient lacked decisional capacity.'' ''No advance directives and surrogate making decisions not based on what the patient would want.'' ''Patient with DNR order but no Durable Power of Attorney (DPOA), unresponsive with implanted defibrillator, which has not been deactivated. Adult child is out of the country. Ex-spouse present, does not want defibrillator deactivated.'' ''Surrogate decision making for an unrepresented patient.'' ''Unclear who is the decision maker.''
6. Discontinuing life-prolonging therapy at end of life	''Discontinuing a percutaneous endoscopic gastrostomy tube feeding.'' ''Deactivation of a pacemaker in a patient who could not express her wishes, but her son, her durable power of attorney for health care, felt that she would view this as an artificial form of life support.'' ''Discontinuing no longer beneficial life-sustaining treatments.''

Nurses also experienced ethical issues when a patient's autonomy was usurped or threatened. A number of concerns were shared related to families and providers not supporting patient wishes. In fact, for many, treatments were provided that were exactly the opposite of what patients stated that they wanted. Some of the decisions about these treatments were made by families, and some of these decisions were made by staff members. One nurse described, "Physicians abdicate to family members rather than advocating for the patient." Other ethical dilemmas encountered by nurses involved family members not wanting the patient to know his/her diagnosis. As 1 hospice nurse described, "We have had several families who don't want the patient to know the diagnosis, the prognosis, or that they are in hospice." The family of another patient did not want the patient to be told that he was dying and did not feel that the patient should be included in any aspect of the decision-making process. Nurses encountered conflicts between patient and family goals for direction of care. Situations were described where family wishes overruled those of the patient despite advance directives stating what the patient wanted. An example was as follows: "The health care directive names an agent and also gives clear instructions about treatment preferences, but the agent is requesting treatments in conflict with the written instructions."

Nurses also described problems that they experienced as they tried to manage distressing symptoms. Most of the ethical dilemmas involved the use of opioids. Some of the examples shared were related to physicians, and some were related to families. One example provided was a nurse who was unable to convince a physician to prescribe medication for a patient who was in pain. Another example occurred when a family member did not want pain medication to be given to a patient because of a fear of adverse effects; this limited the nurse's ability to manage the patient's symptoms. One common struggle described by the nurses was trying to limit the amount of pain medication to promote comfort while still achieving some degree of patient consciousness. Palliative sedation was also an area of concern for some—with a tension expressed between controlling symptoms and hastening death: "A hospice patient who had to be kept overly sedated in order for him to breathe but by overly sedating him he wasn't able to eat. Ultimately, I feel we hastened his death, but had he not been sedated, he would not have been comfortable."

Nurses also described ethical dilemmas related to decision making. Some dilemmas were focused on challenges faced when trying to determine if patients had capacity to make their own decisions, and others were related to issues with surrogate decision making: "The patient had end-stage dementia. He had no health care surrogate or involved family members. The patient lacked decisional capacity." Other dilemmas focused on determining who the right person was to make decisions for patients who did not have decision-making capacity. It was not always clear who should be making decisions and what to do if there was family conflict.

Nurses encountered ethical dilemmas that involved discontinuing life-prolonging therapies at the EOL. Most of the examples were concerns that nurses had with discomfort with stopping nutrition and hydration. One nurse described a concern regarding withdrawal or shutting off a

pacemaker. The nurse described, "Deactivation of a pacemaker in a patient who could not express her wishes, but her son, her durable power of attorney for health care, felt that she would view this as an artificial form of life support."

In summary, nurses' comments reflected an understanding that multiple issues were often embedded in 1 ethical dilemma, a process was involved in sorting the issues out, and that an understanding of the context was essential. Two-thirds of nurses reported that they were able to resolve the dilemma by using available resources and techniques including ethics consultation, family meetings, supporting the family, supporting patient autonomy, palliative medicine involvement, clarifying goals of care, involving the family in care of the patient, staff and family education about ethical principles, and honoring the rights of the patient to have their wishes honored. In some cases, the issue was resolved by the patient's death.

The most recent ethical dilemmas were not resolved for one-third of the nurses. Factors contributing to nonresolution included a child was involved, concern about drug-seeking behavior, the family was insistent that nonbeneficial interventions continue, family avoidance of family meetings and other communication, team not on the same page, palliative care not consulted, financial issues, staff inexperienced in EOL issues, time restraints to help the family process what was happening, and difficulty in accepting the inevitability of death.

The frequency of nurses encountering ethical dilemmas in this survey varied. Eighteen nurses (22.8%) said this was the first time, 2 (2.5%) said daily, 24 (30.4%) said weekly, and 35 (44.3%) said monthly. The practice setting of these nurses or their years of experience is not known.

Question 2: "What Resources Are Available to You to Help Resolve Ethical Dilemmas?"

Most nurses reported that they used 1 or 2 resources to resolve the ethical dilemmas. Figure 1 summarizes the resources used by the nurses when faced with an ethical dilemma. The resources they mentioned most frequently were ethics committee and consultation services, palliative or hospice team, team meetings and discussions, and other health professionals and involvement of the clergy. Educational resources and research were less frequently mentioned. Although most nurses described the ethics committee and consultation services as helpful and sometimes "working in collaboration" with the hospice or palliative care teams, a small minority were dissatisfied with the ethics committee and felt their role was limited because of "insufficient guidance and inactivity." Many nurses mentioned "team meetings and discussions" were a good way of resolving ethical dilemmas. In the team meetings, nurses were able to get help to find a solution from coworkers such as other nurses, nursing faculty, physicians, social workers, and the clergy. Some respondents, however, identified that there was a lack of resources available to help nurses to address ethical dilemmas.

Resources used by nurses when faced with an ethical dilemma

1. Ethics Committee and Consultation Services
2. Palliative or hospice team
3. Team meetings and discussions
4. Consulting other health professionals and the clergy
5. Educational resources and research

FIGURE 1. Resources used by nurses when faced with an ethical dilemma.

Question 3: "How Can HPNA Be of Support to You in Resolving Ethical Dilemmas?"

The participants had several suggestions for how HPNA could be of support in resolving ethical dilemmas. Suggestions included providing educational opportunities and training; advice and consultation; general information and education resources; case studies and discussion; network or group work (eg, SIG, Journal Club); guidelines, policies, and philosophy; and a forum for sharing expert opinions. Promoting research and publishing evidence-based research were also mentioned.

DISCUSSION

The ethical dilemmas identified by hospice and palliative nurses participating in HPNA's Bioethics SIG survey are similar to those found in the literature. These include futile or nonbeneficial care, pain management, patient autonomy (lack of decisional capacity, patient confidentiality or privacy), advance care planning (disregard of patients' wishes), communication difficulties, conflicts between patients/families and health providers, and conflicts between nurses and colleagues.[1,2,5,8-12]

Leuter and colleagues[11] found that most nurses experienced recurrent ethical problems and did not feel effectively supported by the health care system. In our survey, just under 75% of the respondents said that they experienced ethical dilemmas on a weekly or monthly basis; 2 nurses experienced such dilemmas daily.

McLennon and colleagues[5] conducted a content analysis of narrative comments provided by 137 oncology nurses and reported that typical ethical dilemmas are associated with truth telling, conflicting obligations, and futility. Approximately 60% of ethical dilemmas were associated with truth telling. Many nurses felt uncertain, uncomfortable, and unsure of how to provide information about prognosis. Barriers to truth telling included physicians' avoidance of discussing ethical issues, fear of destroying a patient's hope, and patient's lack of decisional capacity.

Nurses also faced ethical dilemmas when confronted with families who did not want the patient to know about their prognosis. The need for nurses to have formal education and training in communication skills when working with patients with progressive diseases or who are at EOL is well supported in the literature. Yet few nurses receive formal education specific to communication, especially in relation to EOL care.[13,14] Nurses, however, rank communication as one of the most important competencies to their clinical practice, and communication has been shown to be a cornerstone to improving a patient's quality of care and quality of life.[14,15]

A dominant ethical issue identified by nurses in our survey and reported in the literature is medical futility.[1,5,9,11,12,16] Futile treatments may lead to increased pain, loss of dignity, and patient's decreased quality of life.[5,16] Previous studies reported that when nurses perceived treatments as futile or that care was inadequate, they experienced more intense moral distress when providing patient care at the EOL.[1,8,12] The impact of moral distress on the nurses' well-being and its effect on patient care was discussed in a recent article in this journal.[17]

As reflected in our survey, respecting patient autonomy and protecting patients' rights can be ethically challenging for nurses, especially concerning withdrawal of life support and artificial hydration and nutrition, when the family wishes are not necessarily the same as that of the patient who no longer has decisional capacity.[2,8,9,18] Although most health care providers respect a competent patient's wishes over families' wishes when those wishes are conflicted,[18] when patients lose decisional capacity, two-thirds of health care providers (60%) override the patient's wishes and honor the family's wishes even if the patient's previously expressed wishes are known.

Pavlish and colleagues[8] also reported that families or physicians refuse to honor the patients' wishes when patients lack decisional capacity. These are troubling findings and are contrary to the intent of the Patient Self-determination Act where the use of advance directives is encouraged to protect the patients' voice if they lose decision-making capacity.[19] The meaning of "autonomy," however, varies in communities and cultures—the "decision maker" in the family may be one other than the appointed health care agent or surrogate. Research is needed in this area so that the appropriate questions can be asked.

In their advocacy role and as key members of the health care team, hospice and palliative nurses have a responsibility to identify ethical dilemmas faced by patients and families and to speak up.[8,20] It is also an institutional responsibility to support nurses in this role and to provide them with the necessary tools and support mechanisms. Although the majority of our survey respondents described the ethics committee and consultation series helpful, a small minority were dissatisfied and felt that they received insufficient guidance. These findings suggest that institutional resources for helping nurses to address ethical issues and supporting them in this role are inadequate in some settings. Standards are needed.

IMPLICATIONS FOR HPNA

Issues related to compassion fatigue and its impact on HPNA members both personally and professionally have been voiced by the membership at various forums. The need for additional programs and services to provide support to its members is evident. In addition, because hospice and palliative nurses work in a variety of practice settings, including patient homes, their access to both formal and informal resources related to ethical issues varies greatly. This was reflected in our survey results. Educational programs and support systems put in place need to be flexible enough to accommodate these various situations. The results of this survey provide information about what type of programs and support are needed. That the need is present is not surprising, given the responsibilities of hospice and palliative nurses in caring for the seriously ill and dying from many different cultures and belief systems.

The Bioethics SIG was developed to provide support, knowledge, skills, and resources for HPNA members to assist them in addressing ethical issues. The HPNA 4 Pillars of Excellence (Education, Leadership, Advocacy, and Research) helped guide the development of the SIG. Because the goal is to focus on the needs of the membership, it was essential to obtain input from the HPNA members regarding the type of ethical issues that they are dealing with and how HPNA can best support and help members. The results of the survey have been used to help plan SIG activities and to help determine topics for the companion ethics series published in the *Journal of Hospice and Palliative Nursing*. Current HPNA Bioethics Resources are summarized in Figure 2.

Current HPNA Bioethics Resources

1. Information related
   a. Section on bioethics in Core Curriculum books; Conversations in Palliative Care book; and Compendium series
   b. Dedicated series on bioethical issues published monthly in the *Journal of Hospice and Palliative Nursing (JHPN)* along with a companion continuing education (CE) activity
2. Education
   a. Interactive bioethics case studies (2014)
   b. Pre-conferences bioethics workshops at the 2013 and 2014 Clinical Practice Forums
3. Support for clinical nurses
   a. Bioethics Special Interest Group (SIG): Initiated in 2014 (https://www.hpna.org)

FIGURE 2. Current HPNA Bioethics Resources.

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