Reenergizing the Hospital Ethics Committee

An Opportunity for Nursing

Mary S. McCabe, MA, RN

Although hospital ethics committees are common throughout the United States, they differ considerably in the number of members, the preparation of these members, how they function, and the perceived quality of their work. Too frequently, an ethics committee is developed without a formal institutional plan, which leads to unfilled expectations, eventual inactivity, and a perception that the committee is not a valued resource within the institution. The focus of this article is to provide a framework for a well-constituted ethics committee with recommendations for revitalizing a committee that does not function optimally, with specific emphasis on the role of nurses as key members.

KEY WORDS
ethics committee, ethics consult service, nurses

In the setting of advanced technology and an era of seemingly endless possibilities to prolong life, value conflicts are bound to arise. At no time is it more important that goals, consistent with the individual’s values, culture, and beliefs, guide the approach to care than in the setting of a progressive or terminal disease.1 Goals of care based on the patient’s values rather than the availability of technology must be the driving force to direct care. Although this seems quite obvious and straightforward, end-of-life (EOL) decision making can be fraught with conflict. We are a pluralistic and multicultural society; beliefs and values differ among us, technology is abundant, access to care is unequal, and advances in medical care make it appear possible to postpone death almost indefinitely. Palliative care and hospice nurses, whose training is focused on caring, have a central role in helping guide patients in changing goals of care, as a disease progresses and curative or life-prolonging measures are no longer effective. How palliative care nurses and an ethics consultant can work together to achieve this goal is reflected in the case discussion presented at the end of the article.

As will be seen in the case discussed, in some situations, differing opinions and conflicts inevitably arise about the “right thing to do” and the “right” focus of care. These differing opinions may occur between clinician and patient or family as well as between members of the health care team.2 Such situations are where a well-functioning ethics committee can provide guidance and support to the patient and family and to the involved nurses and other members of the health care team. Creating a supportive framework about what makes a particular decision or a particular action the “right” choice can be very helpful to all parties concerned.

Reflective of the important role ethics committees play in resolving conflicts about what is the “right thing to do” when caring for patients at EOL, the number of ethics committees in hospitals has grown from 1%3 in 1983 to greater than 93%4 by 1999. Despite their formal establishment, these committees vary considerably in their structure and function. There are differences in the number, professional diversity, and preparation of members, the formal functions they perform, and the perceived quality of their work. For these reasons, some ethics committees thrive, and others struggle to survive and be a resource within their institution. The prevalence and activities of an ethics committee in hospice organizations are much less clear. Limited literature suggests committees may be present in about a third of agencies. Otherwise, hospice organizations appear to access outside facility ethics committees, rely on informal review by administrators and senior clinical staff, or include ethical issues in clinical discussions by the interdisciplinary team.5

The intent of this article is to provide palliative care and hospice nurses who want to become involved in ethics committee work or help develop a well-functioning ethics committee with a background on the history of ethics committees in the United States to use as a framework as they embark on their journey.

HISTORY OF HOSPITAL ETHICS COMMITTEES IN THE UNITED STATES

The establishment of hospital ethics committees began in response to concerns about the utilization and allocation of life-sustaining medical technology, such as dialysis, cardiopulmonary resuscitation, mechanical ventilation, and artificial nutrition. Specifically, there were landmark legal cases

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where there was conflict about the use of these technologies. In the 1970s and 1980s, there were disputes taken to the courts about the discontinuation of ventilator support and artificial nutrition. In the 1976 case of Karen Ann Quinlan, the New Jersey Supreme Court ruled in favor of the father, as the surrogate decision maker, in support of his request to terminate ventilatory support for his daughter who had been in a coma for a number of years. This court opinion was the first to include the mention of ethics committees as a resource to address similar future problems. In its ruling, the court recommended that each hospital in the state of New Jersey establish a multidisciplinary ethics committee to “review the individual circumstances of ethical dilemmas that would provide much in the way of assistance and safeguards for patients and their medical caretakers.”

In response, the New Jersey Department of Health mandated that hospitals establish either an ethics committee or a prognosis committee as a condition of licensure. Subsequently, in 1990, the US Supreme Court ruled in the Nancy Cruzan case that artificial nutrition and hydration (both were defined as medical treatments) could be withdrawn from another young woman in a permanently unconscious state by her parents as surrogate decision makers based on clear and convincing evidence of her wishes. In addition to these court cases, the President’s Commission for the Study of Ethical Problems in Medicine published a seminal report in 1983 on withholding and withdrawing life-sustaining treatment. This document encouraged hospitals to “explore and evaluate various administrative arrangements,” such as ethics committees, “for review and consultation” of cases involving termination of life support for patients who lack capacity in order to protect their interests “and to ensure their well-being and self-determination.” Then in 1985, the Federal Child Abuse Prevention and Treatment Act was amended to include the Baby Doe regulations, which included recommendations for the establishment of committees to evaluate proposals for withholding or withdrawing life-sustaining treatment from a newborn.

Individual states, such as New Jersey and Maryland, began to enact legislation requiring hospitals to establish advisory committees that would review difficult patient care issues, but the impetus for hospitals across the United States to establish ethics committees was provided by the Joint Commission on the Accreditation of Health Care Organizations in 1992 when this organization made having a mechanism to resolve ethical dilemmas in patient care a condition of accreditation.

ETHICS COMMITTEE MEMBERSHIP

Ethics committees vary in size and in the diversity of the membership. The size is often a function of the size of the institution and the breadth of the mission of the committee. Although all hospital ethics committees include physician membership, the inclusion of other professionals is quite variable. That said, it is very important for the success of the committee that its membership be multidisciplinary and represent the variety of care providers, such as physicians, social workers, nurses, chaplains, and others who work in the institution. Palliative care nurses in particular bring an important and necessary perspective to the committee as individuals with a 24-hour presence on inpatient hospital units and a focus on caring for patients and family members, especially those with advanced disease and at EOL where ethical conflict tends to be more prevalent. In total, having the unique perspectives of each professional group adds richness to the discussions and deliberations. Only then can the committee be an effective resource for the institution. Also very important is the inclusion of a member or members with expertise in medical ethics. This committee resource is, unfortunately, not always available in the community, but it is an ideal for which to strive.

Being able to analyze cases from an ethical perspective adds an important dimension to the ongoing efforts to ensure quality care to patients and families. The recently revised Code of Ethics for Nurses with interpretive statements is a useful guide for nurses as are a number of articles and chapters written by nurse ethicists and advanced practice nurses involved in clinical ethics consultation. Another critically important category of committee member is the community member. Having lay members from the community has been a long-standing tradition, but too often the individual has been a retired health professional whose views are similar to the hospital staff. More recently, there has been a movement to include patients as the community members. The inclusion of this group of individuals adds the patient voice to the discussion and keeps the committee focused on a patient-centered approach to its work. In addition to the inclusion of a variety of health professionals and lay members, it is important to include individuals with ethnic and cultural diversity. Many of the ethics consults in a hospital result from a lack of understanding about and sensitivity to the differences in expectations about care and mandates of religious traditions, for example, the importance of input from the rabbi in decisions that Orthodox Jewish patients make regarding EOL care as reflected in the case to be discussed and how personal autonomy is viewed differently in different cultures.

Lastly, the inclusion of hospital legal counsel on the committee, rather than as observers, has been controversial because their primary role may be perceived to protect the institution, which presents a conflict of interest. In addition, the inclusion of lawyers creates confusion about how much focus there is on the legal standards in consultation deliberations and whether the recommendations of the ethics consultants constitute legal advice. Although state and federal law is important to know and
understand, this information can be provided in a way that does not interrupt the ethical deliberation and subsequent recommendations.

**ETHICS COMMITTEE FUNCTIONS**

Traditionally, hospital and hospice ethics committees have a 3-part mission that includes education, consultation, and policy development. However, whether a particular committee focuses on all 3 areas of responsibility is quite variable and may relate to a number of factors: institutional commitment, hospital size and resources, ethics committee leadership focus, and education and training of ethics committee members. In addition, even when there is a commitment to education at the institutional leadership level, there are a number of decisions to be made before beginning.

The intended audience(s) for the effort should be determined early on because this decision will drive the topics for the educational programs and even guide the type of educational format. For example, the focus may be on particular areas of the hospital, such as the intensive care unit, and or it may be focused on particular professional groups, such as nurses. This tailoring will determine the training format to be used: didactic lectures, grand rounds, seminars, webinars, or case-based learning driven by specific requests for help with a troubling situation. Palliative care and hospice nurses have an extremely important role in educating other members of the ethics committees, as well as nursing colleagues, throughout the institution or hospice, about the needs of those with advanced disease and their families and how to navigate sensitive and ethical communication with this vulnerable population.

Ethics committees may also engage in policy development on ethical issues that affect patient care or review such policies. For example, members of the ethics committee may take the lead or collaborate with other groups in developing or revising policies, such as do-not-resuscitate orders, surrogate decision making, advance directives, voluntarily stopping eating and drinking, and palliative sedation. Involvement of a palliative care or hospice nurse in policy development is essential. An important consideration is that the ethics committee does not duplicate the work of other groups, such as the palliative care service, when developing policies on broad topics, such as pain control. In these situations, it is best to collaborate and to reserve the lead role for ethical issues. In the hospital setting, palliative care nurses may be involved in both the palliative care and ethics committee groups and form a bridge between the two. Because this role of the ethics committee requires expertise and knowledge of policy and legislation, it may work well to have a subcommittee of the ethics committee serve as the policy experts. The palliative care or hospice nurse could provide the clinical context for any policy concerning EOL.

The third area of function for the ethics committee is the consultation role. This is the signature role for which ethics committees are known, and yet, it is the most difficult to carry out successfully. The consult review can occur in 2 different time periods, either as a retrospective analysis where a request is made for feedback about a difficult case or a concurrent review where the ethics consult members are actively involved when decisions are being made. An example of a retrospective analysis is of an elderly patient in her mid-90s with far advanced cancer and intractable itching who requested sedation as the quality of her life was intolerable. Sedation was provided, and she died within 48 hours. Nursing staff and other members of the health care team were concerned that her death had been hastened by the sedation, and they requested an ethics review of the case.

There are also 3 major models determining who conducts the ethics consultation, and the choice of which one is used in a hospital or health care facility varies, depending on staffing, training, and support for consultants. The entire committee may receive the details of the case and comment on the appropriate direction; a full-time medical ethicist may do all the consults; or there may be a subset of the ethics committee who is responsible for doing the consults, and these individuals have training in medical ethics. Palliative care and hospice nurses with training in clinical ethics and ethics consultation play a very important role in this area because of their specific clinical perspective.

**ETHICS CONSULTATION**

The health care ethics consultation (HCEC) role of the ethics committee is receiving increasing attention nationally, in large part because of the growing complexity of health care and the resulting options and concerns for patients and their families. The overarching goal of HCEC as stated by the American Society for Bioethics and Humanities is “to improve the quality of health care through the identification, analysis, and resolution of ethics questions and concerns.” To achieve this goal requires that either an individual or group has both the training and expertise to address the “questions from patients, families, surrogates, health care professionals, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care.” Who is better able to identify ethical issues at EOL than the palliative care or hospice nurse as the one who spends at the most time at the bedside and most time interacting with the family. The more specific goal of any HCEC service is to have a consistent process of analysis and information gathering about the value-laden uncertainty or conflict with a resulting action plan that is focused on a resolution of the issue with respect for all involved. While it is important to acknowledge that health care professionals engage in ethical decision making.
on a daily basis, the work of the health care ethics consultant(s) differs because it is a formal activity endorsed by the hospital. In addition, the ethics consultant(s) and their resulting advice also carry weight in resolving conflict across groups and in making recommendations to improve care, both for the situation at hand and similar situations in the future.

The types of issues that generate an ethics consult vary by the patient population; the type of health professional employed in the facility; and the type of medical facility, such as a rehabilitation hospital, cancer center, or home hospice program. However, there are a number of general topics of concern that are common across facilities, such as the ones listed in the Table. Along with a focus on the resolution of these issues is the need to use these consults as examples to inform improvements in care through quality improvement projects or to inform the development of education programs for staff. For example, an ethics consult may reveal problems with handoffs between staff in the hospital that resulted in a patient’s EOL wishes not being honored, or a consult may reveal the need for education about how to deliver bad news to cancer patients who have a cancer recurrence. Similar problems may be identified with inadequate handoffs when a patient is being transitioned from an acute care setting to home hospice, a time of great vulnerability for both patient and family.

Both these situations and others like them lend themselves to staff education programs, significant areas for the palliative care or hospice nurse on the team to be involved with. It is important for any effective ethics committee to not see the consult effort as an isolated effort, but rather to see it as an opportunity to inform the education efforts of the committee by focusing on chronic issues and infrequent but significant issues of importance. In addition, it is also an opportunity to inform hospital policy with a focus on updating or clarifying existing information and developing new information of relevance to the clinical staff.

THE WELL-FUNCTIONING ETHICS COMMITTEE

Although decades have past since ethics committees in the United States received legal recognition to serve as alternatives to the courts in resolving conflicts around EOL care, the success of these ethics committees varies greatly even when the 3 major functions of policy, consultation, and education are all considered part of the committee responsibilities. There are a number of reasons for these differences in effectiveness across committees and why some committees have difficulty operating within the health care system. This is an important background for the palliative care or hospice nurse who plans to initiate or revitalize an ethics committee to be aware of. Two of the most important issues that relate to committee success are (1) where the committee is situated within the hospital organizational structure and (2) leadership of the committee itself.17 In a hospital setting, in order for the committee to be perceived as important to the hospital staff, it should report to the medical board or directly to hospital leadership. Being seen as important to the mission of the hospital gives a clear message about medical ethics to all who work there and seek care at the institution. Without the support of the institution, both from leadership and staff, the committee will not flourish and ultimately be successful. For similar reasons, in hospice programs, some suggest the appropriate reporting line should be to the board of directors or the chief executive officer.5

Direct lines of reporting are also important so that when contentious issues arise, there is support for taking them on and resolving them. It also allows the ethics committee chair an opportunity to request financial support for important educational programs, such as a seminar or grand rounds. But new committees should not be naive and think that the committee is assured of success because of reporting structure. To focus only on a few hospital or hospice leaders at the top is a mistake since it is important to gain the trust and support of influential staff at all levels. This support is most often earned when the ethics committee has a clear set of obvious goals and can demonstrate its value through its activities. Having a consult service that shows interest in clinical issues and is responsive to staff needs throughout the hospital is an excellent way to build ground-level support for the ethics committee.

### Table: Ethics Committee Functions

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<th>Functions</th>
<th>Goals</th>
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<tr>
<td>Education</td>
<td>• Assure knowledgeable ethics committee members</td>
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<td></td>
<td>• Develop knowledgeable clinical staff who are confident in their decision making</td>
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<tr>
<td>Consultation</td>
<td>• Ensure training and support for consultants</td>
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<td>• Provide consistent expertise for cases requiring formal ethics evaluation and recommendations</td>
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<td></td>
<td>• Develop and implement evaluation metrics to ensure quality improvement</td>
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<tr>
<td>Policy development/review</td>
<td>• Work collaboratively with hospital leadership to ensure ethics input and leadership in relevant hospital-wide policies</td>
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A component of the HCEC role is the hybrid activity of debriefing after a difficult case. It serves an educational function, as well as being a part of the consult itself. Providing practical ethics education in forums that are part of the routine schedule, such as making rounds in the ICU or embedding an ethics session in the regular lecture series for nurses and medical trainees, makes the ethics committee a known group that is part of the workings of the institution. Again, the palliative care or hospice nurse plays an important educational role here. Because everyone is so busy, being able to provide value added to the work of busy clinicians becomes key, an added level of support to them. If an influential member of a clinical service or department is not supportive of the ethics committee, this attitude (whether implicit or explicit) will discourage the individuals under and around this individual from seeking help from the ethics committee.

ETHICS COMMITTEE REVITALIZATION

Too often, ethics committees assume that the name of the committee is sufficient to ensure its success because the focus of the committee is to assist with difficult situations involving value uncertainty or conflict. What is absent in this approach, however, is the understanding that the ethics committee needs to demonstrate to clinicians that they can receive assistance in handling ethical problems, both current and future. Theoretical expectations and good will are not nearly as powerful as action, communication, and education. Although starting an ethics committee is not difficult because of the external forces that legitimize its existence, such as state laws and the Joint Commission on Accreditation of Healthcare Organizations, many suffer from what Silverman identifies as the “failure to thrive syndrome.”17 In his article, he identifies a number of reasons from what Silverman identifies as the “failure to thrive syndrome,” such as state laws and the Joint Commission on Accreditation of Healthcare Organizations, many suffer from what Silverman identifies as the “failure to thrive syndrome.”17 In his article, he identifies a number of reasons for this problem, which may develop after the initial enthusiasm for the ethics committee when it is in its infancy. First is the frustration when ethics committee goals are unfulfilled due to unrealistic expectations regarding what can be accomplished. For example, an overambitious ethics education plan may be unsuccessful because the teaching format is not practical for busy clinicians. Second, the number of ethics consults may be disappointing because the clinical staff is unsure of the purpose and scope of the consult service. Third, the ethics committee members may feel unchallenged and uncertain about their role in the ethics committee as a result of inactivity and structure. Fourth, the leadership of the ethics committee may not be sufficient to lead a group in a new, complicated endeavor.17

Although there are general standards and guidelines for things such as the membership of the ethics committee and the training needed for ethics consultants, there is little information available to guide a new ethics committee chair or institutional leader about how to reenergize an ethics committee that is not functioning optimally as a hospital or hospice resource. Although not evidence based, the following are some suggestions for how to think about a revitalization effort, and they include plans and activities to

1. establish leadership support at the top and leadership within the committee;
2. set short and long-term goals;
3. establish metrics and collect data;
4. be in touch with the needs of clinical staff, patients, and families;
5. be willing to revise plans and goals when necessary; and
6. prevent role confusion with other hospital or hospice groups and programs.

The first item to review in a revitalization effort is the reporting structure of the ethics committee as discussed in the previous section. In an acute care setting, support provided by hospital leadership and the medical board that is evident to staff is a first step to legitimacy and acknowledgment of the ethics committee’s importance to the institution. For hospice ethics committees, the reporting structure may be to the board of directors or the chief executive officer.5 The second item is the role of the ethics committee chair. Ideally, this individual has ethics expertise and is a respected individual in the institution. Because this ethics expertise is not always possible, it is critically important to have a chair who is strong clinically and who is willing to embark on a formal, learning effort in medical ethics with individuals who have formal ethics training. If the reverse is true and the chair has strong ethics expertise but is not a clinician, relationships with clinicians on the committee and throughout the hospital are essential. In addition, the ethics committee members should serve as ambassadors for the work of the committee. This ambassadorship requires, of course, ethics expertise and respect by colleagues. Such an effort may require a formal plan for in services and presentations to staff. Nurses, as highly respected caregivers and the “eyes and ears” of an institution or hospice ethical climate, are ideally placed to participate in this function.

The next important step for an ethics committee seeking to improve is to set clear goals with a focus on the 3 traditional areas of responsibility. Establishing clearly what the work of the ethics committee will be and how it will spend its time is critical to energize ethics committee members and to be able to show progress in functioning as an active ethics committee with deliverables and products. For example, it is useful to ask basic questions, such as the following: What efforts will be undertaken and when? Will the consult service be reevaluated and reconstructed with new staff, or will a strategic plan for staff education be developed? It is useful to consider establishing a subcommittee structure for each major function of the HCEC because this provides a focus for members and encourages accountability for work products in each of these areas. Documentation of
committee work, whether ethics education or consultation, is important for clinical staff so they can see evidence of the value of the committee functions. It is equally important for ethics committee members because this documentation can be used for evaluation purposes and as metrics of success. However, there is no 1 specific recipe for how to proceed as one seeks the ingredients for success. What matters is matching goals to institutional priorities and needs. These goals should include short-term ones focused on the reorganization efforts along with long-term ones that focus on ethics committee evaluation and staff-centered outcomes.

Identifying goals is linked to the establishment of metrics for the 3 functional areas of the ethics committee. Starting with simple, practical metrics allows the ethics committee to review how it is doing in the areas that have been prioritized. It is also important for the ethics committee members including a palliative care or hospice nurse to be part of the establishment of the metrics because they will have a collective responsibility for achieving them. For example, establishing a database for consults allows the ethics committee to review the types of consults requested and the groups requesting these consults. This information can then inform the ethics committee plans for how to improve the consult service and inform the ethics education plans to address frequent areas of conflict and uncertainty.

Because a hospital or hospice ethics committee is an institutional or hospice program resource, it is critically important for the unit to be known and respected. This can only be achieved when the ethics committee members, in particular the consult service, are knowledgeable, available, and in touch with the needs of staff. The importance of a nursing presence in these areas is self-evident. Thus, an effort requires the building of relationships throughout the hospital or hospice program and connecting to staff through informal daily interactions, as well as formal interactions as an ethics committee member. For example, the joint review with staff of ethics consults and education sessions that do not go well, in addition to the efforts that are successful, conveys the concept that the ethics committee is an institutional resource and not an isolated committee.

As the ethics committee works to reestablish itself as a vital and active institutional or hospice resource, one of the most important attributes of the leadership is the ability to be flexible about change. No matter how careful and thoughtful the initial goal setting process has been or how simple and practical the metrics are that were established, there will be a need to review and revise the initial plans. For example, the plan to have a separate ethics grand rounds may be poorly attended because the staff is very busy and there are too many meetings already on the schedule. A reassessment of these plans may point to having an ethics presentation in the teaching forums already established at the hospital or hospice program because this is where staff goes for their formal education. Taking a pragmatic approach to the goals initially set out allows the ethics committee to ensure that it is offering services valued by the institutional leadership and clinical staff. This sort of awareness and insight is essential to the ethics committee success. Institutions that provide EOL training for nurses should provide an ethics component. For example, a component should also be provided in new nurses’ orientation.

Finally, it is important for the ethics committee to distinguish itself from other groups that may have related missions, such as the palliative care service and chaplaincy service. Although it is essential to have representatives of these groups as members of the ethics committee, it is important to develop a working relationship that makes distinctions between roles and responsibilities. Certainly, the religious beliefs of a patient and family about EOL goals may cause conflict for the clinical staff, resulting in an ethics consult, but it is the role of chaplaincy to provide religious and spiritual support to them independent of and despite the conflict. In addition, palliative care clinicians and ethics consultants are often contacted jointly about difficult EOL cases. The ethics consult is specific to a particular problem or concern, whereas the role of the palliative care clinician is more general to symptom management and EOL goal setting. One can think of the ethics consult as a short-term intervention, whereas the palliative care or hospice team offers ongoing clinical advice, care, and support.

**ETHICS COMMITTEE OPPORTUNITIES FOR PALLIATIVE CARE AND HOSPICE NURSES**

The profession of nursing has always identified ethical care as an essential obligation and put forth a framework of professional conduct that unites all nurses across setting and specialties. In their code, the International Council of Nurses sets out 4 ethical standards that relate to people requiring care, clinical practice, professionalism, and coworkers. The American Nurses Association has a code of ethics with 9 statements that relate to the commitment of nurses to patients, duty to self and others, and duties beyond individual patient encounters. The codes of ethics of both professional organizations function to set a standard for practice for individuals in deciding on actions in particular situations. These codes are not merely rules, but rather, they are idealized expressions that highlight for nurses their special obligations in caring for individuals and the families when they are sick and most vulnerable. Codes by themselves are only words. They have impact only when actualized as living values to be incorporated into practice. This actualization can be at the individual level, unit level, and institutional level. One important and growing way for nurses to actualize these codes, as indicated above, is through palliative care or hospice nurses’ active participation in hospital and hospice ethics committees as members, as clinical staff involved in calling ethics...
consults on behalf of patients, and as champions for the ethics education of nurses.

Through membership on an ethics committee or through accessing the service of an ethics consult service, the palliative care or hospice nurse has a unique opportunity and important responsibility to make sure that the voice and wishes of the patient are brought forward. For example, the bedside nurse or home hospice nurse is a key individual in ensuring that a patient’s symptoms are being well managed at the EOL. It may be that the parents of a dying child are requesting that the patient not receive pain medication because they want the child to be more alert. It is important for the nurse to be the advocate for this child, so this difficult and stressful situation can be addressed. Another example is of a patient who has told a nurse about his wishes to stop treatment and go to hospice when these goals of care are at odds with the family and the physicians caring for the patient. Only if this nurse calls upon the help of the ethics committee is this issue likely to be resolved.

In addition to the role of patient advocate, the participation of nurses on ethics committees adds depth to the discussions and broadens the education offerings throughout the institution. Palliative care and hospice nurses have an obligation to step forward and participate in the life of the ethics committee in the hospital. This participation is personally rewarding, but it is also an important role that ensures the needs, preferences, and values of patients and families remain at the core of clinical care.

CASE—AN ETHICS CONSULTANT AND PALLIATIVE CARE TEAM WORKING TOGETHER

The ethics consult was requested by the advanced practice nurse on the palliative care team because of conflicts in goals of care and code status.

Mr T. is a 65-year-old man with refractory acute lymphoblastic leukemia admitted as a potential candidate for a new research protocol as a “last ditch effort” by the family to prolong life. During the admission, he developed several life-threatening infections resulting in multiorgan failure. He was then no longer a candidate for the research protocol, and there were no further disease-focused treatments available. A referral was made to the palliative medicine service, and he was seen by the palliative care nurse.

Relevant Social History: Mr T. is married with 3 grown children, 2 daughters, one of whom is a social worker, and a son. The family is orthodox Jewish, and the son has been consulting with the rabbi about treatment decisions, including those around code status.

Decision-Making Capacity: the patient had decision-making capacity at time of admission when he made himself DNAR (do not attempt resuscitation) but lost capacity soon after as he became increasingly ill.

Advanced Directives: Mr T. has an advance directive in which he appointed his wife as his health care agent. His wife transferred this responsibility after the patient lost capacity to their son because of disagreement within the family about honoring his DNAR status. The son, after consulting his rabbi, asked that the DNAR order be revoked. The covering physician honored this request, and the patient returned to full code status. There had been several earlier family meetings involving the primary service and palliative care team regarding the patient’s rapidly deteriorating condition and his closeness to death. Mr T. had been too ill to attend any of these meetings.

Ethics Consult Process

Prior to a family meeting, the ethics consultant (a nurse) met with the patient’s medical team as well as the palliative care team. There was a great deal of distress on the part of the palliative care team and floor nurses that the patient’s DNAR status had been reversed and that his previously expressed wishes were being ignored—he had lost his voice. The patient had been aware of his medical status, knew there were no further life-prolonging treatments available to him, and did not want his suffering to be prolonged. A family meeting was then held with the ethics consultant and clinical team. The family expressed gratitude for the ethics consultant presence as it reflected “an appreciation” of the complexity of decisions around EOL care.

Regarding the patient’s code status, the son and daughter felt that their father had not understood the DNAR discussion because he was receiving pain medication that may have clouded his ability to make these decisions; life is precious, and he would want to do things in accordance with Jewish law. The attending physician clearly articulated that the patient’s leukemia was untreatable, his organs were failing, he was dying, and the dying process could not be reversed. The son asked for specific evidence of irreversible organ failure so that he could convey this information to the rabbi, which he was given in writing. He indicated that the question he would ask the rabbi regarding his father’s code status would be different based on the new information he had just been given. The attending physician offered to speak to the rabbi at any time, but the son declined. Based on the new information presented by the son to the rabbi, he advised that a DNAR was appropriate for Mr T. and in accordance with Jewish law. Mr T.’s full code status was reversed to DNAR, consistent with his earlier wishes.

Summary: The palliative care team and ethics consultant each served a different function in this case. The palliative care nurse advocating for the patient identified an ethics issue and contacted the ethics consultant, who provided both support for the treating teams and an ethics perspective/analysis of the situation. The need for education of the staff on the role of health care agents and that a patient’s advance directives
should always be honored when the patient loses decision-making capacity unless there is an extraordinary change in circumstances was clear. The patient died peacefully 48 hours after the ethics consultation.

References

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