

# Brief Guide to Ethics Committees and Consulation for Hospice Links<sup>1</sup>

## NHPCO Medical Aid in Dying Resource Series



10/11/2021

No comprehensive study of the prevalence, activities, or authorities of hospice ethics committees (HECs) has been undertaken to date.

Limited data suggests (as of 2014) that perhaps 1/3 of hospice agencies had their own internal ethics committee; others utilize hospital committees or informal (e.g., IDT meeting) discussions to resolve conflicts.

In establishing an ethics committee for hospice (or palliative care), a simple transfer of the acute care model is inadequate. The goals of care, with emphasis on autonomy, comfort, and QOL, as well as home-based delivery of care by a team of peers, requires significant adaptations to the model.

From the beginning, many healthcare ethics committees and activities have been concerned with questions about continuation of life-sustaining treatment (e.g., ventilators and feeding tubes), allocation of scarce life-sustaining treatments (e.g., dialysis), and scope of patient autonomy in contemporaneous or prospective decision making.

Some aspects of standards developed in the late twentieth century for healthcare ethics committees (HCECs) in general are applicable to the hospice setting:

- Membership should be “diverse”—including clinical disciplines, administration, and lay representatives—in order to ensure varying viewpoints.
- The committees’ primary functions are to
  - review medical treatment decisions with ethical implications,
  - establish guidelines regarding treatment or other medical decisions, and
  - engage in self-education and education of the facility staff on ethical issues (President’s Commission, 1982).

The American Society of Bioethics and Humanities’ Core Competencies for Health Care Ethics Consultation (2011) remains the standard for expertise required by (at least some) of the members of an ethics committee.

According to two national surveys of HCECs (McGee et al., 2001, and Fox et al., 2007), activities of HCECs typically involve (in order of time allocation):

- Education – of members of the committee, facility staff, and broader community (in that order)
- Case consultation—active and retrospective
- Policy development, review, and analysis

In case consultations, the most frequent outcome is recommendations – of particular actions or communications. Only a small minority of ethics committees are authorized to issue binding decisions.

While data is scant and not current, it suggests that few hospices have developed their own internal ethics committees (~10 to 30%, 1997–2008); although more may have developed less formal or alternative methods of resolving ethical dilemmas.

**Alternatives to an in-house ethics committee are convenient but subpar at best and detrimental at worst, due to the above mentioned differences in goals of care, methods of delivery, settings of care, and emphasis in the hospice and palliative care approach on patient self-determination.**

Of note, the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* (4<sup>th</sup> edition, 2018) include a domain (#8) on legal and ethical issues. The first guideline of that domain reads as follows:

Guideline 8.1 Global: The core ethical principles of autonomy, substituted judgment, beneficence, justice, and nonmaleficence underpin the provision of palliative care.

Criterion 8.1.5 Ethics consultants or committees guide policy development and provide staff education in areas, such as:

- a. Medically nonbeneficial care
- b. A patient's right to decline treatments of any kind
- c. Cessation of medically provided nutrition and hydration
- d. Foregoing or discontinuing technology (e.g., ventilators, dialysis)
- e. Use of high-dose medications
- f. Sedation of the imminently dying
- g. Requests for physician-assisted death

Tenets of hospice care affecting ethics committee deliberations:

- **Autonomy:** Emphasis on supporting patient autonomy and independence, even while decision-making capacity diminishes.
- **Justice:** Patient-and-family as "unit of care" may entail competing obligations to consider needs/concerns of family members that are at odds with those of the patient.
- **Beneficence and Nonmaleficence:** Balance between these principles subject to considerable "tipping" based on patient/family idiosyncratic definitions of "benefit" and "harm."
- Ultimate objectives are to preserve quality of life, maximize comfort, and achieve safe and comfortable death in location of patient's choice.

Ethical risks in hospice care:

- Possible tendency to grant "too much" deference to patient autonomy at the risk of disregarding or disenfranchising other parties and their interests.
- Possible greater degree of moral distress experienced by team members when decisions and choices made by patients run counter to their perspectives on best solutions.
- Radically dispersed "loci of power" between patient and provider, members of family, members of team may lead to higher likelihood of perspectives and objectives coming into conflict.
- Utilization of IDT as informal ethics committee tends to create an "echo chamber" of self-reinforcing viewpoints.

### **Recommendations for Hospice Ethics Committee Formation and Operation**

An ethics committee should be the "ethical hearth of the agency home": "gathering place for focused conversation on ethical matters and source of moral light and heat for the organization, its patient/family care services, provider referral sources and partners, and geographical and professional community" (Ballentine & Dalinis, 2014).

Due to the team-based model of hospice care, the ethics committee is a better model for hospice than is an individual ethics consultant; a small team can be "on-call" for time-sensitive consults.

Membership should be interdisciplinary, including CNAs, volunteers, bereavement services, and administration.

- The latter category, along with legal or regulatory expert and finance representative should be in the minority to avoid the committee being perceived as punitive or mostly concerned with "CYA."
- Other clinical disciplines outside of the core team can also be considered: speech, occupational and physical therapy; nutrition, complementary therapy, etc.
- Social diversity is important, especially in demographically diverse communities.

- Extra-institutional (community) representation can infuse deliberations with general community norms (e.g., general community member, family member of past hospice patient, local civic or faith leaders)

Establish terms of membership (min 2 years, max 5, staggered, including chair) and methods of application or appointment to the committee.

Not everyone on the committee must or should be an expert or hold an academic degree or certification in healthcare ethics. One or two members of the committee with advanced training/certification is sufficient. All ethics committee members should undergo a basic and consistent ethics orientation/ training, especially with respect to methods of deliberation, documentation, and evaluation.

Ensure time attending committee meetings and activities is PAID time; allow a modest budget for supplies, training, and professional development of members. Meetings should occur at a minimum bimonthly, preferably monthly, and as needed for consultations.

**Education:** Should be frequent, and extend beyond the committee to the agency (e.g., in-services, workshops, presentations) and community. With regard to the community, hospices have an obligation to educate their communities on the ethical underpinnings of issues such as rights to refuse treatment, distinctions between types of euthanasia or between euthanasia and companioned dying, appropriate withdrawal of treatment, advance care planning, and access to quality end-of-life care, and others, in order to counter misunderstandings about hospice and palliative care.

**Policy review/development:** may be prompted by case consultations to avoid future conflicts, or of existing policies to ensure ethical basis for the policy is sound. The ethics committee should be involved in crafting and reviewing policies relevant to common “hot button” ethical issues, such as those in the NQF Clinical Guidelines noted above. Beyond the ethics of clinical care, hospices should engage in regular considerations of organizational ethics with respect to financial practices, service delivery, personnel issues, community relations, and good stewardship of public funds.

**Case review and consultation:** should be a consistent and frequent activity to establish and practice a standardized methodology for consultation, resolution, and outcomes. An open discussion is not sufficient and too quickly veers from ethical considerations into clinical or care management issues. See below on one possible method. Case consultations should include documentation of the discussion and evaluation of the outcome (typically a recommendation).

One approach to step-wise ethical deliberation:

1. **Gather the facts.** A helpful tool in this step is the “Four-Box Model” proposed by Jonsen, Siegler, and Winslade, in *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Ethics*. It organizes the fact gathering for an ethics consultation into four domains – medical indications, patient preferences, quality of life, and contextual features – with questions to help the process. However, it’s also a classic example of how an acute-care approach is not ideal for hospice consultations. On the next page is a four-box model with some alternative questions more appropriate to hospice and palliative care approaches and goals.
2. **Use the ethical principles to identify the conflict.** Ethical dilemmas almost always involve a conflict between two or more of the four main ethical principles: respect for autonomy, beneficence, nonmaleficence, justice. In the situation you are examining, what is in conflict? The preferences of the patient vs. those of their family and loved ones? (Respect for autonomy vs. Justice); the care plan approach that is designed to benefit the patient vs. the patient’s refusal to follow the plan? (Beneficence vs. Respect for Autonomy); etc.

3. **Frame the ethical question underlying the conflict:** Clinical questions/answers usually address WHAT should be done? Ethical questions/answers address WHY should X be done? In the example above, the clinical-procedural question might be “How can we get the patient to agree to the care plan we know will help him?” But the ethical question would be “Is it better to respect the patient’s autonomy, even though he won’t get the benefit of the care we propose?”
4. **Develop a position based on moral conviction, sound clinical judgment, and in compliance with law and regulation.** For instance, the resolution of this case might be: In hospice care, we have dual obligations: to respect patient autonomy and to ensure the best quality of life and comfort. In this situation, it seems we can’t do both. Therefore, we will prioritize the patient’s autonomy over our preferences; however, we will first ensure the patient is fully informed of the risks and possible outcomes and has capacity to make his own decisions.
5. **Develop a counterposition.** What additional facts, if you had them, or other ethical considerations might change your approach? (e.g., the patient doesn’t have capacity to make decisions and his surrogate wants to follow the care plan; the patient’s preferred approach puts him, his family caregivers, and the team at risk of harm; the patient’s preferred approach could be considered a crime . . .). How might you come to a conclusion that the expected benefit of the care plan should be prioritized over the patient’s preference?
6. **Complete the consultation.** Determine which conclusion/recommendation best fits the clinical facts, the collective moral and clinical judgment of the committee, and the relevant laws and regulations? Have you taken into account other interested parties? (e.g., family members, clinical team) Make a final determination/recommendation. Document the process. Communicate to relevant internal parties, patient and family, other stakeholders that “need to know.”
7. **Evaluate the outcome.** This could entail a follow-up survey or interview to assess satisfaction with the process or a more detailed look at how the recommendation was implemented (if it was) and what the patient care outcome was.

### The Four-Box Model for Hospice/Palliative Care

<b>Medical Indications</b> <b>Principles of Beneficence/Nonmaleficence</b>	<b>Patient Preferences</b> <b>Principle of Autonomy</b>
What is patient’s stage in disease trajectory/ terminal process? How are symptoms being managed? How effectively? What are patient’s goals of care? How achievable are these goals? How will care team pursue them? Have all appropriate interventions to relieve suffering been attempted? What is patient’s “plan b”? How can this patient be benefited by hospice/palliative care?	Does the patient have decision-making capacity for this decision in this context? If so, what are the patient’s stated preferences for care? Is patient aligned with goals of hospice/palliative care? If the patient lacks capacity, who is the designated legal decision maker? Is the decision maker using appropriate standards for choices? Has the patient expressed prior preferences, e.g., in advance directives, POLST, or prior goals of care conversations? Do current expressed preferences deviate from prior instructions? What is the patient’s primary goal now for treatment/care? Is the patient’s right to choose being respected to the extent possible in ethics and law?

<b>Quality of Life</b> <b>Principles of Beneficence, Nonmaleficence, and Autonomy</b>	<b>Contextual Factors</b> <b>Principles of Justice and Fidelity</b>
<p>How does patient express/define quality of life?</p> <p>Will the proposed care plan support quality of life?</p> <p>Are emotional/psychosocial/ spiritual factors being accounted for in care plan?</p> <p>Are there biases that might prejudice provider's evaluation of the patient's QOL?</p> <p>How are treatment/care goals supporting maximal QOL and comfort now?</p> <p>Are there risks, "downsides," adverse effects associated with care plans that might undermine patient's QOL?</p> <p>Are patient's expressed preferences for treatment/nontreatment/care consistent with stated goals?</p>	<p>Are there family issues affecting patient's preferences for/attitude toward care?</p> <p>How are patient's decisions likely to affect family?</p> <p>Are there provider (institutional care/team members) issues that might influence care decisions?</p> <p>Financial and economic factors?</p> <p>Religious or cultural factors?</p> <p>Are there any justifiable limits on confidentiality?</p> <p>Are there constraints on the allocation of resources that might affect the team's ability to fulfill the care plan?</p> <p>How does the law affect care plan/patient's preferences?</p> <p>Is clinical research or teaching involved?</p> <p>Is there any conflict of interest on the part of the providers or the institution?</p> <p>Are care plans consistent with hospice/palliative philosophy and best practices?</p>

## References

- American Society for Bioethics and Humanities (ASHB). (2011). *Core competencies for health care ethics consultation* (2nd ed.). Glenview, IL: Author.
- Ballentine, J., & Dalinis, P. (2014). Ethics committees for hospice: Moving beyond the acute care model. In T. Kirk & B. Jennings (Eds.), *Hospice Ethics: Policy and Practice in Palliative Care* (pp. 250–281). New York: Oxford University Press.
- Fox, E., Myers, S., & Pearlman, R. A. (2007). Ethics consultation in United States hospitals: A national survey. *American Journal of Bioethics*, 7(2), 13–25.
- Jonsen, A. R., Siegler, M., & Winslade, W. J. (2006). *Clinical ethics: A practical approach to ethical decision making in clinical care* (6th ed.). New York: McGraw-Hill,
- McGee, G., Caplan, A. L., Spanogle, J. P., & Asch, D. A. (2001). A national study of ethics committees. *American Journal of Bioethics*, 1(4), 60–64.
- National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). Richmond, VA: National Coalition for Hospice and Palliative Care. Retrieved from <https://www.nationalcoalitionhpc.org/ncp>
- President's Commission for the Study of Ethical Problems in Medicine. (1982). Making health care decisions, [http://bioethics.georgetown.edu/pcbe/reports/past\\_commissions/making\\_health\\_care\\_decisions.pdf](http://bioethics.georgetown.edu/pcbe/reports/past_commissions/making_health_care_decisions.pdf)