

Top Ten Tips Palliative Care Clinicians Should Know About Their Work's Intersection with Clinical Ethics

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Abstract

Palliative care (PC) subspecialists and clinical ethics consultants often engage in parallel work, as both function primarily as interprofessional consultancy services called upon in complex clinical scenarios and challenging circumstances. Both practices utilize active listening, goals-based communication, conflict mediation or mitigation, and values explorations as care modalities. In this set of tips created by an interprofessional team of ethicists, intensivists, a surgeon, an attorney, and pediatric and adult PC nurses and physicians, we aim to describe some paradigmatic clinical challenges for which partnership may improve collaborative, comprehensive care.

Keywords: clinical ethics; ethics; health care ethics; palliative care; teamwork

Introduction

PALLIATIVE CARE (PC) SUBSPECIALTY and clinical ethics teams function as consultancy services composed of interprofessional personnel. In some hospitals, the overlap of clinicians who practice subspecialty PC and serve as ethics consultants is significant, reflecting the development of the

two fields, the overlapping skill set in strong communication, and the administrative benefits of co-location.¹ However, like with any high-performing team, role clarity is important for these distinct teams. PC clinicians should be familiar with the skills, unique contributions, and limits of their hospital's clinical ethics team. Like subspecialty PC, clinical ethics involvement often only occurs through care invitation. Ensuring

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Accepted October 8, 2021.

that PC specialists know when to request the support services of a clinical ethics consultant is essential to optimizing the full complement of resources.

In this set of tips, our goal was to provide the range of ways in which PC specialists can collaborate with clinical ethics teams by describing some paradigmatic clinical challenges. The expertise of the two groups is distinct (Supplementary Figure S1) and the intention is for clinical ethics teams to complement or partner with palliative specialists to ensure patients, families, and teams can navigate challenging circumstances and conflicts.

Tip 1: Ethics Consultants in the Intensive Care Unit Can Help Redefine Conflict and Realign Expectations

Intensive care is a team sport, making good communication both complicated and essential. Poor communication worsens patient and family outcomes² and can lead to conflict between or within the team and family.³ High-quality communication supports care that meets patient, family, and clinician needs.²

Communication is made more challenging by the uniquely complicated intensive care unit (ICU) team comprising multiple smaller teams interacting during acute, emotionally charged, and sometimes end-of-life situations. An interdisciplinary intensive care team works alongside subspecialty groups, including PC, each composed of interprofessional membership.⁴

Clinical ethics teams indirectly support intensive care communication through ongoing interactions with clinicians.⁴ Ethics brings a needed “outsider’s” perspective provided through a variety of scheduled interactions with the ICU team including educational opportunities or rounding. Many ethics teams provide education through specialized sessions or conferences, giving clinicians a language to describe values, which are either uncertain or in conflict and a forum for communication planning. Some ethics teams round regularly with intensive care and PC teams to preempt potential ethical concerns in complex cases.⁵ Such discussions can provide an outlet for processing difficult experiences and improve intra-team and team/family communication.

Ethicists can help perform direct support by realigning expectations among groups and help identify biases that may unknowingly impact dynamics.³ In cases where ICU clinicians and families differ in communication approaches or end-of-life goals, the ethics team can remind the ICU team that PC clinicians, in particular, bring unique communication skills tailored to such challenges. Ethics consultants can clarify a range of ethically justifiable approaches to care and provide education about the foundations of discordant views.

Tip 2: Ethics Consultants Offer Support and Supplemental Safeguards Around Potentially Inappropriate Medical Treatment

Tension usually exists when clinicians think it is necessary to invoke institutional policies surrounding potentially inappropriate medical treatments. Typically, communication has broken down between clinicians and the patient/family, including the communication experts, the PC specialists. The family may not understand or agree with the offered prognosis and assumes that additional interventions will help. The clinicians, on the contrary, may determine that resuscitation

or some other intervention will primarily cause harm with no or insufficient benefit. In some academic or community hospital settings, there may be a certain number of calendar days given to a surrogate when the medical team engages a formal review process (such as the Texas 10-Day Rule). In other care settings, there may be policies or regulations prohibiting unilateral Do Not Attempt Resuscitation (DNAR) processes.

Although an ethics consult is often procedurally required to assess circumstances when care interventions are under dispute, the ethics team may also have a role in assisting the family. The clinical ethics team may help the surrogate consider what the patient would have wanted if the patient were aware a treatment would not offer any benefit, helping the surrogate to understand that the clinician would not intentionally deny a patient a beneficial treatment. The clinical ethics team can explain that a clinician is duty-bound to “Do no harm,” which is why the clinical team requested ethics review of the case for harm potential, taking a neutral stance. Ethicists can explain why the medical team believes the intervention under question would be harmful, noting that all share the value of regard for the patient.

The ethics team may learn about cultural or religious reasons compelling a patient or family to seek interventions deemed not beneficial by the medical team, striving to navigate mutual understanding, trust, and respect. This type of communication becomes especially important for patients with disorders of consciousness or deviation from typical neurodevelopment, up to and including disputes around determination of death by neurologic criteria.⁶ The ethics team may help the family consider potential for harm from potentially nonbeneficial treatment, so too can the ethics team help the clinical team understand that families value different goals and that unilateral decision making in these situations will not meet the needs of all families, particularly under a disability framework.

The clinical ethics team can explore whether avoiding potentially inappropriate medical care upholds the basic ethical principles of respect for the patient and family and nonmalfeasance.⁷ Ethics consults at the end-of-life are usually well received by the family.^{8,9} The ethics team’s approach supplements the PC team’s attention to symptom control and facilitating caring communication.⁷ The two teams should work closely in this difficult situation, which requires keen knowledge of practice policies and care setting standards.

Tip 3: Employ Palliative and Ethics Consultants Jointly to Address Values Conflicts in Medical Decision Making

Relational autonomy, a respect for individuals while appreciating their interdependence, posits that families are uniquely positioned to advocate for and assist patients with decision making.¹⁰ In pediatrics, it is both a standard legal and ethical principle that parents make medical decisions on behalf of young or incapacitated children.¹¹ In this pediatric context, parental authority is reconceptualized to give priority to the child’s own self-determination, self-realization, and actual or potential autonomy.¹²

When a parent makes medical decisions for their child that differ from the range of recommendations provided by the

medical team, the harm principle (freedom to act unless the action harms another) is applied. This principle suggests interference by the health care team and state authorities if the decision poses imminent, serious harm to the child, not when decisions are contrary to the child's singular best interest.¹³

Ethicists' competencies include strategies to de-escalate conflicts between parents and the health care team. De-escalation is particularly important as conflict arising between clinical teams and families can result in higher rates of state reporting and disproportionate application of behavioral contracts or other restrictions in communities of color.¹⁴ Engagement with PC and clinical ethics services should occur early. This may begin with the palliative domain of understanding parents' concerns, values, and acknowledgment of options.

The teams can together reframe conflict as a mutual scenario that can be resolved through collaboration, facilitate a supportive environment of active listening, and help parents understand long-term decisional outcomes. Family meetings including PC and ethics presence can also provide an opportunity to help clarify goals of care discussions, address mismatched expectations, and aid in resolving ethical issues. Through mutual respect and understanding, clinicians together with ethicists and parents can identify and de-escalate conflict to optimize both parental authority and child well-being.

Tip 4: Successful Partnerships between Ethics, Palliative, and Surgical Consultants Improve Shared Decision-Making Surrounding High-Risk Interventions

High-risk surgical decisions often occur with little prior surgeon-patient rapport, in a time of crisis. Eliciting patients' goals and values in these urgent surgical scenarios can be challenging. Eliciting patient stories through partnership with both ethics and PC teams can support surgeons as they seek to understand their patients' sometimes complex backgrounds and how patients' experiences shape goals and values.¹⁵ This deeper understanding can help surgeons discuss risks and benefits of a given treatment path in the context of their patients' lives. Through this collaborative insight, surgeons may then modify treatment approaches or choose to offer specific recommendations for goal-concordant care.

Patients who are weighing surgical and nonsurgical treatments may avoid voicing preferences for nonoperative care to their surgeons, to appear more committed should they choose an operation. Clinical palliative and ethics teams can help ensure that all decisions, including nonoperative care, are incorporated into conversations.

In controversial surgical scenarios, clinical ethics colleagues can prompt surgeons and their patients to consider how they would proceed with future decision making if a chosen therapy is not successful. Doing so can help patients to appreciate how they would experience the process and potential outcomes, rather than the sole intended surgery. This exploration may facilitate setting limits to surgical treatment, as with a time-limited trial.¹⁶ Similarly, clinical ethics colleagues maintain a role in helping care settings assess how DNAR orders are managed in the perioperative timeframe to foster alignment with patients' goals.

Tip 5: Ethics Consultant Processes and Presence May Reduce Conflict Over Life-Sustaining Treatment Decisions for Patients Without Decisional Capacity

Clinical ethics teams can remind teams of guiding principles such as surrogate hierarchy and decision-making standards in complex scenarios to foster support and clarity.

When caring for a patient without decision-making capacity and without prior documentation of preferences, *substituted judgment* compels surrogate decision making in accordance with the values and preferences of the patient, if the patient previously had capacity and these wishes are known.¹⁷ Ethics teams can support surrogates to recall the patient's goals, values, lifestyle, and preferences. The communication skills of the ethics and palliative teams can bolster the surrogate's ability to voice the patient's prior preferences even if those preferences differ from the personal wishes of the surrogate or even the professional preferences of the medical team. If the patient's values and preferences are unknown, the *best interest standard* maximizes the patient's overall good and minimizes the patient's risks of harm.¹⁸

Surrogate decision making is often complex because of unclear or even conflicting perspectives about the patient's prior preferences that can be further challenged by disagreement among surrogates of equal legal standing. As clinical ethics teams may help navigate complex surrogate decision making by mapping out ethically justifiable approaches to decisions and surrogate hierarchy patterns, a PC team may bring their interpersonal expertise to further humanize the communication dynamics.

Tip 6: Ethics Consultants Can Improve Informed Consent Regarding Advanced Technologies for Children with Chronic Critical Illness

Discussions about chronic technologies require patients and families to (re)define the threshold beyond which they might decline life-sustaining therapies. When prognosis is uncertain, families often value the time for potential improvement that technology affords.¹⁹ In chronic or declining conditions, families may prioritize how escalating technology impacts quality of life.

There are three ways for PC and ethics consultants to enhance informed consent about technology. First, the likelihood that a family will decline technology depends on hearing technology as an option, among others. Data suggest that in the context of pediatric respiratory failure, many families recall no option being provided besides home ventilation.¹⁹ Primary clinicians may need help from clinical ethics teams in considering which options (including compassionate extubation) are relevant and help from PC specialists in discussing those options to further support the family's communication experience.

A second area for support is disentangling child from family interests. Multiple studies demonstrate how home medical technology impacts family finances, work/school responsibilities, physical and emotional wellbeing, and relationships. In turn these factors shape the child's home care and overall wellbeing. Clinical ethics teams can help consider how a family's social context should or should not alter the risks or benefits of technology for a child.²⁰

A third opportunity involves technology decisions for patients with severe neurologic impairment. Comfort, pain, and quality of life can be difficult to ascertain without direct communication from the patient, requiring nuanced evaluation by PC specialists and clinical ethics teams together with families.²¹

Tip 7: When Families Request Prognostic Nondisclosure, Ethics Consultants Can Help Balance the Patient's Preferences, Best Interests, and Possible Harms of Nondisclosure

When asking clinicians not to tell a patient a diagnosis, family members often believe they are protecting their loved ones. This request appears to contradict the traditional assertion of the importance of independent, autonomous decision making supported by medical ethics, law, and positions of medical associations.²² Many medical teams feel stuck when hearing nondisclosure requests.

Respecting the decision-making authority and autonomy of patients with capacity exists as both a legal and ethical standard. In these instances, the clinical team should offer a patient with capacity the opportunity to learn the prognosis if so desired by the patient. It may be acceptable to forego prognostic information if the adult declines, defers information to a surrogate, or refuses. Foregoing disclosure may be intermittently considered in *very* rare circumstances where there is legitimate concern about imminent risk of harm to the patient if the information were released.

For minors or for patients without decisional capacity, a clinical ethics team serves by assessing the patient's best interest and possible harms of nondisclosure using the following techniques: (1) exploring hesitations around information sharing²³; (2) inviting the patient (seen separately) to answer, "What do you want to know about your situation and who do you want to make decisions?"^{22,24,25}; (3) learning about cultural and community context, including that some children will retain role plays to preserve family functional coping; (4) sharing strategies to build trust, express empathic curiosity, and respectfully share evidence behind truth telling; (5) setting limits²³; and (6) finding compromise or common ground.

The clinical ethics team should not police disclosures. Ethics principles serve as guideposts. Ethics recommendations are grounded in the details of the specific request for nondisclosure and clinical circumstances with a recognition of truth as a humanistic value. Although controversy may exist for when to consult clinical ethics teams, palliative clinicians should remember that late referrals with escalating tensions require enormous repair with negotiation opportunities missed earlier in the trust-building process.

Tip 8: Ethics Consultants Are a Resource for PC Teams Responding to Requests for Physician Aid-in-Dying

PC teams may be consulted to help address requests for *physician aid-in-dying* (PAD), which is the practice of prescribing a lethal dose of medication to a person with decisional capacity with a terminal illness upon the patient's request. There are currently 10 states in the United States with formal PAD laws. PAD laws outline extensive processes and safeguards to ensure patients are informed regarding all

their options for end-of-life care and patients have decisional capacity. Canada has a national law for medical aid-in-dying, which permits both PAD and voluntary active euthanasia (VAE), in which a physician directly administers the lethal medication.²⁶ There are some states and organizations that prohibit both PAD and VAE by policy or law, such as the Veterans Health Administration.

Even where PAD is legally available, it remains ethically debated. The National Hospice and Palliative Care Organization (NHPCO) has a formal statement opposing PAD²⁷; the American Academy of Hospice and Palliative Medicine (AAHPM) has a formal statement of neutrality.²⁸ Clinical ethics colleagues can support PC teams through dialog regarding the various ethical issues that arise in responding to PAD requests. Common questions that arise include how PAD differs from VAE and discussing other options of last resort in the face of unmitigated suffering at the end of life, such as palliative sedation or voluntary stopping of eating and drinking.

Whether or not PAD is available in a particular organization or state, clinical ethics teams can help PC teams to address ethical questions or concerns, such as whether individuals desiring control over the timing of their death have been presented with all available palliative options. Although PAD remains a rare event, where PAD is legally available, clinicians, patients, and families must follow each step and requirement in the process. This can be challenging as most physicians, if they are willing to participate in PAD, may only do this a few times in a year. Ethics colleagues may serve as a knowledge source regarding related ethical issues (such as conscience-based objection and nonabandonment by clinicians), as well as local policies and legalities in care settings where PAD remains prohibited to foster providers remaining within authorized and approved scope of care within their practice settings.

Tip 9: Ethics Consultants Can Help Prevent, Address, and Mitigate Moral Distress

Caring for seriously ill patients and their families is a privilege. However, patients or their designated surrogates may choose treatment paths perceived by clinicians to be incongruent with a peaceful end of life, and that increases the patient's suffering and clinicians' angst. Care discussions stall, raw emotional outbursts manifest, and moral distress takes hold.

PC clinicians often find themselves in morally complex situations that affect their physical, emotional, and moral reserves. Distraught family members may express anger and distrust. Hospitals may follow standards of care that prioritize family decisional autonomy over considerations of medical appropriateness.²⁹ Team members may feel powerless in the moment—and later burdened by moral regret.³⁰

Finding support through clinical ethics teams might help a PC clinician or team experiencing moral distress by: (1) addressing the salient ethical issues; (2) debriefing how goals of care and patient-and-family preferences were or were not met; (3) promoting a nonjudgmental discussion of factors that contributed to distress; (4) asking clinicians to describe alternative decisions and possible outcomes; (5) highlighting/clarifying the importance of patient autonomy and of supporting designated surrogates to make decisions in accordance

with the patient's preferences; (6) seeking valued advisory expertise to elucidate the root causes of moral distress and emotional reactions; (7) addressing system-related factors that hindered or facilitated care; (8) advocating for system-level changes that played a role in the distress; and (9) reinforcing that clinicians are responsible for ensuring the process of decision making meets an acceptable standard while patients/surrogates live with the final decisional outcome.

Without venues to discuss values and care principles, team-based care for patients and family can be shortsighted and risk the health and wellbeing of PC clinicians who give so much of themselves to helping others.

Tip 10: Clinicians Who Practice Both as PC and Ethics Consultants Should Be Careful Not to Blur the Lines Between the Two Roles and Recuse Themselves from One Role When Necessary

PC specialists will frequently support primary clinical teams, patients, and families when questions may arise about which treatment options are considered acceptable. In some circumstances, teams may not offer comfort-focused care or limited interventions when they believe the patient still has a good probability to survive, despite family values that may be consistent with these limitations. Or, primary teams may want to only recommend withdrawal of life-sustaining technology when the family is strongly in favor of continuing such treatments and have lost trust in the team's guidance because the team has made prognostic errors previously. Although palliative specialists are experts in communication and are familiar with the medical options, PC teams should recognize that some of these clinical scenarios require resources beyond their expertise and that the clinical ethics team should be allowed to offer guidance.

The unique challenge arises when the PC subspecialist also serves as a clinical ethics consultant in the hospital. Although a single individual can possess both sets of skills (clinical expertise and ethics expertise), it is confusing and problematic to serve both roles simultaneously. For conceptual and team clarity, ethics-trained palliative specialists should formally consult ethics colleagues to seek their separate expert input.¹ Serving in a clinical role can either lead to a bias in the perspective of ethically appropriate treatment options or at least lend the perception of bias. For the same reasons, if an ethics consultant has previously played a significant role in caring for patient as clinician, they should recuse themselves if possible given staffing availability of other ethics consultants.

Conclusion

PC represents a necessary service for patients and families; the roadmap of PC is driven not by self-sufficiency but by shared grounding. PC and clinical ethics represent a natural and necessary partnership that can best be navigated through task delineation and role clarity. Complex care presents opportunities for convergence of the values and principles central to quality care while recognizing the unique lanes of PC and domains of clinical ethics. Innovative, integrative models of partnerships within and across health care systems can foster foundational grounding of shared principles and practices.

Authors' Contributions

All authors meet authorship criteria per established ethics guidelines. Dr Weaver contributed to this article in a private capacity.

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The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the National Institutes of Health, U.S. Department of Veterans Affairs, the U.S. Government, or the National Center for Ethics in Health Care. No official support or endorsement by the U.S. Department of Veterans Affairs is intended, nor should be inferred.

Funding Information

Dr. Walter's contribution to this publication was supported by the National Heart, Lung, And Blood Institute of the National Institutes of Health under Award Number K23HL141700.

Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Figure S1

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