Ethics and Palliative Care

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1. Background

- Defining palliative care:
  - The American Academy of Hospice and Palliative Medicine has defined palliative care.
  - Disease and death are unavoidable in any medical practice. This basic understanding was seen as far back as Hippocrates, 460-370 B.C.: "I would define medicine as the complete removal of the distress of the sick, the alleviation of the more violent disease, and the refusal to undertake to cure cases in which the disease has already won the mastery, knowing that everything is not possible to medicine" (1).
  - The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care (2; 3).
  - Palliative care involves all aspects of health, including physical, mental (intellectual and psychological), spiritual, and social well-being, not just of disease.
  - Palliative care is appropriate for all patients with life-altering disease; it is a fundamental component of the practice of medicine in all disciplines and at all levels of health.
  - Some patients with a terminal illness may elect to enroll in hospice. Hospice is a service delivery system, appropriate for patients in the last 6 months of life. Hospice provides comprehensive care focused on alleviating symptoms and maximizing quality of life through an interdisciplinary approach. Patients enrolled in hospice represent only a portion of individuals who may benefit from palliative care.
  - The origin of palliative medicine can be traced back to 1940s England, when a nurse named Cicely Saunders described her work at St. Luke's Hospital, one of the early homes for "terminal care" (4). After attending medical school, Dr. Saunders returned to St. Luke's, where she and others developed strategies for dealing with end-of-life issues, including intractable pain. In 1967, Cicely Saunders established London's St. Christopher's Hospice, the first modern hospice. Her concepts of palliative care medicine and hospice organization are now considered ideal for the care of dying patients. Today, most hospice services are provided at home or in skilled nursing facilities.
  - Palliative care programs are growing rapidly in U.S. hospitals. The number of palliative care programs increased from 15% of all hospitals responding to the American Hospital Association national survey in 2000 (5) to 63% of hospitals with 50 beds or more in 2009 (3).
  - Despite the recognized importance of quality palliative care in the dying population, not all patients near the end of life may receive the highest quality care:
    - The 1995 SUPPORT study examined seriously ill patients whose dying proved to be predictable; timely discussions and decisions about death were uncommon. Caregivers expressed concerns about adequate physician communication near the end of life. Nearly half of all DNR orders were written in the last 2 days of life (6)
    - The Institute of Medicine 1997 report Approaching Death: Improving Care at the End of Life found major deficiencies in the delivery of quality comfort care (7)
    - A 2002 report entitled Means to a Better End: A Report on Dying in America Today by Last Acts Partnership graded all 50 states on eight key elements of end-of-life care. Most states earned Cs, Ds, and Es (8)
    - A 2010 study evaluating quality measures in patients who died in the hospital suggested a number of areas for improvement, including prompt transition of DNR orders from a skilled facility to the hospital, documentation of patient participation in goals of care discussions, and deactivation of internal defibrillators at the end of life (2).
- Ethical and legal foundation:
  - Consistent with the principle of respect for patient autonomy, individuals have the right to participate in their own plan of care, including making choices that affect their physical, mental, spiritual, and social health; therefore, patients should be fully informed all available treatment options, including those involving palliative care (9).
• The principle of beneficence requires that providers have the fiduciary responsibility to care for the whole patient, rather than the disease alone. In order to do good for dying patients, physicians must facilitate patient access to palliative care (9).

• When caring for a dying patient, treatment plans must continue to provide the patient with basic needs such as pain relief, treatment of depression, and anxiety. Neglecting to offer aggressive symptom management may cause harm to patients, which would contradict the principle of nonmaleficence.

• In interpreting the principle of justice, many health professionals and laypersons believe that each individual should have affordable access to basic health care, including palliative care and quality end-of-life care (9).

Legal considerations:

• Because legislation concerning advance directives, surrogacy, and even assisted suicide differs from state to state, providers should know the law for the states in which they practice. For instance, in 2006 the Supreme Court rejected the U.S. attorney general's authority to prohibit physicians in Oregon from prescribing Schedule II drugs for their terminally ill patients to commit suicide, in effect upholding rights of the individual states to legislate availability of physician-assisted suicide (Gonzales v. Oregon, 126 S.Ct. 904 2006).

• Currently, the number of lawsuits filed for the undertreatment of pain is quite low. Pain as a component of a tort suit shows up primarily in pain and suffering awards for a physician's negligent treatment or diagnosis of a patient that leads to physical harm and accompanying pain. As more pain and palliative treatment guidelines emerge and become standard of care, it is likely that law suits involving undertreatment of pain and omission of comfort care will increase (10):

  o In Bergman v Chin (11), an 85-year-old man suffering from chronic lung disease spent the last few weeks of his life in acute pain. Despite high self-assessed pain scores he was not prescribed liquid morphine. The Medical Board of California agreed with the family that pain management was indeed inadequate but concluded there was insufficient evidence at the time to warrant pursuing further action in this case. The survivors brought suit against the treating physician and hospital. The hospital settled with the family, and the settlement included an agreement by the hospital to provide pain management classes to its staff and doctors. The case against Dr. Chin went to trial, and he was found liable for elder abuse and reckless negligence. The jury awarded Bergman's family $1.5 million in compensatory damages.

• To date, the U.S. Congress has not yet passed new pain or palliative care legislation, although there have been several unsuccessful attempts recently to amend through new legislation the Controlled Substances Act to affect pain management and palliative care (12). Proposed legislation has included the Pain Relief Promotion Act of 1999 (S. 1272/H.R. 2260) (13) and the Conquering Pain Act of 2001 (S. 1024/H.R. 2156) (14).

• In 1997, in Vacco v Quill, the Supreme Court stated that although a state may prohibit assisting suicide, it may permit palliative care, which may have the foreseen but unintended “double effect” of hastening the patient's death (15).

• New York state's Palliative Care Information Act stipulates that, "If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including but not limited to: the range of options appropriate to the patient; the prognosis, risks, and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life" (16).

• Language that listed advance care planning as a service that could be provided during annual wellness visits for Medicare beneficiaries was deleted from Medicare policy taking effect in January 2011, following a heated debate over a provision in the 2009 health care bill passed by the House of Representatives, allowing for physician reimbursement for discussions related to end-of-life care (17).
2. Indications

2.1 Provide palliative care options for every patient with life-altering illness, regardless of the stage of disease and goals of treatment.

- Discuss strategies for symptom management with all patients (and their caregivers) who are experiencing symptoms that have a negative impact on quality of life.
- Recognize that suffering, “a state of severe distress associated with events that threaten the intactness of the person,” can occur not only within the physical realm, but within the spiritual, psychological, and social arenas as well (18).
- Recognize that most treatment plans combine palliative measures intended to alleviate symptoms with more aggressive measures intended to achieve disease remission or cure. For example, in rheumatoid arthritis, patients are treated with disease-modifying agents as well as symptom-controlling analgesics.
- Be aware that for any condition, the balance between palliation and curative or remissive treatments offered will depend on local medical standards of care, available technologies and resources, provider opinion, and ultimately, patient preference:
  - Periodically review the patient's goals of treatment
  - Discuss significant progression of chronic diseases or symptoms with the patient to screen for unmet palliative needs
  - Offer palliative care plans to all patients with life-altering illness
  - Encourage surrogates, care providers, and significant others to take part in these conversations
  - Encourage collaboration between the care team and the patient or surrogate when developing a plan of care
  - Screen for social, environmental, and spiritual concerns that commonly arise with debilitating and or terminal illnesses. Because patients and significant others may limit discussions to physical problems, actively screen for problems in these other realms of health.
  - Enroll the aid of content experts (chaplains, social workers, and others) when patients show a need for guidance and support outside the purview of the treating clinician.
3. Implementation

3.1 Implement palliative treatment options for all patients through good communication skills in discussion of goals of care.

- Understand that discussions about goals of care require preparation:
  - Thoroughly review medical information
  - Invite appropriate members of the medical team
  - Clarify the goals of the discussion with the medical team
  - Arrange for a comfortable environment free of distractions

- Begin conversations by eliciting the patient's own understanding of the current situation and then discussing the patient's preferences regarding the next steps in management, given the diagnosis and prognosis:
  - Determine patient and family perception about the disease process, including their understanding of the etiology, expected clinical trajectory, and prognosis
  - After ensuring the patient's emotional readiness and willingness to discuss his or her condition, fully inform the patient about his or her condition, prognosis, treatment options, benefits, and burdens of each therapeutic choice to ensure fully informed decision-making
  - Consider making a recommendation based on the medical information available and a clear understanding of the patient's goals and values
  - To elicit patient concerns that could otherwise go undetected, try to use open-ended questions about patient understanding and desires concerning terminal and irreversible conditions. Acknowledge and understand the patient's emotions in order to respectfully offer steadfast support, such as: "I will support you during this illness"; utilize empathic, exploratory statements such as, "Can you tell me more about what worries you most?" (19; 20)
  - When prognosis is poor and cure or remission is not possible, or when the patient decides against treatments to cure or control, emphasize comfort care as the focus for treatment (palliative medicine)
  - When cure or remission is possible, discuss palliative care plans to help alleviate burdensome treatment effects
  - Understand that by first addressing the goals of treatment, rather than immediately focusing on clinical decisions, subsequent health care plans are more likely to be congruent with the patient's true desires for living and dying (19)

- Center discussions with the patient and his or her significant others on the desired goals of planned therapies, emphasizing interventions that achieve those goals, and discouraging procedures that are unrelated to or in conflict with those goals:
  - Types of "aggressive" technologies include cardiopulmonary resuscitation, dialysis, antibiotics, central lines, vasopressors, and artificial fluids and nutrition. Explain that the goals of such therapies are to cure, control, or curtail a disease process
  - For example, a dying patient suffering from fluid overload and complications of third spacing may choose to remove or forgo the placement of a nutrition gastric tube or intravenous placement for fluids. Both intravenous fluids and artificial nutrition are medical technologies that can be employed, withdrawn, withheld, and may be accepted or refused by the patient or surrogate

- When a patient no longer has the ability to discuss care plans, look to patient surrogates and prior directives for guidance (see module Advance Care Planning):
  - Educate the surrogate on the role of surrogacy. Specifically, surrogates must understand that they are making decisions they feel the patient would have made, not necessarily decisions they would make
  - Ascertain that the surrogate's decisions are in the best interest of the patient and consistent with the patient's preferences when known
  - Understand that significant limitations exist on accuracy of surrogates to provide patients' end-of-life preferences (21)
• Once fully informed about the options, be sure the patient or surrogate demonstrates their understanding of the medical situation and treatment options, makes decisions based on this information, and communicates decisions.

• Screen for these specific areas when assessing palliative care needs:
  - Physical signs and symptoms including but not limited to somatic pain, cachexia, anorexia, nausea, anxiety, recurrent hospitalizations, progressive organ failure, recurrent secondary infections, and dyspnea.
  - Psychological issues such as mental capacity and function, depression, anxiety, and despair. A single question, “Are you depressed?” is an outstanding screening tool for depression in terminally ill patients (22).
  - Spiritual concerns such as existential crises arising from or worsened by consideration of one’s morbidity or mortality. A single question, “Are you at peace?” offers excellent screening characteristics for discerning spiritual distress (23).
  - Social stressors such as increasing physical, financial, and emotional dependence on others for activities of daily living, presence of adequate social supports, availability of reliable medical surrogates, and quality of the patient’s environment to accommodate these needs.

• Address spirituality and religion with the patient. Acknowledge the patient’s current and desired religious involvement, including situations in which the doctor and patient have different philosophical beliefs. Refer patients to spiritual and religious resources from the hospital, the hospice, or the local community.

• Be aware that social health issues are often best addressed by an interdisciplinary team:
  - Social work can assist with issues of insurance, concerns of elder abuse, and long-term placement.
  - Occupational and physical health specialists can address issues of ambulation, transferring, and mechanical aids to help with activities of daily life.
  - Medical legal offices can assist patients and surrogates with wills and other such issues.
  - Support groups can help patients and significant others with many social issues.

• Be aware that when many aspects of health are threatened by irreversible or terminal illness, coordination of such care may become demanding. Hospice organizations are structured to deal with such cases. Know the hospice services in the community and the basic criteria for admission. A brief and simple communication about hospice availability may significantly increase hospice enrollment of nursing home residents (24). Even if a patient does not qualify, the discussion of hospice care will provide information about hospice as a resource, which can be reassuring to the patient and his or her loved ones as the disease progresses:
  - Hospice services have been covered by Medicare Part A since 1983. According to the National Hospice and Palliative Care Organization, 80% of the people using hospice are over 65 and therefore eligible for Part A (25). See also Medicare Hospice Benefits.
  - For patients under 65, most private health plans and state Medicaid programs cover hospice services.

• Include therapies to be withheld, withdrawn, continued, and started in palliative care treatment orders, and include informed consent by the patient or surrogate in documentation for withdrawal or withholding of interventions.

• Include practical and concrete plans at the time of imminent death in treatment plans for terminal patients:
  - The patient and family or significant others must understand what to expect during the final stages of dying.
  - Plans should address what to do if new symptoms arise during the dying process.

• Strongly consider referring the following types of patients to a palliative care expert:
  - Patients implanted with left ventricular assist devices or other forms of mechanical circulatory support, especially those who are experiencing a decline in functional capacity (26).
  - Patients with heart failure, particularly those experiencing intractable symptoms or worsened quality of life (27).
- Patients with implanted cardiac defibrillators or cardiac resynchronization therapy, especially those with comorbidities or decreased quality of life (28; 29)
- Intubated patients who have elected to undergo terminal extubation (30)
- Dying patients experiencing symptom distress refractory to standard palliative measures, in whom palliative sedation is being considered (31)
- Ensure that documentation of therapeutic intent, plan, and expected outcome are all consistent and unambiguous.
4. Complications

4.1 As with any treatment plan, recognize that difficulties may arise in the discussion and implementation of palliative care measures.

- Palliative care should be the standard of care for dying patients, yet this is not the case. In the 1997 report *Approaching Death: Improving Care at the End of Life*, the Institute of Medicine found significant deficiencies in care for the dying (7):
  - Too many people suffer needlessly at the end of life because caregivers fail to provide supportive care known to be effective while continuing practices that are known to be ineffective, such as the misapplication of life-sustaining technologies
  - Legal, organizational, and economic obstacles continue to obstruct excellent palliative care for the dying. Examples include reimbursement systems that provide incentives for procedures and disincentives for supportive services
  - The general training of physicians and other care professionals in the area of palliative medicine is inadequate. In 2006 however, American Council for Graduate Medical Education approved hospice and palliative medicine as a new subspecialty. This decision opens a path towards formal and rigorous fellowship-level training to physicians certified in primary specialties
  - There is a deficiency in evidence-based medicine concerning end-of-life issues
- Many physicians do not recognize when death is nearing. One study investigated the extent of error in doctors' prognoses in terminally ill patients. Three hundred forty-three doctors estimated survival for 468 terminally ill patients. Only 20% of predictions were accurate (within 33% of actual survival). Of the 80% inaccurate predictions, 63% overestimated the time until death (32).
- Furthermore, even when physicians know a patient may be dying, a significant percentage do not communicate poor prognoses to their patients. A study looked at rates of prognostic disclosure to 300 patients with cancer near the end of life. The analysis of questionnaires filled out by their physicians revealed that they had provided an accurate estimate only 37% of the time (33).
- Discussing a patient's physical, psychological, spiritual, and social well-being not only takes time but also requires that the provider have an understanding of cultures and philosophies with which he or she may not be familiar. The current health care environment does not promote intimate and lengthy dialogue with patients.
- Physicians historically prefer to work independently, yet palliative care for the ill or dying patient is best accomplished in an interdisciplinary manner. Hospice programs are usually modeled after this team approach but may go underutilized if the physicians are unfamiliar with the benefits and availability of such programs. Providers should employ the consultation of other professionals when needed to include combinations of palliative and pain specialists, psychiatric services, social services, support groups, and clergy.
- Family and significant others may not be in agreement with palliative care plans created by the patient and medical team. Solutions include facilitating communication between patient (or surrogate), family and significant others, and the health care team. An evidence-based approach derived from nonmedical disciplines has been recommended for negotiating conflict in caring for the seriously ill (34). Disagreement causing distress may require mediation by an ethics consult service or other neutral entity.
- The AMA Report of the Council on Ethical and Judicial Affairs (35) recommends a four-step process for considering futility cases:
  - Attempt to negotiate a common understanding
  - Employ joint decision-making
  - Involve a facilitator such as a patient representative
  - Consider ethics consult for unresolved cases
- Pain medicine is a central aspect of palliative care. Undertreatment and overtreatment of pain, and even failure to refer to pain specialists, have been legal issues for physicians. Fear of litigation has had an effect on pain management for some physicians.
In a 1990s California survey, 69% of respondents said that the potential for disciplinary action made doctors more conservative in their use of opioids in pain management, and one third reported that their own patients may be suffering from untreated pain (36).

A 2002 study by Last Acts Partnership, Means to a Better End: A Report on Dying in America Today, shows that nearly half of the 1.6 million Americans living in nursing homes suffer from inadequately treated persistent, severe pain (8).

Racial and ethnic minority populations are at higher risk for the undertreatment of pain (37). Pain is often overlooked and undertreated in patients with HIV, women, those who are less educated, and in patients with a history of intravenous drug use (38).

There is often the concern that the use of palliative therapies in dying patients may hasten death. For example, opioids and benzodiazepines may have the side effect of respiratory depression. There is no evidence however, that appropriate use of medications for symptom management hastens death (39). Physicians must understand the difference between euthanasia or physician-assisted suicide and palliative treatments, inclusive of palliative sedation, that are justified under the concept of “double effect” (40):

- Double effect refers to the relationship between therapeutic intent and outcome: the intent of a treatment plan is to alleviate symptoms, but the treatment may in fact hasten the dying process due to possible side effects.
- The intention and action of palliative care treatments should be congruent and follow standard of care for the therapies employed, and documentation should be detailed.

When discussing end-of-life issues, patients may ask their doctors about euthanasia or physician-assisted suicide, topics with which some doctors are not comfortable. Furthermore, patients and families may confuse palliative care with euthanasia or physician-assisted suicide (40; 41):

- Physicians must understand the difference between euthanasia or assisted suicide and withdrawal or withholding of medical technologies. Withdrawal or withholding allows the person to experience the dying process without specified aggressive therapies.
- Physicians must use requests for euthanasia or assisted suicide as a prompt for quality conversations about palliative care.
5. Patient Education

5.1 Use patient education as a fundamental component of a palliative care plan.

- Initiate discussion of goals of care early in the course of disease, and continue these discussions as the disease progresses:
  - Address advance directives and the medical power of attorney document with adults routinely as part of the well-patient visit
  - Recognize that advance care planning is part of the standard of care for pediatricians and other health care practitioners involved in the care of pediatric patients with chronic life-threatening conditions (42)
  - Be aware of the Canadian Paediatric Society position statements and guidelines regarding advance care planning for pediatric patients (42)
  - Fully inform the patient and his or her surrogates on the patient's condition, prognosis, and treatment options, including comfort measures and the surrogate's role in care decisions. Include family and significant others in such discussions throughout the disease course in order to facilitate understanding of both the patient's illness and treatment choices.
  - Be a primary source of information on comfort and palliative care and hospice. Make education ongoing and readily available, modifying it as the patient desires or as conditions change. Address issues of grief and loss both before and after the death of the patient.
  - Focus on cultural similarities as well as differences when working with individuals of different cultures (43).
  - Be aware that local hospice organizations are often aware of local providers trained in end-of-life teaching for audiences ranging from clinicians to patient groups. Remember that there are also several organizations and Web sites patients can access for further information on death, dying, and palliative care.
  - Be aware that the National Hospice and Palliative Care Organization offers many resources, including how to select and where to find hospice providers.
  - Be aware of the numerous organizations that provide online and printed provider and patient education in palliative care, including the American Academy of Hospice and Palliative Medicine, the National Hospice and Palliative Care Organization, and the Center to Advance Palliative Care.
  - See module Advance Care Planning.
6. Follow-up

6.1 Reassess the efficacy of treatment plans at regular intervals and modify them as necessary.

- In all treatment plans, including those focussing on comfort, include plans for follow-up to address new issues and evaluate the status of problems already identified, as well as the efficacy and tolerability of the treatments employed. Follow-up is especially important for the very ill or the dying for whom ongoing holistic, supportive care may be all that prevents despair.
- Remember that quality palliative care may be time-intensive. Schedule frequent follow-up visits to facilitate the prioritization and evaluation all of the patient's needs and concerns. Furthermore, frequent follow-up provides the opportunity to get to know the unique biopsychosocial background of each patient, allowing for customized health care.
- As with any other treatment plan, assess the efficacy of the palliative care measures regularly and modify them as needed. Address issues such as symptom control, social support, caregiver burnout, and nonphysical suffering at each visit.
- Ultimately, be certain to follow-up with patients and family members as part of provider responsibility and accountability for quality end-of-life care.
- After death, consider follow-up with family or significant others to address issues of grief and loss, which is critical in assisting them with the grieving process and can have medical implications as well. A 1998 Swedish study using twin siblings as controls confirmed spousal bereavement as a risk factor for mortality (44).
References

Glossary

**Advance care planning**
A method of implementing patient preferences about care in the event that the patient is ever unable to participate in health care decision-making. It can take the form of written directives, conversations between the patient and family, or discussions between the patient and physician that are documented in the medical record.

**Comfort care**
A fundamental component of palliative care employed for dying patients. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families (World Health Organization definition).

**Euthanasia**
The act or practice of putting to death people or animals suffering from incurable conditions or diseases (Online Medical Dictionary, Dept. of Medical Oncology, University of Newcastle upon Tyne, 2002).

**Health**
The state of complete physical, mental and social well-being, and not merely the absence of disease (World Health Organization).

**Hospice**
An institution that provides a centralized program of palliative and supportive services to dying persons and their families in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings (Stedman's Medical Dictionary, 26th ed).

**Medical surrogate**
A person who substitutes for a patient who is incapable of making or stating their preferences for medical decisions. A person may be appointed surrogate through advance directives, generally accepted family hierarchy, or by a judge.

**Palliative care**
The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families (World Health Organization definition).

**Palliative care medicine**
A medicine subspecialty that focuses on the study and treatment of patients with terminal or severely debilitating, irreversible conditions.

**Physician-assisted suicide**
The act of providing the method (e.g., a lethal dose of medication) for suicide by a physician for a requesting patient.