



Ethical Issues Related to Palliative Care

SCHARLOTTE SPENCER DNP, APRN, FNP-C ,ACHPN

SYMPTOM MANAGEMENT CONSULTANTS

HUMBLE, TX

Objectives

- ▶ Define Ethics
- ▶ What is palliative versus hospice care
- ▶ Ethical issues related to palliative care
- ▶ Ethical issues at end of life
- ▶ Moral distress
- ▶ Resilience/Self care

Define Ethics

- ▶ Clinical Ethics: Practical discipline that provides a structured approach for identifying, analyzing and resolving ethical issues in clinical care.
- ▶ Examples of ethical issues in healthcare:
 - ▶ Not providing patient and families with information to make informed decisions .
 - ▶ Continued life support not perceived as to be in the best interest of the patient
 - ▶ Withholding or withdrawing treatment
 - ▶ Inadequate communication about end of life care between providers, patients and families
 - ▶ False hope given to patients and families
 - ▶ Advance directives not present or not honored.

Evolution of Bioethics

- ▶ The National Commission for the protection of human subjects of biomedical and behavioral research
- ▶ The Belmont Report
- ▶ Federal and State laws:
 - ▶ The Patient Self-determination act
 - ▶ The New York State Palliative Care Information Act

Bio Ethical Principal Theory

- ▶ Autonomy
- ▶ Beneficence
- ▶ Non-maleficence
- ▶ Justice

What is palliative care?

- ▶ Focuses on relief from physical suffering. The patient may be receiving treatment for a disease or may be living with a chronic disease, may or may not be terminally ill.
- ▶ Addresses the patient's physical, mental, social, and spiritual well-being, is appropriate for patients in all disease stages, and accompanies the patient from diagnosis to cure.
- ▶ Uses life-prolonging medications.
- ▶ Uses a multi-disciplinary approach using highly trained professionals. Is usually offered where the patient first sought treatment.

Palliative Care Umbrella

Palliative Care



Hospice care is...

Hospice focuses on caring, not curing and in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Palliative care vs hospice

Characteristics	Hospice	Palliative Care
Interdisciplinary Approach	YES	YES
< 6 month prognosis required	YES	NO
Services Provided	At the end-of-life and when curative tx not effective or desired	At any stage in the illness with ongoing curative or palliative treatments
Efforts to cure and prolong life covered	NO	YES
Focus on relief of suffering	YES	YES

Palliative care vs Hospice care

Palliative care vs. hospice care

Palliative care is aimed at anyone who has been diagnosed with a life-threatening illness



Palliative care helps maintain quality of life and reduce illness symptoms – and recent findings suggest that cancer patients who receive palliative care alongside standard treatments can live longer

Hospice care is mostly aimed at patients who have been diagnosed with a terminal illness



Hospice care is aimed at providing patients with a dignified, pain-free death – in the U.S., hospice care is mostly meant to be administered inside the patient's home, while in Russia, the concept of hospice care is just beginning to gain ground

Source: The Mayo Clinic (mayoclinic.com) and OncologyNurseAdvisor.com

Ethical Issues in palliative care

- ▶ Decision making capacity
- ▶ Medical power of attorney/surrogate decision maker
- ▶ Advance Directives
- ▶ Informed consent
- ▶ Autonomy
- ▶ Medical futility

Ethical issues at end of life

- ▶ Code status (Full Code, DNR, DNI, comfort measures)
- ▶ Artificial nutrition and hydration
- ▶ Refusal of life sustaining treatment
- ▶ The right to comfort care
- ▶ Euthanasia

The Case of Ms. Daylily

Ms. Daylily is an 85 y/o female with history of hypertension, Alzheimer's dementia (moderate), hyperlipidemia, GERD, atrial fibrillation, COPD, diabetes mellitus, history of gastric bypass, chronic sacral wound, bed ridden, osteoarthritis who presents from a SNF with left facial drop of unknown duration. Diagnostic studies reveal right insular and right parieto-occipital subacute and acute ischemia. She presents with acute respiratory failure on admission requiring intubation. She was admitted for acute CVA, acute respiratory failure, hyperglycemia, AKI vs CKD, severe protein malnutrition and stage III sacral wound.

Palliative Care was consulted for discussion and clarification of goals of care

Ms. Daylily information:

- ▶ Patient from a Skilled Nursing facility
- ▶ Decision making capacity: **Patient lacks decision making capacity**
- ▶ Advance directives on chart: Medical Power of attorney (MPOA)/surrogate decision maker: Sister Tina. No Advance Directives
- ▶ Code status: Full code in place

Palliative care family meeting # 1

- ▶ A family meeting was held with pts MPOA/ Tina and friend. Tina states that patient is the oldest of 6 adult siblings. Tina states that prior to this hospitalization and the CVA, Ms. Daylily was completely **DEPENDENT** of all activities of daily living (ADL's) and was not eating or drinking much.
- ▶ After discussion of patient's current medical condition in the setting of a new CVA, Tina decided to compassionately remove artificial life support and transition patient to comfort care and consult hospice team.
- ▶ Tina also stated she did not want chest compressions or reintubation. Code status was changed to NO CPR/DNR/Allow natural death following the meeting.

Goals of care established

- ▶ Compassionately remove artificial means of life support
- ▶ Change code status to NO CPR/DNR/Allow natural death
- ▶ No reintubation
- ▶ Consult hospice for comfort care back at nursing facility

Palliative care encounter #2

- ▶ Patient was compassionately extubated and transitioned to medical floor. Now, comfort care and hospice has been consulted. Patient remains unresponsive with occasional grimacing and moans. Today, MPOA/Sister Tina and another sister Ruth is at bedside.
- ▶ Palliative care NP assessed pt. and ask MPOA if she met with hospice liaison. MPOA very withdrawn during visit. Ruth states, “We are not going with hospice, so they can starve her!!!”. MPOA puts head down.
- ▶ Palliative care team asked to speak with family in conference room to discuss next steps as it appears the goals have changed.

Family meeting #2

- ▶ Ruth states that she was told patient has not had food since admission. She states that she will starve to death an they want a feeding tube. Tina nods her head in agreement. Tina states she would like all her siblings present for a meeting so that they all can help with the decision.
- ▶ In the meantime, hospice is on hold and tube feeding was ordered despite education provided to family on nutrition at end of life.

Goals of care

- ▶ Hospice cancelled
- ▶ GI consulted for feeding tube
- ▶ Wound care consult ordered
- ▶ Patient hypotensive nursing reluctant to give pain meds despite pt.'s signs of pain
- ▶ **NOT** tolerating NG tube feeding <400cc residual
- ▶ Now with diarrhea

Palliative care encounter # 3

- ▶ Palliative care team approached by bedside nurse prior to entering room and told that patient is suffering. She is moaning and having rapid breathing, fevers, diarrhea and family will not let nurse relieve Ms. Daylily's suffering. Day shift nurse also reports that night shift nurse was scared to give pt medication to relieve her suffering as she felt it would hasten her death.
- ▶ A family meeting was arranged with all family members later that afternoon. Four of the six siblings are present for the meeting with a cousin on the phone who is a physician out of state. Family is provided a medical update and detailed information regarding prognosis, aggressive care vs nonaggressive care and hospice support.

Goals of Care Re-established

- ▶ Family meeting concluded, and family decided to continue aggressive care despite pt.'s poor prognosis and poor quality of life despite members of the family sharing that patient. would not want to live this way. Patient went so far as to tell one sibling if she could not care for herself let her go home to the Lord.
- ▶ Family wants pt to continue aggressive care at Skilled Nursing Facility with **NO HOSPICE SUPPORT**. They are hopeful she will turn around. MPOA is tearful during the meeting.
- ▶ SNF evaluation ordered and pt discharged to SNF facility for wound care (maggot therapy per family request, they googled it) management and IV antibiotics.

Palliative care encounter #4

- ▶ Patient returns to hospital for respiratory distress as she was found to be aspirating her feedings 3 days after discharge to SNF.
- ▶ Palliative care consulted to clarify goals of care by new hospitalist. Family withdrawn this admission and tell bedside nurse they do not want to meet with palliative care. Unaware of family decision, palliative care social worker calls MPOA to arrange meeting and was told by MPOA that she has given up her decision-making responsibilities. She shared with the Social worker that her family members were sending her hate emails stating she was trying to kill their sister and that she was going to **HELL**. MPOA also shared that she was instructed not to communicate with palliative care. Palliative care updated hospital case management and primary physician. Ethics consult was also ordered.

Disposition

- ▶ **Ms. Daylily was sent to LTACH for continued aggressive care where she died three days later.**

Bio ethical Principles for Ms. Daylily

- ▶ Autonomy
- ▶ Beneficence
- ▶ Nonmaleficence
- ▶ Justice

Moral Distress

- ▶ What is moral distress?
- ▶ Acting in a manner that is contrary to your personal or professional values, which undermines your integrity and authenticity.
- ▶ Signs of moral distress
 - ▶ Physical, emotional, behavioral and spiritual
- ▶ Moral distress in the care of *Ms. Daylily*

(Rashton & Westphal (2004))

Resilience and Self Care

- ▶ The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma.
- ▶ Self Care- Holistic approach
 - ▶ Emotional boundaries
 - ▶ Connecting with colleagues
 - ▶ Acquiring new skills

Questions



Thank you

Scharlotte@supportivemedicine.net

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