Ethical Issues in Palliative Care Nursing

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Disclaimer

• Dr. Supanich has no conflicts of interest to declare to the group.
Learner Objectives

- Discuss ethical issues and dilemmas that may arise in Palliative Care and at the EOL.
- Describe specific roles of the nurse in ethical decision-making.
- Describe advance directives and their role in preventing ethical dilemmas.
- Apply ethical principles utilized in addressing Palliative Care/EOL dilemmas through:
  - Case model discussions
  - Use of Bioethics Committees
Palliative Care: A Clarification

- Palliative Care - - -
  - Provides relief from pain and other distressing sx
  - Affirms life and regards dying as a normal process
  - Intends neither to hasten or postpone death
  - Integrates the psychological and spiritual aspects of the person
  - Offers a support system to help the family cope during the patient’s illness and in their own bereavement
  - Uses a team approach to address the needs of patients and their families, including bereavement counseling
  - Will enhance quality of life and may also positively influence the course of illness
  - Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life... and includes those investigations needed to better understand and manage distressing
Palliative Medicine’s Scope

• Available to persons of any age
• For anyone with a diagnosis that causes suffering
  • CHF, COPD, hepatic failure, renal failure, stroke, ALS, AIDS, Cancers, Arthritis, etc
• At any time patients or families have a need and are willing to integrate palliative care with therapies to manage the disease process
• In any setting where patients receive care - -
  • Home, palliative units, hospice units, LTC, SNF, OP Palliative Care Clinic, etc.
• With the patient’s primary health team - -
  • Family Physician, Internist, Geriatrician, Cardiologist, Pulmonologist, Intensivist, Nurses, NP’s, etc.
Integration Of Palliative Care

Therapy to modify disease

Palliative Care - Therapy to relieve suffering
And/or improve quality of life

Focus Of Care

Diagnosis Presents

Time →

Chronic Illness
Advanced Life-threat
EOL Care
Death
Bereavement
Hospice and End of Life Care

• Model for quality, compassionate care for people facing a life-limiting illness
• Involves a multi-disciplinary team that provides – medical care, pain and sx management, emotional and spiritual support to person and family members
• Focus –
  • “It’s about how you live.”
  • Develop a plan to die pain-free, with dignity, without suffering, and engage others in family to live well afterwards (your legacy).
Ethical Issues in Palliative Care

- Respond as a multi-disciplinary team
- “Usual” issues include:
  - Goals of Care
  - A.D. issues
  - Patient and family goal conflicts
  - Physician and patient goal conflicts
  - Transitioning focus of care
  - Pain and symptom management
  - IP Hospice Treatments
Ethical Issues in Palliative Care

- Physicians, nurses, patients, and families are all engaged in decision-making.
- Nurse and Physician Issues* --- dissatisfaction:
  - Insufficient pt involvement in tx decisions
  - Concerns re: overly burdensome txs
  - Disagreements over withholding or withdrawing treatments
- Nurses/Volunteers Issues**:
  - Communication, confidentiality
  - Conflict of interest, compromised care


Emerging Ethical Issues

• Inadequate or Insufficient Communication:
  • Staff and patient/family
  • Physician and patient/family
  • Physician and nurse or other staff
  • Physician to physician
  • Language barriers
  • Inadequate discussion re: treatment goals and expectations, degree of suffering, measure of success
Emerging Ethical Issues

- **Resource Allocation:**
  - Staff allocation
  - Lack of bedside time
  - Lack of time for quality communication
  - Level of care, WH/WD treatments

- **Competencies in Palliative Care Skills:**
  - Communication skills
  - Understanding of euthanasia, terminal sedation
  - Cultural and religious issues related to dying persons
  - Power issues
  - Pain and symptom management
  - Balance of patient choices and family needs and choices
Ethical Principles – Decision-Making Guides

• Autonomy
  • ability of the person to choose and act for one’s self free of controlling influences.
    • coercion from physician, nurse, consultant
    • coercion from family members
    • coercion/pressure from religious group, dogmas
  • ability to make decisions based upon our personal values and pertinent information, which will enhance our personal growth and goals.
Ethical Principles – Decision-Making Guides

- Respect for autonomy requires:
  - honoring each person’s values and viewpoints
  - listening to the other person as they share their values and choices and questions
  - that we assess each patient, to assure that they are capable of autonomous decisions.
Ethical Principles – Decision-Making Guides

• **Beneficence:** acting in the best interests of the patient.

• **Best case scenario** --
  • we interact with the patient in a way which maximizes the patient’s values and their understanding of a good quality of life.

• **Worst case scenario** --
  • we are paternalistic in our interactions with the patient; don’t honor their values.
Ethical Principles – Decision-Making Guides

- **Nonmaleficence:**
  - Do no harm
  - Make no knowing act or decision, or lack of sharing information which will cause direct harm to the patient.
  - More subtle -- not sharing treatment options which you disagree with, but which are beneficial.
Ethical Principles – Decision-Making Guides

• Truth-telling: share all truly beneficial information which will assist the person in making a good decision.
• Confidentiality: duty to respect the privacy of shared information.
• overridden when
  • we need to enlist others to confront a patient who has made a decision which is inconsistent with prior decisions
  • duty to protect others (homicidal/suicidal)
Ethical Principles – Decision-Making Guides

- Justice: consider our individual decisions in context of the needs of the greater society.
  - we are an integral part and an interrelated part of society.
  - what I do, how I do things does have an influence beyond my own personal sphere.
  - responsible for health status of the community...
Shared Decision Making Transparency Model

- Transparency Model of Informed Consent
  - create a participatory and collaborative practice environment.
  - conversational approach, inform of all options (including no treatment).
  - openly (no bias) share pros/cons of relevant treatment options in “English”!
  - offer to clarify info and answer questions.
  - patient then tells us her preference(s).
Capacity- Ethical Definition

- Elements of Capacity to Make Decisions
  1. Patient appreciates that there are choices
  2. Patient is able to make choices
  3. Patient understands the relevant medical information (dx, prognosis, risk/benefit, alternatives).
  4. Patient appreciates the significance of the medical information in light of her own situation and how that influences the current treatment options.
5. Patient appreciates the consequences of the decision.

6. Patient’s choice is stable over time and is consistent with the patient’s own values and goals.

- **Self-determination:**
  - the decision to accept or decline treatment rests with the patient.
  - patient’s right to refuse treatment is stronger than to demand treatment.
Capacity – Ethical Definition

• If the patient lacks the capacity to make decisions, then we:
  • follow advance directives
  • find out patient’s choices and follow them
  • act in patient’s best interests

• Corollary Principle:
  • responsibility and accountability of both the physician and patient to each other and larger society.
ACP Definition

• Advance Care Planning
  • a process which assists individuals, family, friends and advocate(s) to:
  • understand, reflect upon, discuss and plan current and future care choices based upon the values of the patient
  • An organized approach to initiating conversations, reflection and understanding regarding an individual’s:
  • Current state of health, goals, values/preferences for healthcare treatments, at key intervals in the illness experience as well as at the end of life.
Components of Successful ACP

• Gain understanding and clarification of your medical conditions from your physician.
• Clarification of your treatment choices at significant junctures in your illness with your family and physician.
• Discussion of common scenarios of the natural history of your chronic illness - its progression over time
• Discussion of common scenarios of how people die from your chronic illness.
• These discussions, done on an on-going basis with family, friends, and your doctor will maintain transparency and prevent future conflicts …
Components of Successful ACP

• Identify the person (s) in your life with the following skills:
  • Perform well under stressful conditions
  • Articulate
  • Comfortable in hospital settings – E.D., ICU’s, etc
  • Not intimidated by physicians
  • Their emotions will not inappropriately interfere with critical decision-making moments in your care.
Maryland ACP Highlights

- Health Care Planning thru the Adv Directive.
- Name a HC Agent.
- State your preferences for treatments, including txs that might sustain your life.
- Meant to reflect your preferences.
- You decide when you want your HC Agent to speak for you – now or when you have lost capacity for decision-making.
Maryland ACP Highlights

• Living Will and LST procedures
• Standardized Order form: Emergency Medical Services Palliative Care/Do Not Resuscitate Order Form.
  • Must also have this order signed by doctor
  • EMS will then honor this order
• Preference in Case of Terminal Condition
Maryland ACP Highlights

- Maryland Handbook for HC Surrogates or DPOA’s:
  - Make decisions based on patient’s values and prior choices
  - Make decisions consistent with statements in A.D.
  - CPR, Art Nut/Hyd, Respirators --- all in context of risks/benefits.
  - Court Appointed Guardians
Living Will Issues

• Follows “If … then …” model
  • “If I lose capacity and I’m in [specified conditions],
  • Then no CPR, ventilator, feeding tube, etc.”
  • Or: aggressive interventions requested
• Decision to forgo carried out if two physicians certify:
  • Terminal condition
  • End-stage condition
  • Persistent vegetative state
Ethical Topics in Palliative Care

• Ethical Guides for Treatment Choices
  • All treatment decisions are made in context of person’s values, dx, prognosis, risks/benefits of any treatment option. (DNR, dialysis, use of mech. Ventilation, antibiotics, etc.)
  • Withholding and withdrawing a treatment are based on the same ethical principle of beneficence and consideration of risk/benefits.
  • “Double Effect”: the intent of the treatment is to relieve “x” symptom. The dose of medicine did not “kill” the patient, the disease killed the patient.
Ethical Topics in Palliative Care

- **Medical Futility**
  - Connotes inappropriate rationing
  - Connotes “worthy” v.s. “unworthy”
  - Connotes decision based on financials only.

- **Nonbeneficial Care**
  - Based upon understanding context of this person’s illness experience and values
  - Based on knowledge of dx, prognosis, risks/benefits of treatments
  - Uses ethical principle of justice as part of the decision
Preventive Ethics

- Focus your efforts on preventing the occurrence of conflicts
- Identify issues early from perspective of:
  - Patient and/or family, friends
  - Nurses and other affiliated professionals
  - Physicians
- Natural history of chronic diseases
- Cultural and spiritual domains of care
- Communication skills – shared decisionmaking
4 Box Method – Facilitating Ethical and Legal Practice

- Clinical Indications
- Patient Preferences
- Quality of Life
- Contextual Features
Clinical Indications

- Indications for and against a treatment
  - Benefits and burdens
- Consistent with goals of care
- Common ethical dilemmas
  - Nonbeneficial care issues
  - DNAR, DNH
- Transition of care to palliative approaches
- Care of an actively dying patient
Patient Preferences

- Ongoing, dynamic process of assessment that decreases chances of conflict
- Cultural, ethnic and age related differences
- Common ethical dilemmas
  - Religious and cultural diversity conflicts
  - Truthful communication, disclosure
  - Refusal of treatments
  - ACP
Quality of Life

- Understanding patient’s prior QOL
- Sharing expected QOL with or without a certain treatment
- Common ethical dilemmas
  - Art nut/hyd
  - Withhold/withdrawal of nonbeneficial care, including mech vent, dialysis, etc
  - Assisted suicide
  - Principle of double effect
Contextual Features

• Social, legal, economic and institutional policies

• Contextual features
  • Family or provider issues that might influence decisions?
  • Financial factors? Legal issues?
  • Conflict of interest on part of provider or institution?

• Common Ethical Dilemmas
  • Research, justice and allocation of scarce resources
  • Economic issues, confidentiality and legal issues
Standards of Professional Nursing Practice

- Scope and practice and standards of care
  - Code for Nurses (2001)
  - The Nurse Practice Act (Matzo and Sherman, 2006)
- HPNA and ANA
  - Scope and Standards of Hospice and Palliative Nursing Practice (2002)
  - Professional Competencies for Generalist Hospice and Palliative Nurses (2001)
Standards of Professional Nursing Practice

- ANA
  - Position Statements on Assisted Suicide and Active Euthanasia (1994)
Hospital Ethics Resources

• Organizational Ethics
  • Develop structures, policies and mechanisms to enable excellent pain/sx management, ACP, resource allocation, nonbeneficial care.

• Ethics Case Consultations
  • Improve the process and outcome of care for the patient and family, professionals.

• Bioethics Committee
  • Involved in policy development
  • Case Review
  • CQI - hospital process improvement activities
Conclusions

• Engage in process of ethical discernment, discourse and decision-making.
• Discussed how ethical principles are a framework for understanding complex cases.
• Discussed importance of understanding patient’s perspective, culture, personal values.
• Importance of advocating for patient/family rights.
• Importance of interdisciplinary aspect of palliative care nursing
Resources

• Holy Cross Palliative Care Website
  • https://hch.palliativecare.webexone.com

• General Website
  • www.getpalliativecare.org
  • www.supportivecarecoalition.org
  • www.capc.org
Questions/Comments