Ethical Issues in Palliative Care Nursing

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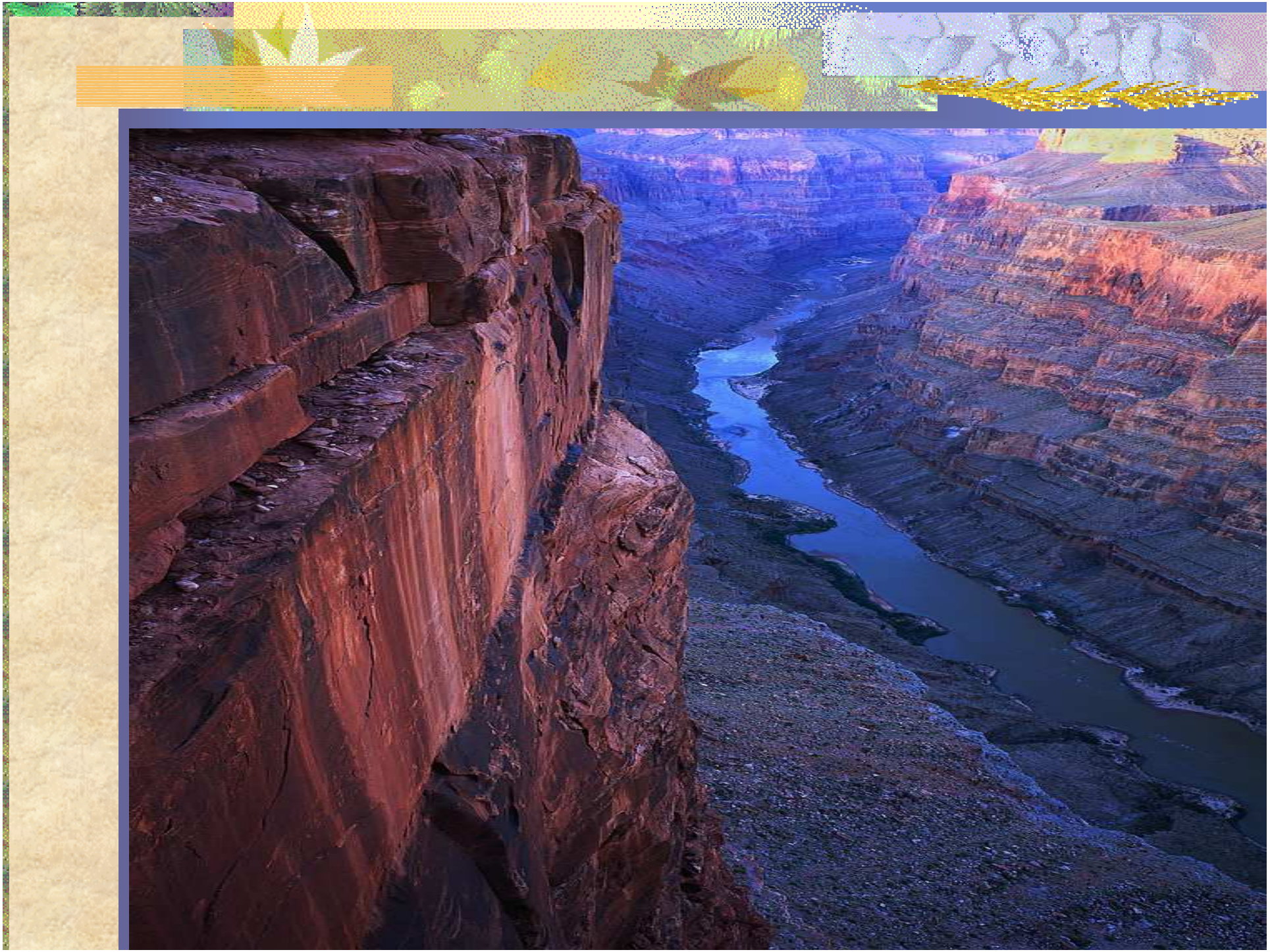
Disclaimer

- 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**

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

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

*Solomon, et. al., Decisions near the end of life: professional views on life-sustaining treatments. Am J Public Health 1993;83(1):14-23.

** Rothstein JM. Ethical challenges to the palliative care volunteer. J Palliat Care 1994;10(3):79-82

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.

Capacity – Ethical Definition

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

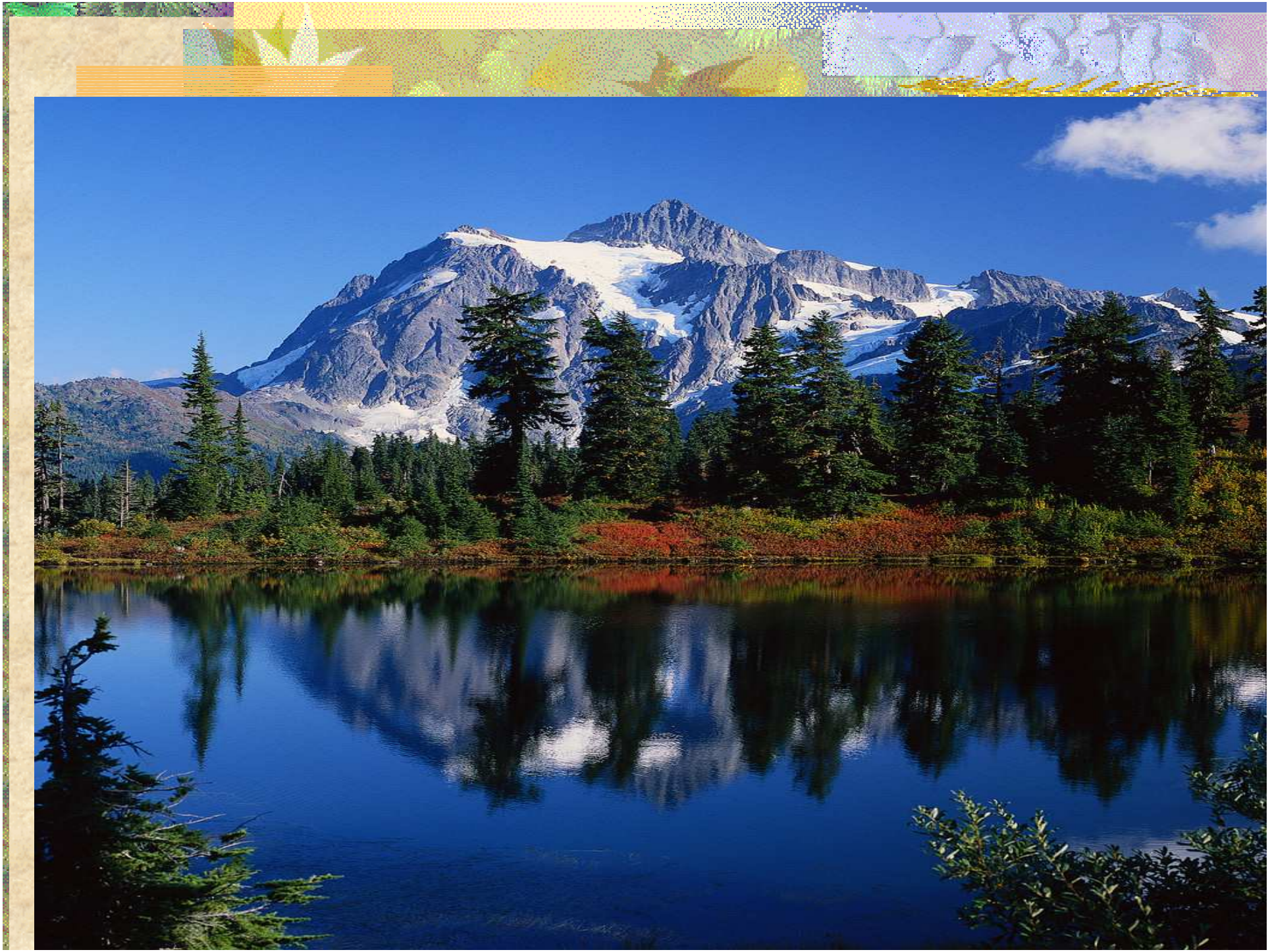
- Living Will and LST procedures
- Standardized Order form: Emergency Medical Services Palliative Care/Do Not Resuscitate Order Form.
  - Must also have this order signed by doctor
  - EMS will then honor this order
- Preference in Case of Terminal Condition

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 Statement on Pain Management and Control of Distressing Symptoms in Dying Patients (2003)
  - 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