Ethical Challenges in Palliative and End of Life Care

Dr. Huda Abu-Saad Huijer
Director, Hariri School of Nursing
Futile Care

- Development of palliative care has raised awareness of ethical problems in practice.
- Multi-professional nature of palliative care, difficulties of caring for the terminally ill, & multitude of medical and nursing problems involved increased sensitivity to ethical and moral problems.
Futile Care

Futile care refers to medical care that

- Prolongs suffering
- Doesn’t improve quality of life, or
- Fails to achieve a good outcome for patients

(Romesberg, 2003)
Medical Futility Debate

- Conflict between physician and patient/family over the right to decide whether a specific life-saving treatment is futile and should not be tried.
- Debate is between family’s need for futile treatment and physician’s professional obligation aiming not to harm the patient.
Definitions of Futile Care

- Medical interventions at end of life include withdrawing or withholding interventions such as mechanical ventilation, CPR, intubation, nutrition and hydration.
- Decisions concerning withholding treatment should be consistent with patient’s wishes and if treatment is able to achieve a goal established by physician, patient or family caregiver.
Ethical Principles

Providing good care requires knowledge of ethical principles:

- Autonomy
- Beneficence
- Nonmaleficence
- Justice
- Fidelity

The patient should be central in all decision-making and his or her autonomy respected.
Nursing Code of Ethics

- Safe, competent, and ethical care;
- Health and well-being;
- Choice;
- Dignity;
- Confidentiality;
- Justice;
- Accountability; and
- Quality practice environments.
Autonomy

- To claim that patients have autonomy is to argue that they have the capacity and right to decide for themselves the values and rules that will govern their existence.

- This will limit the physician’s power of decision making and judgment regarding treatment in end of life care without knowledge, understanding or consent of the patient.

  (Mackie, 2001)
Views on Autonomy

Nurses and physicians view patient autonomy differently:

- Nurses focus on patient autonomy; physicians focus on the principle of beneficence.
- Main goal for nurses: continuous care and helping patients live as normally and independently as possible.
- Main goal for physicians: systematic problem solving and improving organ function.
**END-OF-LIFE CARE**

**PRINCIPLE**

**AUTONOMY**—The patient’s right to self-determination

**APPLICATION TO END-OF-LIFE CARE**

- Physicians should encourage dialogue about end-of-life care and use of advance directives so that autonomy can be preserved even if patient’s decision-making capacity is lost.

**BENEFICENCE**—Doing what is good or beneficial for the patient

**APPLICATION TO END-OF-LIFE CARE**

- Physicians should do what they believe is in the patient’s best interest, but this action must not conflict with the patient’s right to self-determination.

**NONMALEFICENCE**—Avoidance of infliction of intentional harm

**APPLICATION TO END-OF-LIFE CARE**

- Many physicians view participation in physician-assisted suicide as a violation of this principle.

**JUSTICE**—Fairness in the delivery of healthcare

**APPLICATION TO END-OF-LIFE CARE**

- Physicians should advocate for treatment of their dying patients which is just and without discrimination.

**FIDELITY**—Truthfulness and faithfulness in delivering healthcare

**APPLICATION TO END-OF-LIFE CARE**

- Physicians should be truthful to their dying patients regarding the diagnosis and prognosis and advocate for their dying patients’ wishes even when those patients’ decision-making capacity has been lost.
Moral Deliberations; Research Study

- Qualitative study using semi-structured interviews with caregivers; medical oncology wards, hospice, nursing home, & general practice.

- Purpose: to examine how health care professionals deal with moral problems in palliative care & to study how communication takes place.

- Results: caregivers recognized the importance of respecting the autonomy of patients and their relatives. Access to detailed & clear information is a pre-condition to make an autonomous decision.

(Hermsen & ten Have, 2005)
Moral & Ethical Deliberations in PC

Communication with patients and relatives was found to be paramount.

• Advance knowledge about illness
• Assessment of expectations & readiness
• Extent of patients’ acceptance of their illness
• Right to information
• Breaking bad news
• Education of caregivers in communication skills

(Hermsen & ten Have, 2005)
The Change in Norms

- Increasing availability of very aggressive, burdensome, and expensive treatment that delays death and offers no cure.
- The shift of decision making from a paternalistic decision to a consumer-driven, patient-autonomy model. There is a need for better understanding the patient’s needs and decisions in end of life.
- Passage of Advance Directive legislation; establishment of a legal mechanism that assures respect for patients’ decisions.

(Gruenigen & Daly, 2005)
Ethical Dilemmas in Pediatrics

- Declaring diagnosis to child’s parents
- Withholding treatment and withdrawing ventilatory support
- Deciding child’s code status
- Discharging patient or continuing hospital care

Open Communication between health care team and parents was found essential and effective.

Ethical Dilemmas in Adult Care in Sweden

Powerlessness
   Being subjected to demands
   Feeling inadequate
   Being dependent

Frustration
   Lack of confidence
   Disappointment

Concern
   Being worried
   Lack of consensus

Moral conflicts when dealing with Honesty

- Forced to act against own desire to be honest
- Problems within the team
- Nurses knew more about patients than patients themselves
- Family members asked nurses not to tell a patient how ill he was

Ethical Dilemmas in Terminal Care for patients with cancer in Taiwan

- Truth telling; families only informed
- Place of care; home vs hospital/hospice
- Artificial nutrition and hydration; viewed by MDs as medical failure if not provided
- Use of antimicrobial agents

Ethical Dilemmas in Geriatric Care

- Sources of ethical issues; physicians
- Lack of financial and personnel resources
- Patients’ families; gap between patients & families needs
- Societal and organizational attitudes
- Routine-centered care vs patient-centered care
- Relationship with peer nurses

Developing Countries

Challenging ETHICAL DILEMMAS

Extended families

Spiritual support

Poverty

Lack of hospice care

Inadequate infrastructure


Common Dilemmas

Wish of patient to die at home
Religion/Spirituality

Developed

Developing


Communication in End-of-Life Care

- Communication with health care providers is identified as being the most important and least accomplished factor in end of life care.

- When communication is inadequate, physicians are left to decide whether to use aggressive treatment or not at end of life; this creates conflict with patient/family.
Communication in End-of-Life Care

- Nurses must be equipped with ethical knowledge and communication skills that are needed to cope with futile care, personally, professionally and morally in order to be competent in ethical decision making.
- Physicians should be trained in adequate communication skills to discuss palliative care and end-of-life care with patients and families.
Communication in End-of-Life Care

- Of importance is having an honest, listening, sensitive and hopeful approach in discussing the prognosis with the patient.

- If effective communication occurs futility will not become an issue.
Education in End-of-Life Care

- Educational programs for physicians & nurses on palliative care; prevent futile care.
- Education of health care providers on ethics of palliative care is essential; enhances end of life decisions.
- Palliative care to be included in medical & nursing schools curricula.
Public Education

- Public education and awareness on ethics of care and importance of communication is crucial.
- Public education on palliative care of the terminally ill, and knowledge of available alternatives to care is paramount.
Advanced Directives

• Advanced planning is helpful in making the patients’ wishes known when they are incompetent to take decisions regarding end of life care.

• Allows discussion of end of life issues between patient, physician and caregivers.

• Ensures autonomy at end of life when the patient becomes incompetent and unable to make decisions.
Role of the Nurse

- Nurses play an important role in the care of dying people, yet they feel disempowered by the medical paternalism in the decision making process.
- Nurses are in a unique position to discuss the patients’ needs and preferences for treatment and quality of life with members of the multi-professional health care team.
Conclusion

- Health care professionals are confronted daily with ethical issues.
- No health care provider can say the right thing or give the right medication to end the sorrow that patients & families go through.
- They can however communicate with them truthfully and regularly and keep them abreast on treatment options and futile care.
Conclusion

• Learning how to communicate these issues to patients and families & how to facilitate end of life decisions is a new and ongoing process for physicians and nurses.

• Education in palliative care and medical futility is as a result a must.