MODULE 4: ETHICAL/LEGAL ISSUES IN PEDIATRIC PALLIATIVE CARE

Ethics in Pediatric Palliative Care

- What ought to be
- Determining the best course of action
- Ethical issues are inevitable
- Societal changes

Nurse’s Role in Addressing Ethical Issues

- Promoting family-centered care
- Respecting preferences
- Role models of clinical proficiency, integrity, and compassion
- Balancing competing objectives
Standards of Professional Nursing Practice

- ANA Code of Ethics
- Nurse Practice Act
- Standards for professional organizations

Issues of Decision-Making and Communication

- Capacity
- Consent
  - Children are “legally” capable of giving consent at age 18
- Confidentiality
- Assent
- Disclosure

Assent: Duties of Healthcare Providers

- Assist the child to develop an awareness of the nature of the illness.
- Disclose the nature of the treatment, what the child is likely to experience.
- Assess the child’s understanding of the situation and forces influencing their response.
- Solicit a willingness to undertake the proposed treatment.

Jones et al., 2015
Disclosure

- Previous belief in not discussing diagnosis
- Explore reasons for not disclosing
- The CHILD’S right not to know

Hinds et al., 2015

Ethical Dilemmas

- Prolongation of life
  - Curative intent
  - Acute therapeutic care
  - Life sustaining treatments (LST)

Jonsen et al., 2015; Prince-Paul & Daly, 2015

Ethical Dilemmas (cont)

- Redirection of care (toward comfort)
  - NOT withholding or withdrawing
- Balancing benefits and burdens
  - Expected benefit does not outweigh burdens, risks and disadvantages.
- Redirection of care is not withdrawal of care
Ethical Dilemmas (cont)

- Redirection of care

Ethical Dilemmas (cont)

- Do Not Resuscitate (DNR) - considered obsolete?
- Do Not Attempt Resuscitation (DNAR)
- Allow Natural Death (AND)
- Medical Futility

DNI/DNR ≠ Do Not Treat

Ethical Dilemmas (cont)

- Futility
  - Defined in terms of the goals of care.
    - "the unacceptably low chance of achieving a therapeutic benefit for the patient"
  - Futility is not a conclusion but a signal that it is time for a difficult discussion.
Ethical Dilemmas (cont)

- Assisted death
- Euthanasia
- Hastening death
  - Principle of double effect

Principle of Double Effect

- An ethically permissible effect can be allowed, even if the ethically undesirable one will inevitably follow.

- Clash of values/principles
  - Nonmalficence: do not hasten death
  - Beneficence: provide comfort, alleviate suffering

Issues of Justice in Palliative Care

- Provision of quality palliative care
- Costs of palliative care
Research in Pediatric Care

- Is research appropriate?
  - Informed consent
- National Commission for Protection of Human Subjects

Facilitating Ethical and Legal Practice

- The Four Box Method

Medical Indications

- Indications for and against the intervention
  - Interdisciplinary team input
  - Medical specialists
- Reflect the goals of care
- Common ethical dilemmas
Child and Family Preferences

- Parents as moral and legal agents
  - Determine relevant weight of parenteral preferences and child’s best interest
- Principle of respect for persons
  - Autonomy, privacy, veracity
- Assess child/family understanding
- POLST

Advance Care Planning

- Promote ongoing conversations with patient, family and team.
- Cultural, ethnic, and age-related differences
- Interdisciplinary
  - Child Life Specialists, Social Work Workers, Chaplains
- My Wishes™/Voicing My Choice ™

Quality of Life (QOL)

- Evaluation of prior QOL
- Expected QOL with and without treatment
- Common ethical dilemmas addressing QOL

Jonsen et al., 2015
Contextual Features

- Social, legal, economic and institutional circumstances
- Typically involve issues of justice
- Common ethical dilemmas

Jonsen et al., 2015

Managing Disagreement

- Intra-Family
  - Parent-child conflict, Parent-Parent
- Family-physician
- Physician-nurse
- Minors
- Legal issues, etc.

Parental Insistence on Treatment
Organizational Ethics & Legal Practices

- Organizational ethics
- Ethics committees and consultation
  - Education
  - Policy development
  - Case consultation

Preventative Ethics

- Early identification of issues
- Know the natural history illnesses
- Solicit patient/family wishes
- Cultural and spiritual assessment
- Communication skills

Moral Distress

- Feeling distressed:
  - when a practitioner feels certain of the ethical course of action but is constrained from taking action.
  - due to situations that involve ethical dimensions, and when the individual feels s/he is not able to preserve all interests and values at stake.

Hamric & Blackhall, 2007
Kalve mark et al., 2004
Common Causes of Moral Distress

- Clinical situations
  - Unnecessary treatment, inadequate informed consent, incompetent providers
- Factors internal to caregiver
  - Perceived powerlessness, lack of knowledge about alternatives, fear of reprisals
- External factors in the situation
  - Work environment/culture, legal/regulatory issues, co-worker issues

Whitehead et al., 2015

Significance of Moral Distress

- For Nurses
  - Physical and Emotional symptoms
  - Loss of capacity for caring
- For Patients
  - Inconsistent and less attentive care
- For Organizations
  - Employee dissatisfaction, increase turnover

Kuoppala et al., 2008; Sauerland, et al., 2015

AACN’S 4 A’s Model

ASK

ACT

AFFIRM

ASSESS

Sherman, 2012
ASK

- Am I feeling distressed or showing signs of suffering?
- Am I observing symptoms of distress within my team?
- Have coworkers, friends, or family members noticed these signs and behaviors in me?

GOAL: You are aware of moral distress

AFFIRM

- Your distress
- Commitment to take care of yourself
- Validate your feelings and perceptions
- Professional obligation to act

GOAL: You make a commitment to address moral distress (don’t ignore it)

ASSESS

- What is the source of the distress?
- Determine the severity.
- Contemplate your readiness to act.
- The 4 R’s
  - Relevance, risks, rewards, roadblocks

GOAL: You establish an action plan
ACT

- Anticipate setbacks
- Maintain desired change
- Continue to evaluate

GOAL: You preserve your integrity and authenticity

Moral Distress Thermometer

Wocial et al., 2010; Wocial & Weaver, 2013

Dealing with Moral Distress

- Self awareness
- Self care
- Focus on changes in the work environment that preserve moral integrity.
- Three levels of intervention:
  - Patient care
  - Unit/team culture
  - Organization
Conclusion

- Engage in a process of ethical discernment
- Apply principles of ethics
- Use ethical process to seek balance in decision-making
- Advocate for children and families