



Pediatric Palliative Care

End-of-Life Nursing Education Consortium

Module 4: Ethical/Legal Issues in Pediatric Palliative Care



Responding to Ethical Issues

- Advances in medical technology
- Children as a vulnerable group
 - Lack full maturity and legal authority to make decisions
- Social changes
 - Increased fear of litigation
 - Medical futility concept
 - Lack of caregivers
 - Reimbursement for pediatric palliative care
 - Lack of knowledge of pediatric palliative care options
 - Uncertainty of prognosis in pediatric disease
- Ethical issues are inevitable



Responding to Ethical Issues

- **"Fight the good fight"**
- **Influence of values, culture, religion**
- **Questions of meaning**
- **Conflicts prevented by communication and shared decision-making**



Nurses Role in Addressing Ethical Issues

- **Promoting family-centered care**
- **Respecting preferences**
- **Being knowledgeable about the ethical and legal dimensions of professional practice**
- **Role models of clinical proficiency, integrity and compassion**
- **Balancing competing objectives**
- **Learning principles of pediatric palliative care**
- **Working as a member of an interdisciplinary team**



Standards of Professional Nursing Practice

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



Issues of Decision-Making and Communication

- **Capacity**

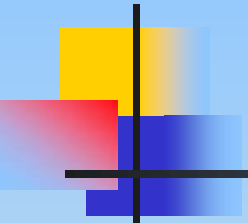
- ➔ Ability to comprehend information, contemplate options, evaluate risks and consequences, communicate decisions

- **Consent**

- ➔ Legal term meaning willing acceptance of an intervention after full description of the intervention



A Mother's Touch



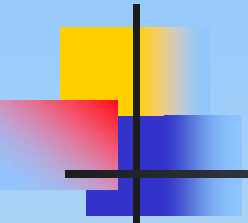
Issues of Decision-Making and Communication (cont.)

■ Assent

- Incorporates opinions of the child in decision-making
- Requires team to disclose the plan of care prior to decision-making
- Treatment still depends on parent or guardian

■ Confidentiality

Hockenberry et al., 2003



Issues of Decision-Making and Communication (cont.)

- **Disclosure**

- Previous belief in not discussing diagnosis with child
 - Children have a right to be offered developmentally appropriate information about their treatment options
- Explore parent reasons for not disclosing
- The CHILD'S right not to know
 - Right to decline information or to not know

Bluebond-Langer, 1978



Ethical Issues in Palliative Care

- **Prolongation of life**
 - **Curative intent**
 - **Acute therapeutic care**
 - **Treating pneumonia in a dying child**
 - **Life sustaining treatments**
 - **Relief of symptoms**
 - **Prolonging suffering**

Jonsen et al., 2002;
Stanley & Zoloth-Dorfman, 2006



Ethical Issues in Palliative Care (cont'd)

- **Withholding/withdrawing of medical interventions**
 - Burden outweighs benefit
 - Prolonging suffering
 - Child/family choice
 - Poor quality of life
- **Situations for withholding/withdrawing**
 - Death by Brain criteria
 - Irreversible fatal condition
 - No effective treatment available
 - Neonates
 - Lethal abnormalities



Ethical Issues in Palliative Care

(cont.)

- **Do Not Attempt Resuscitation**
 - Requires written order by MD
 - Family can change mind at any time
- **Medical Futility**
 - Conflicts regarding belief of the beneficial nature of a treatment
 - Asking the question – “For whom are we doing this?” can avoid conflict situations
 - Institutional policies regarding futility



Ethical Issues in Palliative Care

(cont.)

- **Assisted suicide**

- ➔ **Adult issue**

- **Euthanasia**

- ➔ **More relevant to children than assisted suicide**

- ➔ **Illegal in US** ANA, 1994; Field & Cassel, 1997; Foley, 1995; Sulmasy, 1998



Principle of Double Effect

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

Jonsen et al., 2002



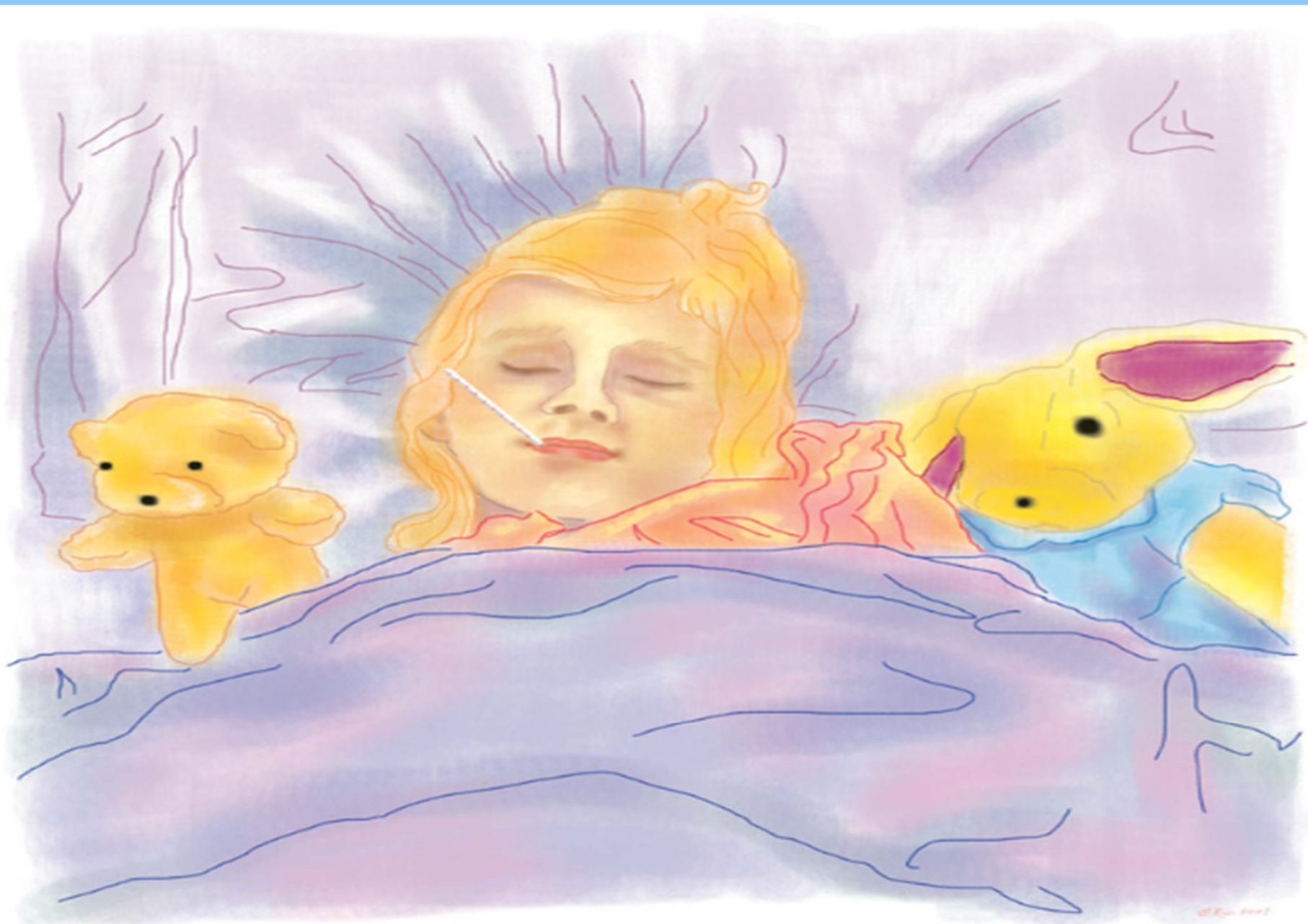
Issues of Justice in Palliative Care

- **Provision of quality palliative care**
 - Inequity in care delivery
 - >56% of child deaths in hospital (US)
 - Obstacles to access
 - Lack of knowledge regarding pediatric palliative care
 - Responsibility to provide bereavement
- **Costs of palliative care**
 - Cost effective option
 - Quality palliative care is a right for all people but there are reimbursement issues



Research In Pediatric Care

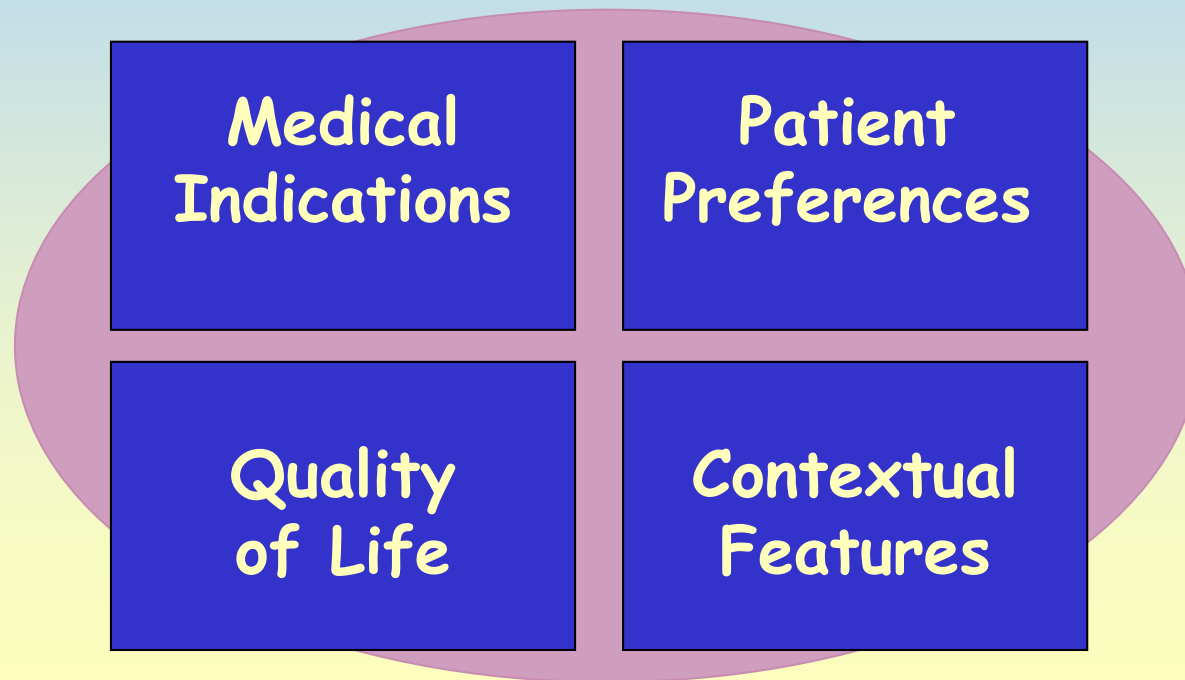
- **Is research appropriate?**
- **National Commission for Protection of Subjects**
 - Sound reasons for why research must be done with children
 - Studies should be done in adults before children, if feasible
 - Level of risk to the child must be carefully assessed
 - Research involving more than minimal risk and offering no personal benefit requires special review
 - Informed consent of parents/guardians required



Best Friends

Facilitating Ethical and Legal Practice

The 4 Box Method





Medical Indications

- **Indications for and against the intervention**
- **Reflect the goals of care**
- **Common ethical dilemmas**
 - **Medical futility**
 - **Withholding/withdrawing interventions**
 - **DNAR**
 - **Care of dying patient**
 - **Determination of death**



Patient Preferences

- Principle of respect for persons
 - Autonomy – person with decisional capacity has the moral and legal right to determine what will be done with their own person
 - Privacy – right to privacy and the nurse acts to safeguard that right
 - Veracity – the duty to be truthful
- Assess child/family understanding
 - Understanding of medical condition and prognosis
 - Prior preferences of child
 - What are child and family hoping for and what would be helpful



Patient Preferences - Advance Care Planning

- **Process of decision-making and communicating about goals of future care**
- **Nurses role in assessing wishes for care**
 - **Ability to have ongoing conversations with children and families regarding preferences and wishes for care**
 - **Never too early to begin discussions**



Patient Preferences - Advance Care Planning (cont.)

- **Decreases chance of conflict**
- **An ongoing, dynamic process**
- **Cultural, ethnic and age related differences**



Patient Preferences - Living Wills

- A less formal way to communicate advance directives
- Rarely used in pediatrics



Praying for a Miracle



Patient Preferences – Advance Directives

- **Written method for child and family to plan and communicate choices**
- **Less common in pediatrics**
 - ➔ **Parents initiate directives**
- **State statutes differ**



Patient Preferences - Authority of Parents

- Children are deemed legally capable of consent at age 18
- Challenge of determining relevance and weight of parental and patient preferences
 - Preferences conflict with the recommendations of the providers
 - Determining how reasonable and relevant child's preferences are



Patient Preferences - Standard for Parental Preferences

- Parents as moral and legal agents
- Parents evaluation of treatment efficacy or futility
- Instances of parent and physician conflict
 - ➔ Ethics consultation

Jonsen et al., 2002



Quality of Life (QOL)

- Evaluation of prior QOL
 - Expected QOL with and without treatment
 - Common ethical dilemmas addressing QOL
 - Nutrition and hydration
 - Withhold/withdraw life support interventions
 - Euthanasia
 - Suicide
 - Principle of double effect
- Jonsen et al., 2002



Contextual Features

- **Social, legal, economic and institutional circumstances**
 - Family or provider issues affecting treatment decisions
 - Financial/economic factors
 - Cultural/religious factors
 - Problems with allocation of resources
 - How does the law affect treatment decisions?
 - Conflict of interest on part of providers or institution
- **Common ethical dilemmas**
 - Research/Justice and allocation of resources/
Economic issues/Confidentiality Jonsen et al., 2002



Managing Disagreement

- **Parent – Child conflict**
 - ➔ Some states with minor treatment statutes
 - ➔ Emancipated minor
 - ➔ Adolescent-parent conflict
- **Parent – Parent conflict**
 - ➔ Prior history of conflict will exacerbate when child at end of life
 - ➔ Assessment of conflict history
 - ➔ Mediation plays big role

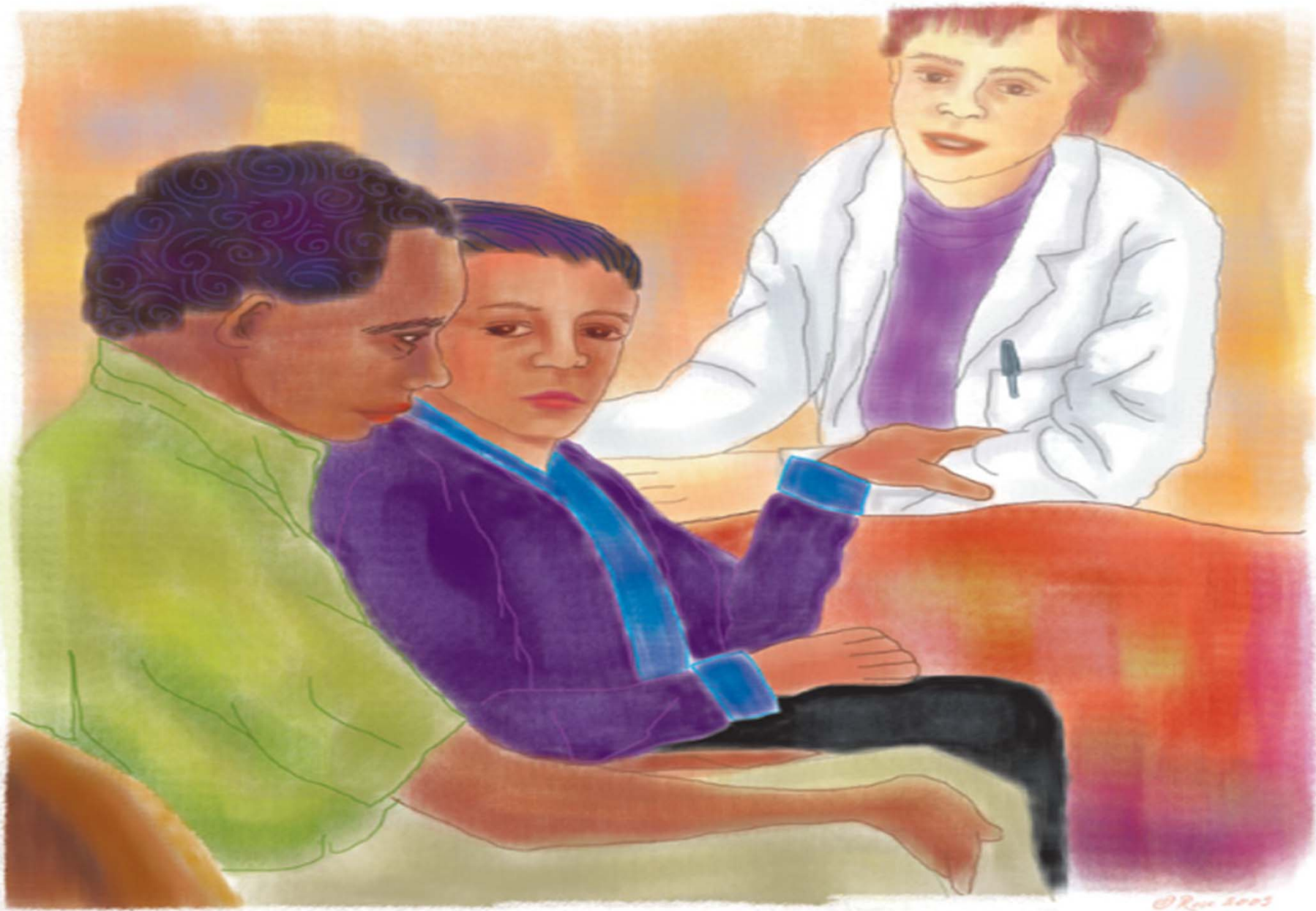
Field & Behrman, 2003



Managing Disagreement (cont.)

- **Parent – Physician conflict**
 - **Parental refusal of treatment**
 - Religious conviction never a defense for life saving measure
 - Criminal offense to not provide medical treatment to a child
 - When cure is unlikely or impossible, courts allow for parents to make decisions
 - **Parental insistence on treatment**
 - Medical futility
 - Ethics consultation

Field & Behrman, 2003



Answering the Unanswerable Questions



Organizational Ethics & Legal Practices

- **Organizational ethics**
 - **Mechanisms to respond to pain and symptom management, advance care planning, treatment cessation, and resource allocation**
- **Ethics committees and consultation**
 - **Education**
 - **Policy development**
 - **Case consultation**



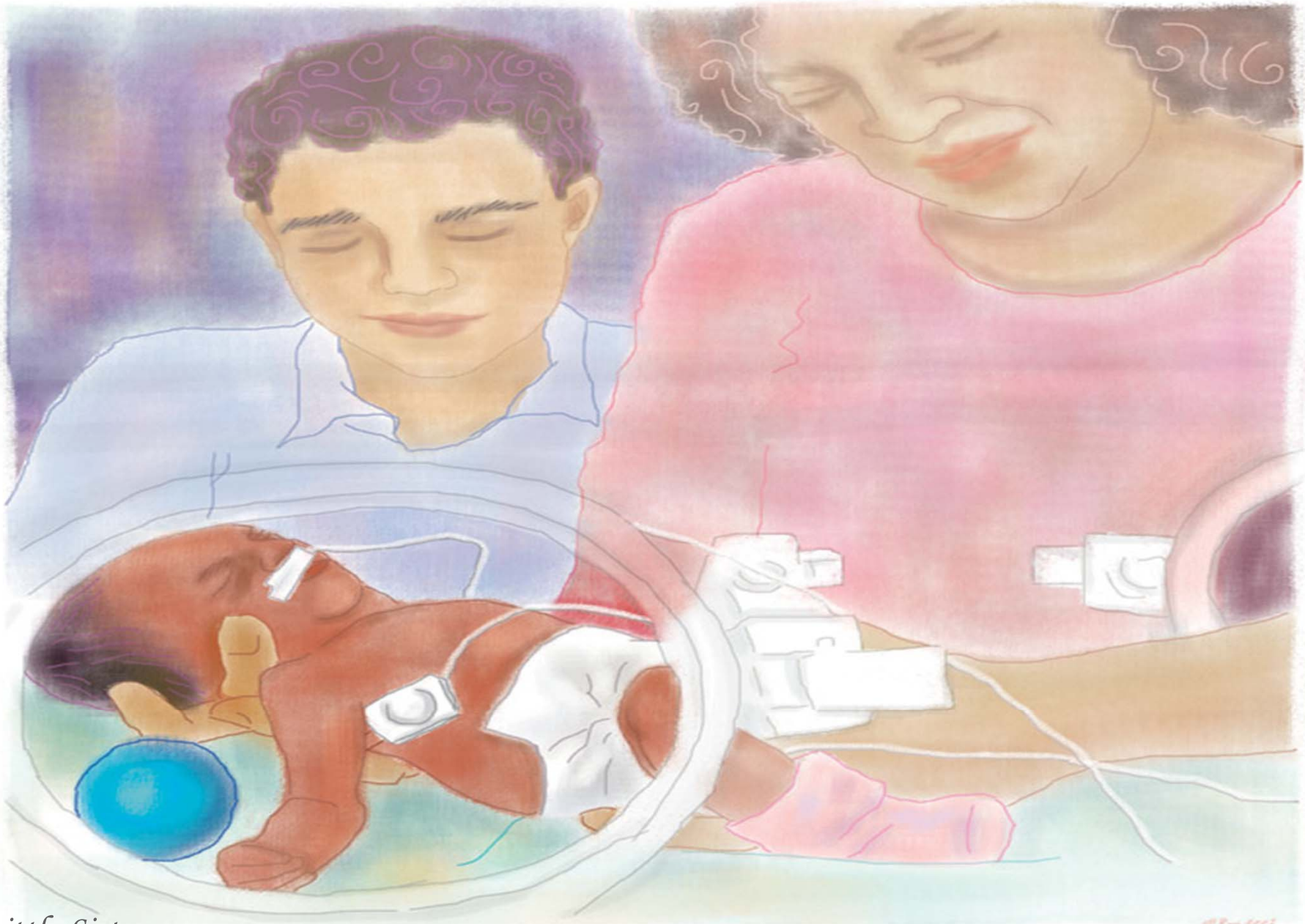
Conclusion

- **Nurses need to engage in a process of ethical discernment**
- **Application of principles of ethics can assist in finding best solutions**



Conclusion (cont.)

- **An ethical process is a way to seek balance in decision-making**
- **Nurses, working with other disciplines, advocate for children and families**



Little Sister