

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

(PP Notes should be used as a study aid and basis for class notes. PP Notes reflect the most important concepts of the current unit **but are not a substitution for required reading of the text.**) Students are responsible for all text references that listed in **RED** as these may be the basis for test questions.

#1. Rudd & Kocisko: Ch. 4: cultural, Spiritual, and Environmental Influences on the Child

#2.

#3. Learning Objectives

#4. What is cultural competence? What is cultural bias?

Culturally competent care is “the ongoing capacity of healthcare systems, organizations and professionals to provide for diverse patient populations high quality care that is safe, patient and family centered, evidence based, and equitable” (National Quality Forum, 2009).

Cultural bias may occur when the nurse places his or her own values before the values of a different culture.

Nurses must examine how their own belief system may influence the care that is provided to prevent bias. Although it is not necessary for the nurse to agree with a patient’s cultural and spiritual beliefs, the health-care team must respect the beliefs of others.

Culturally competent care must consider the child and family’s culture, spiritual beliefs, values, traditions, behaviors, and environment and how these factors affect care in order to provide optimal outcomes.

Respect for cultures is fundamental to cultural competence.

Each family and each individual is unique, and family members of the same culture may apply and interpret their culture in different ways.

Culture may change with time or be interpreted differently from one generation to the next. A person’s culture will affect both verbal and nonverbal communication styles.

Children learn about culture from parents or caregivers who serve as role models and teachers in demonstrating how culture is applied to everyday living and how illness is perceived (**Fig. 4-1**). They also may dictate the

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

child's cultural needs. The child's age and stage of development will influence his or her ability to recognize and articulate these needs.

#5. To create a culture of comparable access and equitable care for all patients, it is important to recognize disparities and inequalities. **Health disparities** include social and economic conditions that systematically create obstacles to health based on a group's:

- Race or ethnicity
- Religion
- Socioeconomic status
- Sex
- Age
- Mental health
- Cognitive, sensory, or physical disability
- Sexual orientation or gender identity
- Geographic location

An agency's policies steer a client's overall care, including visitation and diet. These components of care may not align with the nurse's own cultural and spiritual beliefs.

If these policies cause cultural or spiritual distress to the nurse, culturally competent patient care will be difficult to implement.

The agency's policy and procedures drive the type of information provided to the nursing staff. Each nurse has the professional responsibility to appraise the cultural differences and concerns of the patient. It should be the goal of every health-care professional to tailor care to meet the holistic health needs of the patient.

#6. Effective cross-cultural communication requires the health-care team to communicate with each patient and family in a manner that is well received within their culture.

Communication, a term that encompasses words, tone, body language, and rate of speech, is influenced by the relationship of the individuals in question, the culture of origin, and the individual interpretation of the receiver.

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

Communication involves a sender and a receiver. Even with the best intentions, there can be miscommunication.

A therapeutic relationship with the client and family is based on mutual respect and trust.

Multidisciplinary Relationships

- Health-care providers work as a team and share information as appropriate.
- Individuals have different perspectives and different experiences.
- Respect differences of opinion.

Language Barriers

Language barriers include any circumstances in which the sender of communication and/or his or her message is not accurately understood by the intended receiver of communication.

Working With Interpreters

- Avoid using “charades” to communicate; wait for the interpreter.
- Pictures can be used to communicate ideas when an immediate interpreter is not available.
- Family members may serve as an interpreter as long as they are able to accurately convey the care provider’s message. It is always best to use an interpreter.

#7. Characteristics and Behaviors Determined by Culture

- Individuals will act and respond as they have been taught to act and respond.
- Children may “pretend” by responding in the way that their caregivers would respond, or by responding in an acceptable way rather than accurately communicating their feelings.

Personal Space

The nurse’s interpretation of personal space may differ from that of individuals from other cultures. Learn about expected personal space and respect that space during interactions.

Eye Contact

Know the etiquette of eye contact among different cultures—some may prefer direct eye contact, whereas others may not. Provide eye contact if unsure whether it is appropriate.

Diet

- Most children do not have control over the food stored in the home.

Time

- Perceptions of time may differ among individuals of varying cultures.

Touch

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

- Touch with communication may be offensive to patients and caregivers.

Family Use of Alternative Medicine

- Herbs may have drug interactions.
- Treatments or remedies may be called “old wives’ tales.”
- A family leader may dictate how to treat symptoms.

#8. Question

#9. In the health-care setting, the cultural assessment is a mechanism through which the nurse gathers subjective data to identify beliefs and values of the patient’s culture.

The cultural aspect of a patient assessment usually comes last and is often inaccurately perceived as less important than other assessment data. A cultural assessment should evaluate the following areas that affect health care and may differ by culture:

- Religious beliefs
- Client and family perception of current health status
- Food preferences
- Typical daily schedule

Review the Clinical Judgment box on pg. 61 in your textbook.

#10. A transcultural assessment model can assist the nurse by ensuring that multiple aspects of culture are being considered.

Overall, the nurse should consider any aspect of the nurse-patient relationship that may impede or hinder patient care.

Giger and Davidhizar (2002) note that individuals are unique and provide a transcultural assessment model that consists of evaluating six aspects:

- Communication and how thoughts and feelings are expressed
- Personal space between the individuals who are communicating
- Biological variations, such as appropriate weight and development
- Time, both the perception of time in general (e.g., fast-paced, time-centered lifestyle versus more leisurely lifestyle) and when daily events should occur (e.g., mealtimes)
- The degree to which individuals feel they can influence or control their environment or experiences
- Social organizations that the patient and family are part of (e.g., family, religious affiliation, social groups)

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

#11. Spirituality

Spirituality describes a person's belief in a greater being that affects his or her daily and world events. This belief typically encompasses the person's concept of where and how humanity began and views of the afterlife. For many individuals, spirituality takes the form of a religious affiliation: a group or formal community of individuals with shared spiritual beliefs. Health-care providers must be aware of a client's religious beliefs and alter care as appropriate.

Environmental Considerations

A patient's home environment has a substantial impact on care outcomes. It influences how care is delivered, the types of food available, how medication is stored, whether the patient has privacy at home, and countless other aspects of well-being. When caring for a pediatric client, the nurse should be especially aware of how the home environment influences care.

FICA Spiritual History Tool

The FICA tool can be used by the nurse to identify the patient's spiritual and religious history (Box 4-1; Puchalski, 2006; Puchalski & Romer, 2000). FICA stands for Faith, Belief, Meaning; Importance and Influence; Community; Address/Action in Care—the four components of the tool—which provide the nurse with baseline patient data that can be used to individualize care.

Review Box 4-1 on pg. 63 in your textbook.

#12. Question

#13. End-of Life Care Rudd & Kocisko: Ch. 5

#14. Learning Objectives

#15. A terminal diagnosis results from either trauma or physiological causes. Categorizations include:

- Trauma, caused by outside forces
- Accidental, such as a car accident or drowning
- Nonaccidental, such as intentional self-injury or abuse
- Physiological, caused by forces within the body
- Disease such as cancer
- Congenital defect, such as Edward's syndrome

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

Routine nursing care in pediatrics differs from end-of-life care in pediatrics, based on the hospice needs of the patient's family rather than treatment of a diagnosis or disease. The goal is a peaceful death rather than the continuation of a healthy life.

Review Box 5-1 on pg. 66 for the "Causes of Pediatric Death".

#16. Communication with the patient and family is an essential nurse role in pediatric end-of-life care.

When communicating with the family, nurse assessments should be conducted to:

- **Determine how the family unit functions.**
- **Understand the level of information the family desires.**
- **Determine the cognitive level of family members to provide an appropriate education.**
- **Determine the family's overall understanding of the patient's diagnosis and potential outcomes.**
- **Establish who can legally receive information about the patient.**

Family-centered care is the basis for all interactions with the family of a patient receiving end-of-life care. Communication with the family should be compassionate, cognitively appropriate, and based on the health-care provider's assessment. Communication with the patient should be both compassionate and developmentally appropriate.

In addition to patient communication, communication within a multidisciplinary care team occurs during rounds or through charting. Nurses have an important communication role in end-of-life care; within the multidisciplinary care team, the nurse has the most contact with the patient and family and acts as an advocate and voice for their care. Nurse communication with each member of the care team on an individual basis ensures optimum care of the patient and family. The nurse must communicate to all staff that end-of-life care is occurring, so the entire unit understands the process and the patient's and family's needs.

#17. Pediatric palliative care (PPC) creates opportunities to support the bereaved. The specialized team is trained to care for children and families facing difficult circumstances.

Teams typically include physicians, nurses, chaplains, psychologists, child life specialists, and social workers. One of the many benefits of the PPC team is the interdisciplinary and holistic approach to grief and bereavement support

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

that begins well before death and continues throughout the grieving process (Schuelke et al, 2021).

Initiation of palliative or hospice care is generally done by the physician with input from the multidisciplinary care team.

Access to pain management is a fundamental human right, yet compared with adult patients, pain prevention and management in pediatrics are often inadequate. In pediatric end-of-life care, pain is defined as any uncomfortable feeling that prevents patient relaxation or rest. Pediatric pain can manifest very differently from adult pain, with symptoms very different from adult pain symptoms.

The multidisciplinary care team members involved in pain control include the physician, nurse, pharmacist, and child life specialist. Involvement of family in determination of pain is an essential aspect of pediatric pain control; parents/caregivers can be excellent judges of their child's comfort level. Involvement of the family in alternative pain treatments includes discussing and suggesting options such as the following:

- Massage therapy provides relaxation for the patient and potentially decreases pain.
- Relaxation therapy helps the child relax using techniques such as music, holding, and positioning. Some facilities offer complementary or alternative therapies such as healing touch or aromatherapy.
- Play therapy distracts the patient from the pain with calm, developmentally appropriate activities such as puzzles and coloring.

Providing culturally competent care requires the nurse to respect and incorporate the cultural and spiritual beliefs of the family and patient into daily care (**Fig. 5-5**).

Disparities in culturally diverse populations exist, especially in the management of pain and underuse of palliative care. Nurses should be aware of the many different cultural beliefs surrounding end-of-life decisions and feel comfortable asking pediatric patients and their families about their personal preferences regarding pain management and end-of-life care.

#18. Understanding overall child development and how it relates to a child's view of death is necessary to provide competent care. (See the discussions of development in [Chapters 7 to 10.](#))

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

Nursing interactions with children at end of life should be based on the child's developmental level and cultural needs. A child's view of life is based on developmental level and created from experiences and perception. If a child is dying from a congenital condition or disease, their developmental level may be lower than expected; delays must be considered in the developmental assessment. **A child's view of death is based on developmental stage and life experiences, so expect varied behavior and opinions (Table 5-1).**

Education for parents and caregivers needs to be appropriate to a dying child and sibling's developmental stage, addressing their understanding of death and including appropriate grief and loss interventions.

Review Table 5-1 on pg. 70 in your textbook and the Death and Dying Handout

#19. Most theories indicate that individuals progress through their grief on an individual timeline but through similar stages. **Kübler-Ross** (2009) is a respected grief theorist who defined the common stages of grief (**Table 5-2**).

These stages include (Kübler-Ross, 2009):

- **Anticipatory grief** occurs before the stages of grief and is common in infant and pediatric death when the family of a patient with a terminal diagnosis prepares for death before the dying process.
- **Denial:** After anticipatory grief is denial, which is a refusal to believe that an infant or child is dead or dying.
- **Anger:** Anger concerning death results in feelings of wrath or indignation; it will often manifest as anger toward the disease, the cause of death of the infant or child, or even the medical staff and caregivers of the child.
- **Bargaining or negotiations:** Attempts to create a change in the situation through an agreement for services exchanged.
- **Depression or depressed mood:** This stage of grief often manifests as loss of interest in life and everyday activities, along with feelings of guilt or low self-worth.
- **Acceptance:** Acceptance is to receive or agree with what is offered. In pediatric grief, it is when the parents or family come to terms with the event and the associated loss.

Family members may grieve at different stages; everyone will not grieve in the same manner at the same time. The family should be educated that this is normal.

#20. Question

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

#21. Nursing education focuses on the emotional and physical process of dying. The last hours and days before and after a child's death are sacred and represent the last times together as a family. The nurse should allow families to engage in cultural and religious practices and provide support and privacy.

Education for the patient (when appropriate for age and development) should include:

- Explanation of the cause for the terminal diagnosis and how the disease will cause death
- Explanation of current medical interventions needed and what the patient should expect
- Explanation of the dying process, with appropriate explanation of what to expect

Parent/caregiver education should include information about:

- What to expect at the time of death, such as how the child will look, the involvement of the staff, and whom the family wants in the room.
- What to expect after death, such as care and disposition of the body and funeral arrangements

#22. Withdrawal of care occurs when the family decides to stop all lifesaving measures and allow the infant or child to die naturally with the family at the bedside, rather than the attempted end-of-life resuscitation with the child surrounded by medical staff.

Parental rights in withdrawal of care allow them to consent to end interventions and determine when the interventions will be stopped; **they also have the right to change their minds** and continue care. Parent and family education regarding withdrawal of care—how it is done and what to expect in the child's response—is important to prevent misunderstandings. When appropriate, the siblings and patient should be educated on withdrawal of care and what to expect.

#23. Family presence in pediatric code situations is handled differently in all hospitals, so knowledge of hospital-specific guidelines is paramount.

- Family involvement in pediatric code situations provides family-centered care in a very stressful situation.

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

- The desired outcome of family-centered care in pediatric code situations is to enhance communication and decrease confusion for the family.

#24. WATCH THIS: Family Presence During a Code: A Pediatric Event 4:49 minutes

#25. Family involvement in the daily nursing care of the dying child will be different for all families, but when appropriate and desired, the family should be involved in all aspects of care.

Accommodating visitors despite unit rules is the nurse's role. It should be done appropriately while respecting the needs of the other patients on the unit.

Accommodations for religious or spiritual ceremonies must be included in the bedside care of the dying patient.

When the child dies, follow hospital protocol for declaration of death and disposition of the body, which will vary based on facility policy. Follow state regulations and hospital protocol for autopsy. Some patients require an autopsy, generally at the discretion of the local coroner. Follow facility protocol related to patient death and contacting the coroner. Proper documentation at time of death is the responsibility of the nurse. Ensure that all care, nursing interventions, and patient outcomes are documented thoroughly in the child's medical record.

#26. Question

27. WATCH: Who has had the honor to participate in an honor walk? Who has heard of an honor walk?

Mars' Honor Walk (2:49 minutes)

Organ donation occurs when a patient who dies gives viable organs to patients in need of specific organs. Pediatric organs can be transplanted into adult and pediatric patients.

There are specific protocols that must be followed for a patient to be an organ donor.

A national government-funded organ donor branch of the federal government oversees and acts as a watchdog for organ donation, which

N433 Infant, Child, and Adolescent Health Cultural and End-of-Life Care

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

currently works in conjunction with the United Network for Organ Sharing (U.S. Department of Health and Human Services, 2021).

- The **Organ Procurement and Transplantation Network (OPTN)** is the unified transplant network established by the U.S. Congress under the National Organ Transplant Act in 1984.
- The OPTN oversees the federal laws related to organ donation and procurement and ensures that organs are distributed fairly and given to patients based on diagnosis, stage in life, and matching percentage.
- The OPTN facilitates organ matching and placement through a computer system and a fully staffed organ center operating 24 hours a day that works in conjunction with individual state organ donation networks.

#28. It is the nurse's responsibility to understand and adhere to the nursing scope of practice.

Autopsies can be requested by the family, physician, and/or coroner; note that autopsy policies and procedures differ by state and facility. Families may request an autopsy if they wish to know the exact cause of the death; if the coroner does not agree that an autopsy needs to be performed, the family may be responsible for the cost.

Some terminal children will have a do not resuscitate (DNR) order, and just as in adult medicine, this order must be respected.

Nurses should be aware of the following:

- All facilities have specific policies relating to DNR orders; be sure to follow facility policies when caring for a patient with such an order.
- Only the legal guardians can determine a minor patient's DNR status.
- A DNR order can be reversed at any time by the legal guardians.
- DNR orders can range from provision of no life-sustaining interventions to provision of partial or limited life-sustaining interventions.
- Parents or legal guardians need to be fully educated on all aspects of a DNR order.
- If you are the nurse caring for a terminal child, it is your responsibility to know if the child has a DNR and the limitations within the specific DNR.
- When a patient has a legal DNR order, it is the responsibility of the health-care team to follow it.

The person who is legally able to consent for the child must be determined on admission based on facility policies and state laws.

Many types of family units exist in society, and people in the patient's life who function as a family unit are not always legally seen as such. Some

**N433 Infant, Child, and Adolescent Health
Cultural and End-of-Life Care**

Week 1

Text: Pediatric Nursing-Critical Components of Nursing Care, 3rd Edition, F.A. Davis
(Advantage)
(Reviewed/Updated 5/2024)

pediatric patients can give self-consent depending on state laws or individual legal rulings making the minor independent. Every state has individual laws that determine the age of consent or the age at which children are considered legal adults and able to sign for their own medical care.