The Child with a Chronic Condition or Terminal Illness

HELPFUL HINT

Review Elizabeth Kübler-Ross’s work on death and dying.

MATCHING KEY TERMS

Match the term with the correct definition.

1. _______ anticipatory grief  
   a. The course of an illness, including its impact on those involved
2. _______ chronic condition  
   b. Responses used to counteract an illness or abnormal behavior in order to maintain appropriate and valued social roles
3. _______ chronic grief  
   c. A system of comprehensive care that provides support and assistance to clients and families affected by terminal illness
4. _______ chronic sorrow  
   d. Recurrent feelings of grief, loss, and fear related to the child’s illness and the loss of the ideal, healthy child
5. _______ hospice care  
   e. The processes of mourning, coping, interacting, planning, and psychosocial reorganization that occur as part of the response to the impending death of a loved one
6. _______ illness trajectory  
   f. Treatments or procedures that promote comfort and quality of life, rather than aiming to cure the underlying disease
7. _______ normalization  
   g. An illness that is long term and either without cure or with residual effects that limit activities of daily living
8. _______ palliative care  
   h. Excessively long mourning that interferes with resuming normal activities

9. In what ways has the experience of childhood chronic illness changed?

10. What is meant by the term children with special health care needs?

THE FAMILY OF THE CHILD WITH SPECIAL HEALTH CARE NEEDS

1. What does the term situational crisis mean?

2. The predominant trait exhibited by resilient families is _________________________________.

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3. List four processes that enhance a family’s resilience.
   a. __________________________
   b. __________________________
   c. __________________________
   d. __________________________

Answer as either true (T) or false (F).

4. ______ In resilient families, the child’s condition-related needs become the focus around which family activities revolve.

5. ______ For resilient families, coping is an active process that involves learning about their child’s condition and available resources.

THE GRIEVING PROCESS

1. The nurse caring for a child with a chronic illness must keep in mind that the most important aspect of a chronic illness is that it affects __________________________.

2. Identify the five stages of the grieving process delineated by Kübler-Ross.
   a. __________________________
   b. __________________________
   c. __________________________
   d. __________________________
   e. __________________________

Answer as either true (T) or false (F).

3. ______ Children move through the five stages of the grieving process sequentially.

4. ______ Children with chronic conditions tend to use denial more often than do adults.

THE CHILD WITH SPECIAL HEALTH CARE NEEDS

1. Children’s responses to chronic illness are influenced by their __________________________ and their __________________________.

2. Nurses caring for children with chronic conditions must understand issues concerning __________________________ and __________________________ in relation to each stage of growth and development.
Answer as either true (T) or false (F).
3. _______ Temporary regression may be observed in children of all ages.
4. _______ Rearing a child with a chronic illness necessitates that parents learn a different set of child-rearing techniques.

THE CHILD WITH A CHRONIC ILLNESS

1. The goal for a child with a chronic illness is ________________________________________________________________________________
______________________________________________________________________________

2. List three goals for the family of a child with a chronic illness.
   a. __________________________
   b. __________________________
   c. __________________________

3. What is the first factor the nurse must consider when planning care for a child with a chronic illness?

4. List five ways health care professionals can support the parents of children with a chronic condition.
   a. __________________________
   b. __________________________
   c. __________________________
   d. __________________________
   e. __________________________

Answer as either true (T) or false (F).
5. _______ The nurse should convince parents that it is always better to express emotions than to hold them inside.
6. _______ Honesty and trust must be maintained at all times when caring for a child with a chronic condition.
7. _______ Siblings of a chronically ill child may also experience developmental regression.
8. _______ Siblings should not participate in the ill child’s physical care.
THE TERMINALLY ILL OR DYING CHILD

Match each age-group with the corresponding concept of death.

1. ______ Infants/toddlers   a. Death is temporary and reversible
2. ______ Preschoolers       b. Death is a sad and irreversible event
3. ______ School-age children c. Death is viewed as the loss of a caretaker
4. ______ Adolescents        d. Death is inevitable and irreversible

Answer as either true (T) or false (F).

5. ______ One of the primary concerns of dying children is the fear of being alone.
6. ______ The health care team must uphold the family’s decisions about continuing curative care for their child.
7. ______ An important aspect of supporting the sibling of a child who has died is to acknowledge that the loss is significant.

CARING FOR THE DYING CHILD

1. Identify three self-care measures that can assist nurses caring for terminally ill children.
   a. __________________________
   b. __________________________
   c. __________________________

2. The most common issue for families surrounding a child’s impending death is __________________________
   __________________________

   Answer as either true (T) or false (F).

3. ______ Pain control is a primary concern for dying children, their families, and the nursing staff.
4. ______ Many hospice organizations offer palliative care for families after their child dies.
5. ______ The nurse should make every effort to provide privacy for the dying child and family.
6. ______ Adequate oral intake is crucial to the dying child’s comfort.
7. ______ Hearing is the last sense to close down before death.
8. ______ The young child is usually not aware of the presence of parents during the dying process.
9. ______ Respiratory changes are always the earliest indicators of imminent death.
10. ______ Hypercapnia has a sedative effect.
11. ______ The nurse’s response to caring for a dying child correlates to a certain degree with the Kübler-Ross stages of grieving.
12. ______ Nurses with many years of experience in caring for dying children will typically not experience grief when a child dies.
SUGGESTED LEARNING ACTIVITIES

1. Investigate the availability of pediatric hospice care in your area.

2. Arrange to make a home visit to the family of a child with a chronic illness. How does home care compare with hospital care?

STUDENT LEARNING APPLICATIONS

Enhance your learning by discussing your answers with other students.

1. What are your fears or concerns about caring for a child who is dying? Talk with other students about your thoughts. Are your fears or concerns similar to or different from those of the other students?

2. Talk to a nurse who has worked with dying children and their families. What has been the most rewarding aspect of this work? The most difficult? Share what you learned with other students.

REVIEW QUESTIONS

Choose the correct answer.

1. The most significant concern of the parents of a dying child is the child’s
   a. pain.
   b. hydration.
   c. safety.
   d. privacy.

2. A 5-year-old child understands death as
   a. the loss of a caretaker.
   b. a temporary separation.
   c. sad and permanent.
   d. something that happens to everyone.

3. Although an individual may move back and forth among the various stages of the grieving process, the first stage is usually
   a. denial.
   b. resentment.
   c. bargaining.
   d. depression.

4. Chronic illness with frequent hospitalizations can affect the psychosocial development of a school-age child by
   a. leading to feelings of inferiority.
   b. preventing a sense of initiative.
   c. interfering with parental attachment.
   d. blocking the development of identity.
5. What is the best response to an adolescent who asks whether he should talk to his dying brother?
   a. “You might want to hold his hand instead because he cannot hear you.”
   b. “Although he may not answer you, your brother can still hear what you are saying.”
   c. “He can’t hear you but he can feel your presence nearby.”
   d. “Talk about happy things because you don’t want to upset him.”

6. Which of the following represents the predominant trait of resilient families?
   a. Disengaging the family from the community
   b. Maintaining rigid family roles
   c. Engaging in efforts to keep the family intact
   d. Focusing on the child’s condition-related needs

7. Which of the following interventions is appropriate when caring for a chronically ill toddler?
   a. Prepare for procedures days in advance.
   b. Arrange for friends to visit in the hospital.
   c. Limit parental participation in the child’s care.
   d. Keep security objects nearby.

8. What is the nurse’s first consideration when planning care for the child with a chronic illness?
   a. Child’s physiological condition
   b. Child’s development
   c. Family’s coping mechanisms
   d. Family’s understanding of prognosis