Chronic Illness and Home Care, Disability, and Death Issues in Pediatric Nursing

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Common Terms Regarding Children with Special Needs
- Chronic Illness
- Congenital Disability
- Developmental Delay
- Disability
- Handicap
- Impairment
- Technology-Dependent Child

Scope of the Problem
- Children with special health care needs are defined as:
  - those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition requiring health and related services of a type or amount beyond what are required by health children.
Most Common Conditions causing Disabilities in Children
- Respiratory tract disease
- Impairments of speech, special senses, and intelligence
- Mental and nervous system disorders account for 1/6 of all childhood disability.

Impact of Chronic Illness
- Additional family task/responsibility/concerns
- Days lost from school
- Increased risk for behavior or emotional problems
- Parents lose days from work
- Financial strain
- Coping
- Siblings feel guilt/anger/jealousy

Trends in Care
- Developmental level
- Focus attention on normalizing experiences
- Adapting the child's environment
- Promote coping skills for child and family
- Family development
Family-Centered Care

- A philosophy that considers the family as the constant in the child’s life.

Health Care Provider Information

- **DO**
  - Be open and honest
  - Use a process of repeated discussions, a little information at a time repeated as necessary
  - Assess understanding of information
  - Assess coping, both cognitively and emotionally
  - Assure privacy when discussing diagnosis

- **DO NOT**
  - Be unsympathetic
  - Be brief

Culture

- Perception of chronic illness and disability may differ
- Social and family roles may differ from mainstream American culture.
Normalization

- Normal: can be redefined by individuals or families based on their particular experience, needs and circumstances.
- Nurses can assist by:
  - Assessing support systems
  - Assessing coping strategies
  - Assessing family cohesiveness
  - Knowing family/community resources

The Family of the Child with Special Needs

- Comprehensive care involves:
  - Forming parent-professional partnerships
  - Assessing background knowledge/experience
  - Choosing strategies that fit the family’s situation/culture
  - Evaluating family’s understanding of given information
  - Optimum support at time of diagnosis and throughout the treatment course of the child

Parents: Mother/Father or Single Parent

- Routine aspects of parenting plus added responsibilities:
  1. Complex technical care
  2. Symptom management
  3. Advocacy
  4. Seeking and coordinating health and social services
  5. Balancing needs of other family members
  6. Personal health and maintenance
  7. Additional demands placed on parental time
  8. Additional financial demands
Anticipated Parental Stress Points
- Diagnosis of condition
- Developmental Milestones
- Start of Schooling
- Reaching the ultimate attainment
- Adolescence
- Future Placement
- Death of a Child

Nursing: Early Teaching and Coping Mechanisms for Stress Points
- Burden of care assumed by only one parent
- Financial burden
- Fear of the child dying
- Pressure from relatives and friends
- Hereditary nature of disease
- Fear of pregnancy

Siblings
- Evidence of a negative effect
- Brothers and sisters of children with special needs are no more at risk for severe psychiatric problems than are siblings of children without chronic or disabling conditions.
Helping Siblings Cope
Box 41-5 page 1223

- Promote Healthy Sibling Relationships
- Help Siblings Cope
- Involve Siblings

Concurrent Family Stresses

- Situational or developmental
- Marital difficulties
- Sibling needs/Daycare
- Cost/Financial concerns
- Homelessness
- Social isolation
- Alcohol or drug problems
Coping Mechanisms

Guidelines page 1225

- Approach behaviors: coping mechanisms that result in movement toward adjustment and resolution of the crisis.
- Avoidance behaviors: result in movement away from adjustments and maladaptation to the crisis.

Shock and Denial

- Shock, Disbelief, or Denial: Can last from days to months, or even years. May be exhibited at the time of diagnosis.

Adjustment

- Generally, gradually follows shock
- Guilt
  - Especially if cause is directly linked to the parent
  - Genetics
  - Accident
  - Personal wrongdoing
  - Cultural or religious beliefs
  - Children may feel it is a punishment
- Anger and bitterness
Types of Parental Reaction

- Overprotection
- Rejection
- Denial
- Gradual Acceptance

Developmental Aspects of the Child with Chronic Illness or Disability

- Infant (Table 41-2, p.1237)
  - Trust through intimate, satisfying, consistent relationships with parents.
  - Lack of pleasant touching can lead to irritable and unhappy child.

- Nurses should advocate for:
  - 24 Hour Visitation in NICU
  - Teaching parents how to handle infant
  - "Kangaroo Care"
  - Encourage breast feeding/pumping
  - Sibling Visitation

"Kangaroo Care"

- Kangaroo care is a form of skin-to-skin contact between a parent and their baby. The baby is held and their chest for 20 minutes to four hours a day.

- Benefits of this method of care include:
  - Bonding between the parent and child
  - Calming of the infant as he/she responds to the parent’s heartbeat and enjoys deeper levels of sleep.

- Studies have also shown that parents who use this method benefit from decreased hospital stays, and increased joy in helping to care for their child.
- Infants have been shown to demonstrate fewer breathing pauses and a decreased number of low heart rate spells.
Developmental Aspects of the Child with Chronic Illness or Disability

**Toddler** (Table 41-2, p.1237)
- Need to master locomotor and language skills
- Chronic illness/disability can hinder walking/talking
- Overprotective parents can hinder the progression
- Age-appropriate tasks may be delayed

**Nurses should advocate for:**
- Maximum opportunities for independence
- Maintain attachment
- Allow the parent to participate

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Developmental Aspects of the Child with Chronic Illness or Disability

**Preschooler** (Table 41-2, p.1237)
- Slow to develop social skills if not involved in activities outside of the home
- Establish sexual identity with gender related activities

**Nurses should advise:**
- Day cares are required by law to make reasonable modifications for disabled
- Socialize with family and friends
- Teach about illness to child’s understanding
- Praise all positive experiences

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Developmental Aspects of the Child with Chronic Illness or Disability

**School-Aged Child**
- Develop a sense of accomplishment
- Learn through concrete operations
- Many school absences due to limited opportunities for socialization

**Nurses should advise:**
- Encourage school attendance
- Educate teachers and student peers about child’s condition
- Encourage sports activities
- Encourage socialization
- Encourage creative activities
Developmental Aspects of the Child with Chronic Illness or Disability

- Adolescents (12-19 yrs)
  - Develop personal and sexual identity
  - Achieve independence from family
  - Form heterosexual relationships
  - Learn through abstract thinking
  - Increased feeling different
  - Limited opportunity for relationships

Nurses should advise:
- Encourage socialization
- Encourage increased responsibility for own care
- Encourage attendance of normal activities
- Emphasize good appearance

Coping Mechanisms for the Child with Disability

- Box 41-6, p.1229
  - Develops competence and optimism
  - Feels different and withdraws
  - Irritable, moody and acts out
  - Complies with treatment
  - Seeks support

Health, Education and Self-Care

- Developing skills and judgment needed for self-care of a chronic illness is a process that occurs over time.
- Self-care requires negotiation between parent and child
- Nurses can assist families by offering information on methods for instructing children at various ages
- Answer questions honestly in an age-appropriate manner
Nursing Care of the Family and Child with Special Needs

- Assessment
- Nursing Diagnosis
- Plan of Care
- Implementation
- Evaluation
- Expected Outcomes

The Dying Child

Perspectives on Care of Children at the End of Life

- Principles of Palliative Care
- Decision Making at End of Life
- Ethical Considerations in End-of-Life Decision
- Physician/Health Care Team Decision Making
- Parental Decision Making
The Dying Child
- Family of the dying child  p. 1242
- Child’s understanding and reaction to death  p. 1243-1244
- Be honest and accurate with information. Processing of information takes time.
- Provide appropriate literature about illness and death.
- Assist with professional support and treatment.

Treatment Options for Terminally Ill Children
- Hospital
- Home Care
- Hospice Care

Fear of Pain and Suffering
- Fear of dying alone
- Fear of child dying
- Fear of actual death
- Fear of unrelied pain
- Give pain meds
- Teach relaxation techniques
- Treat other symptoms
Fear of Actual Death

- Home Deaths
- Hospital Deaths

Grief and Mourning

- The loss of a life is only the beginning.
- Hospice recognizes the need to provide regular follow-up after the death.
- Acute grief develops within hours to days.
- Resolution
  - Guidance through the process may be helpful so they can recognize normalcy of their experience.

Family Centered Home Care
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HOME CARE DEFINED

- Care provided in the family's residence for children with complex health care needs and their families.
- Purpose: To promote, maintain, restore, health or to maximize the level of independence while minimizing the effects of disability and illness, including terminal illness.

HOSPICE CARE

- Program of palliative and supportive care services providing physical, psychologic, social, and spiritual care for dying persons, their families and other loved ones.
- Hospice Services are available in both the home and inpatient settings.

HOME CARE TRENDS

- Technology advances have resulted in increased survival.
- Ventilator dependent children are now living at home.
- A natural family environment optimizes growth and development when stress is minimal and support is optimal.
EFFECTIVENESS OF HOME CARE
- Nursing opportunity to assess and interact with the family in their environment
- Intermittent skilled Nursing Visits
- Private duty of Block Nursing
- The home health nurse is responsible for patient and family assessment and evaluating the appropriateness of the plan of care.
- Communication with all healthcare disciplines is key to ultimate patient care.

DISCHARGE PLANNING
- Know local community resources
- Ultimate goal is for the family to become familiar with the child’s needs and to be competent in providing that care.
- Success depends on careful planning and preparation.
- Discharge planning begins on admission.

CASE MANAGEMENT CARE COORDINATION
- Defined as: focus on cost control, attainment of desired clinical outcomes, and monitoring and evaluation of care provided.
- Care Path
QUALITIES OF A PEDIATRIC HOME HEALTH NURSE

- Demonstrate flexibility in skills and case management
- Recognize that the nurse is a guest in the home
- Respect family culture and adapt appropriately
- Work as an interdisciplinary team member
- Demonstrate expertise in pediatric care (assessment and technical skills)

FAMILY CENTERED HOME CARE

- Home as Familiar
- Home as Center
- Home as Protector

RESPECT FOR DIVERSITY

- Respect for family background, racial, ethnic, cultural, spiritual and socioeconomic
- Assess relationship among culture, religion and family beliefs about child’s illness
- Personal values drive behavior
- Ask questions without implying judgment
- Build on family strengths and coping
NURSE ALERT

Do not allow infant to go to sleep drinking a bottle

Increase fluids Must complete entire contents of bottle over next 10 days.

Needed to treat ear infection

3cc pink antibiotic Amoxicillin

8pm 2000

4pm 1600

12pm 1200

8am 0800

PARENT PROFESSIONAL COLLABORATION

Collaborative care allows the nurse and the family to work together and share outcomes in a deep and meaningful way.

Do not be intrusive when it comes to collecting data.

Families have the right to expect confidentiality in regard to data collected.

Respect parental preferences in any situation that will not pose danger or risk for the child.
KNOWLEDGEABLE PARENTS

- It is not unusual for parents of a child with chronic illness to be more knowledgeable about their child's condition than the nurse who is assigned to the care of the child.
- Parents will always know more about their child than the professional caring for the child.
- Listen to the parents.

THE NURSING PROCESS

- Communicate openly the assessment.
- Family priorities should guide the planning process.
- Agree on long-term and short-term goals.
- Written schedule of daily routines should be developed and followed.
- Goals are supported by intervention strategies that reflect normalization.
- Evaluation through family participation.

Safety Issues in the Home

- Priority phone and electrical service provided.
- Emergency protocols (including CPR) provided by appropriately trained people.
- Medications, sharps, hazardous materials.
- Night safety concerns.