



**Family-Centered Care  
&  
Standards of Care**

# Historical Perspectives

- 19th century
  - Immigration led to increase in infectious diseases and epidemics
  - Public health efforts for safe milk supply and compulsory vaccination programs
- 20th century through 21st century
  - Urban public health improvements → safer cities
  - Decreased threat of childhood diseases
  - Unintentional injuries surpassing disease as leading cause of death for children > age 1
  - Technological advances → increase survival rates but with chronic disabilities; earlier diagnosis and treatment
  - National and international organizations for children's rights

# Health Status: Mortality

- Mortality: number who have died over a specific period
- Fetal mortality rate: number of fetal deaths (20 weeks or older)/1,000 live births
- Neonatal mortality rate: number of infant deaths (in first 28 days)/1,000 live births
- Infant mortality rate: number of infant deaths (in first 12 months)/1,000 live births
  - U.S. ranking: 41st among industrialized nations
  - Congenital anomalies: leading cause
  - Low birth weight and prematurity: significant predictors of infant mortality
- Childhood mortality rate: number of deaths/100,000 population in children 1 to 14 years of age
  - Leading cause
    - Ages 1 to 4: unintentional injuries, then congenital malformations
    - Ages 5 to 14: unintentional injuries, then cancer
  - Other causes: suicide, homicide, diseases of the heart, influenza and pneumonia

# Health Status: Morbidity

- Morbidity
  - Measure of prevalence of specific illness in a population over a given time; rates per 1,000 population
  - Women's health indicators
    - Cardiovascular disease as the #1 cause of death
    - Cancer as the 2nd leading cause of death
- Childhood Morbidity
  - Key issues endangering children's health: obesity, environmental toxins, allergies, drug abuse, child abuse and neglect, and mental health problems
  - Factors increasing morbidity: homelessness, poverty, low birth weight, chronic health disorders, foreign-born adoptions, day care attendance, and barriers to health care
  - Degree of disability most important aspect, measured as number of days missed from school or confined to bed

# Families

- Family
  - Definitions changing over time
  - U.S. Census Bureau definition: a group of two or more persons related by birth, marriage, or adoption and living together
- Family structure
  - Organization of the family unit
  - Members gained or lost through various events
  - Traditional nuclear family no longer considered the dominant family structure
- Family roles and functions: providing physical and emotional care, imparting rules and expected behaviors of society through teaching and discipline
- Caregiver-child interaction: crucial to survival and healthy development
- Parental roles: nurturer, provider, decision maker, financial manager, problem solver, health manager, gatekeeper
- Parenting styles: authoritarian, authoritative, and permissive, uninvolved or rejecting-neglecting

# Family Empowerment

- Increase in responsibility by individuals and families for their own health
- Family desire for information and participation in decision-making process
- Respect for family's views and concerns; addressing issues and concerns; regard for client, partner, and parents as important participants

# Barriers to Health Care

- Finances: limited or no health insurance; poverty
- Sociocultural barriers: lack of transportation; need for both parents to work; knowledge, language, or spiritual barriers
- Health care delivery system: cost containment issues with insurance plans; earlier discharge; possible limits for specialty care; clinic hours; negative attitudes toward poor or culturally diverse families by some health care providers



# Standards of Care



- Informed consent
  - Age of majority – 18 years
  - Parent or legal guardian for minors
  - Nurse's responsibility
    - Ensuring form completed with signatures
    - Serving as witness to signature process
    - Determining client and family understanding of what they are signing through appropriate questions
- Special situations with informed consent
  - Parent unavailable, person in charge with written permission from parent for emergency treatment
  - Verbal consent via telephone for emergency
  - Emergency or urgent situations
- Exceptions to parental consent
  - Mature minor (over age 14)
  - Emancipated minor
    - Armed services member
    - Marriage or college attendance
    - Court-determined emancipation
    - Financial independence living apart from parents
    - Pregnancy; mother < 18 years; runaway



# Implications for Nurses

- Proactive role in advocating, empowering clients
- Need for solid knowledge base about factors affecting health and barriers to health care
- Anticipatory guidance
- Activity within framework of the nursing process
- Need to be alert to new technologies and treatments
- Integration of high-quality evidence-based interventions in care

# Family-Centered Care

- Collaborative partnership, mutual trust, sensitivity to client's and family's beliefs and those of their culture
- Family as the constant
- Support for uniqueness and diversity; encouragement and enhancement of family strengths and competencies
- Greater family self-determination, decision-making, control and self-efficacy
- Collaborative care
  - Interdisciplinary plan of care to meet physical, developmental, educational, spiritual, and psychosocial needs
  - Case management
    - Advocacy, communication, resource management
    - Client-focused comprehensive care across a continuum
    - Coordinated care with interdisciplinary approach

# Educating Families

- Assessment:
  - Learning needs assessment Impact of culture
  - Health literacy
- Planning
  - Mutually agreed-upon, achievable learning goals and objectives
  - Input from interdisciplinary team
- Interventions
  - Slow down and repeat
  - Speak in conversational style
  - Chunk information
  - Prioritize; teach “survival skills” first
  - Use of pictures, illustrations, videos, color-coding for those with poor health literacy
- Evaluation
  - Demonstration
  - Repeating back information
  - Open-ended questions
  - Pretend scenarios

# Preventative Care

- Primary prevention
  - Prevention before disease or condition occurs through health promotion activities, environmental protection, and specific protection against disease or injury
  - Nutrition, good hygiene, sanitation, immunizations, protection from UV rays, genetic counseling, bicycle helmets, handrails on bathtubs, drug education, adequate shelter, smoking cessation, family planning and seat-belt use
- Secondary prevention
  - Early detection and treatment of adverse health conditions
  - Health screenings
- Tertiary prevention
  - Reduction or limitation of the progress of a permanent, irreversible disease or disability
  - Supportive and restorative

# Case Study

- An oncology nurse is caring for Tyler, a 12-year-old boy who lives in a large metropolitan city. Tyler lives with his mother and four siblings. Tyler's mother is raising her children by herself and recently lost her job as a result of the economic downturn. Tyler has been tired and running a low-grade fever for several weeks. Tyler's mother recently took him to the local emergency department because she lost her insurance coverage and Tyler was diagnosed with leukemia. In addition to this devastating news, Tyler's mother just found out that she and the children are going to be evicted from their apartment due to her inability to pay the rent.
  - A. What are some of the factors that increase morbidity in children, and what may be some of the outcomes of experiencing these factors?
  - B. What are the legal/ethical issues Tyler's nurse must consider when providing care to Tyler and his family?

# Case Study

- Since the initial visit where Tyler, the 12-year-old boy, was diagnosed with leukemia, his mother has been unable to find work, and as a result they were evicted from their apartment. Tyler is still in the process of receiving treatment for the leukemia but is now homeless. Tyler's mother has begun to notice that Tyler's siblings' behavior has become more defiant and negative. Previously, Tyler's mother expected the children to adhere to the rules but allowed them to be individuals. She exhibited warmth, consistency, and fairness. Now the nurse notes that the mother has begun to yell at the children more and threaten to spank them, a behavior she never demonstrated previously. They are living day to day in an inner-city shelter.
- A. What is Tyler's mother's parenting style, and how has it changed recently in relation to the changes in the family's financial and living status?
- B. Which form of discipline is Tyler's mother using currently, and what suggestions could the nurse offer her regarding more effective forms of discipline?
- C. What might be the impact of poverty and homelessness on the health status of Tyler and his family?

## Unit #1 Notes:

Test: Tuesday, September 10th (9:30 am AH 208)

- Unintentional injuries surpassing disease as leading cause of death for children over the age of 1.
- To prevent infant mortality, encourage early and ongoing prenatal care
- Lead poisoning is drinking water from old and corrosive pipes that have been sitting for several hours. This could lead to neurological damage.
- Healthy People 2020:
  - Defined as health care priorities:
    - Disease prevention
    - Health promotion
  - Goal: to increase quality of life through diet, exercise, health promotion, screening, etc.
  - 142 goals overall
- Different Types of Family:
  - Nuclear Family:
    - Traditional male and female partner and their children. Extended family may live in household as well
  - Married Single Parent Family:
    - Includes biological or adoptive parents
  - Single Parent Family:
    - Unmarried biological or adoptive parents who may or may not be living with other adults of same sex partners who live together with and without children. May be gay or lesbian parents or multiple parenting figures
  - Married Blended Family:
    - Formed as a result of death or divorce, consist of unrelated family members who join together to form new household
  - Cohabiting Family:
    - Children who live with 2 unmarried biological parents or 2 adoptive parents
  - No Parent Family:
    - Children live independently in foster or kinship care such as grandparent or aunt
- Part of the Nurses goal is to enable and empower parents

- Nursing Process:
  - Analyze - Assessment
  - Determine - Diagnose
  - Select Interventions - Plan
  - Develop Goals with Families
  - Prioritize Patient Responses - Actions
  - Evaluate Progress - Outcomes
- Patients mostly use primary care physicians first before pediatric ER
- Blue collar or working class parents view corporal punishment (spanking) as normal approach to discipline
- White collar or professional class tend to favor discipline measures that include time out, positive reinforcement and non physical methods
- Types of Parenting:
  - Authoritarian / Dictatorial:
    - enforcing absolute rules, strict expectations.
    - Children have little say and punishment follows any deviation
    - Children tend to be shy, conforming, submissive, loyal and honest
  - Laissez - Faire / Permissive:
    - allows children to control own environment
    - subsequent behavior with less input from parents
    - few rules and inconsistent punishment
    - Children tend to be disrespectful, aggressive, disobedient, and irresponsible
  - Authoritative / Democratic:
    - Combination of previous parenting styles
    - Allows children some freedom to participate in decision making
    - Firm but realistic expectations are set
    - Children tend to be assertive, self reliant and highly interactive with high self esteem.
    - THIS PARENTING STYLE TENDS TO MEET CHILDS NEEDS BETTER THAN OTHER STYLES.
- Only physician can provide informed consent
- Get consent form parent or child under 18. Not needed if child is:
  - married
  - is a parent
  - self supporting
  - member of military
- Purpose of standard of care is to protect the consumer by evaluating quality of care nurses provide and become legal guidelines for nursing practice.



- Cultural Sensitivity:
    - learning, recognizing, and comprehending that these cultural factors are what shape a family's perception of their health and health related events
  - Cultural Competence:
    - Nurse must be open and receptive to gaining awareness and respect of cultural influences
  - Cultural Prescriptions:
    - folk beliefs, practices, values of a group that tell women/children what they should do in their roles
  - Cultural Proscriptions:
    - folk beliefs, practices, values of a group that tell women/children what they should NOT do in their roles
  - Anticipatory Guidances:
    - Key to achieving 2 of the primary goals of pediatric care
      - Promoting health
      - preventing disease
        - 3 Steps to achieve task:
          - gather information
          - establish therapeutic alliance
          - provide education and guidance
- Primary Prevention:
  - Health Prevention and Screening
  - Teaching children the importance of hand washing, covering their mouth when they cough and promoting the use of condoms to prevent STDs
  - Most desirable level specifically meant to prevent disease from occurring
    - example: taking patient to physician for appt and scheduling follow up care
- Secondary Prevention:
  - Early Detection and Prompt Treatment before opportunity to spread and become more serious
  - Goal is to halt or slow progress of disease in earliest stage
- Tertiary Prevention:
  - Restore Health
  - Rehab, Health Restoration, and Palliative Care
  - Intended to restore health to the highest functional state possible
  - Examples: Keeping child home sick, administering fluids or antibiotics, encourage rest, rehab therapy, etc

- **Four Basic Ethical Principles:**
  - **Beneficence:** professional duty to do good
  - **Non-Maleficence:** do no harm and greatest good to others
  - **Respect for Autonomy:** self care
  - **Justice or Fairness:** unbiased care