Pediatric Challenges in Case Management: Decades of Change

Gwen Fosse RN BSN MSA
Clinical Outreach Specialist
University of Michigan
Congenital Heart Center
CS Mott Children’s Hospital
gfosse@med.umich.edu
Disclosures

• No conflicts of interest to disclose
Objectives

• The participant will be able to:
  – Describe advances in care of children that have evolved to the current characteristics of pediatric case management.
  – Discuss three examples of adventures and realities of pediatric case management.
Background – Decades of Change
Nature of Pediatric Illnesses

– Many variables contribute to illness
  • Age (Infants more prone to respiratory difficulties, etc.)
  • Season (RSV, trauma, meningitis, etc.)
  • Time of Day (fevers more prevalent in the evening hours)

– 5% of children presenting to hospitals have life-threatening conditions
  • Rapid onset
  • Frequently involves the respiratory or central nervous system
Pediatric Care in the USA

- Most pediatric admissions in acute care hospitals are infectious diseases
  - These admissions are being reduced by new immunizations
- More than 40% of the pediatric population is on Medicaid with reimbursement at about 60% - creates administrative challenges
- Most acute care hospitals accept pediatric patients
  - children are <5% of their total patient population and this percentage is decreasing
- Reimbursement issues and the low numbers of patients in community hospitals results in challenges to the staff of acute care hospitals to provide quality care. Partnering offers ways to work together.

SG2; Skokie, IL. 2003.
Pediatric Population

Infants and children make up a very small minority of hospitalized patients in the USA.
– Their needs are different – they are not just small adults
– Their diseases and responses are different
– Most children grow up without ever needing a hospital but when children need a hospital, they present the staff with great challenges
Survivors of Pediatric Conditions -
A population with needs

- Children are surviving conditions that previously were associated with greater childhood death
  - Cancer, trauma
- Premature birth, complicated birth, prenatal exposures
  - Bronchopulmonary dysplasia/ chronic lung disease, developmental concerns
- Birth defects
  - Craniofacial, genitourinary, nephrology, musculoskeletal, gastrointestinal, etc.
  - Cardiac conditions
  - Neurological - Spina bifida (decreased incidence)
- Technology improves life expectancy
  - Now have populations of chronically technology dependent - Oxygen/Vents, TPN
Pediatric inpatient care

- 1991-2005 inpatient pediatric admissions
  - Single diagnosis – rate increased by 20%
  - Multiple diagnoses – rate more than doubled

Burns KH et al. Peds 2010; 126: 638-646
Children are Special
So Are Their Health Care Needs
What is our perception of illness?
Society’s perception of childhood illness
Pediatric population in hospitals is changing

- In children’s hospitals many of the patients are those with chronic childhood conditions.

- Emergency Department - It is changing in volume and character
  - ED’s are the primary source of care: 1 in 4 American children live in poverty with no medical insurance coverage.
  - There is a greater referral rate by primary care physicians to the hospital ED’s d/t the 24 hour availability and their reluctance to handle complex cases.
Legislative and economic implications

- Federal
- State
- Affordable care act
- Healthcare policy and economic climate impacts inpatient and home healthcare of children
What do children want from health care?
Healthcare of Children

- Requires collaboration between community hospitals and children’s hospitals
Children’s Hospitals
Resources for Providing Care for Children

• Concentration of pediatric subspecialty services (equipment and PEOPLE)
  • Tertiary
  • Quarternary

52-54 free standing children’s hospitals across the USA – over 100 within larger institutions

• 55% (and growing) of admissions are due to chronic conditions
  • Episodic care instead of single acute interventions
Providing care for children

- Care of children requires a very special team and place
  - Physicians–residents, attendees
  - Mid-levels–nurse practitioners, physician assistants
  - Nurses
  - Therapists–respiratory, occupational, physical, speech, etc
  - Pharmacists, dieticians, teachers
  - Child life therapists–special visitors: teams, celebrities
Case management - Definition

- A managed care technique within the healthcare coverage system of the US. Medical case management – general term referring to facilitation of treatment plans to assure appropriate medical care. [www.wikipedia.org - accessed 9/15/12]

- “a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote quality cost-effective outcomes.”  
  Case Management Society of America  [www.cmsa.org]

- “a collaborative practice model including patients, nurses, social workers, physicians, other practitioners, caregivers and the community… ..encompasses communication and facilitates care across a continuum through effective resource coordination.”  
  Am Case Management Assoc  [www.acmaweb.org]
Case management - Definition

- Embellished, liberal definitions –
  - Team case management
    - Always really the case
  - Chronic care case management
  - Episode of care case management
- Inpatient and outpatient aspects
Care Coordination/Case Management

• Targeting at-risk people for focused
  – assessment of medical, functional, social, and emotional needs
  – provision of optimal treatment, health education, & integrated services
  – monitoring of progress & early signs of problems

Case Management/Care Coordination Outcomes

- Reductions in hospitalizations
  - Decreased lengths of stay
- Optimizing management of complex cases in and out of the hospital
- Decreased ER visits
- Reduced costs
- Fewer hospital-reported errors
  
Do kids need case management?

- Disparities in access to health care exist
- How are children affected?
  - Lower likelihood of having usual source of care
  - Providers have inadequate time
  - Communication challenges when patient isn’t responsible for self
  - Less access to appropriate management of chronic conditions

Historical Perspective

- **Case management in 1986**
  - Nursing case management for home-based care of chronically ill children in a rural area
    - Designed health care plans- coordination of care
    - Assured care plan implementation
    - Provide a community-based link between child/family and the physician/tertiary care center
  - Barriers/challenges
    - Isolation
    - Chronicity
    - Lack of transportation
    - Scarcity of providers/resources

Management strategies

Adventures and realities of pediatric case management
Prevention Opportunities with Pediatrics

- Prevention strategies – every encounter is an opportunity to address prevention issues – safekids.org
  - Tobacco
  - Drugs
  - Immunizations
  - Car safety
  - Fall prevention
  - Environmental Health
  » Size, low to ground, play

- Advocacy
  - Schools, health care access, community
Pediatric Safety Issues – Implications for Case Management

• Children are among the most vulnerable patients
• Example: Medications
  – Errors occur in 39.1/100 orders for adults and children (Potts, Peds 2004)
    • Med error 3 times more likely in children
  – With children the risk for error is large –
    • 11.1% rate of adverse drug events in pediatrics. (The Joint Commission, Sentinel Event Alert, Issue 39, 4/11/08)
      – Due to variations in doses – weight-based dosing
      – Fractional dosing
      – Drugs packaged for adults
      – Most healthcare settings are based on adult care
• Children have narrower therapeutic margins
  – less tolerance for errors
Safety

Children are vulnerable

Equipment, medications and other interventions are often designed with adults in mind but adapted for children

• Size

• Behavior/curiosity
  – With children the risk for error is large
  – Look around what do you see?
  – What would a child’s view be?
  – Are things safe?
Management strategies - Beyond prevention & safety, the real goal.....

- "Normalizing" life
  - Make the environment and process of care as close to normal life as possible
  - Being at home sure helps but .....
  - Attempt to have child in school/daycare – normal environment as much as possible

- Risk of exposure to communicable diseases
  - Routine childhood illnesses present a unique challenge for kids who need case management

- Improves quality of life

Peterson-Carmichael S, Cheifetz I. Resp Care 2012; 57: 993-1003
Strategies for Leadership

The American Hospital Association partnered with the Institute to produce the Strategies for Leadership: Patient- and Family-Centered Care toolkit. This resource was distributed to the CEO of every U.S. hospital in the fall of 2004. It contains a video and companion discussion guide, a resource guide and a self-assessment tool for hospitals. The entire toolkit can be downloaded from the AHA website.

Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory

Strategies for Leadership: Patient- and Family-Centered Care

www.ipfcc.org
Family-centered care
IPFCC Tools/Checklists

Tools to Foster the Collaboration with Patient and Family Advisors – tools for healthcare professionals and families
  Applying Patient and Family-Centered Concepts to Bedside Rounds in Newborn Intensive Care
  Applying Patient and Family-Centered Concepts to Bedside Pediatric Rounds

Other Tools to Foster the Practice of Patient- and Family-Centered Care

Tools to Assist in Designing Supportive Health Care Environments

www.ipfcc.org/tools
Patient & Family Centered Care Program

Patient Family Advisory Council

The Patient and Family Advisory Council is largely a family council with staff representation. The Council provides leadership for all subordinate Mott Patient and Family-Centered Care Organization (PFCC) committees and reports to the PFCC Executive Committee. The Council shares their views, experiences, and ideas with senior clinicians and administration during their monthly meetings and through their regular reporting to the Executive Committee.

This structure has been designed to provide a primary voice and leading role for patients and families. At the same time the organization ensures active participation and leadership by senior clinicians and administrators and the active involvement of staff and student members dedicated to the principles and philosophy of patient and family-centered care. The overall mission is to help Mott Children's and Women's Hospital deliver patient and family-centered care through collaborative efforts. These efforts will enhance the University of Michigan Health System's vision of attaining the Ideal Patient Experience.
Parent – family perceptions of care

Unexpected
Stories from mothers of children with special health needs

— “Be ready for a flood of emotions because Julie takes you for a ride through the depths of the human condition when a child’s life is threatened with illness and disease.”

- Performed by Julie Newland, mom
Communication & relationships

• **Hand offs**
  – Fully provide directions; request clarification
    • “I didn’t pee!”
    • “Plain old doughnuts”
  – Send the right message
    • Screwfest express
    • AED – abbreviations can confuse everyone

• **Intimidation**
  – When an adult scolds, child may feel like hiding
    • Nurse/nurse, doctor/nurse, colleague/colleague
  – Reduced performance, decreased confidence
Communication & relationships

- Adoration to defiance
  - Young and idealistic - respect experience when shared well
  - Changes to defiance if respect is lost
  - Inexperienced and experienced must work on this
For Best Pediatric Case Management – Each member of the team must know

- How to approach children
  - Smile, be calm, on their level, appreciate their play

- Developmental levels

- How to communicate with children
  - Positive, fun – if ‘mood of room’ allows
  - Concrete terms
  - Appropriate choices
  - With honesty
  - Remember body language messages
Communicating with children as patients

Generic conversation starters

– Pets
– Siblings
– Family
– School
– Seasonal

Cautions

– Be aware of body language
– Be aware of tone
– Don’t talk about food
– Don’t talk about medical stuff unless necessary
Communication Strategies – Special needs children

- Children with multiple handicaps
  - Avoid labeling
    - Down syndrome
  - Use sensitive words such as developmentally delayed instead of retarded
  - Avoid words like “normal”
Communication – Breaking bad news

- Based on information from hundreds of parents of children with heart disease – factors in receiving the diagnosis or new
  - Setting and emotions –
  - Demeanor
  - Timeframes
  - Accessibility of professionals
  - Control
  - Repetition

Kamm DH. Cong Card Today 2005; 3: 12-16
www.caheartconnection.org
Case Management Strategies – Care Coordination Programs for Children

- Features that contribute to program success
  - Based on 5 coordination programs that serve children and families: First 5 Initiative (IA), Pediatric Practice Enhancement Project (RI), Colorado Children’s Healthcare Access Program (CO), Assuring Better Child Health & Development (NC), and Help Me Grow (CT)
  - Maximizing efficiencies through shared resources
  - Engaging pediatric practices
  - Providing training and tools
  - Leveraging existing systems and creating partnerships
  - Making funding and sustainability a priority
  - Incorporating flexible program design
  - Assessing service gaps and evaluating effectiveness
  - Taking a holistic approach to care coordination

Silow-Carroll S & Hagelow G. CareManagement 2011; 17: 7-13
Management Strategies – Medical Home Partnership

- **American Academy of Pediatrics definition**
  - Model of delivering primary medical care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. (AAP 2002)
- Partnership is perfect with case management

- **Medical home benefits can include**
  - Ability to advocate
  - Care coordination in disease management
  - Coordinate preventive services
  - Interdisciplinary collaboration – enhanced skills
  - Improved quality and reduced costs

Management Strategies – Community Asthma Initiative

- 283 patients from low-income families in urban setting offered enhanced asthma care with nurse case management and home visits

- **Results**
  - Decreased ED visits by 68% and hospitalizations by 42.6%
  - Reduced school absence by 41% and parent work absence by 49.7%
  - Days with activity limitations declined by 42.6%
  - Hospital costs reduced compared to data from comparison community

Asthma case management

- 139 children/100,000 population in Michigan in 2008 had potentially preventable hospitalization
- National Asthma Education and Prevention Program (NAEPP) strategies reduces hospitalization, ER visits, urgent office visits, and missed school.
- Management strategies
  - Patient – focus on self-management to avoid triggers, anticipation of problems, and medication compliance
  - Providers – focus on accurate diagnosis, appropriate medication prescribing, patient monitoring, and patient education

Case Management – Ambulatory Care

- Ambulatory Care Coordination Program (Australia)
  - Team of experienced tertiary nurses led interventions
    - 24/7 phone support, personalized integrated care plans (emergency and/or symptom plans), familiarity with pt conditions, enhanced communication between specialists and community professionals, & proactivity in DC planning when hospitalization occurred
    - Results - phone contacts supported home management, decreased unnecessary hospital/ED visits, continuum inpatient and outpatient services
    - Interventions most valued by parents – 24/7 phone access and nurses’ familiarity with child’s condition

Case Manager – Decision Making

• Balancing act –
  – Must strategize and work with clients to balance and weigh influencing factors and constraints to achieve home care for children with complex needs.
  – Interplay for decisions involves relational ethics
    • Ethical practice situated in a relationship
  – Based on knowledge and collective experience

Fraser KD et al. Care management Journals 2010; 11: 151-156
Impacts of Case Management Strategies in Other Specific Areas


- Prenatal Care Coordination for mothers on Medicaid led to fewer NICU admissions, low-birth-weight infants and preterm babies. Van Dijk JAW et al. JOGNN 2011;40:98-108

- Coordinating case management that includes periodic developmental surveillance throughout childhood in children with congenital heart disease can enhance allow intervention and enhance later academic, behavioral, and psychosocial functioning. Marino BS et al. Circulation 2012;126:00-00.
Management strategies

• **Discharge planning**
  – Start as early as possible
  – Multidisciplinary process
  – Determine destination – facility or home
  – Assess psychosocial readiness – pt and family
  – Availability of resources
    • Therapists
    • Education – school
  – Home environment – water, power, safety
  – 2 care providers – consider “care contract”
    • Training – care, equipment
Discharge Planning

• AAP recommends a systematic approach of family-centered, coordinated care with advanced planning for best outcomes for kids, families and providers.
  – This is especially true for patients with complex issues
  – To accomplish this, must have DC planning when pediatric hospitalization occurs

• AAP guidelines for discharge to home for kids with complex needs include:
  – Predischarge planning
  – Maintaining optimal home care – Medical Home
  – Making the transition from hospital to home
  – Maintaining home care

Pediatrics 2012
Palliative care

• With increased care of complex pediatric patients at home – increased need for the role of palliative care
  – Odds of a complex pediatric patient dying at home increased significantly from 1989 to 2003
    Feudtner C et al. JAMA 2007; 297:2725-2732
  • Early introduction of concept of palliative care

– Goals of consultation
  • Symptom management
  • Facilitating communication
  • Decision making
  • Coordination of care
D’Anna Saul, MD, FAAP
University of Michigan
Department of Pediatrics
Grand Rounds
August 21, 2012
Decision Making at End of Life in Pediatrics

- **Advance Care Planning/Advance Care Directives**
  - Case management with colleagues experienced in palliative care

- **Decision-making at the end of life can be more complicated for children and adolescents than for adults because of issues with competency and capacity.**
Why is ACP important?

Data from 3 pediatric palliative care programs 2000-2006.
Adult vs. Pediatric ACP

• Much more attention to ACP for adults than children

• Available information cannot always be extrapolated to children:
  – Parents, not children, have legal authority to make decisions
  – Children’s preferences might only be honored if parents agree

• Families can focus on life-sustaining therapies longer, postponing EOL plans
Death of a child – case management

- Childhood death is particularly traumatic
- Case management team should have a plan for addressing pediatric death
  - Recognize the profound effect on parents and staff
  - Expertise can make a difference
  - Multidisciplinary education using simulation
    - Utilize appropriate scenario(s)
    - Provides practice for complex communication in a realistic environment
    - Debriefing allows discovery of best communication and support

Youngblood AQ et al. Crit Care Ns 2012; 32: 55-61
Barriers and challenges
Barriers/Challenges

• Behavioral disorders/Autism spectrum – unmet needs in medical homes
  – Parent concerns
    • Delayed recognition of behavioral and developmental disorders
    • Less comprehensive, coordinated and family-centered care and inadequate advocacy for services
    • Caregiver stress
  – Challenges for providers
    • Time
    • Patience required
    • Resources

Chronically critically ill children/chronically medically supported

- Technology dependence; medically fragile
- Increased risk for physical, developmental, behavioral, and/or emotional conditions
- Elevated need for healthcare services – PT, OT, SLP…. – coordination challenges
- Care setting for this population
  - Adults – ICU to long term acute care (LTAC) or skilled nursing facility
  - Peds - acute care to home

Peterson-Carmichael S, Cheifetz I. Resp Care 2012; 57: 993-1003
Barriers - Complex patients


• Lack of experience of primary care providers with this population

• Emergency preparedness

• Knowledge gaps of home health care personnel
  – Home ventilators in particular
Home Healthcare for Complex Pediatrics

- Issue – maintaining adequacy and competency of qualified home healthcare nursing
- Home care nurses must have resources –
  - Nursing education – basic and continuing
  - Access to acute care practitioners in the tertiary care center

Home Healthcare for Complex Pediatrics

- Initial short term goals for initiation of home care
  - Safety
  - Medication administration
  - Psychosocial support
  - Prevention of infection
  - Prevention of complications
  - Comfort/Promotion of bonding

Home Healthcare for Complex Pediatrics

- When home care plan has been established and short term goals met the care for a child with special needs must transition with continuity of care
  - Identifying long term care
    - Early Intervention Programs
    - Programs through Medicaid or waiver programs
    - Services – nursing, therapy, counseling
  - Joint visit from acute home care nurse to longer term program staff to transition

Increased frequency of inpatient care

2000-2006

- Discharges for vent dependent children increased by 55%
- Total charges for admissions – increased by 70%
- Nearly doubling of number supported by public financing
- Population served by private insurance only increased by 12%

Benneyworth BD et al. Ped 2011; 127: e1533-e1541
Ventilator dependent children - Care issues for case management

- Tracheostomy care
- Ventilator management
- Monitoring
- Neuromuscular weakness
- Airway clearance – vulnerability related to smaller airway and smaller trach tubes
- Feeding issues

Benneyworth BD et al. Ped 2011; 127: e1533-e1541
Ventilator dependent children - Care issues for case management

• Withdrawal of life-supporting treatment - management requires
  – Interdisciplinary team must assure that they agree about information to present to patient and family
  – Team should gather information about the family’s coping abilities
  – Conferences with patient and parents
    • Decision about whether patient will participate
    • All must understand the process
  – Emotional support
  – Clear communication
  – Organized approach to achieve a peaceful death

Stacy KM. Crit Care Ns 2012; 32: 14-23
Complex child care - benefits

- Survey of parents of 79 children with Trisomy 13 or 18 who elected “full” treatment for their children and were in support groups
  - 50% reported care for disabled child was more difficult than anticipated
  - 97% described their child as happy
  - Reported that the experience enriched their family

Javier A et al. Peds 2012; 130:293-298
Challenge – Assessing Quality of Life

- Successful case management must consider quality of life in children – allows team to go from helping them survive to helping them thrive
  - With ability to aggressively manage complex conditions there are ongoing quality of life issues – family, self-management, school, peers, activities…..
  - Strategies that may be appropriate for assessing some pediatric populations
    - Routine screening of QOL for cardiac children (Uzark K et al. Peds 2008; 121:1060e-1067e)
    - Use of standardized psychosocial status testing
    - Simple questions – what makes days good/easy or bad/hard (Green et al. 2007; Green et al. 2011)
    - Green A. J Ped Nsg 2012; 27: 193
Other barriers


- Lack of some services challenges case management – Pediatric long term care, rehabilitation, and inpatient pediatric psychiatric facilities lacking and reimbursement of this care may be poor. Hosp Case Management 2010

- Immigration status with lack of coverage may result in inability to find appropriate home care. Hosp Case Management 2010
Barriers/Challenges

- Insurance dictating location of care regardless of outcome data
- Parental custody
- Foster care
- Transportation
- Reimbursement
Transitioning care

• Transition from pediatric to adult healthcare
  – Allows patient more independence
  – Categories to address for successful transition
    • Focused education
    • Skills training
    • Staffing
      – Transition coordinators
      – Combined/transition clinics
      – Targeted services –
        » Young adult clinics
        » Telephone services

Peterson-Carmichael S, Cheifetz I. Resp Care 2012; 57: 993-1003
Transitioning care

• Transition from pediatric to adult healthcare
  – Adult physicians may not be familiar with “childhood illnesses” and there can be adverse outcomes as a result during transition
    • Delayed recognition of needs
    • Unfamiliar with specialized follow-up surveillance and management needs
Transition of care team – complex adult congenital heart disease (CHD)

- Adults who had complex pediatric heart surgery may have unique sets of issues
  - Hemodynamic, electrophysiologic, multisystem dysfunction, and others

- Establishing a team to address CHD care plus address the medical/social needs of adulthood is necessary – nurses as coordinators
  - Cardiology, CV surgery, EP, internal medicine, psychiatry, social work, chaplain service, etc.

- PNPs experienced in CHD may be uniquely qualified to coordinate care for this population to improve outcomes and quality of life.

Dechert BE, Deal BJ. J of Ped Health Care 2008; 22: 246-253
Lessons learned
Summary

- **Effective pediatric case management**
  - Assists families in navigating complex services
  - Creates a feedback loop with all practitioners
  - Promotes earlier identification of developmental delays and complications
  - Helps families who are risk for falling through the cracks

Silow-Carroll S & Hagelow G. CareManagement 2011; 17: 7-13
Summary

- **Remember**
  - Children are NOT miniature adults!
  - Chronological age does NOT always = developmental age/stage
  - Caring for a child means that the family is your patient
  - You can make your interactions impact a child’s life in a positive fashion –

  WHAT A NEAT OPPORTUNITY!!!