Exploring the Care of Medically Complex Children

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Learning Objectives
At the end of this presentation the participant will be able to:
1. Recognize and classify a child with medical complexity
2. Describe medical home model and support services needed to support a medically complex child
3. Discuss ways of improving care for these children

Disclosure
Wisdeen Wu, D.O. has no relationships with commercial companies to disclose.

Children with Complex needs
• Other terms: Children with medical complexity (CMC), children with special health care needs (CSHCN), complex chronic conditions (CCC)
• Definitions:
  • Condition expected to last longer than 12 months
  • More than 2 organ systems
  • Technology dependence
  • Medication dependence
  • Complex medical decision making (surgeries, goals of care)

Children with Complex Needs
Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.
Children with Complex needs

- Growing population and proportion of pediatric care
- Goals of optimizing child’s health, function, and quality of life
- Benefit from a comprehensive medical home model or care coordination

Classification

- CCC numbers
  - Last 6 months
    - Clinic visits: > 700
    - Unique patients ~350
    - Most patients seen once every 6 months
Serving South Texas

Sampling of Underlying Diagnoses
- Anoxic brain injury
- Congenital hydrocephalus
- Severe Cerebral palsy
- Septo-optic dysplasia
- Mitochondrial disorders
- Muscular Dystrophies
- Spina Bifida
- VACTERL
- Cornelia De Lange Syndrome
- Treacher Collins syndrome
- DiGeorge syndrome
- Chromosomal abnormalities (Trisomy 18, Trisomy 21)
- Congenital Heart with complications

Financial impact
- They are high resource utilizers of medical system:
  - Hospitalizations and ER visits
  - Specialist and clinic visits
  - Medical equipment
  - Home-based services - nursing care and therapies

Medical Home
- Routine preventive care/well child care
- Specialty referrals (and prioritization)
- Medical equipment
- Medication management
- Nursing support services
- Therapy services
- School services
Preventive Care

- Vaccinations
- Growth/nutrition
  - Using specific growth charts
- Disease Surveillance
  - Published guidelines for Down Syndrome, Turner Syndrome, Williams syndrome, Neurofibromatosis, Cornelia de Lange, etc.

Medical Equipment

- Mobility
  - Wheelchair
  - Adapted car seat
  - Lift system
  - Stander
  - Orthotics

- Respiratory
  - Oxygen, pulse oximeter
  - Nebulizer machine
  - Suction machine
  - Tracheostomy
  - Ventilator
  - Cough assist
  - Vest

- Feeding
  - Gastrostomy tube (what size and type)
  - Feeding pump
  - Syringes or feeding bags

- Elimination
  - Urinary catheters
  - Colostomy
  - Urostomy
Medication Management

• Updating medications at every encounter (hospitalization, discharge, clinic visits)
• Updating dosages
• Reviewing interactions
• Prior Authorizations
• Home remedies

Nursing support

• Private duty nursing (PDN)
• Skilled nursing
• Provider care services

School support

• Special education
  • 504 plan
• Adaptive equipment
• School nurse support
  • Medications
  • Intermittent care (like colostomy or catheterization)
• Dietary adjustments

Community Support

• Syndrome specific support group
• Online support groups
• Sibling support groups
• Family
• Religious groups
• Camps

Areas for improvement

• Resident education
  • Acknowledge challenges in caring for this population
  • Extending learning experiences
  • Continuity

Areas for improvement
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Quality Measures
1. Primary care
2. Patient/family-centered care
3. Chronic care
4. Coordination of care
5. Transition of care

Areas for improvement

• Transition care to adult providers
• Community support and networking
• Parent navigators
• Written emergency care plan

Our CCC team

• Physicians/Providers
• Nurse case managers
• Social Worker
• Dietician
• YOU

How to refer

• Call 210-358-KIDS (5437) for intake interview
• Secure health message in Sunrise
• Email
• Phone call

References

References


Thanks!