MULTIDIMENSIONAL SYMPTOM MANAGEMENT

In Children with Complex Medical Conditions

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Objectives

1) Identify key characteristics of children with complex conditions

2) Recognize the impact of symptom burden on the child and family

3) Discuss the role of interdisciplinary care management
The Population

- Children with Complex Chronic Conditions (CCC)
  - Chronic, irreversible condition requiring ongoing medical care
  - Life-threatening/Life Limiting Illnesses
  - Medically Fragile
  - Technology Dependent
  - Increased risk of symptoms and suffering due to medical condition, treatment
  - Probability of premature death in childhood, adolescents or early adulthood
Primary Diagnoses

- Cancer and Hematologic conditions
- Congenital Anomalies
- Static and Progressive Neurologic disorders
- Neuromuscular disorders
- HIV
- Metabolic Disorders
- End-stage organ failure
- Neurological Devastation/Trauma
- Cystic Fibrosis
- Rare/Orphan Conditions
Symptom Burden in CCC

• **Cancer**
  - pain, fatigue, sleep disturbance, loss of energy, nausea and vomiting, hair loss, and behavior and mood changes
  - Report up to 11 symptoms per week
  - Higher severity associated with lower health related QOL
Symptom Burden in CCC

- Cystic Fibrosis (Dellen et al 2010)
  - Dyspnea (100%)
  - Fatigue (96%)
  - Anorexia (85%)
  - Anxiety (74%)
  - Cough (56%)

- Symptom control ‘somewhat good’ 71%

- Medications/treatments caused discomfort but were felt to be necessary
Symptom Burden in CCC

• Metabolic Disease (Malcolm, C 2011)
  • Batten; Sanfilippo; Morquio
    • Pain, cold hands/feet, joint stiffness, disturbed sleep
    • Agitation, repetitive behaviors, nausea/vomiting, constipation, diarrhea
    • Cough, choking, drooling, muscle spasms, seizures, breathing difficulties, secretions, sleep problems,
  • Pain, spasms, seizures and breathing were most difficult to control
  • Sanfilippo had most symptom frequency and severity, followed by Batten, then Morquio
Symptom Management - Parents

- Families employ numerous pharmacologic and non-pharmacologic strategies to provide symptom relief for their children
  - Parent intuition, knowledge, experience; home management; flexibility in medication management; expertise in condition/management over time
  - Worry and distress about uncontrolled symptoms creates a sense of helplessness that leads to seeking medical attention
  - Parents value advice from providers who understand the disease and their child
Challenges for Providers

• Difficulty assessing symptom due to communication challenges

• Most challenging symptoms
  • Behavioral; seizure

• Relentless nature of symptoms as disease progresses leads to sense of helplessness
SYMPTOM ASSESSMENT
Challenges in Symptom Assessment and Management

- Children are living longer with complex medical conditions
  - Worsening with disease progression
  - Cognitive and communication impairments

- Numerous care providers
  - Ambulatory Care; Inpatient Care; Community based care

- Numerous transitions in care

- Wide range of disease management options
  - Pharmacological
  - Technological
  - Supportive

- Multidimensional/Inter-related nature of distress
Multidimensional Distress

- Physical
- Emotional
- Social
- Spiritual
- Child Family
Multidimensional Distress

- Pain; Dyspnea; Fatigue
- Spiritual Mortality; Faith; Hope
- Cancer; CF; Sickle Cell
- Emotional Coping; Sadness; Worry
- Social Isolation; withdrawal

Emotional Coping; Sadness; Worry

Social Isolation; withdrawal

Spiritual Mortality; Faith; Hope

Cancer; CF; Sickle Cell

Pain; Dyspnea; Fatigue

Multidimensional Distress
Inter-related Distress

Disease

Complication s/Side Effects

Child

Symptoms

Co/Multi morbidity
Inter-related Distress

- HIE
- Child
- VP Shunt Complications
- Gastrostomy Complications
- Medication SE
- Gastroparesis
- Feeding Difficulties
- Vomiting
- Constipation
- Seizures
Disease Trajectory

Goal
- Cure
- Prolong life
- Prolong life
- End of life

Morbidity
- High
  - Moderate
  - Minimal
  - Mild

Attitude
- Win
  - Fight
  - Live with it
  - Surrender

Disease effect
- Eradicate
  - Response
  - Arrest growth
  - None

Original slide design – J. Kane MD
Anticipatory Guidance

• This is what parents want from us!
  • Majority of parents prefer partnership, want information, but ultimately feel responsible for final decision

• Most presenting co-morbidities will have more than one potential intervention
  • Align interventions with child/family goal for the symptom or problem

• Difficult symptom management decisions
  • Surgery
  • Balancing disease directed therapy and comfort
  • Technology
Transdisciplinary Symptom Management

• “No man is an island, entire of itself; every man is a piece of the continent, a part of the main.” John Donne, 1624

• Optimal approach for successful management of medically complex children

• Provides holistic assessment and management

• “Many hands make light work” John Heywood. 1546
Summary

• Children with complex medical conditions experience significant symptom burden throughout their disease process

• Family provides substantial care, leading to the potential for distress in the family system

• Anticipating, assessing and managing symptom distress for children and family members on a regular basis is imperative

• Develop symptom management plans for the child that provides family with tools to achieve comfort for their child.

• Clarify goals of care, child/parent hopes and potential for symptom management interventions to achieve their goals


References


References