



# MULTIDIMENSIONAL SYMPTOM MANAGEMENT

## In Children with Complex Medical Conditions



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Hospital®**

**BCM**

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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

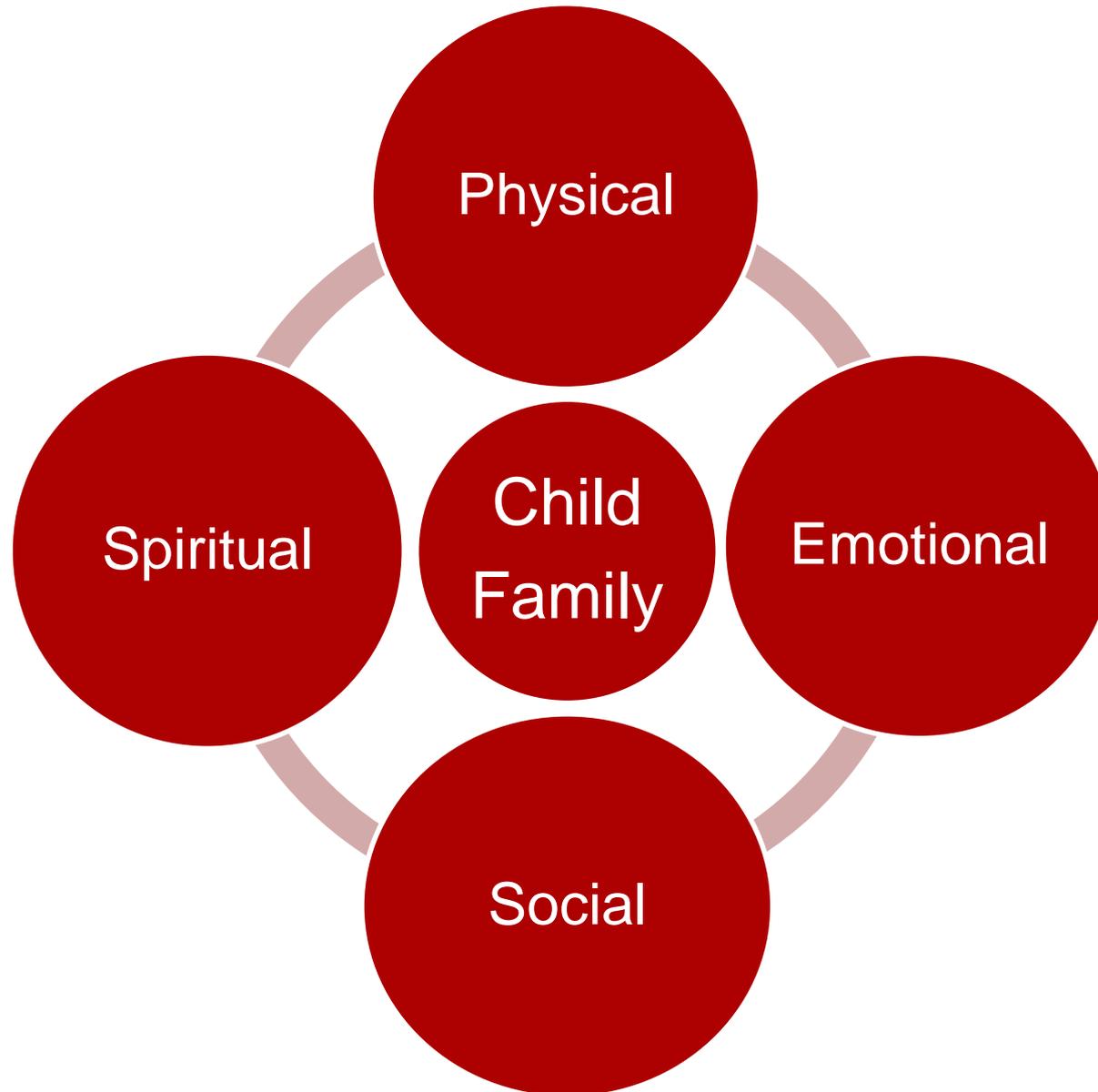
# SYMPTOM ASSESSMENT

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# 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

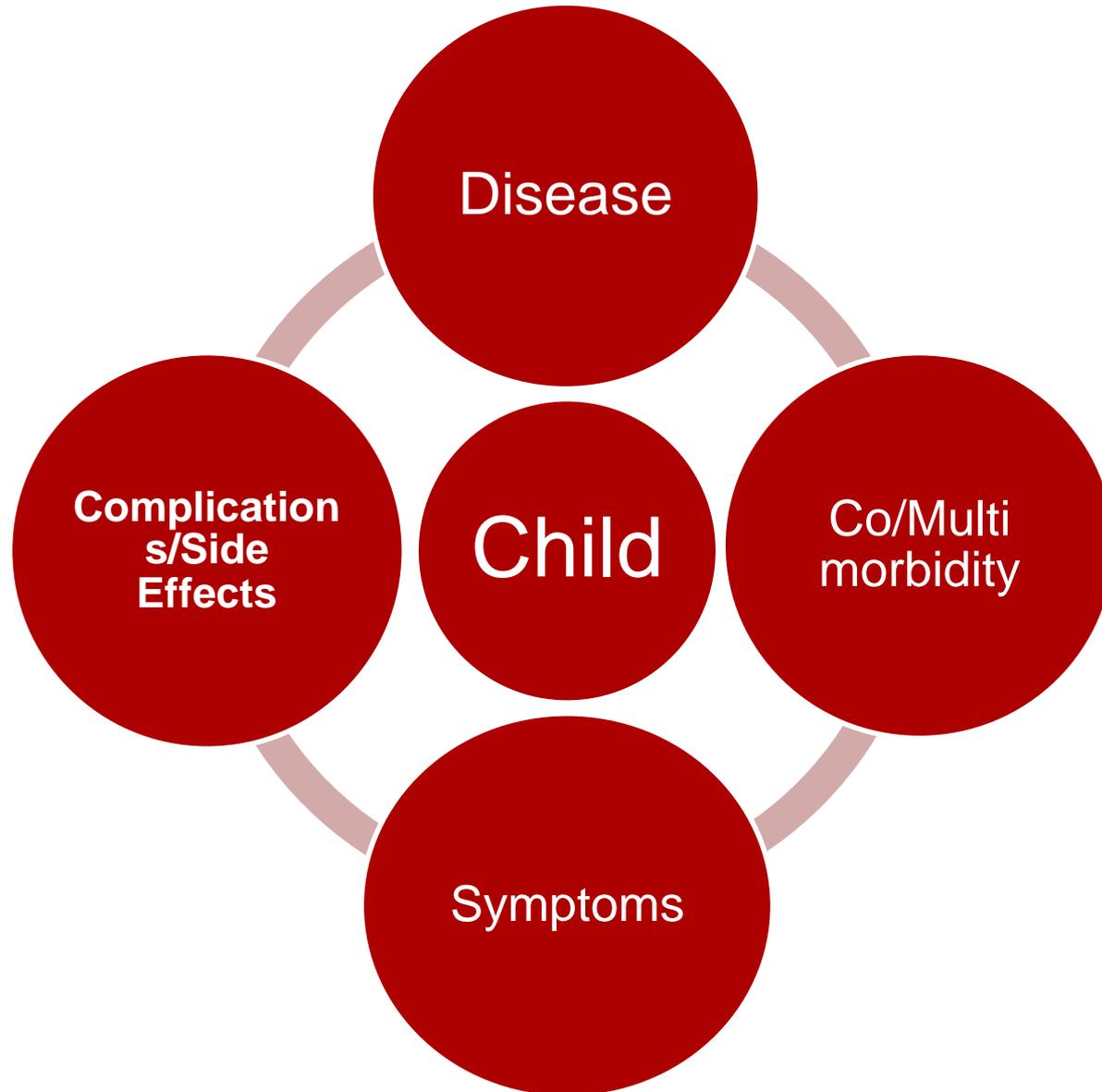
# Multidimensional Distress



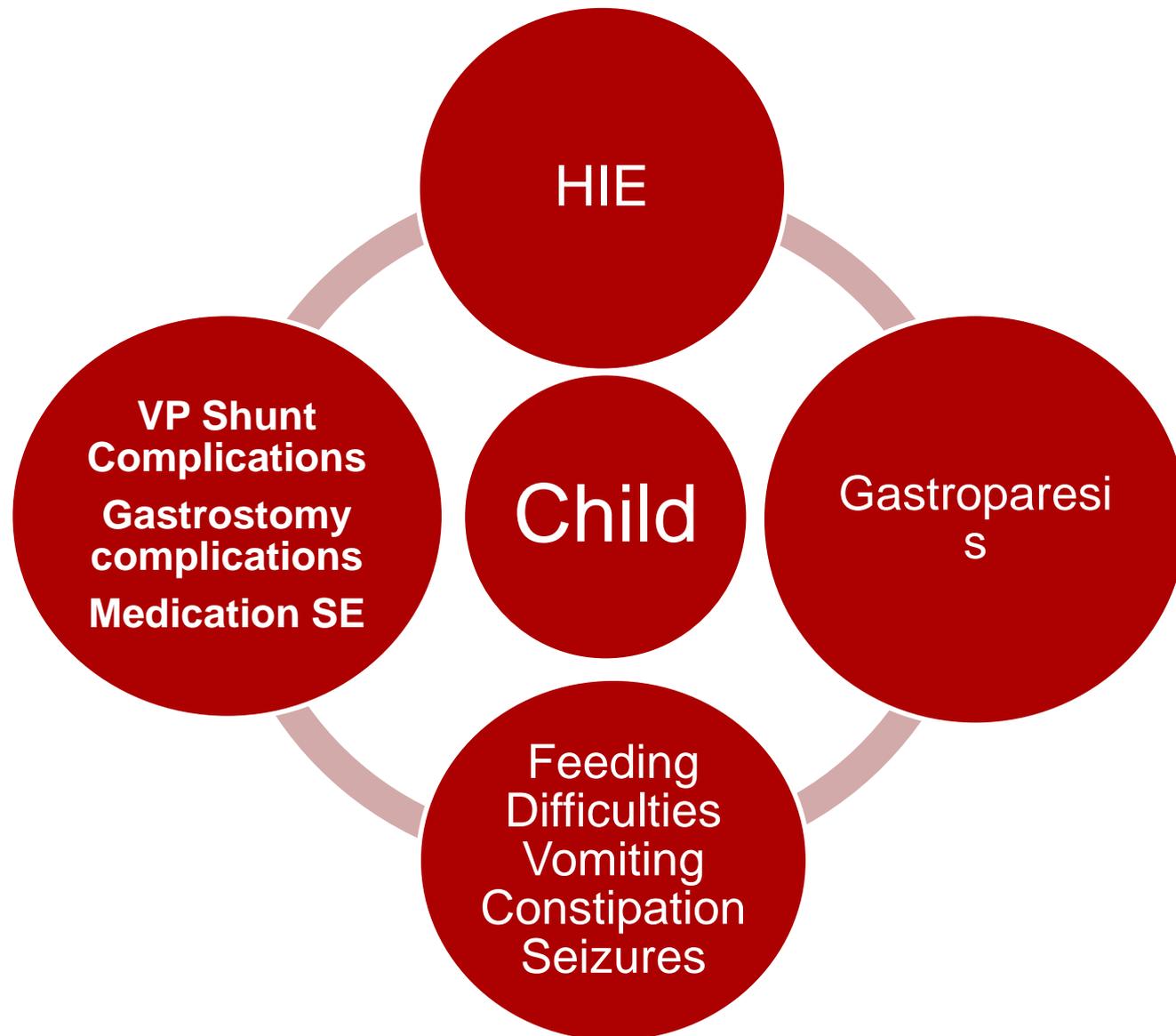
# Multidimensional Distress



# Inter-related Distress



# Inter-related Distress



# 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

# 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

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