

MULTIDIMENSIONAL SYMPTOM MANAGEMENT

In Children with Complex Medical Conditions



**Texas Children's
Hospital®**

BCM

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Pediatrics

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

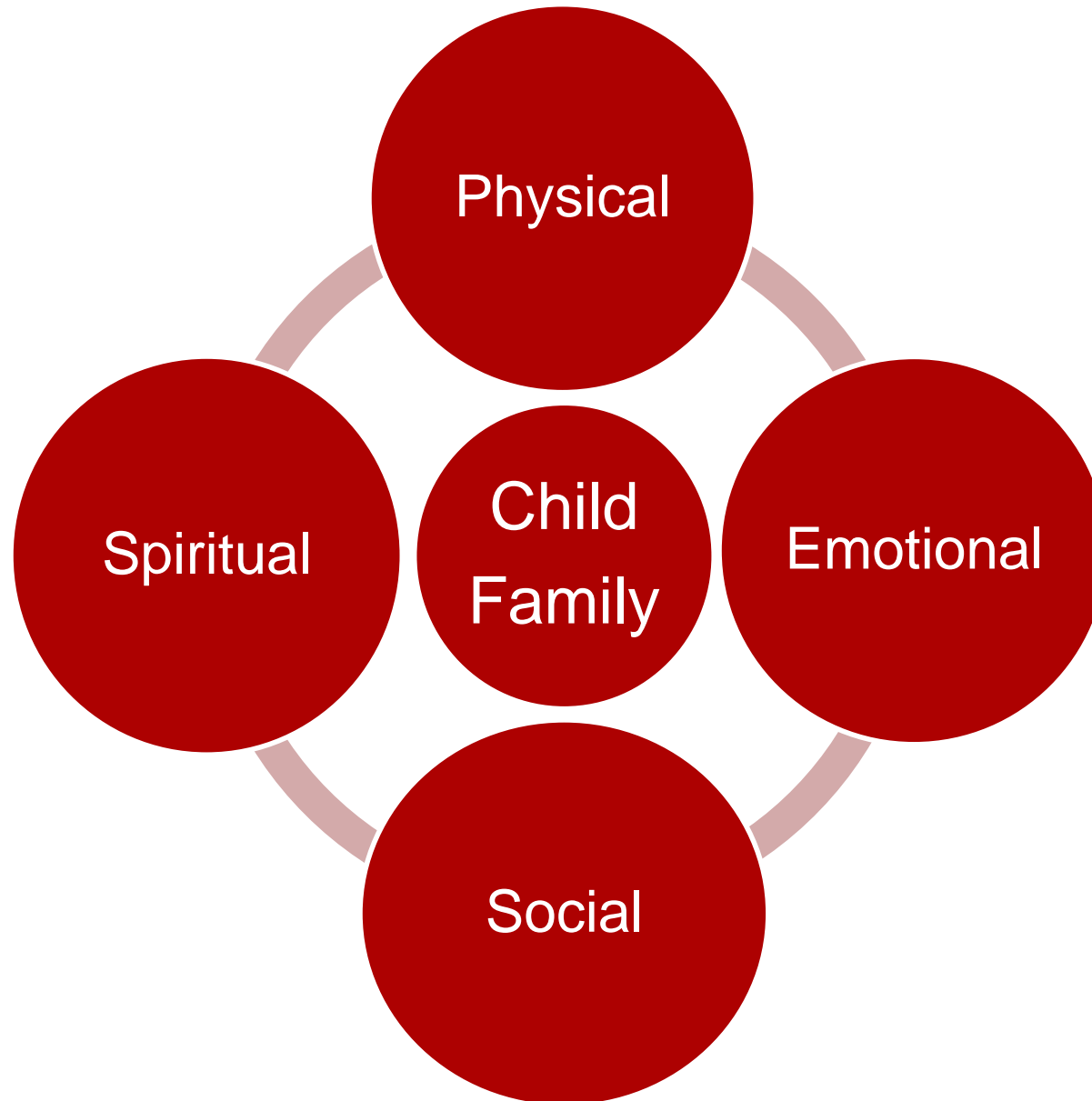
- Difficulty assessing symptom due to communication challenges
- Most challenging symptoms
 - Behavioral; seizure
- Relentless nature of symptoms as disease progresses leads to sense of helplessness

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

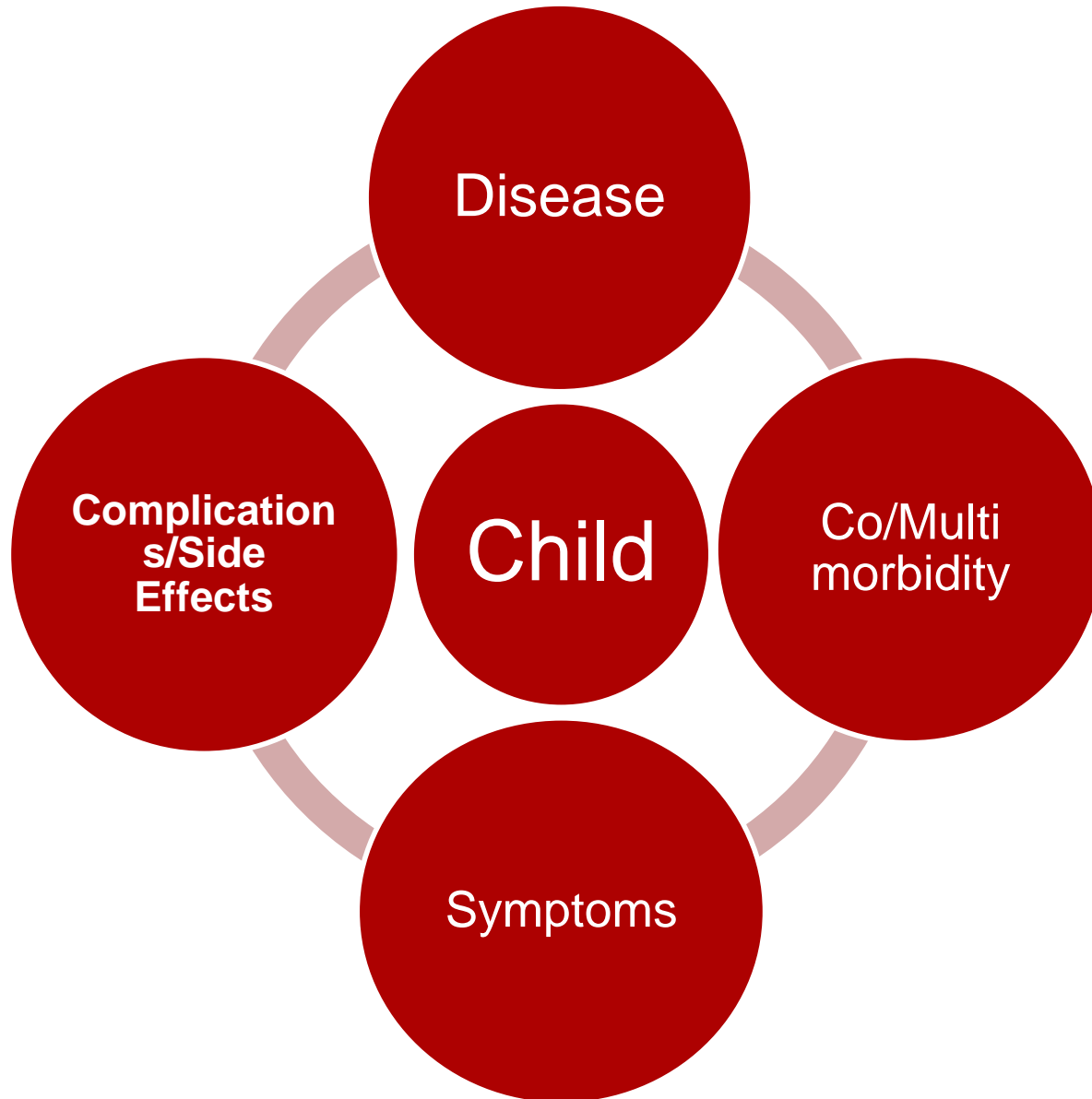
Multidimensional Distress



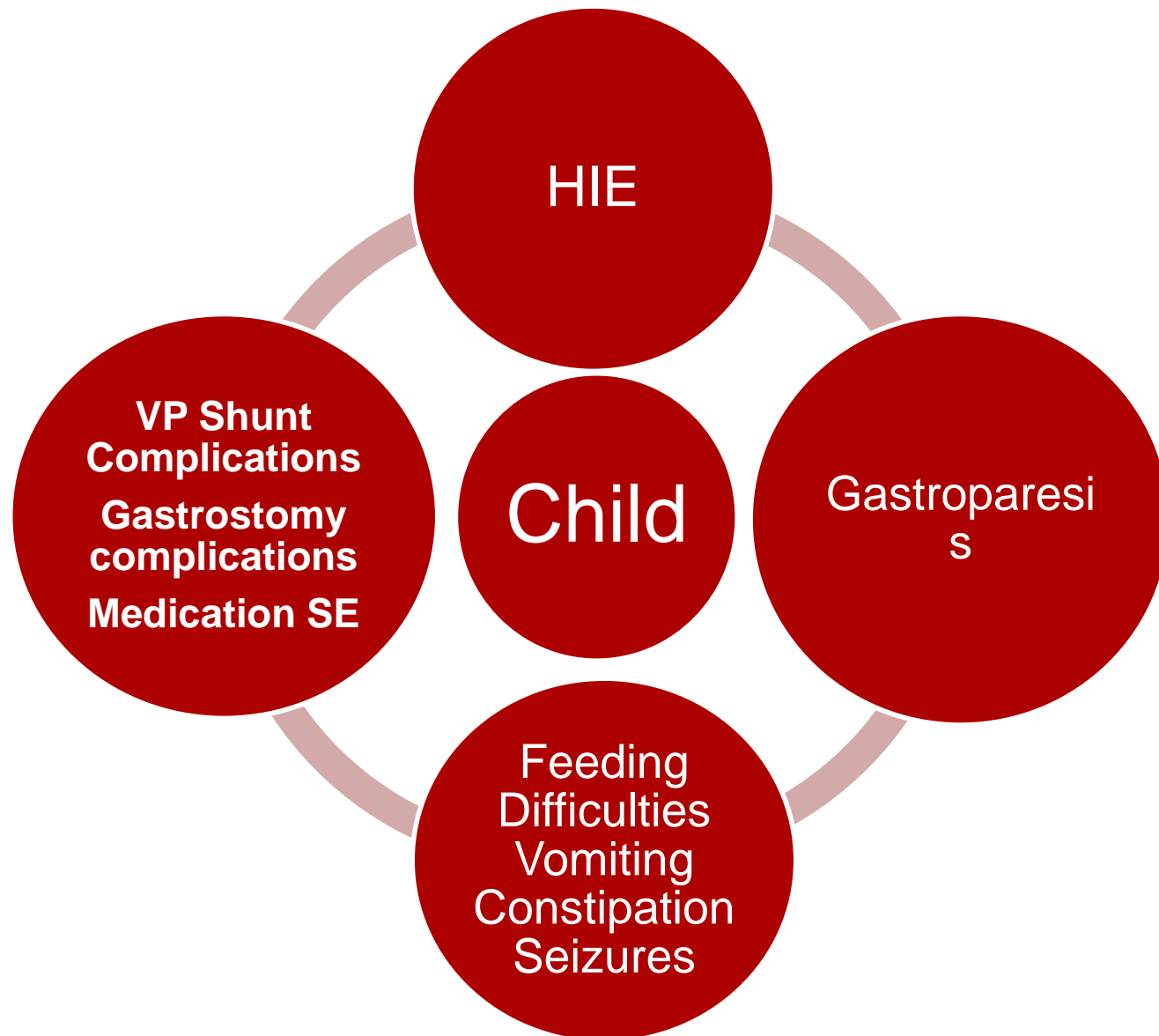
Multidimensional Distress



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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