



Department of Pediatrics
and Human Development
College of Human Medicine
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Primary Care Perspective

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Disclosure

- I have no financial interests related to this presentation to disclose.
- I will not discuss any off-label uses of medications or medical devices.

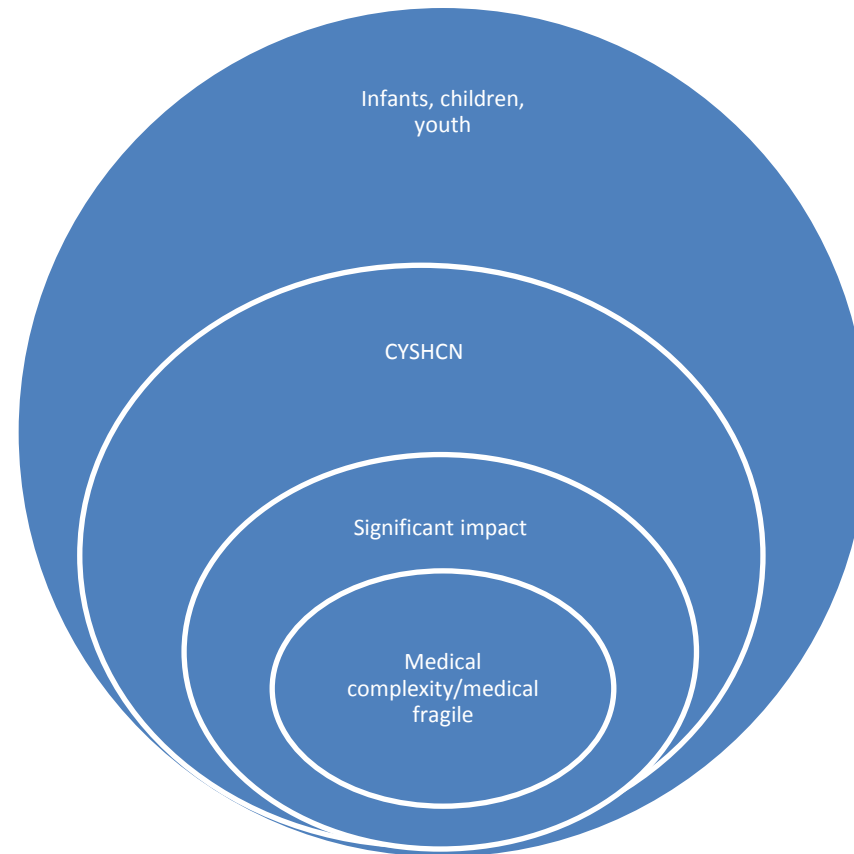
Learning Objectives

- Describe the role of the medical home in caring for children with life-limiting conditions.
- Describe three models of care for children with life-limiting or complex medical conditions.
- Identify one strategy for your practice to improve services for children with serious and life-limiting conditions.

Family-centered medical home

- Preventive care
 - Identify special needs through screening
 - Promote health and development
- Treat acute illnesses
- Manage chronic conditions
- Coordinate care when other professionals are involved
- Central repository of health records

The population we serve



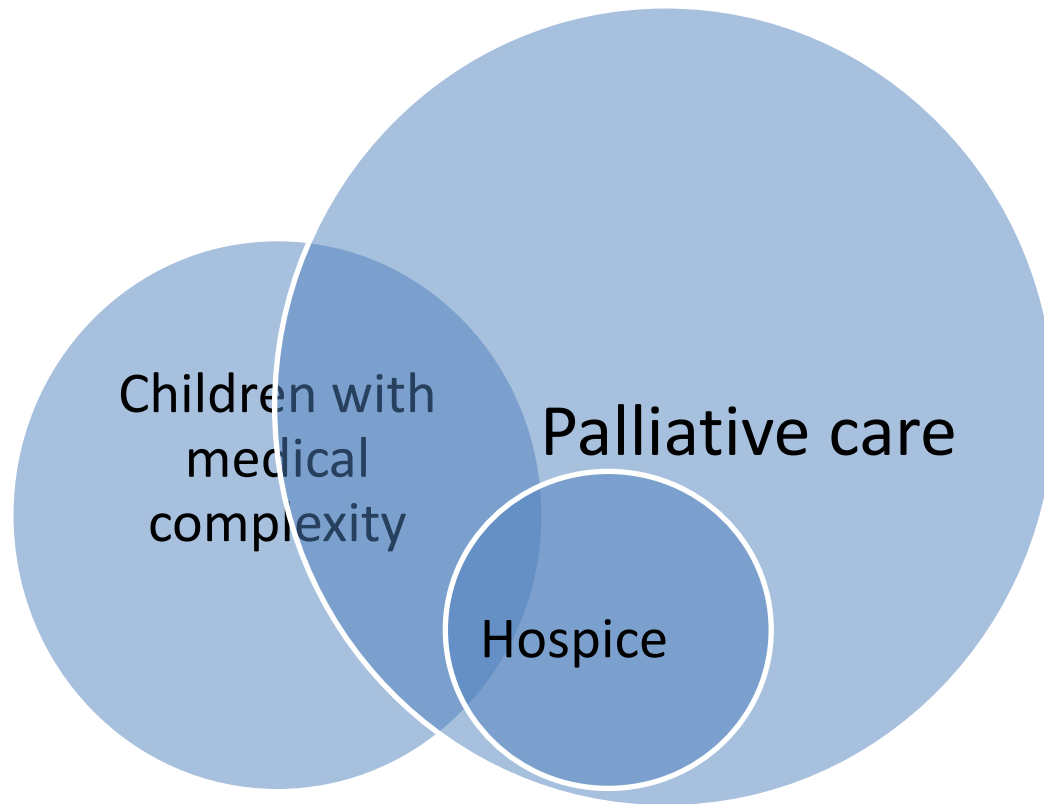
Palliative care is.....

- Comprehensive treatment of the discomfort, symptoms and stress of a serious illness.
- Individuals can receive palliative care at any stage of their disease.
- It does not have to be a “terminal” condition.
- The goal is to prevent and ease suffering and improve quality of life.

Palliative care as subspecialty

- The ABP recognizes Hospice and Palliative Care as a Pediatric Subspecialty
- CSHCS recognizes palliative care subspecialists and covers the physician fees.
- Palliative care is best provided as a team service
- Palliative care addresses emotional needs of the patient and family as well as the medical.
- Primary care pediatricians can *extend the reach*, just as we do in so many subspecialty fields.

children with life-limiting conditions



Models of care for children with life-limiting conditions and/or medical complexity

- Primary Care Centered
- Collaboration – Co-management with subspecialists
- Episodic consultation

Case 1: Primary Care Centered

- Samantha is 24 months old.
- She has holoprosencephaly.
- She was followed by pediatric surgery (for G-tube), ENT (upper airway obstruction), endocrine (diabetes insipidus), and pulmonology (chronic lung disease due to aspiration).
- All her care is now provided by her medical home team.

Samantha

- Medical home team works with parents to manage her nutrition and fluids.
- Pediatrician works with parents to clarify goals and wishes
 - No trache
 - Resuscitation status clarified: do everything needed
 - Minimize visits to subspecialists
 - Minimize visitors in the home
 - Prioritize therapies

Case 2: Collaboration – co-management

- Matthew is 11 years and he had tumor in his neck when he was 6 years old
- Not all the tumor was removed
- He has ongoing endocrine and neurological conditions
- He has significant behavioral/emotional and social complications

Matthew

- Subspecialty care at major children's medical center
- Endocrinology, neurology, neurosurgery, gastroenterology, psychology and **palliative care** at children's center
- Medical home provides preventive care, manages acute illnesses and manages medications for ADHD symptoms (in consultation with psychologist)

Case 3: Episodic consultation

- Alex is 18 months and has a serious metabolic condition that is deteriorating
- His care is managed by his medical home in consultation with the pediatric geneticist
- Palliative care was consulted during a PICU stay for pneumonia and respiratory distress.
- His mother declines palliative care services except when he is seriously ill.

Primary Care Strategies to Improve Palliative Care

- Learn about resources in the community and at the children's centers.
- Offer referral to palliative care team EARLY in children's illness
- Clarify the difference between palliative care and hospice .

More strategies

- Learn communication skills for difficult conversations
 - Conferences
 - Workshops
 - Readings
- Utilize your team –
 - Nurses
 - Medical assistants
 - Behavioral health consultants

More strategies

Join the Children's Palliative Care Coalition of Michigan: <https://childpalliative.org/>

Attend the Children's Palliative Care Conference:
November 2, 2018
East Lansing, MI

Discussion and references

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