

# *Palliative Care of Children and Families*

May 2, 2023  
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# What is Palliative Care?



## Objectives:

- Describe Pediatric Palliative Care services
- Discuss the broad range of patients followed by Palliative Care team
- Discuss common misconceptions about Palliative Care in Pediatrics
- Review the role of Palliative Care team in care of children with serious medical illness including children with cancer

# Pediatric Palliative Care

- **Pediatric Palliative Care prevents, identifies and treats suffering in children with serious illnesses, their families, and the teams that care for them. It is appropriate at any stage of the illness and can be provided together with disease-directed treatment.**
- “The AAP supports an integrated model of palliative care in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death”



***“The goal is to add life to the child’s years,  
not simply years to the child’s life”***

# Pediatric Palliative Care

- Who are the patients?
  - Children with:
    - Severe neurologic issues
      - Anatomic anomalies, hypoxic ischemic encephalopathy
    - Genetic syndromes
    - Metabolic disease
    - Progressive neurologic disorders
    - Respiratory disease
    - Congenital Heart Disease
    - **Cancer**



# Uncertainty in Palliative Care

- Diagnosis?
- Treatment?
- Prognosis?
- Outcome?





## Pediatric Palliative Care

- Aims to improve the **quality of life** and **reduce suffering** in children with complex medical conditions and their families

Every child and family is unique → medical care should be based on their goals, values, and beliefs.



[www.getpalliative.org](http://www.getpalliative.org)

## Primary palliative care: Skills for all clinicians

Sue S. Sreedhar, MD,<sup>a,\*</sup> Colleen Kraft, MD, MBA,<sup>b</sup> and Sarah Friebert, MD

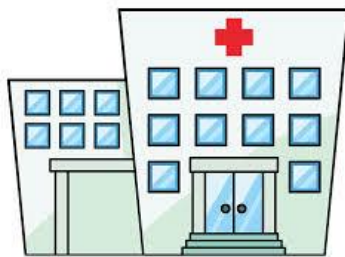
The Goals of Pediatric PC are to:

- (1) **Relieve suffering** – physical (pain), psychological (suffering, depression, anxiety), social (isolation), practical (home-based services, financial stress), and existential or spiritual (why is this happening to me?).
- (2) **Improve the child's enjoyment and QOL** while helping families adapt and function during the illness and bereavement.
- (3) **Facilitate informed decision making** by patients, families, and health care professionals.
- (4) Assist with ongoing **coordination of care** among clinicians and across various sites of care.



## HDVCH Pediatric Palliative Care

**HOSPITAL** ↔ **CLINIC** ↔ **HOME**

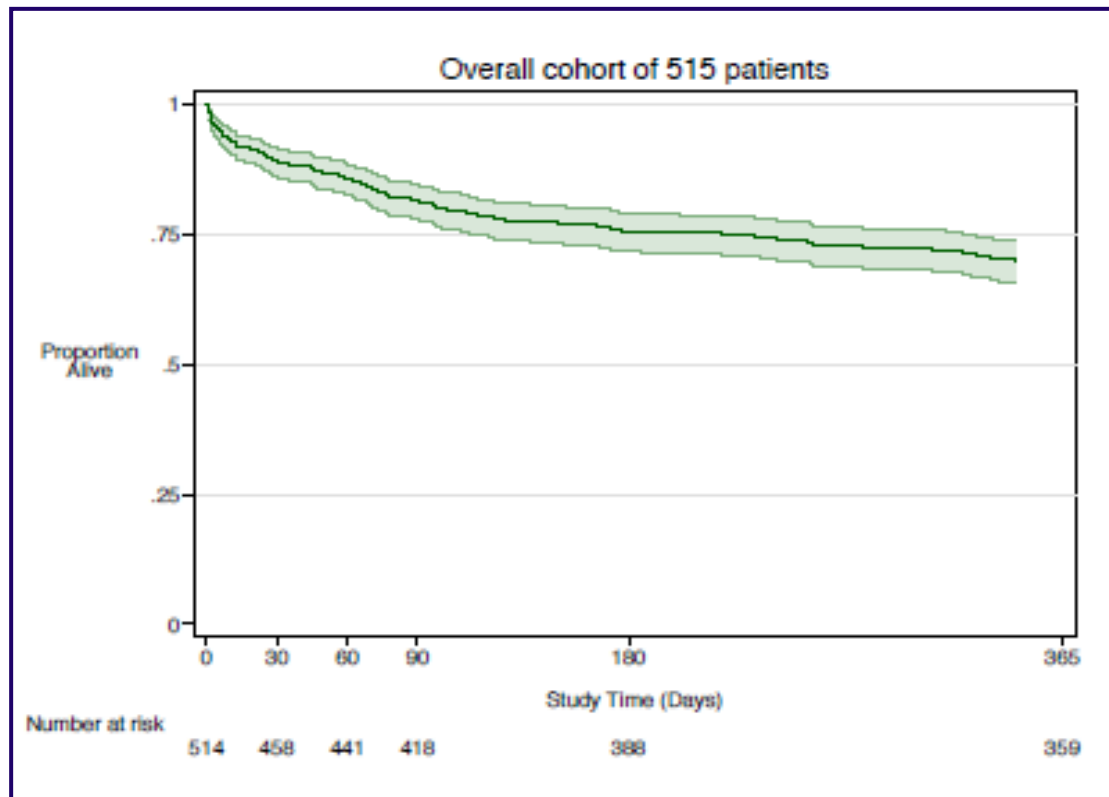


# Common Misconceptions

- Patient is not dying, why would they need your team?
- Palliative Care = Hospice
- Family is not ready to give up hope...



## Survival of patients receiving pediatric palliative care



Prognosis doesn't matter!

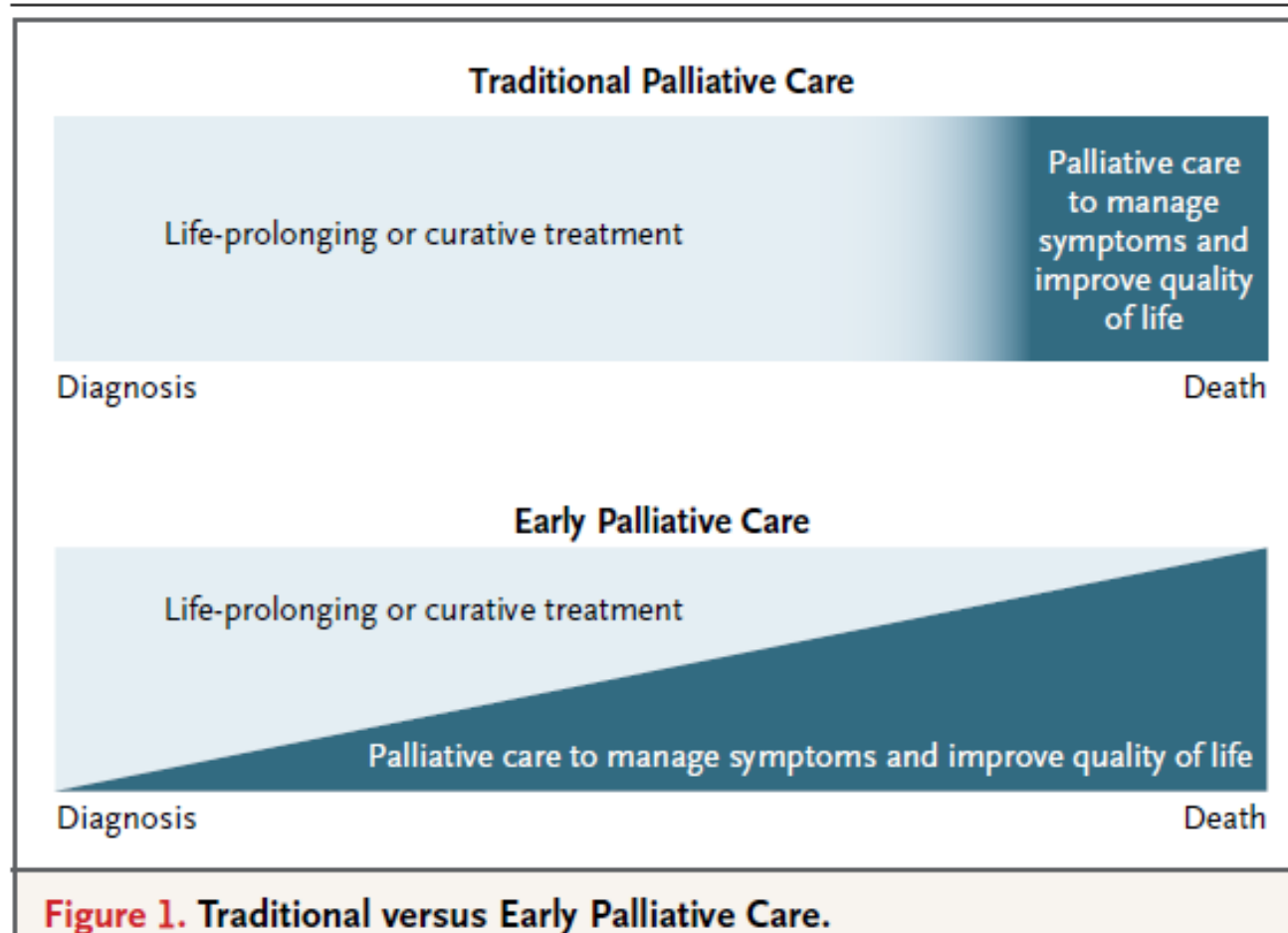
It's not about dying—it's about living with a serious illness

# Hope in face of serious illness

- **Parents and pediatric patients may opt for continued treatment of underlying disease even when there is no realistic hope for cure**
  - Wolfe J et al. JAMA 2000. 284(19)2469-75
  - Goldman A et al. J Pall Med 2000 3(3)353-359
  - JCO Oncol Pract 17:e730-e739, 2021
- Hope for a miracle
- Desire to extend life
- Desire to palliate symptoms related to progressive disease
- **Hope often needs to be reframed**
- Lack of curative options or aggressive treatment does not mean lack of caring
- **Best medical care does not always involve the most medical technology**



# When should palliative care involvement start?



Disease Progression - Conditions appropriate for Palliative Care may or may not progress to death



## Common Trajectory Of Decline In Progressive Life-Limiting Illness In Children





## PPC: Better care, improved QOL, cost savings?

- **Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions.**

Policy Brief UCLA Cent Health Policy Res. Aug 2012

- **Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution.**
  - 425 children (age 1-21) receiving home-based PPC or hospice services 2000-2010
  - Compared pediatric resource utilization before and after enrollment
  - Non-cancer patients: LOS decreased 38 days, decreased hospital charges \$275,000/patient

J Palliat Med 2014;17(2):183-8

### ■ **Impact of Specialized Palliative Care: A Systemic Review**

- 24 studies over 22 years
- Improved overall QOL was most consistent impact

*J Pain Symptom Manage.* 2020 February ; 59(2): 339–364.e10.

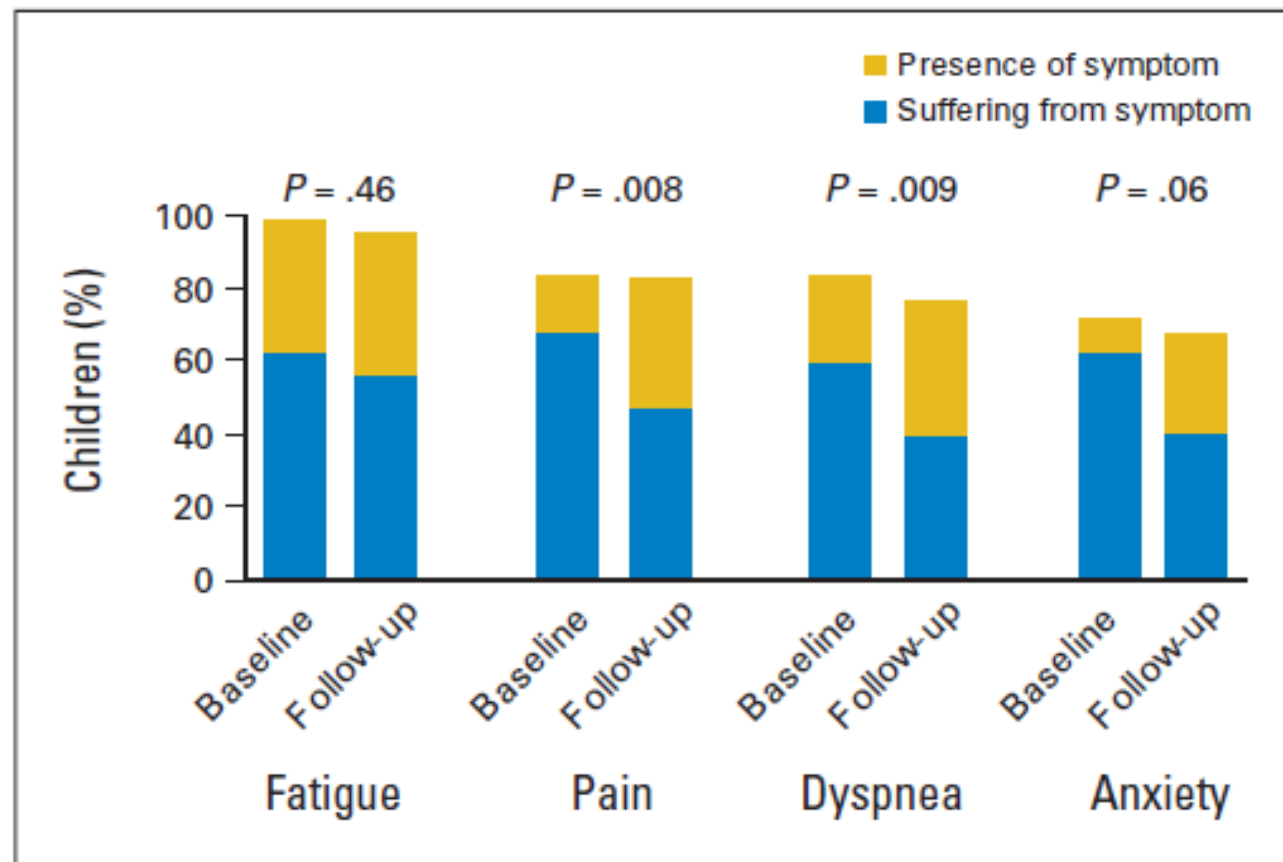
## Common Trajectory Of Children with Cancer



# Does Palliative Care involvement make a difference?

- Adult data
  - Prolongs survival
  - Improved quality of life and mood *NEJM 2010;363(8):733-742*
  - Decreases caregiver burden *J Pall Medicine 2011;14(4):465-473*
  - Improved nursing perception of quality of dying *Am J Resp Crit Care Med 2008;178(3)*
  - ASCO 2012 → early integration of palliative care into standard cancer treatment in malignancies with high symptom burden *J Clinical Oncology 2012;30(8):880-887*

# Does Palliative Care involvement make a difference?



# Does Palliative Care involvement make a difference?

- **Children with cancer → 3 new symptoms identified per patient**

Journal of Palliative Medicine 2009;12(4):343-349

- **Parents of children with cancer report less distress from pain, dyspnea and anxiety at EOL**

Wolfe et al J Clin Onc 2008

- **Children who received PPC in Oncology more likely to have fun (70% versus 45%) and to experience events that added meaning to life (89% versus 63%)**

Friedrichsdorf SJ et al, J Palliat Med 2015

- **Families who received PPC in Oncology reported improved communication**

Kassam A et al. Pediatr Blood Cancer 2015

# Does Palliative Care involvement make a difference?

## The Impact of Specialty Palliative Care in Pediatric Oncology: A Systematic Review

- Reviewed 32 studies including 15,635 children and 342 parents
- Children receiving specialized palliative care:
  - Improved symptom burden (including pain)
  - Improved quality of life
  - Decreased intensive procedures
  - Increased completion of advanced care planning documentation
  - Fewer end-of-life intensive care stays
  - Higher likelihood of dying at home
  - Improved communication



## Palliative Care involvement in Pediatric Oncology?



- **Earlier involvement = bigger impact**
- **Automatic referrals**
  - AML
  - Bone Marrow Transplant
  - Metastatic sarcomas
  - Relapsed disease
- **Challenging symptoms (pain)**
- **Psychosocial needs**



# Transition to Hospice Care...

## **Section 2302 of the Affordable Care Act, titled Concurrent Care for Children<sup>†</sup>**

Seriously ill children who are <21 years of age and have a 6-month prognosis are entitled to receive hospice benefit in addition to all necessary disease-directed therapies with the goal of providing access to comprehensive care to live as long and as well as possible. Medicaid shall continue to be responsible to pay for disease-directed therapies in addition to the hospice benefit providing comfort-directed therapies.

Medicaid shall reimburse appropriate Medicaid-enrolled providers directly through the usual and customary Medicaid billing procedures. A hospice provider shall not be responsible for life-prolonging treatment, medications prescribed by non-hospice providers/subspecialists, or any aspect of the patient's medical care plan that is focused on treating, modifying, or curing a medical condition (even if that medical condition is also the hospice-qualifying diagnosis). Life-prolonging services and hospice services shall be billed and reimbursed separately, meaning the child can receive services concurrently.

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Michigan Department of Health and Human Services

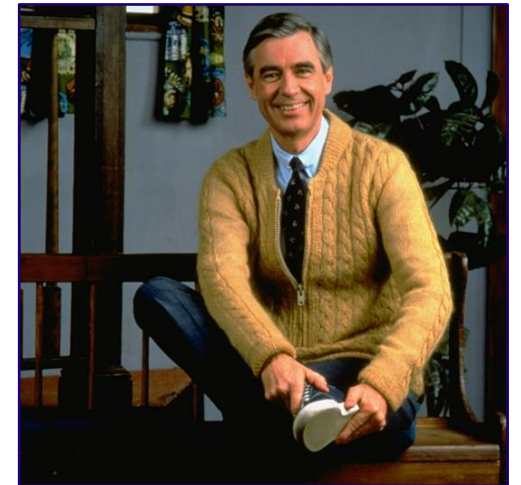
**Medicaid Provider Manual**



## **6.8 CONCURRENT HOSPICE AND CURATIVE CARE FOR CHILDREN**

# In summary

- **Pediatric Palliative Care . . .**
  - Specialized medical care for children with serious illness
  - **Works with primary care providers and specialists**
  - Focuses on relieving pain, distressing symptoms, and stress of serious illness
  - Helps families navigate the **uncertainty** that comes with **serious medical illness**
  - Appropriate at any age and at any stage, together with curative treatment
  - Goal is to **improve quality of life** for child and family (and provider well-being)



# Thank You!



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