



# *Strengthening of Pediatric Palliative Care as a Component of Comprehensive Care*

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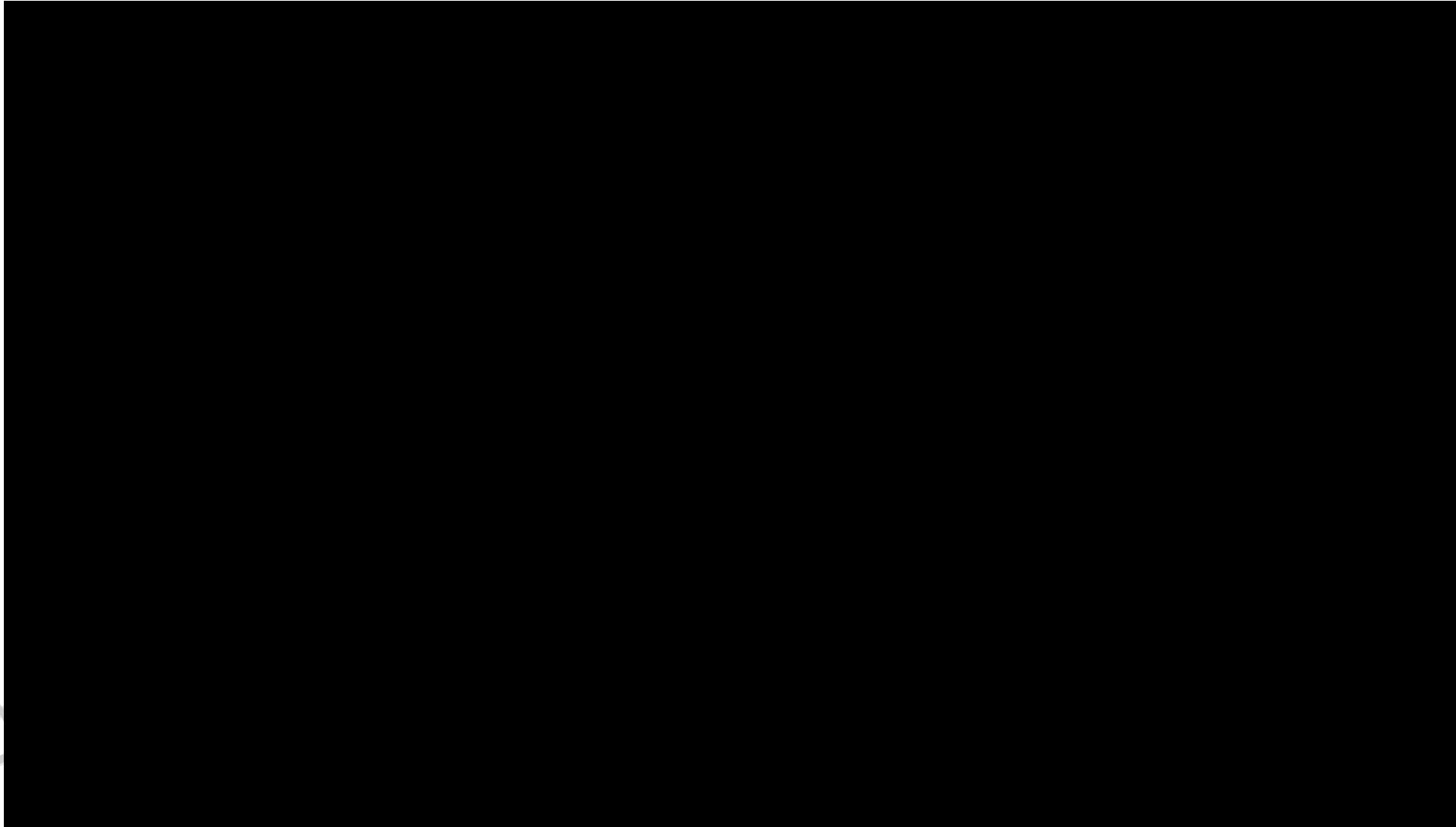
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# Jessica, Shadow and the QoLA Team



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# Objectives

- Discuss Pediatric Palliative Care as a response to Suffering
- Promote Multidisciplinary Collaboration in Pediatric Palliative Care
- Demonstrate strategies for Pediatric Palliative Care Integration





QoLA Kids = Quality of Life for All Kids



Palliative = “to cloak/cover”  
Compassion →  
com (together/with)  
pati (to suffer)



Compassion = to suffer with

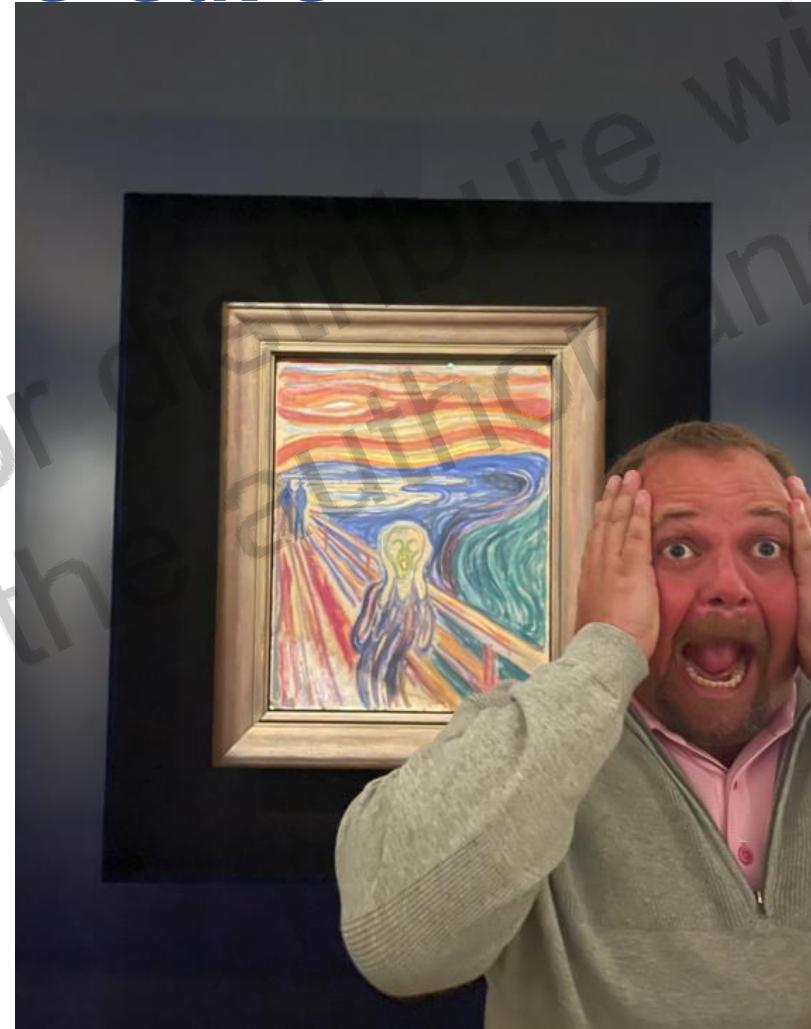
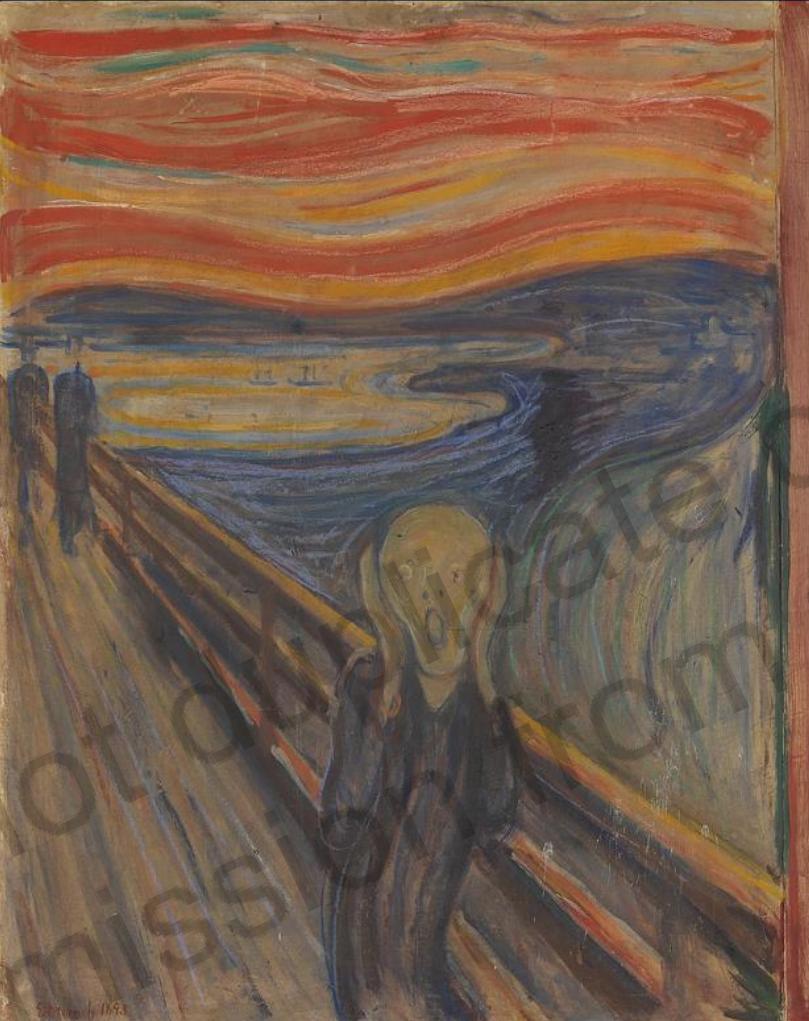


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# *Suffering...the “disease” we attend to in Palliative Care*



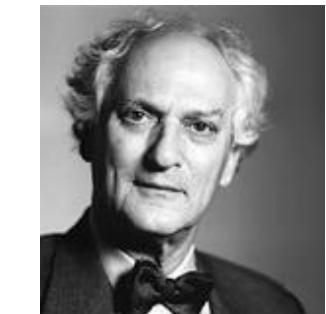
# The “disease” of Suffering



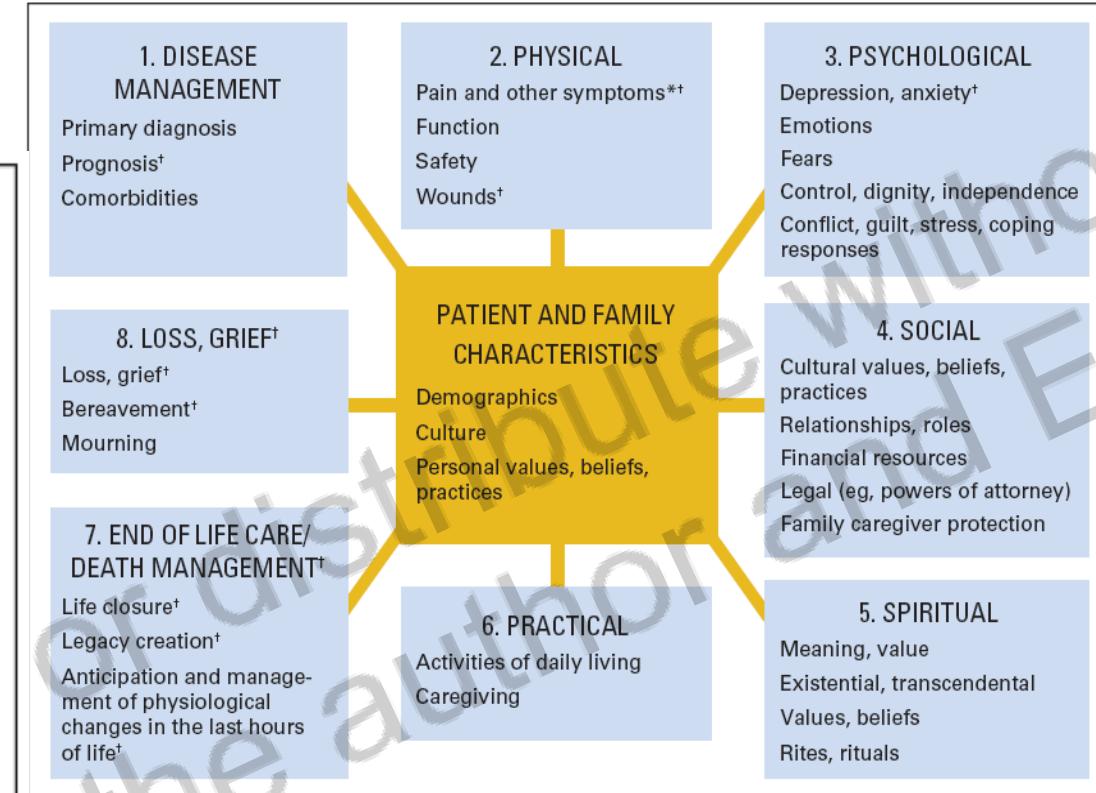
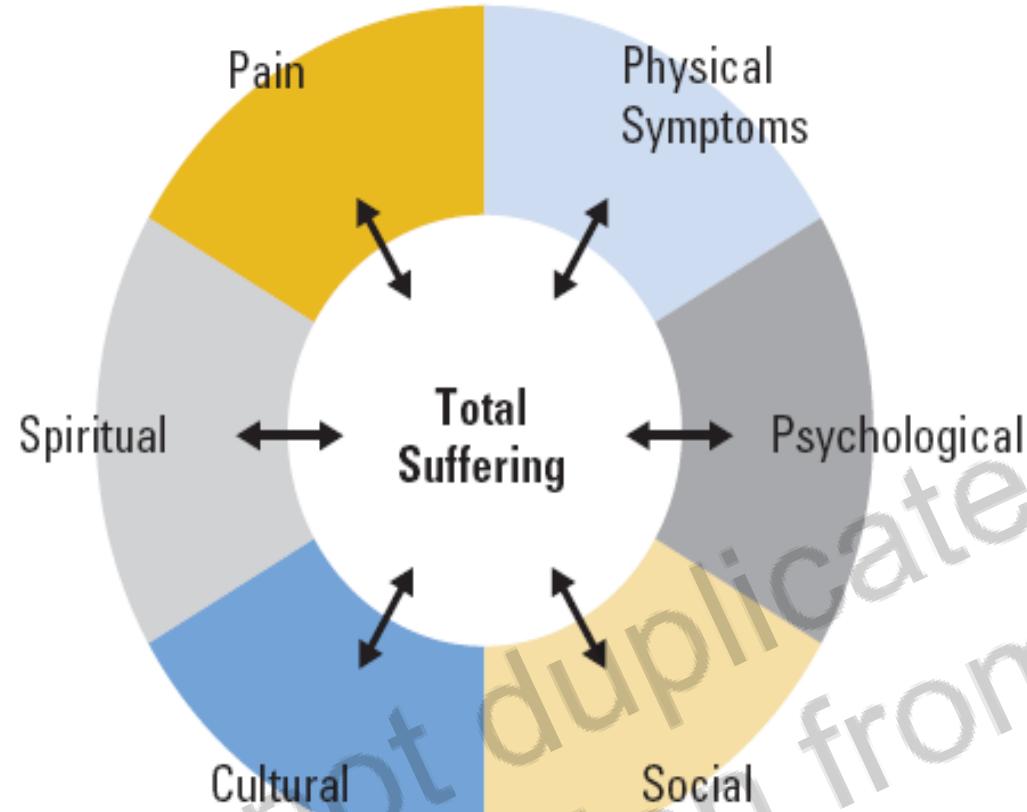
Suffering is a specific state of distress that occurs when the ***intactness or integrity of the person is threatened or disrupted***. It lasts until the threat is gone or integrity is restored.

The meanings and the fear are personal and individual, so that even if two patients have the same symptoms, their suffering would be different.

The Nature of Suffering, 1986  
Eric Cassel, MD



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# TOTAL SUFFERING

JCO - VOLUME 27 NUMBER 18 JUNE 2009



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# A Framework for Easing Suffering

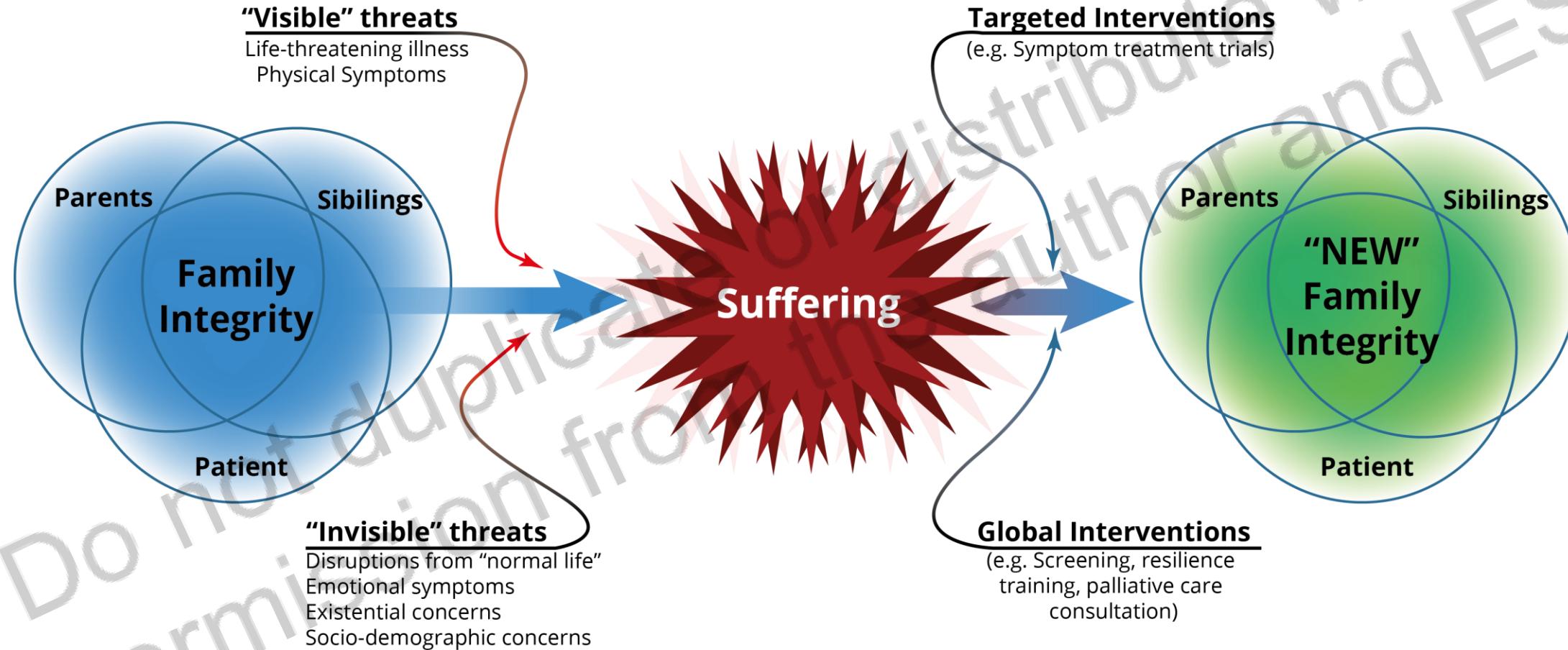


Image used with permission from Dr Joanne Wolfe and EPEC-P

# What is Palliative Care



- Palliative care (PC) is a ***holistic approach*** that improves the ***quality of life*** of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of ***early identification*** and assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2015)
- ***Clearly proven to improve QoL, psychosocial outcomes and caregiver burden***
- ***Can reduce overall cost of care while improving key quality metrics of care***

# World Health Organization

“Acknowledging that palliative care is an ***ethical responsibility*** of health systems, and that it is the ***ethical duty*** of health care professionals to alleviate pain and suffering, physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals among the critical components of palliative care.” (World Health Assembly Resolution 67.19 May 2014)



# The most important tools for providing high quality PPC

- Ears



- Heart



- Team

*“To listen is to continually give up all expectations and to give our attention, completely and freshly, to what is before us. **Com – Together With** not really knowing what we will hear **Participate To Suffer** will mean. In the practice of our days, to listen is to lean in, **Compassion = To Suffer WITH** softly, with a willingness to be changed by what we hear.”*

- Mark Nepo

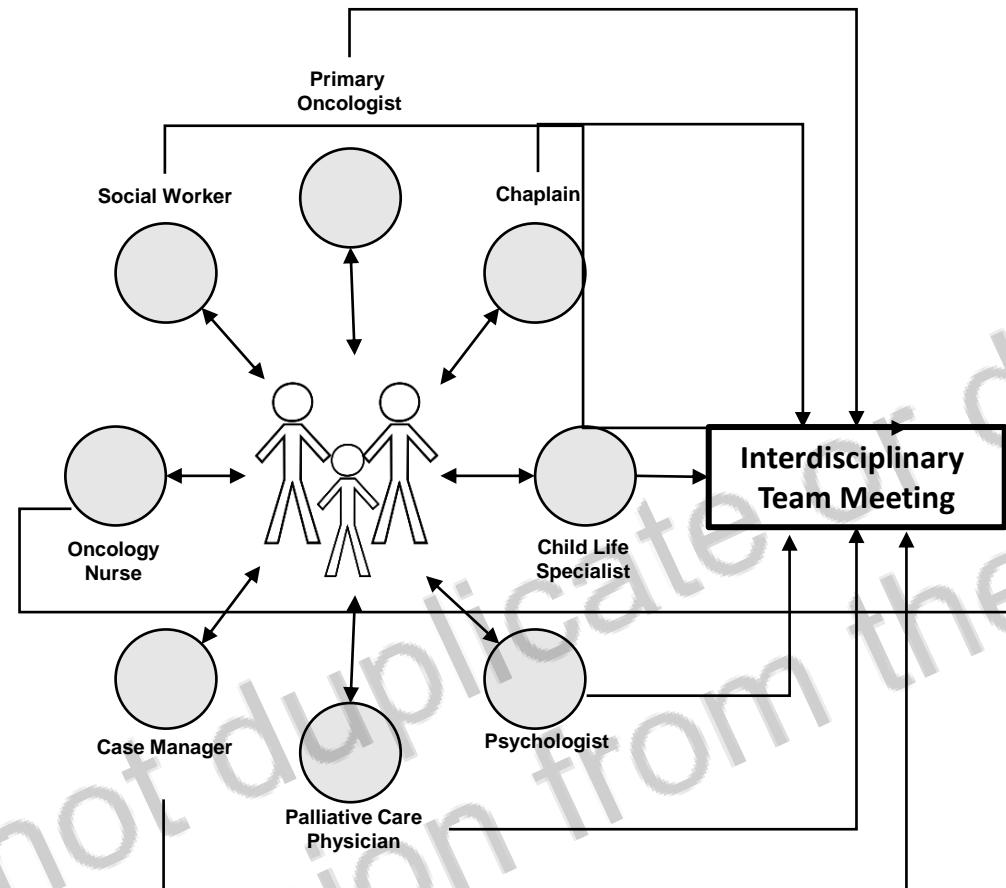


*If you truly are functioning as a team...DELIVER HOLISTIC CARE.*

1

2

3



## Family Care Conference



- Each team member meets with family with a goal of relationship-based information gathering
- IDT conducted based on Discussion Tool
- Family care conference conducted based on recommendations from IDT

\*Team members chosen to participate based on information needed to be communicated with family.

# Multidisciplinary Care + IDT

# Key Concepts in PPC

## *INVOLVE THE CHILD*

- What are their questions/concerns
- Welcome questions even though there may not be an immediate answer
- Help children not to feel alone

## *Communication should be:*

- Culturally appropriate
- Honest
- Child-centered
- Developmentally appropriate
- Timely, linked to concrete experience

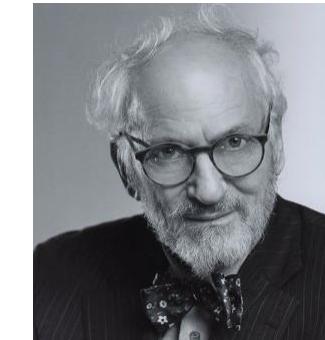


# Our Words Matter...Communication is the "Procedure" of the HPM Clinician

*"Speak clearly, if you speak at all; carve every word before you let it fall." - Oliver Wendall Holmes*



*"Similar to scalpels for surgeons, **words** are the palliative care clinician's greatest tools. Surgeons learn to use their tools with extreme precision, because any error can be devastating. So, too, should clinicians who rely on words." - Eric Cassell*



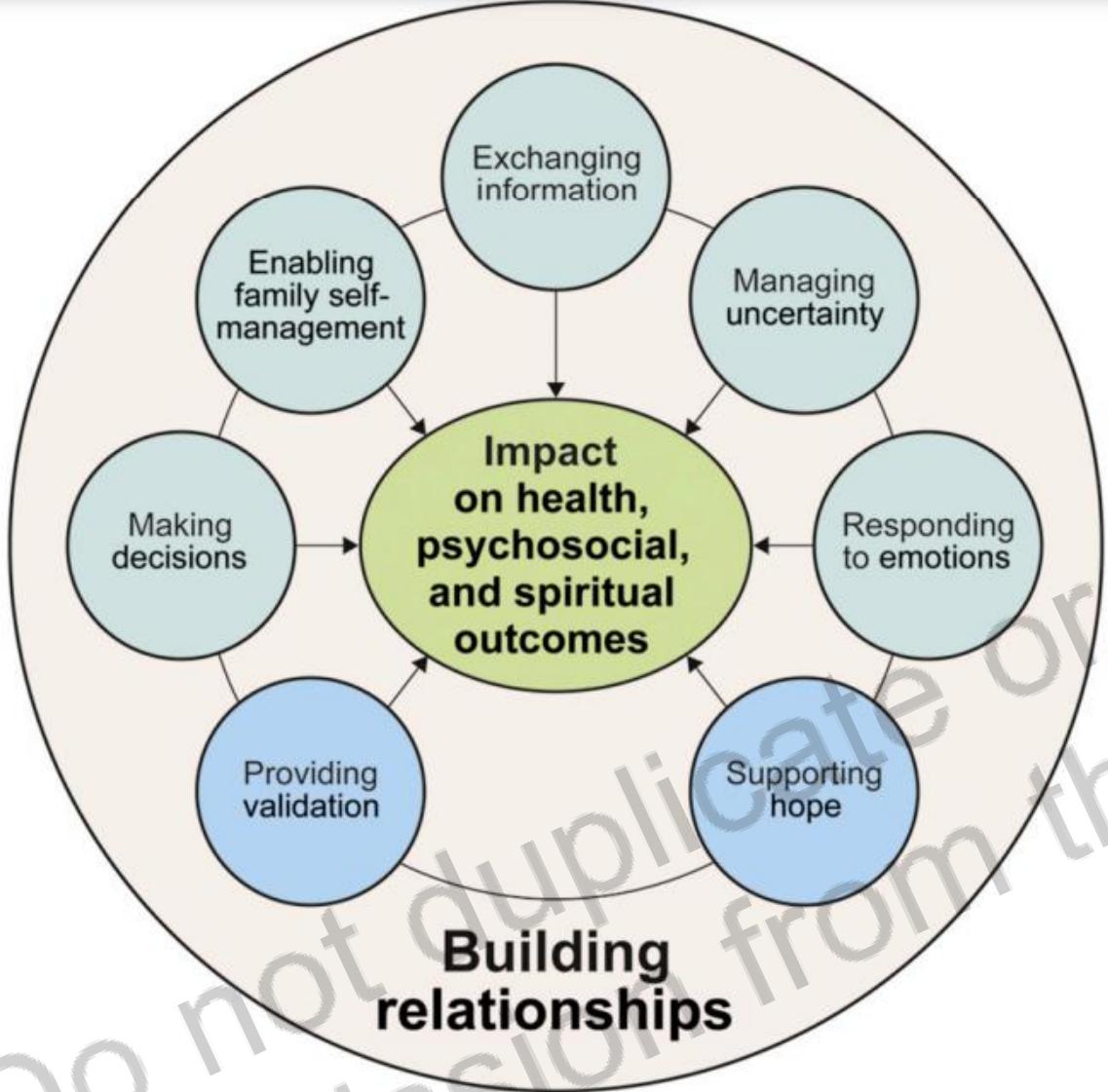
*"The way you **tell the truth** to families makes a huge difference...if you know the person that's coming in there and they're **telling the truth**, as hard as it is, but you know they care about you and they love your child, it's okay. As hard as it is, it's okay and it makes all the difference."*

*St Jude Bereaved parent*



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**FIGURE 1**

Functional model of communication in pediatric oncology. In this model, we propose that all functions of interpersonal communication are affected by the strength of the clinician-family relationship. Furthermore, we hypothesize that facilitating these communication functions might have positive effects on health, psychosocial, and spiritual outcomes for the patient and family. Factors within green circles are similar to findings from past studies in adult oncology. Factors within blue circles were newly identified in this study.

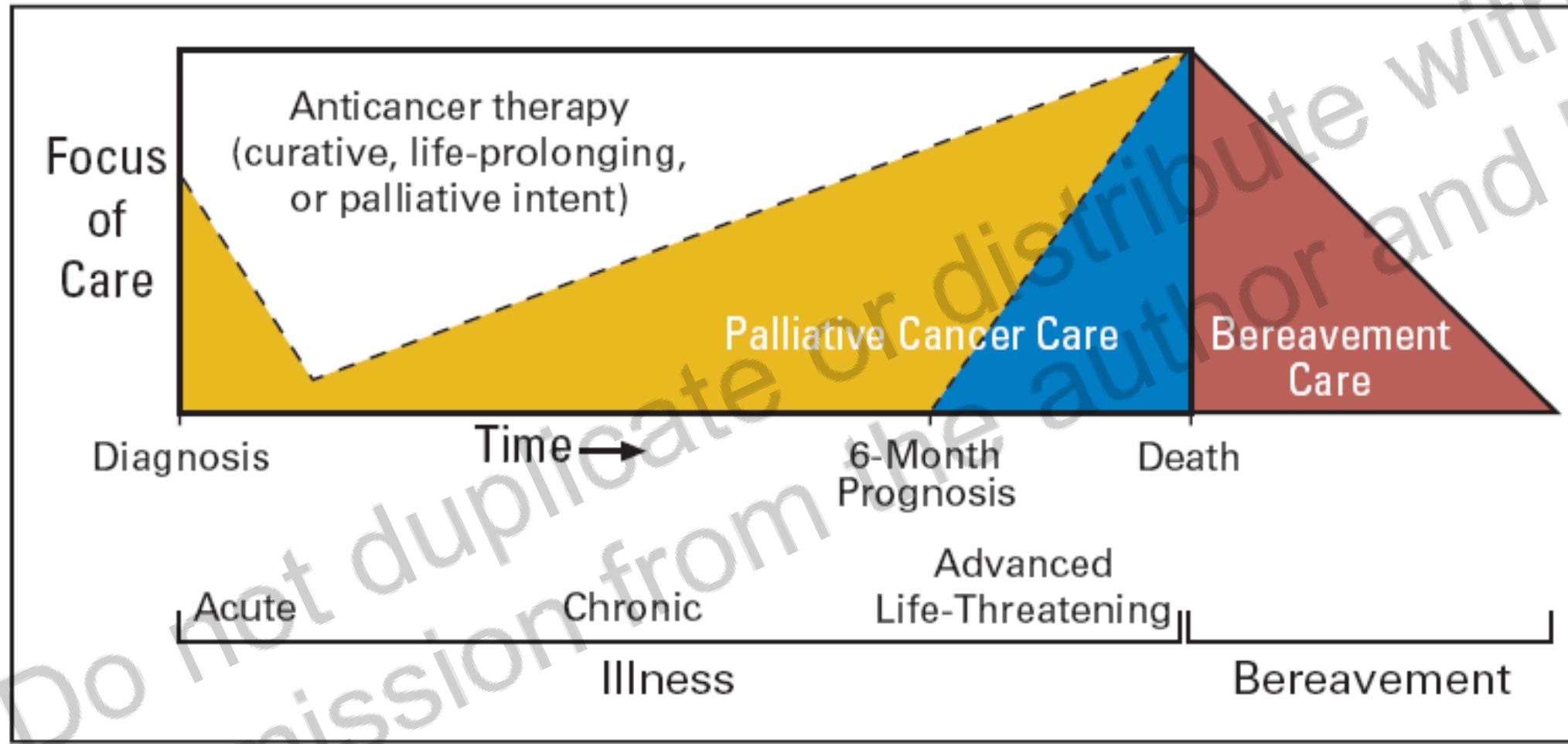


# Skillful Combination of Roles

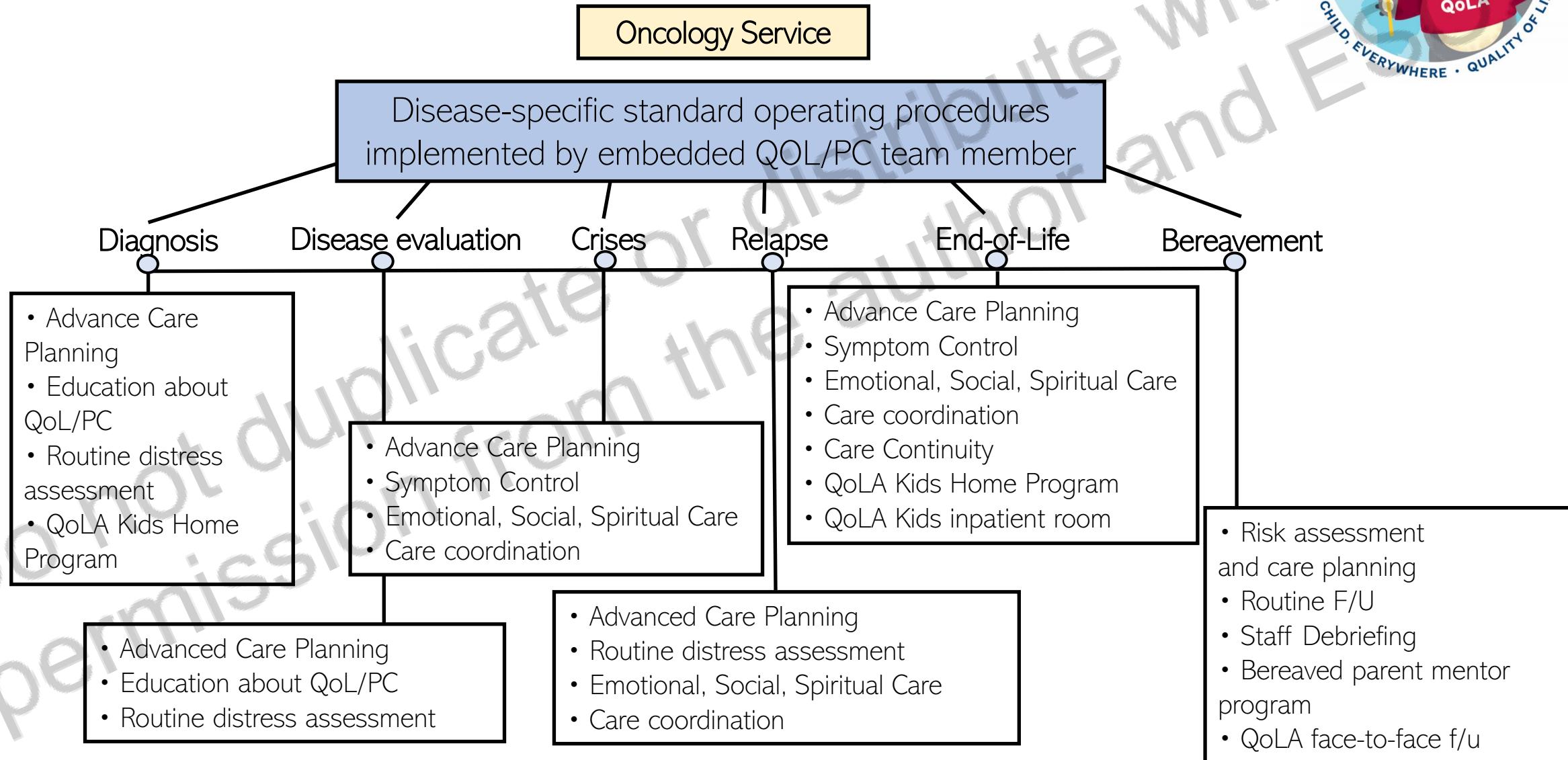


Dedicated to discovery (CURE) Committed to caring (HEAL)

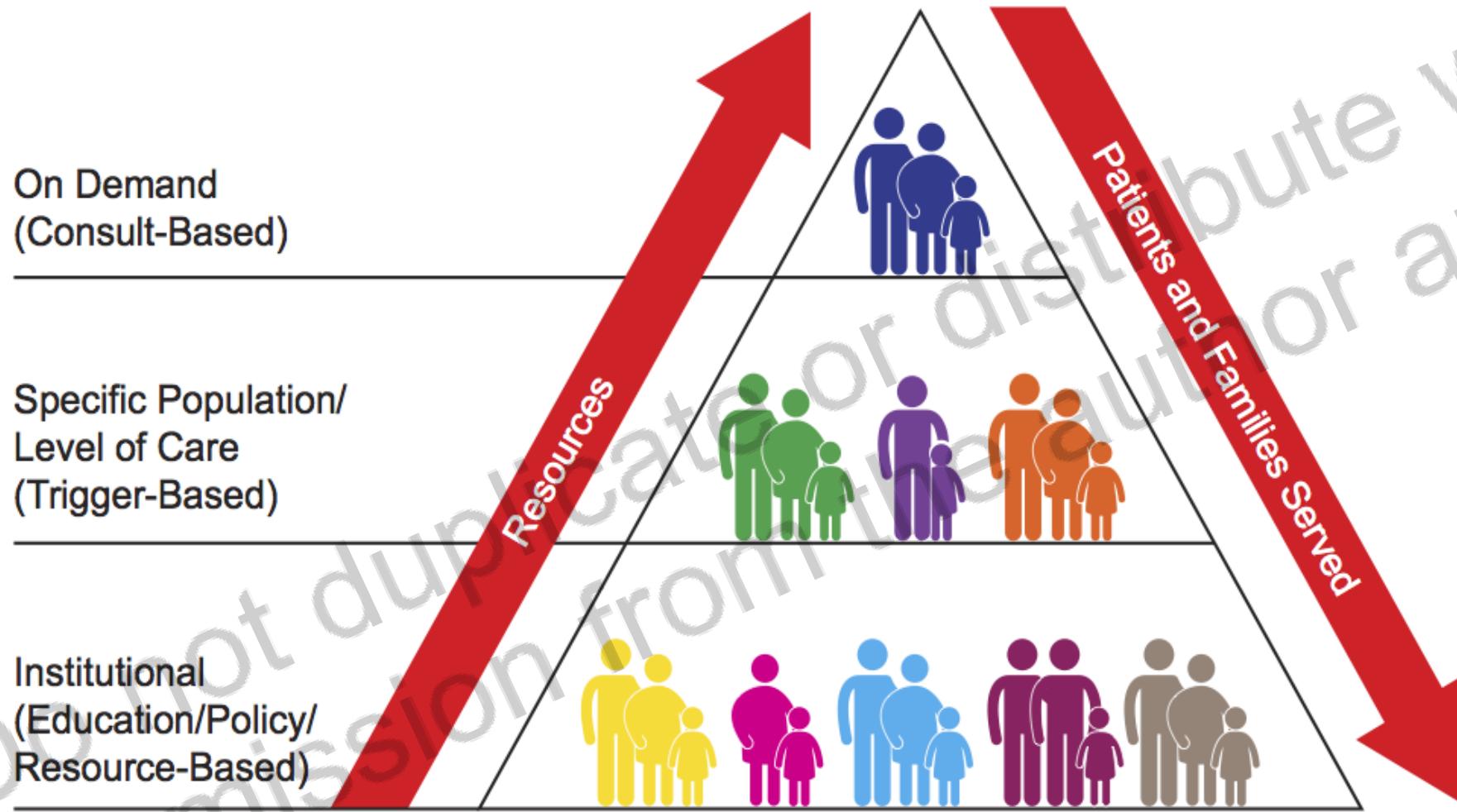
# Model of INTEGRATED palliative care



# “Embedded QoLA” model of Integrated PPC



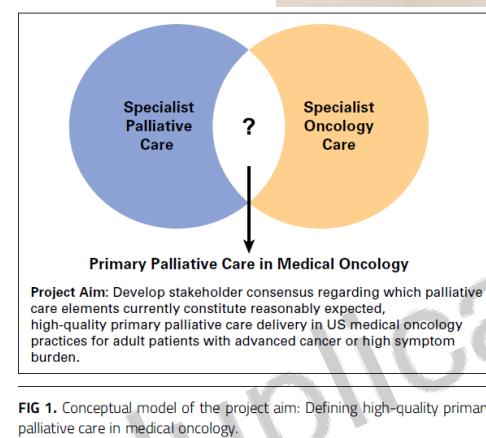
# Model of *INTEGRATED* palliative care



# Pediatric Palliative Oncology

Defining High-Quality Palliative Care in Oncology Practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine Guidance Statement

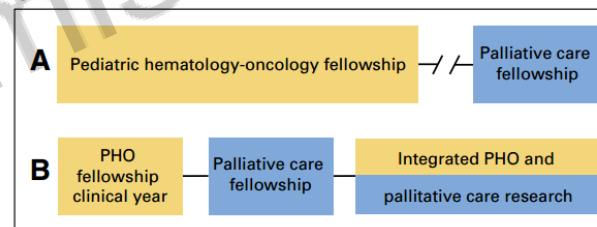
J Oncol Pract. 2016 Sep;12(9):e828-38.



JOURNAL OF CLINICAL ONCOLOGY

Pediatric Palliative Oncology: A New Training Model for an Emerging Field

Curr Opin Pediatr. 2018 Feb;30(1):40-48.



# Does integrating PC make a difference?

Findings from a systematic review – Kaye EC et al. JPSM 2020

## Increase in the integration of SPPC over time

- ↑ referral patterns with a trend toward earlier consultation and long-term follow up.
- SPPC > in children with solid tumors.
- Hospice and died at home > in children with brain tumors and solid tumors.

### Significant improvements in children's:

- Improve symptoms.
- Improve QoL
- More likely to report experiencing fun or a **meaningful event** in last month of life.

- ↑↑↑ Documentation psychological diagnoses/mental health needs.
- Parents stated that their **child's dying place had been "a good place"** for their child with noted "peaceful death"

- **Less intensive care** at the end of life and less likely to die in the intensive care unit or be on a ventilator.
- Underwent **fewer intensive procedures/tx** – esp. in final days of life.
- **Not associated with a decreased duration of survival.**
- **Improved family satisfaction.**

- ↑↑↑ the number of EoL, and these took place earlier
- ↑↑↑ number of do-not-resuscitate orders in charts
- Parents - SPPC team "helpful/very helpful" in managing symptoms and stresses.
- **Caregivers** endorsed improvement in **QoL and caregiver burden**, anxiety and depression also decreased following palliative care involvement
- Family members reported that health care providers' **willingness to listen** to parental.
- Improve of communication among health care providers.



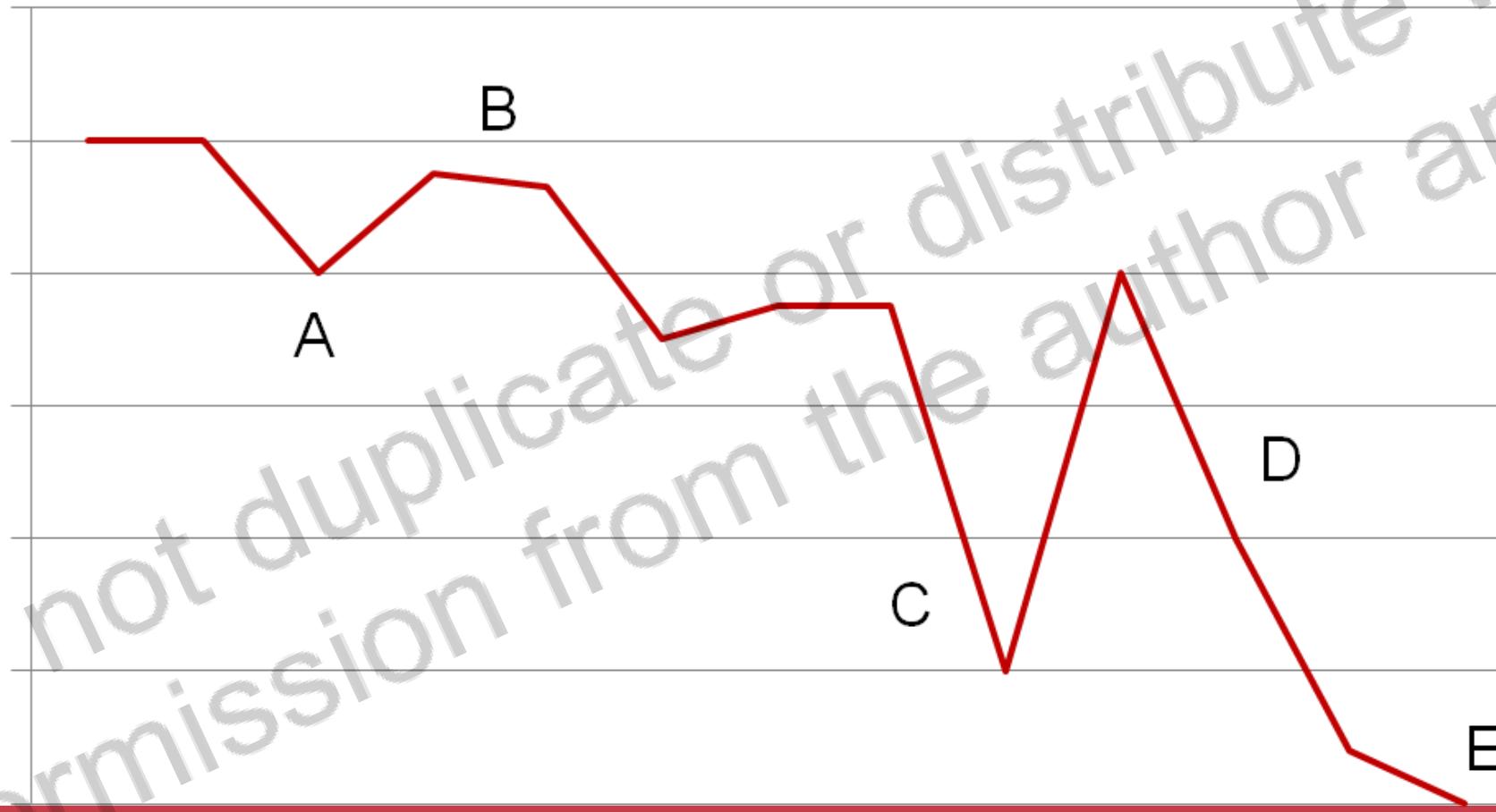
# A child's illness and suffering:

## Healthy/Functional Status Over Time



# Predictable opportunities to initiate PPC tasks

## Healthy/Functional Status Over Time



# Acute decompensation and hearing bad news (Point A)

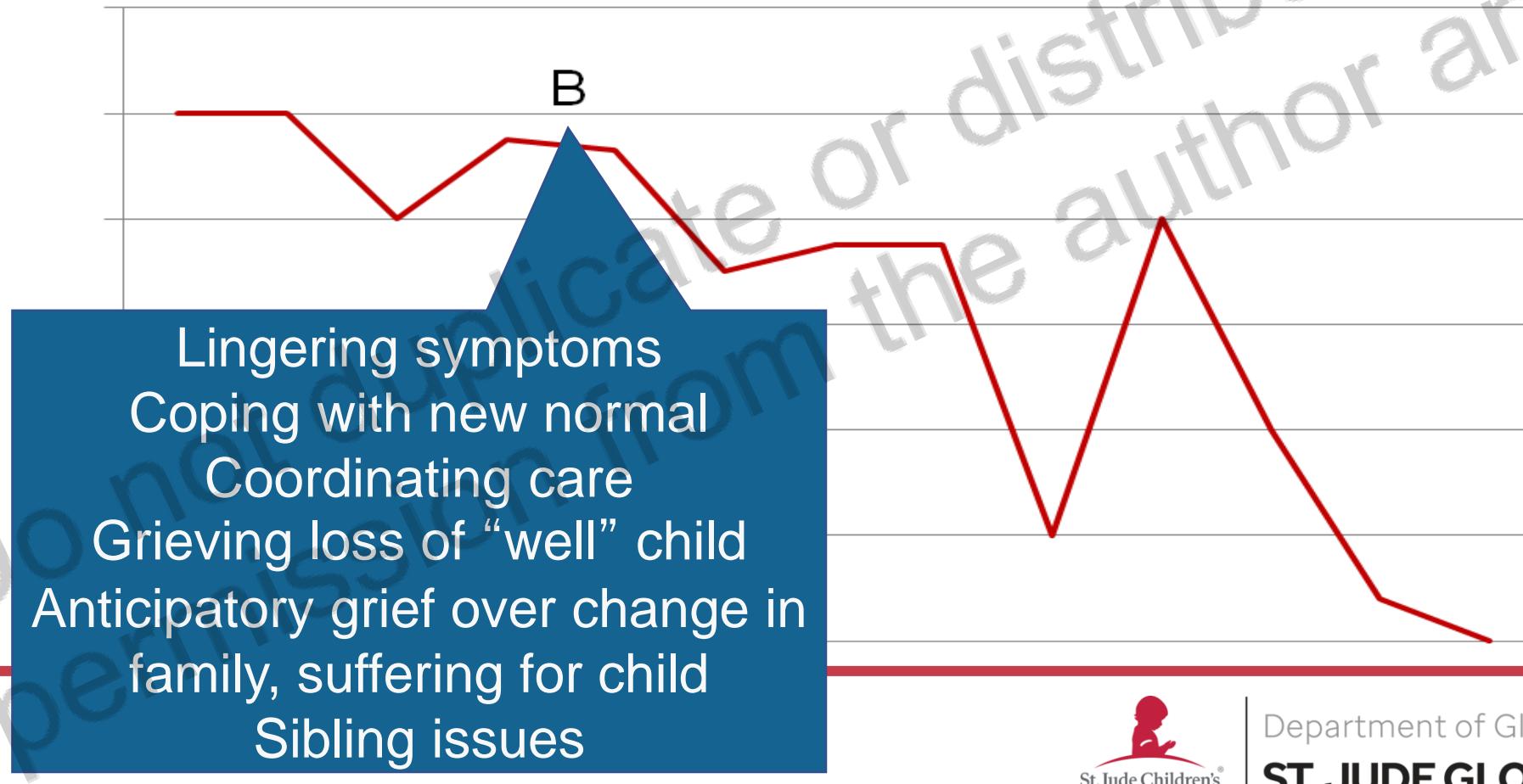
## Healthy/Functional Status Over Time



# Recovery and Accommodating to a New Life/New Normal (Point B)



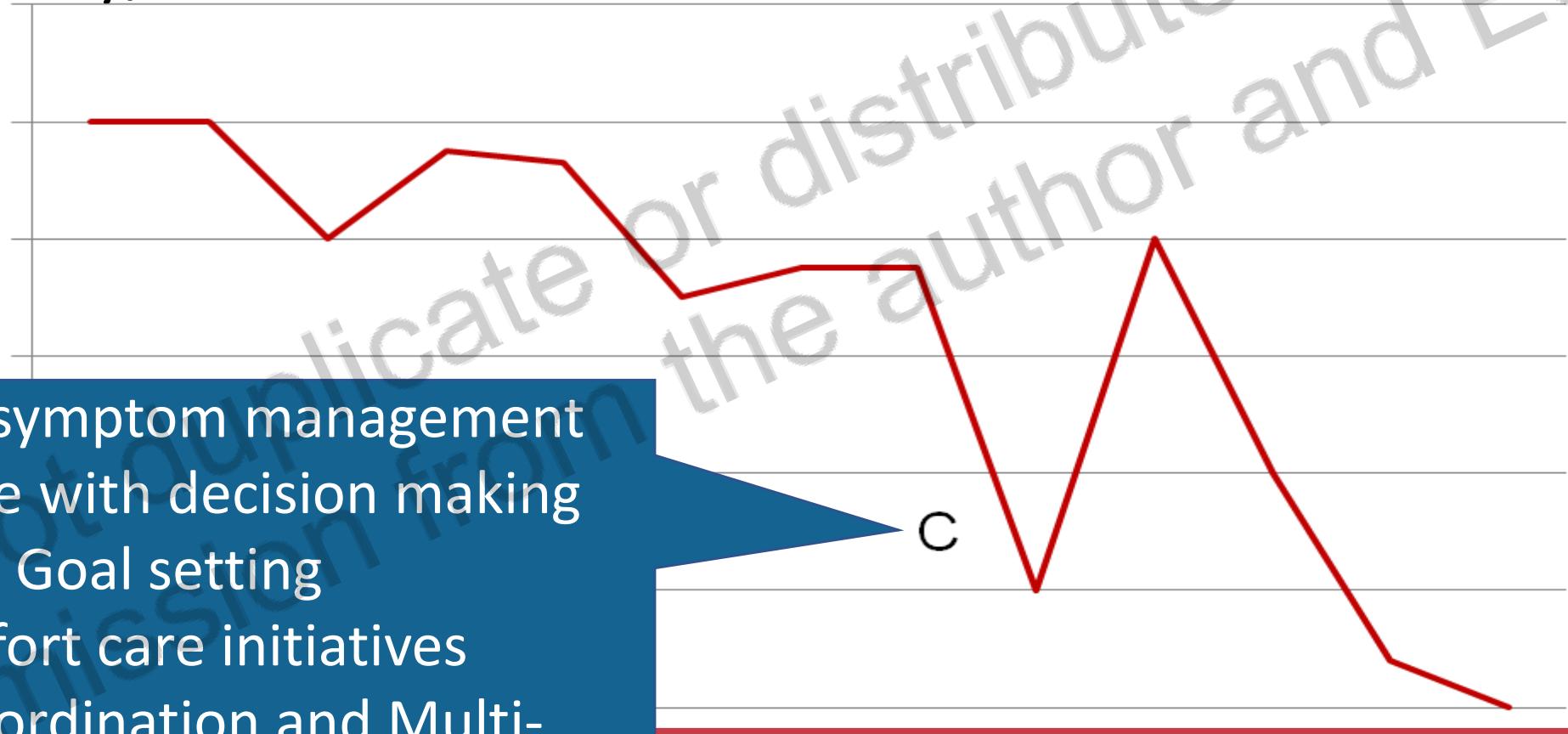
## Healthy/Functional Status Over Time



# Acute decompensations and unexpected recoveries (Point C)



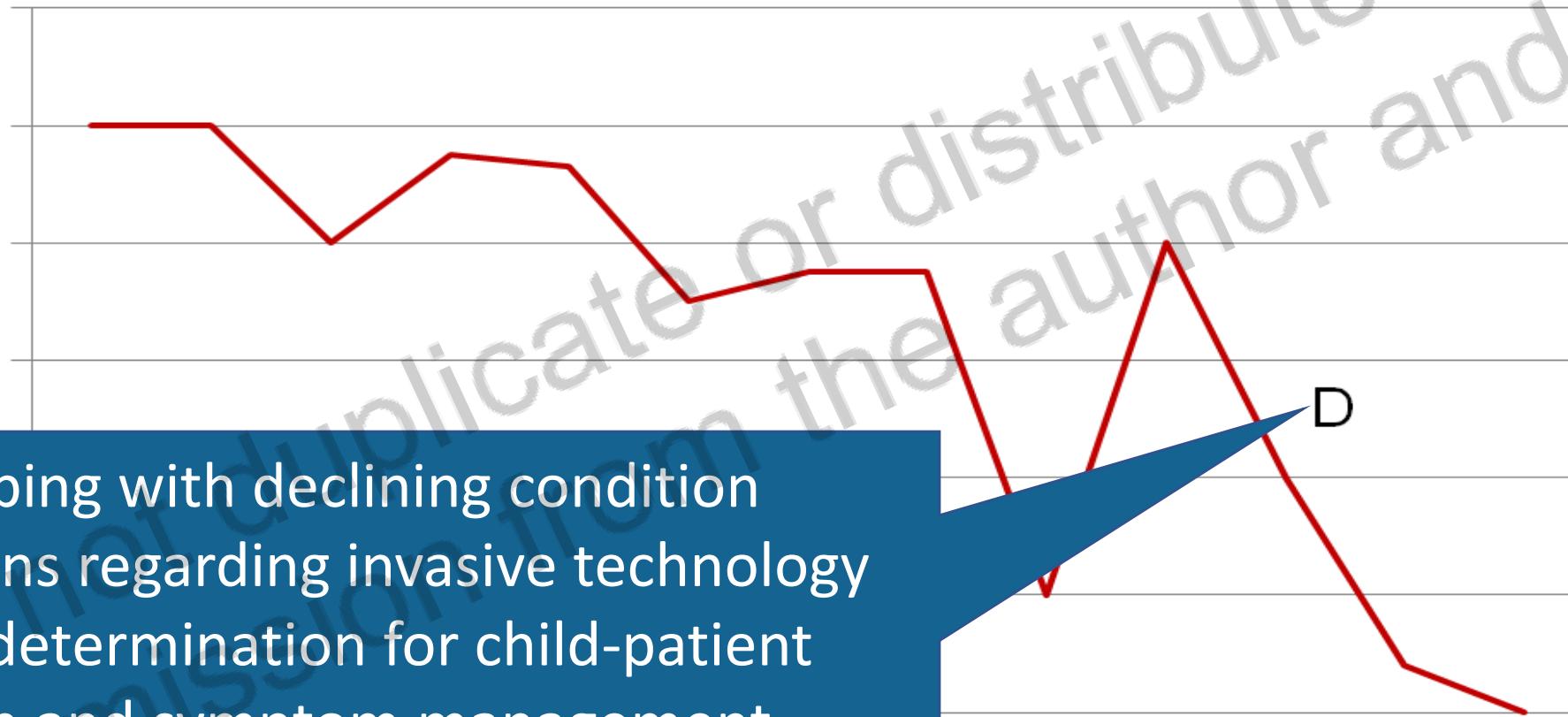
## Healthy/Functional Status Over Time



Pain and symptom management  
Assistance with decision making  
Goal setting  
Comfort care initiatives  
Care Coordination and Multi-disciplinary support

# Slow or precipitous decline preceding end-of-life (Point D)

## Healthy/Functional Status Over Time



Coping with declining condition  
Decisions regarding invasive technology  
Self-determination for child-patient  
Pain and symptom management  
Increasing sibling distress  
Bereavement

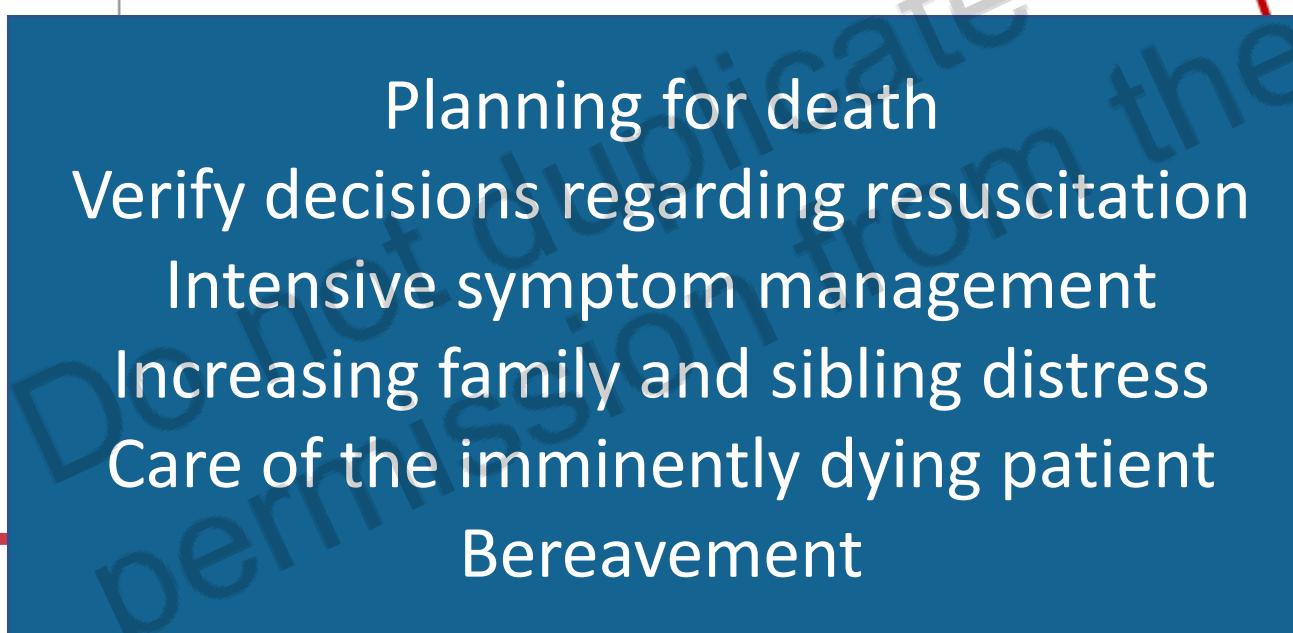


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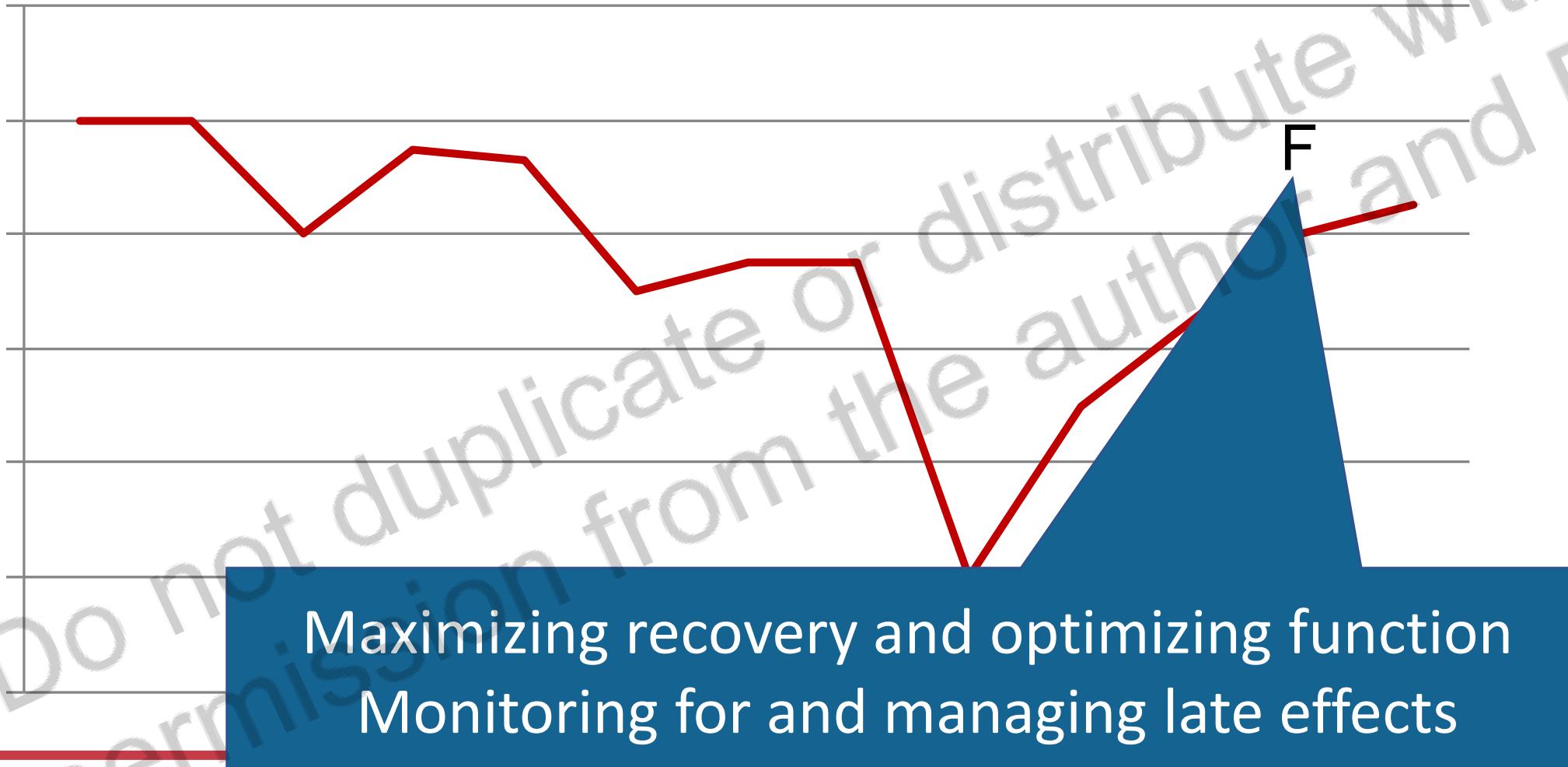
# End of Life (Point E)

## Healthy/Functional Status Over Time



# Recovery (Point F)

## Healthy/Functional Status Over Time

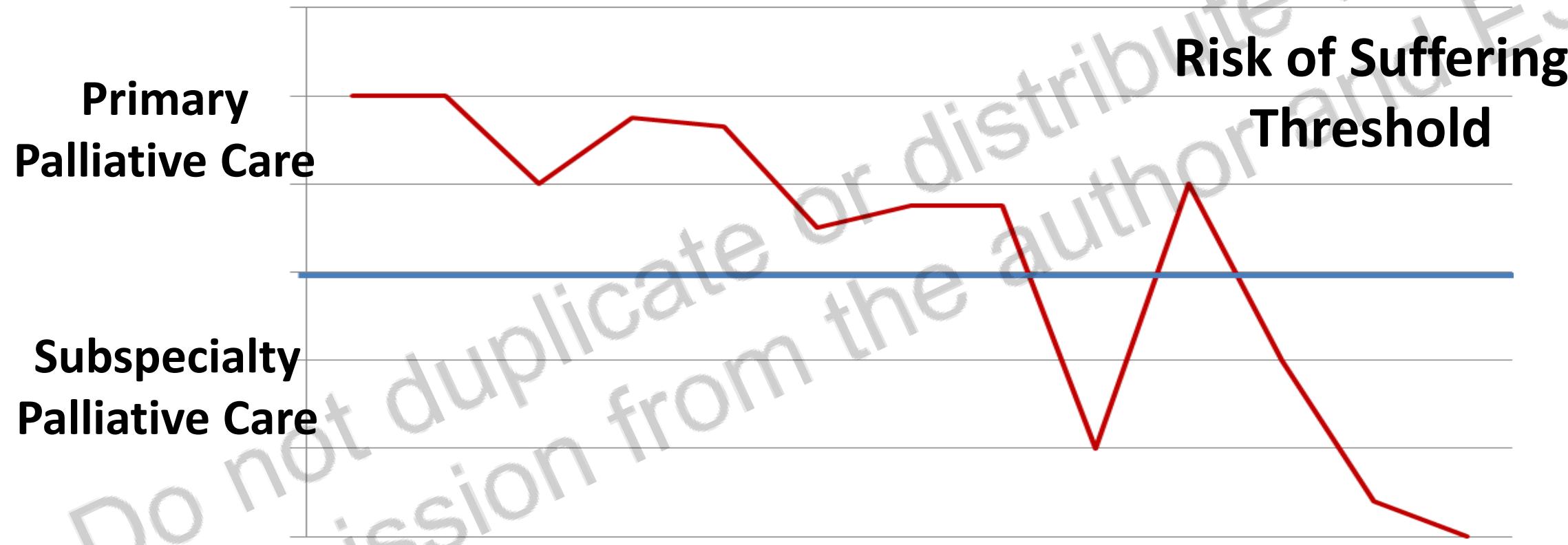


Maximizing recovery and optimizing function  
Monitoring for and managing late effects

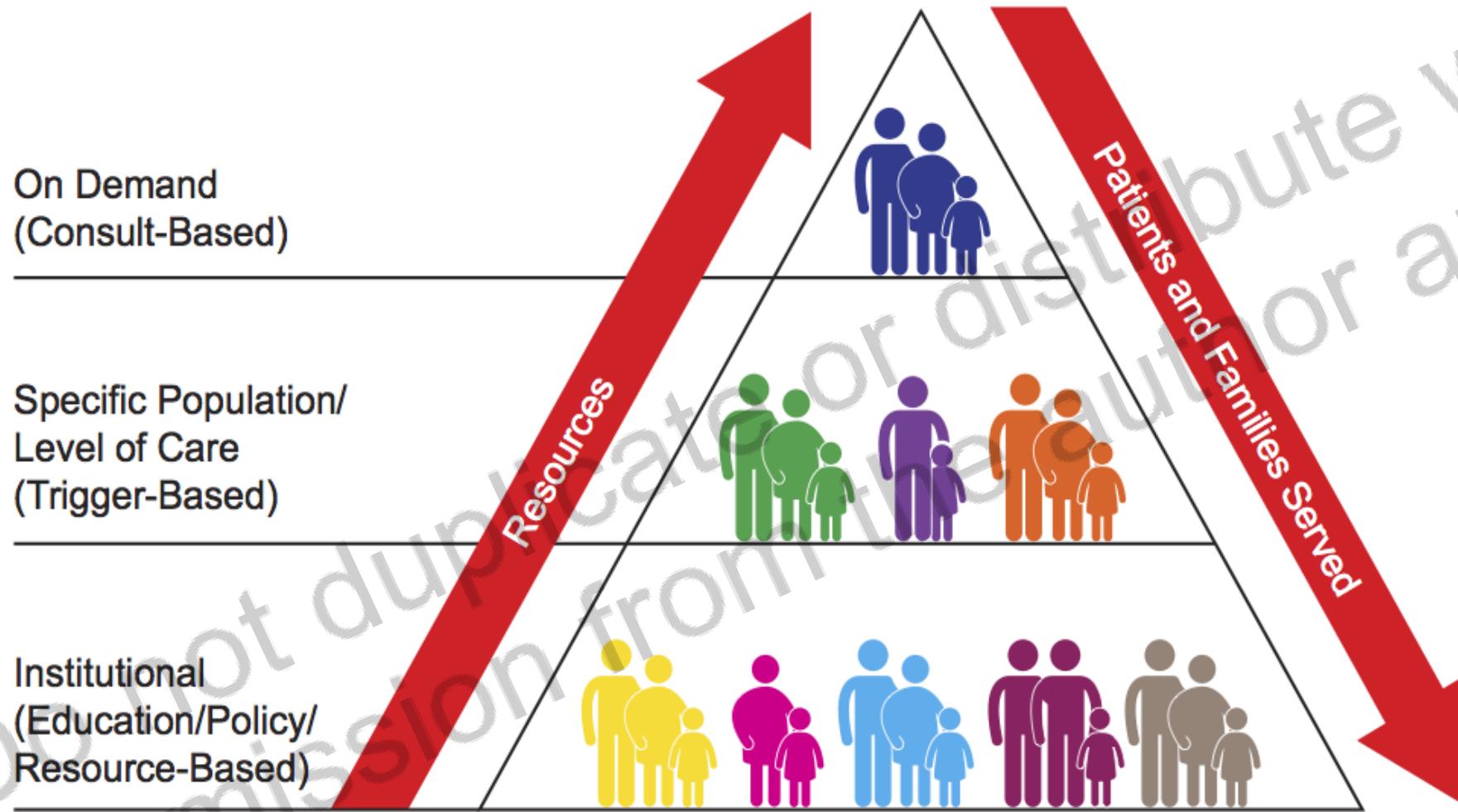
# Primary vs. Subspecialty Palliative Care



## Healthy/Functional Status Over Time



# Model of *INTEGRATED* palliative care



# *The POWER of HUMAN CONNECTION*



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# Summary/Pearls

- PPC is a fundamental human right
- ***Use your tools!***
- Communication is the cornerstone to being a great clinician
- *Integrating PPC improves outcomes, so think of ways to integrate*
- Use the three-tiered approach to integration of PPC
- Recognize the power of human connection
- This is so, so difficult...



# Global Palliative Care Community

- The Global Palliative Care Community is for health care professionals from all over the world, to get together and review topics about palliative care in children with cancer and to discuss challenging clinical cases. This group provides a way to Connect, Contribute and Collaborate with health care professionals around the world.



For support, please contact  
[support.alliance@stjude.org](mailto:support.alliance@stjude.org)



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# Questions and Discussion



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