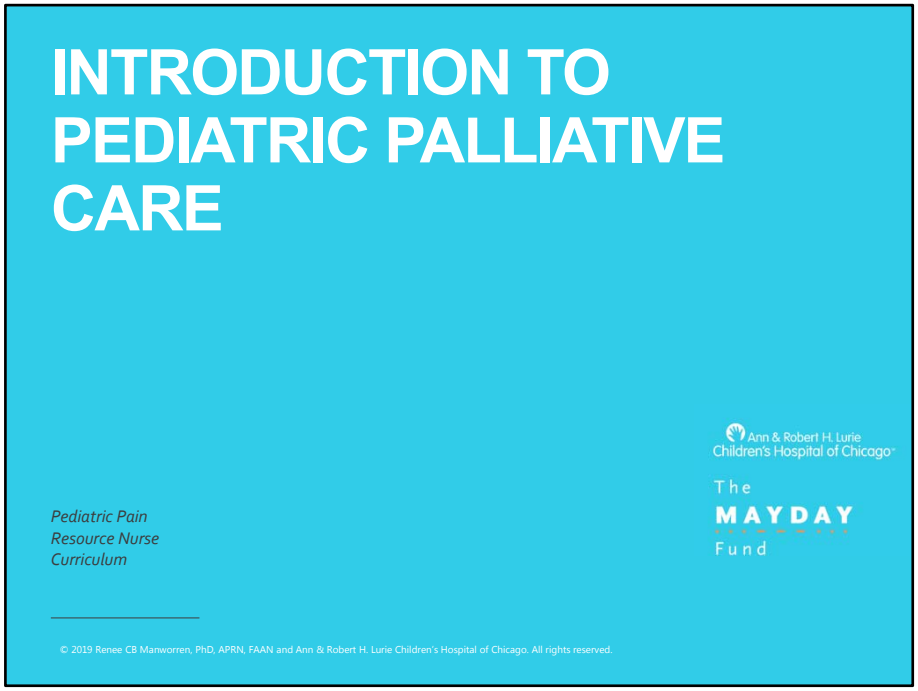
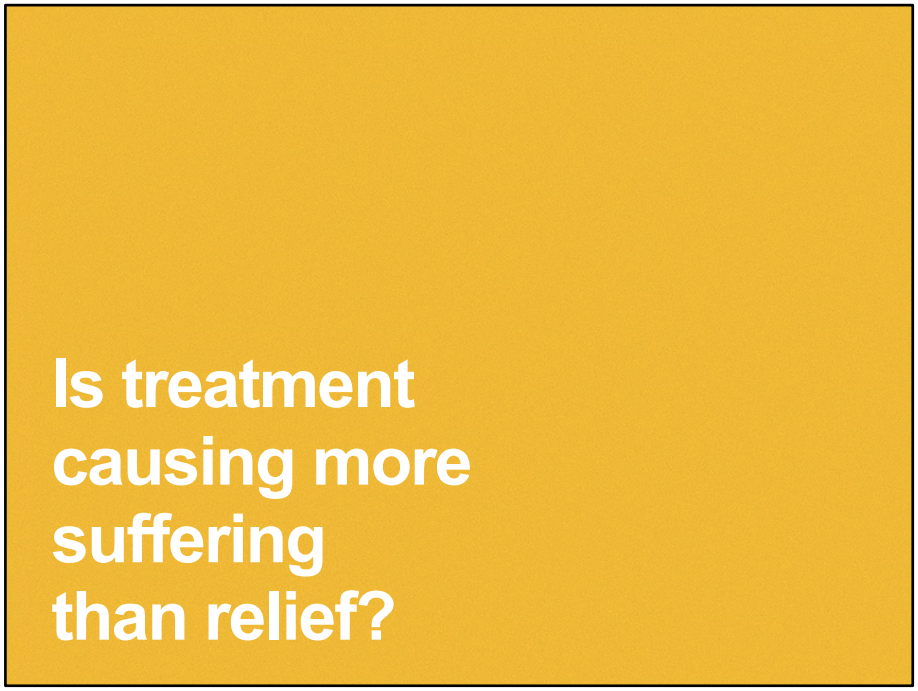


Materials: Flip chart or Whiteboard and Markers
Room Setup: In tables of 4 or 6-8 depending on number of participants
Display slide as participants walk in
This session is **45 minutes**

Welcome & Introductions: *Introduce facilitator if necessary.*

READ: The learning objectives for this content are to:

- Describe different populations of children who benefit from pediatric palliative care
- Explain the benefits of pediatric palliative care for children suffering from serious life limiting or life-threatening illness and their families.
- Discuss palliative care pain and symptom management strategies for children with serious illness and at end of life.



<u>ASK</u>: Is treatment causing more suffering than relief?

Select participants willing to share their answers to this question.

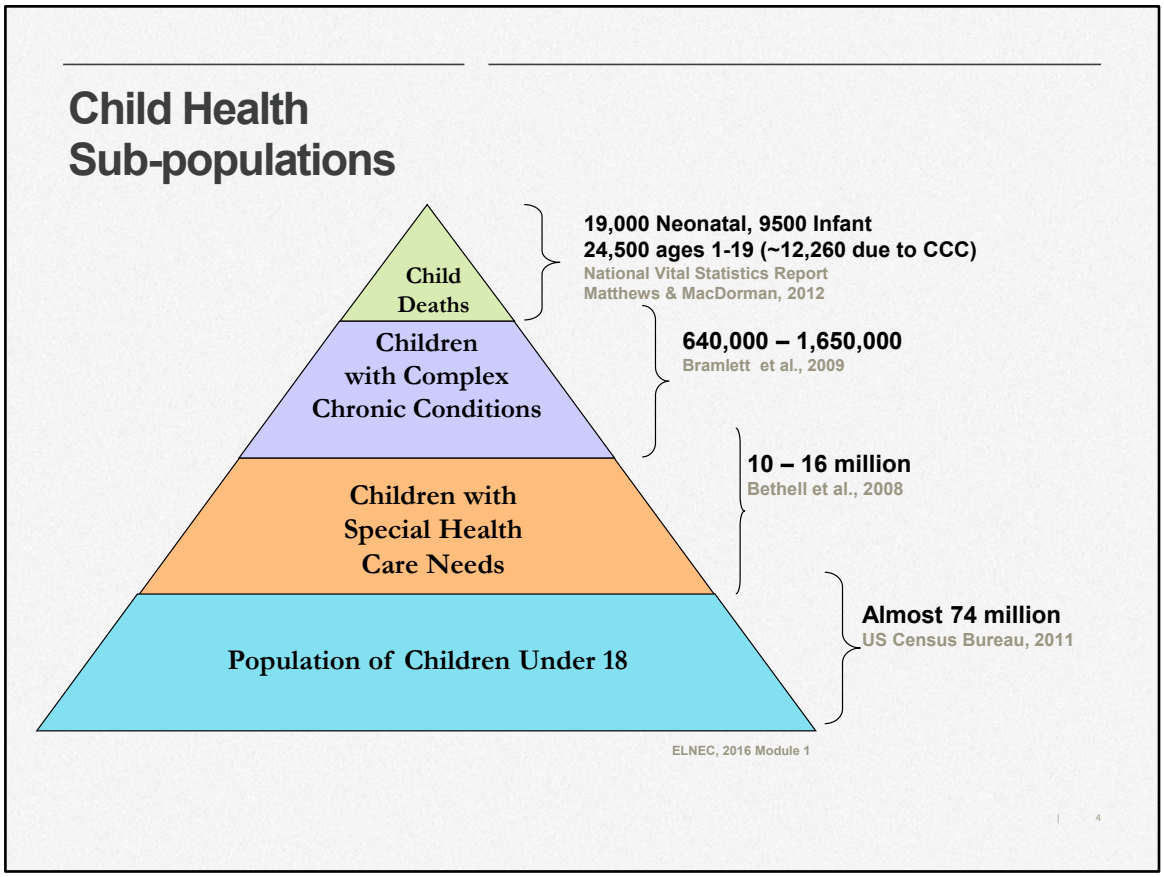
[Limit to 5 of 45 minutes]

READ: Pair up for this "Pair and share activity." Each group should discuss these four questions. ***[Limit to 5 minutes]***

Select participants from each group to share their answers to this question.

Write on flipchart or board ***[Limit to 3 minute]***

[15 MINUTES of 45 minute session is complete]



READ: 42,328 USA children aged 0-19 died in 2013

55% of these deaths were neonates & infants

- Neonatal mortality rate (0-30 days) = 4.2/1000 live births
- Infant mortality rate= 6.42/1000 live births

ASK: What are the common causes?

Select participants willing to share their answers to this question.

READ** these Key points (**if not included by participants):

- 20% of deaths are due to congenital malformations with congenital heart disease (>4%) the most common congenital/chromosomal anomaly
- Gestational age/Low birth weight
- Sudden infant death
- Unintentional injury
- Birth complications

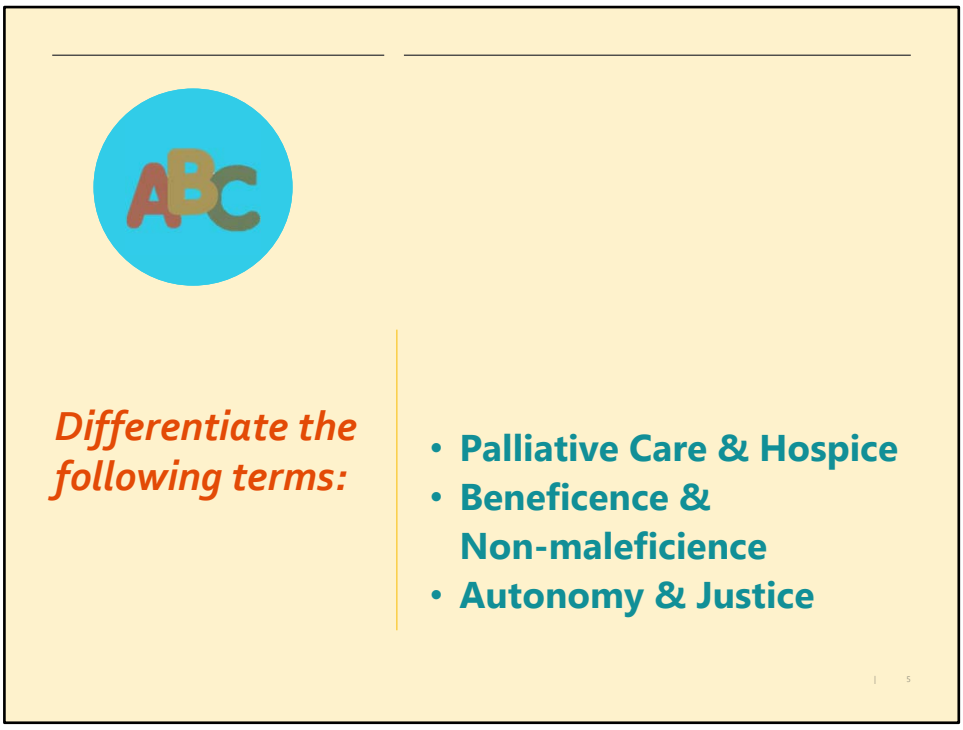
ASK: What are the common causes after 1 year of age?

Select participants willing to share their answers to this question.

READ** these Key points (**if not included by participants):

- Congenital anomalies
- Malignant neoplasms
- Assault
- Unintentional injury
- Cardiac disease

[Limit to 20 of 45 minutes]



READ: These terms are often used interchangeably despite their different definitions, which contributes to confusion among healthcare professionals.

ASK : How do you define the following terms:

- **Palliative Care** *Select participants willing to share their responses* ***[Limit to 1 minute]***
- **Hospice** *Select participants willing to share their responses* ***[Limit to 1 minute]***

These are the specific differences If clarification is needed:

Palliative care *is an interdisciplinary team approach to optimize symptom management and physical, psychosocial, and spiritual needs, quality of life, and patient/family preferences.*

- *Palliative care* ***does not exclude any medical therapy*** *or life-prolonging treatment.*
- *Used when a patient has a life-limiting or threatening illness*
- *Supports patient and family's hopes for peace and dignity throughout the course of illness, during the dying process, and after death.*
- *Works collaboratively with primary care team to provides an added layer of support.*

Hospice care *is specific to the terminal phase of illness, the dying process.*

Beneficence *- Acting from a spirit of compassion and kindness to benefit others*

Nonmaleficence *- Non-harming or inflicting the least harm possible to reach a beneficial outcome*

Autonomy *Self-determination; encompasses veracity, disclosure/informed consent, confidentiality, and promise keeping*

Justice *- Acting out of sense of equality for all, fair allocation of resources*

Barriers to Pediatric Palliative Care?

Multifactorial

- Individual beliefs
- Misunderstood in both public and healthcare community
- Providers, nursing and staff, parents and patients lack understanding on how Pediatric Palliative Care helps
- Lack of training and education of providers and staff with pediatric palliative care expertise
- Financial and insurance , lack of reimbursement
- Geographic unavailability, poor access to services
- Health care policy does not place an emphasis on palliative care

Linton & Feudtner, 2011; Thienprayoon et al, 2013

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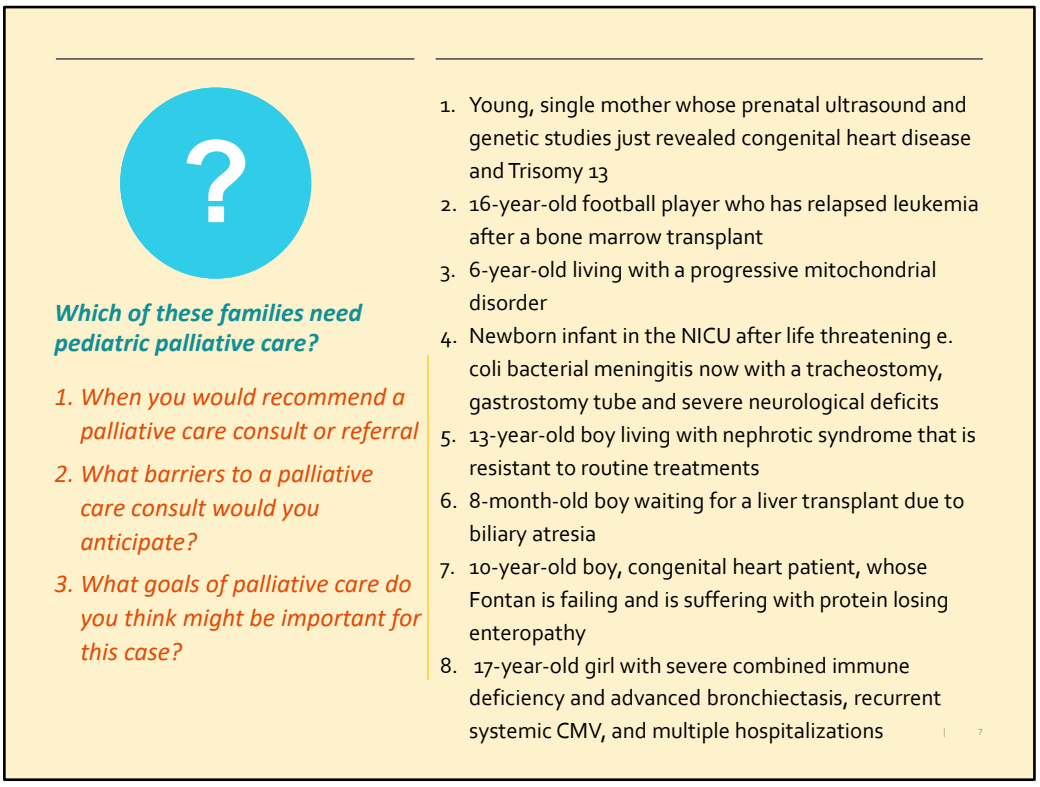
READ: The biggest barrier to palliative care is a misunderstanding of the definition – healthcare providers and families avoid "the talk," and struggle with the "correct" timing of the talk.

But is there ever a wrong time to promote quality of life?

[Limit to 25 of 45 minutes]



ASK: Which of these families need pediatric palliative care?

READ: Each table should choose 1 of the 8 cases, each table a different case. You have 5 minutes to formulate a plan of care.

First consider the ethical principles:

Then determine:

1. When you would recommend a palliative care consult or referral (PG provides several prompts for referral).
2. What barriers to a palliative care consult would you anticipate?
3. What goals of palliative care do you think might be important for this case?

- Pain and symptom management
- Care coordination
- Advanced care planning and continual re-assessment of care goals.
- Emotional, social, and spiritual support that respects cultural & family values.
- Support for providers & staff caring for seriously ill children
- Facilitate difficult conversations and decision making
- Provide bereavement care as needed.

Choose a table representative willing to share your plan with the other groups ***[Limit discussion to 5 minutes]*** *Walk and eavesdrop on each table and coach*

[Limit to 35 of 45 minutes]

<u>ASK</u>: How does palliative care symptom management differ from acute symptom management for:

- Pain?
- Dyspnea?
- Secretion management?
- Neurologic Impairment such as seizures, spasticity?
- Anxiety, agitation, delirium?
- End of Life?

Select participants willing to share their responses ***[Limit to 1 minute]***

[Limit to 41 of 45 minutes]

The Principle of Double Effect

Some interventions have both good & bad effects

The treatments we use to decrease suffering sometimes have side effects that could be considered "dangerous".

INTENT is important

It is ethical to give medication if the INTENT is to relieve suffering not to cause death

There will always be a last dose.

But it is the disease taking the child's life not the medication, parent or provider.

READ: All healthcare providers worry about cause and effect; risks and benefits to treatments and procedures

Some interventions can have both good and bad effects

For Example: The treatments that we use to decrease suffering sometimes have side effects that could be considered "dangerous".

INTENT is important

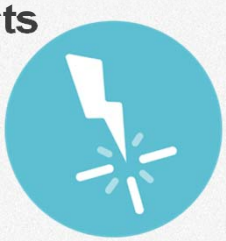
It is ethically allowed to give medication if the INTENT is to relieve suffering not to cause death

There will always be a last dose.

But it is the disease taking the child's life not the medication, parent or provider.

[Limit to 42 of 45 minutes]

Key Points



Curing:
Making the problem go away.
Healing:
Giving someone the resources to deal with problems that will not go away.
- Rabbi Harold Kushner

Pediatric palliative care helps redirect goals of care and address questions regarding the "right thing" for each child and family suffering with serious illness.

More than 2 of 3 patients referred to pediatric palliative care are still alive a year after referral

Children and their families in the care of palliative care teams report higher quality of life

The concept of TOTAL PAIN is an important way that these teams frame the care they give

Parents want:

- *The best quality of life for as long as possible for their child*
- *Their child to be comfortable even in the face of serious illness and death*
- *Someone to advocate for them and their family– to achieve their wishes for their child*
- *Recommendations to come from a place of compassion and understanding*
- *To be able to look back 1 day, 6 months, 5, and 10 years later and know they did the best for their child.*

"Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself…" *Eric Cassel (1982)*

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<u>ASK</u>: Are there any questions related to treating Palliative care?

[45 MINUTE SESSION COMPLETE]