

This isn't supposed to happen:

Understanding palliative care's role in pediatrics

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A little bit about me...



...Debbie Downer. I mean who *really* works with dying children?

Objectives

- Describe palliative care's utility within the pediatric population
- Define palliative care vs. hospice care
- Identify different models of delivering palliative care to pediatric patients
- Outline misconceptions that may inhibit palliative care's utility to children/adolescents
- Identify special considerations within pediatric palliative care

Ms. Brin has no disclosures

You know more than you think
you know, just as you know less
than you want to know.

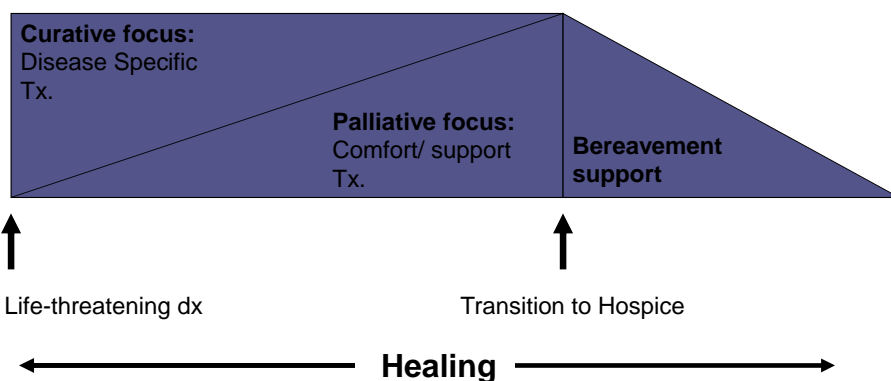
Oscar Wilde

So why is pediatric palliative
care important to
understand?

#1: It affects more kids than you would think. And kids you see.

- Approx 55,000 children die annually in the U.S.
- 8,600 children on any given day in U.S. qualify for palliative services
 - 1979-1997: 21% of pediatric deaths result of chronic condition
 - Past 2 decades: inc in late adolescent/early adulthood deaths from chronic conditions
- 17.2% of children with CC die in home
 - 7.8 – 11.6% <1yo with CC (1980-1998)
 - 21 – 48% >1yo with CC (1980-1998)
 - Preferred site with appropriate planning
- 52% of children with CC die in hospital

Palliative Care vs. Hospice



Common Diagnosis

1: **Life-threatening conditions for which curative treatment may be feasible but can fail:**

- Advanced cancer or cancer with poor prognosis
- Complex and severe congenital or acquired heart disease

2: **Conditions where early death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life:**

- Cystic Fibrosis
- HIV
- Chronic or severe respiratory failure
- Renal failure without available or indicated treatment
- Muscular Dystrophy, Myopathies, Neuropathies without available treatment

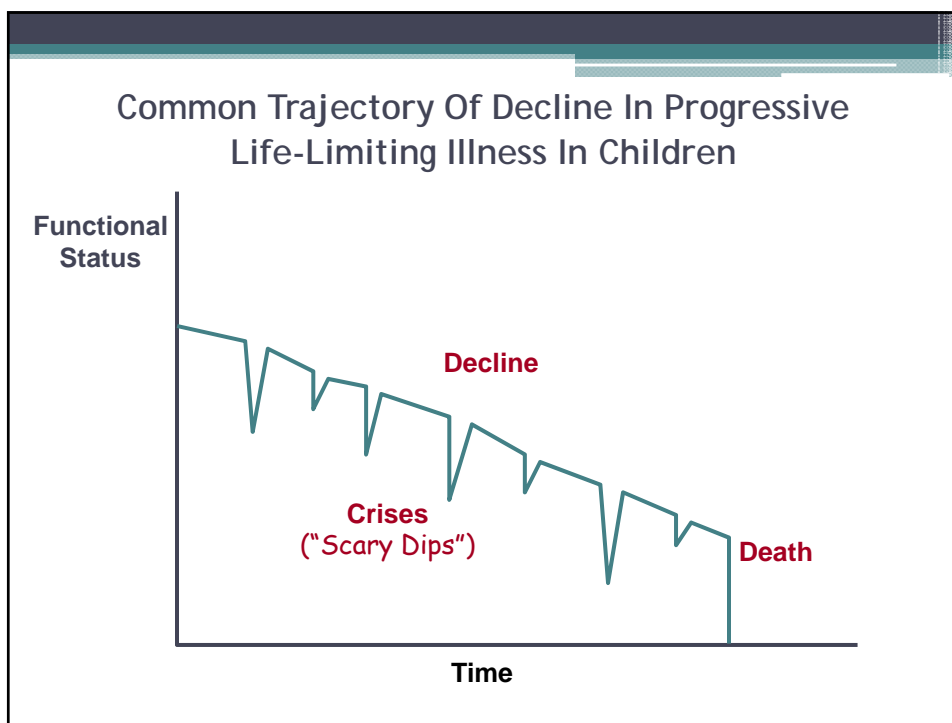
Common Diagnoses (cont'd)

3: **Progressive conditions without curative treatment options, where treatment is exclusively palliative after diagnosis:**

- Progressive severe metabolic disorders
- Certain chromosomal disorders
- Severe osteogenesis imperfecta
- Batten Disease

4: **Irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death**

- Severe cerebral palsy
- Extreme prematurity
- Severe brain malformations (hydrocephaly, ancephaly)



Prognostic Uncertainty

Pediatric Palliative Care services providers must **acknowledge the uncertainty** involved in determining if a specific circumstance or condition is life-limiting / life-threatening

#2: It's the reality we don't want, but if we have to; want to do it right.

- 80% of peds do NOT receive effective pain/symptom management
- MDs know of terminal prognosis ~ 350 dys prior to PED death; families are informed ~ 130 dys
- Providers express incompetence, anxiety and fear:
 - "I don't know what I'm doing"
 - "It's haunting"
 - "What am I even supposed to say?"

#3: It's good for the system, too.

- CSHCN 16% of pediatric population; 80% of pediatric expenditure
- Mostly Medicaid patients
- Cost avoidance:
 - Readmissions
 - Lengthy LOS
 - Capacity (ED; ICU beds)
- Staff retention
- Family satisfaction scores

So where are kids receiving palliative care?

- **Medicaid Waiver Programs - California, Colorado and Florida**
 - Concurrent Care via Healthcare Reform March 2010
- **Hospice**
 - Some large hospices may offer palliative care under separate service tier
- **Home Health**
- **Hospital Based Programs**
 - 40% of children's hospitals have a palliative service (undefined)
 - Interdisciplinary teams owned by hospital system
 - Nurse case manager owned by community-hospice; works inside children's hospital

Pediatric palliative and hospice care: In Kentucky

Palliative

- **Inpatient**
 - Kentucky Children's
 - Kosair Children's
- **Community**
 - Palliative Care Center of the Bluegrass
 - Clinic
 - Home (32-counties)
 - Various hospices

Hospice

- **Inpatient**
 - Kentucky Children's
 - Hospice of the Bluegrass
 - Lexington
 - Hazard
 - Hospice Care Plus
- **Community**
 - Daniel's Care (32-counties)
 - Certificate of need state/ various hospices

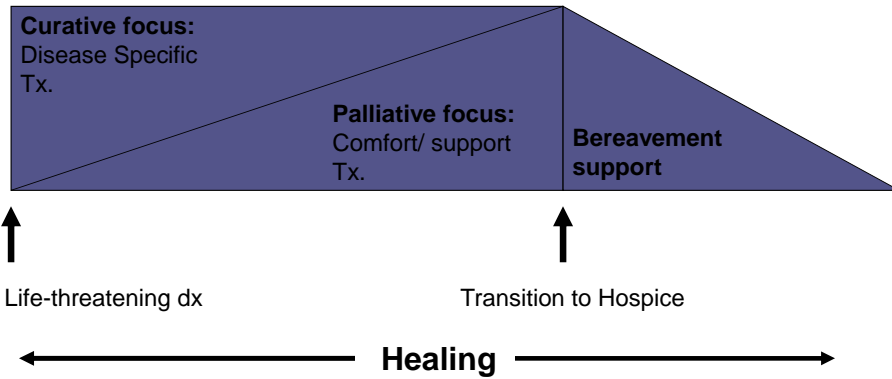
Ever get looked at like this?



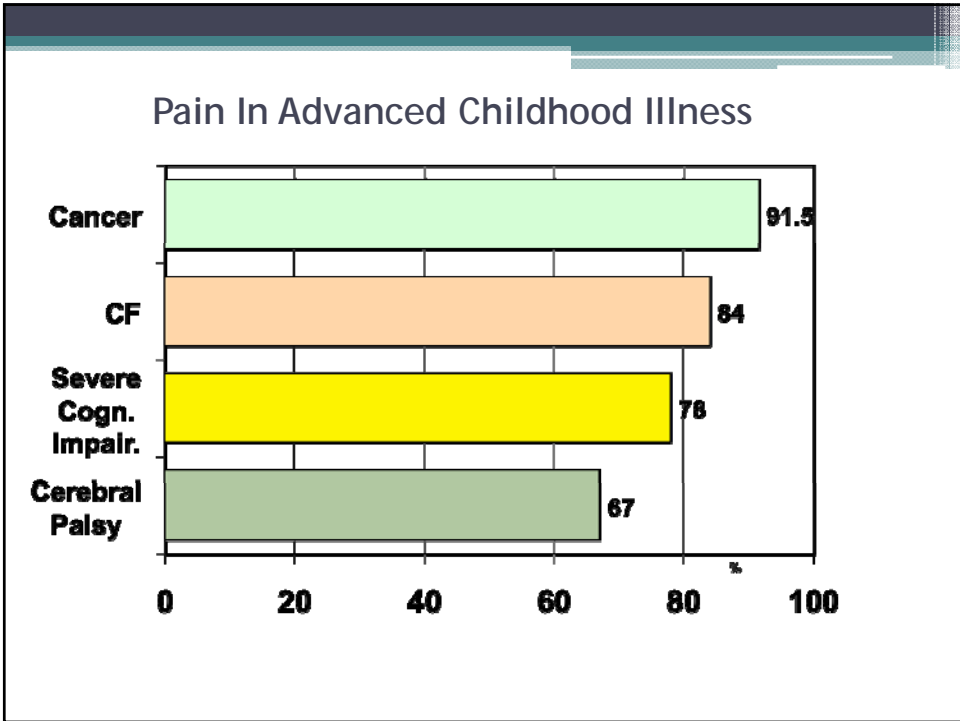
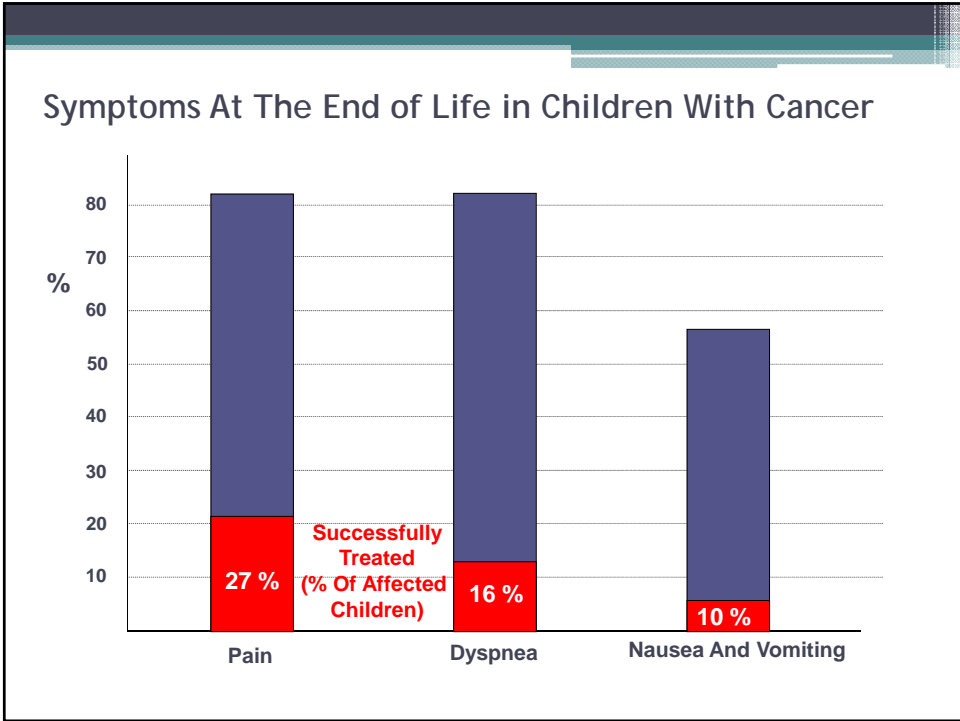
Confronting misconceptions about pediatric palliative care

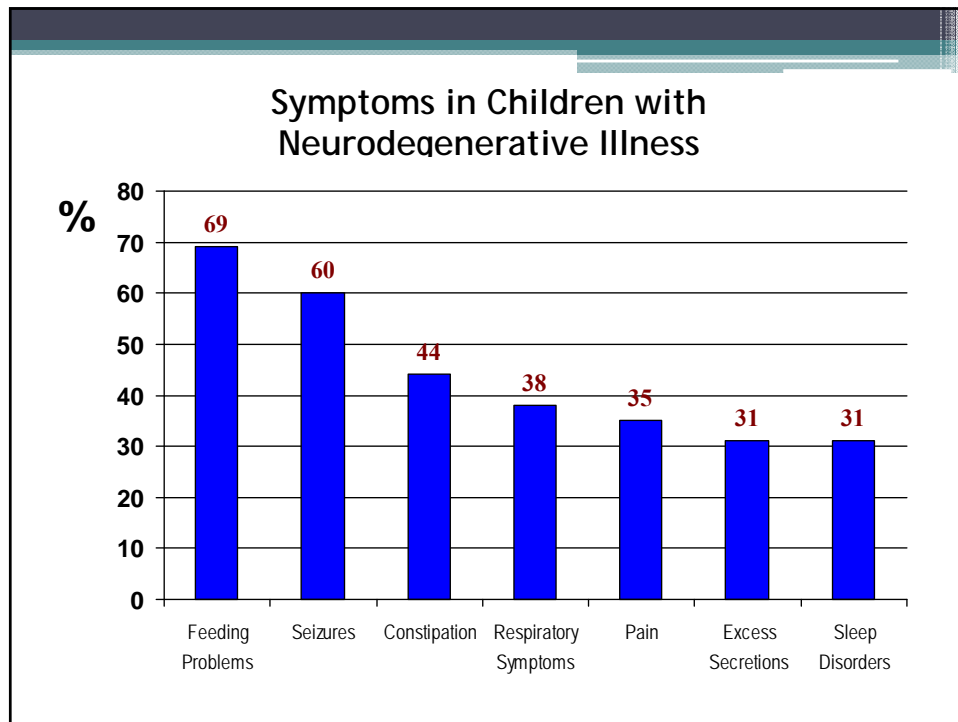
“Palliative care means end-of-life care”

Palliative Care vs. Hospice



“Kids have different symptoms than adults.”





“You can’t use the same medicines to treat kids’ symptoms that you use with adults.”

Recommended Opioid Analgesic Doses

Morphine Sulfate	Enteral	0.2 – 0.3 mg/kg q 4h	0.05 mg/kg IV load over 10 min then 0.01 – 0.03 mg/kg/hr
	IV/SQ	0.05 – 0.2 mg/kg q 2-4h	
Hydromorphone	Enteral	0.06mg/kg/dose q 3h	10 – 20 micrograms/kg IV load over 10 min then 2 – 8 micrograms/kg/hr
	IV/SQ	0.02mg/kg/dose q 3h	
Oxycodone	0.1mg/kg/dose po q4h		N/A
Fentanyl	0.5 – 5 micrograms/kg patch or IV		0.5 – 5 micrograms/kg/hr IV

* For infants < 12 months start with 1/2 of the pediatric starting dose and titrate

STRONG OPIOIDS

- Children > 3 months are probably at no greater risk of signif. resp depression than adults; younger infants may have ↑ risk due to metabolic immaturity affecting pharmacokinetics
- Most commonly use:
 - Morphine
 - Hydromorphone
 - Fentanyl
 - Oxycodone
 - Methadone

PCA Opioids

Same as adults; some considerations:

- A child able to play a video game can also operate a PCA pump (~6-7y.o.)
- Varying policies on whether nurse or parent are allowed to initiate a bolus

“You have to have a DNR to have hospice care.”

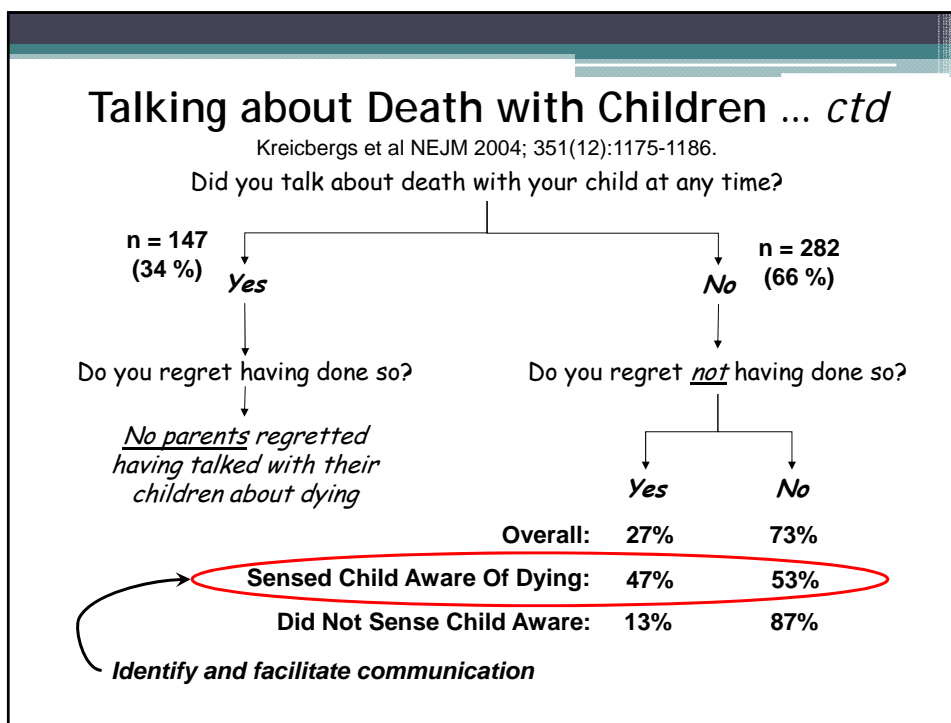
Code Status is a Goal of Care

- Discussing Benefit vs. Burden
- Palliative care facilitates establishing goals of care
 - Resuscitation (“AND” vs. “DNR”)
 - Artificial nutrition/hydration
 - Pulmonary support (tracheostomy; ventilator)
 - Antibiotics
 - Limits of intervention re: surgery? Additional tx?
- Limits of intervention/therapy
 - Medical Orders Scope of Treatment (MOST)
 - Physician Orders Scope of Treatment (POST)
 - EMS DNR

Main question I get?

But what do I say?

(To parent? To child? To sibling?)



Silence Is Not Golden

Children (even young children) are very perceptive and can tell when something serious is happening

- Per cognitive development, they will 'make up' what's going on if an adult does not explicitly tell them

- Remember **C.H.I.L.D.**
 - Consider developmental age
 - be Honest
 - Involve
 - Listen
 - Do it over and over again

Take Home Message:

1. Provider(s) talked to my child
2. We had a consistent provider

Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we may fear less.

- Marie Curie

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