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Relevant Disclosure

Morris Gessouroun, MD
Rachna May, MD

Hello, thank you for attending Pediatric Grand Rounds. The moderator(s) have nothing to disclose. This session is approved for *AMA PRA Category 1 Credit™*. For reporting purposes of the ACCME, **ALL** attendees are required to text in. To receive credit or attendance confirmation you must complete the session evaluation at the end. The evaluation will be available at cme.ouhsc.edu or on the CloudCME App at the end of the session. Once you have completed the evaluation, you will be able to print your CME certificate.

COLLEGE OF MEDICINE
PEDIATRICS
HEALTH SCIENCES CENTER

Jackson William Cook Memorial Endowed Visiting Lectureship

Jackson William Cook was born on October 26, 2006. Before his birth, Jackson was diagnosed with a rare unbalanced chromosomal translocation which had not specifically been described in the medical literature. Although some of the challenges Jackson would face were anticipated, much of his condition was uncharted territory. Initially Jackson improved steadily as many premature babies do, but after a point his medical condition became progressively more complex. Ultimately, Jackson underwent seven surgeries and experienced complications of six different organ systems. After struggling for 110 days, Jackson passed away surrounded by his family. Throughout Jackson's short life, his mother had the unique experience as a pediatrician of balancing the quest for answers and treatments with helplessness when the answers were simply not available. It is the hope of Jackson's parents that the Jackson W. Cook Endowed Visiting Professorship will serve to commemorate Jackson's struggle as well as to educate us all on clinical issues and research related to children like Jackson

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The Myths and Truths of Palliative Care for Children with Serious Illness

Jackson William Cook Memorial Lecture
May 10, 2017

Tammy I. Kang, MD MSCE
Section Chief, Palliative Care
Texas Children's Hospital

Pediatrics

Learning Objectives

- List common myths and truths surrounding palliative care for children with serious illness including the differences between hospice care and palliative care
- Explain the differences between the traditional model of curative/palliative trajectory versus palliative as a continuum of care including Concurrent Care for Children.
- Reflect on personal and professional experiences and values related to care of the seriously ill patients

Pediatrics

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Relevant Disclosure

Under Accreditation Council for Continuing Medical Education guidelines disclosure must be made regarding <u>relevant</u> financial relationships with commercial interests within the last 12 months.

Tammy I. Kang, MD MSCE

I have no relevant financial relationships or affiliations with commercial interests to disclose.

Pediatrics

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Pediatrics

Pediatrics

What is Pediatric Palliative Care?

Pediatrics

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Palliative care is about understanding the patient's / family's goals, hopes and values in order to best support them with appropriate disease directed treatments

Pediatrics

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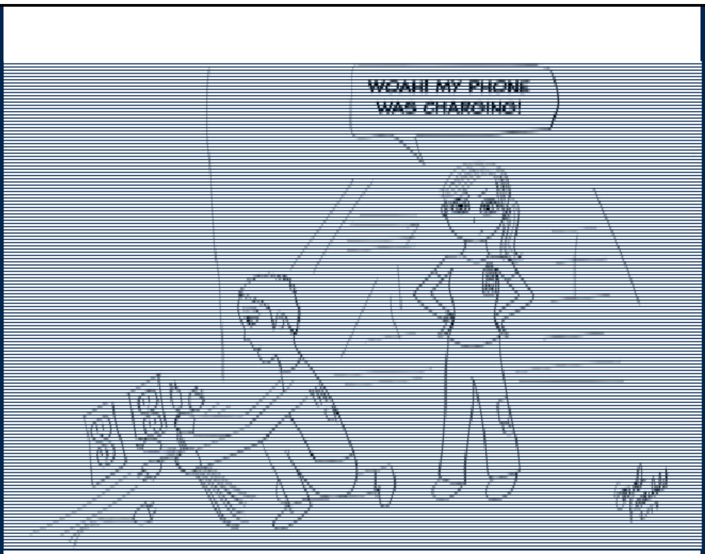
Why do we need PPC?

- Children even in the most technologically advanced medical centers in the world continue to suffer from **pain and other symptoms** at the end of life
- **Decisions** that families are faced with in an era of increasing medical technology are more and more difficult and require active physician support to navigate and communicate the medical complexities of care.
- More children are **dying at home** – Most parents would prefer for their child to die at home
- Families including **siblings** need continuous, long term compassionate, support



A TYPICAL DAY ON THE PALLIATIVE CARE TEAM, UNPLUGGING EVERYTHING THAT CAN BE UNPLUGGED.

Myths surrounding palliative care

- Palliative care only applies to patients who are “terminal” or have a clear poor prognosis
- Palliative care is the same as Hospice care and excludes disease directed treatments
- Recommending Palliative Care to patients means you’re giving up hope for cure or life extension
- Palliative Care is just psychosocial – it’s not real medicine
- There’s no real data that Palliative Care is beneficial

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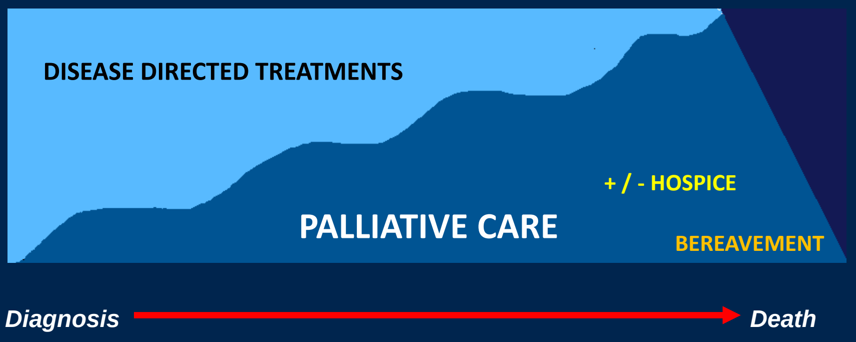

DISEASE DIRECTED TREATMENTS

+ / - HOSPICE

PALLIATIVE CARE

BEREAVEMENT

Diagnosis → *Death*

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A Snapshot of the PPC patients in hospitals: Multicenter cohort study

- Prospective observational cohort study conducted at 6 sites in the United States and Canada, each with an established hospital-based PPC team.
- All patients served by teams from January-March 2008 were eligible for enrollment, and subjects were observed for 3 months.

Feudtner C et al. Pediatrics 2011;127:1094-1101

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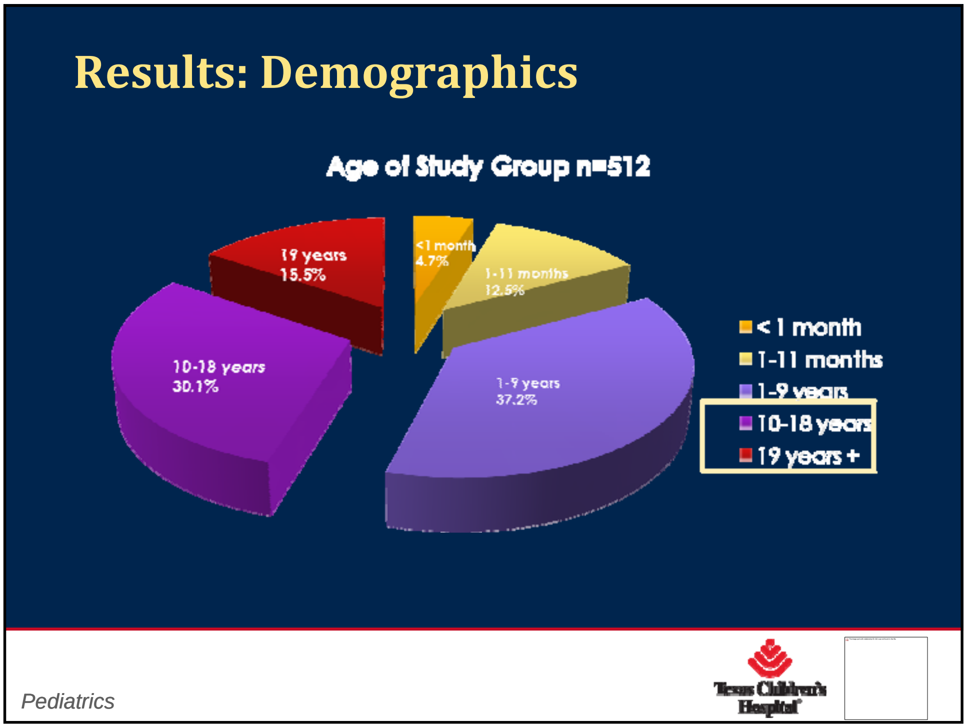

Results: Demographics

Age of Study Group n=512

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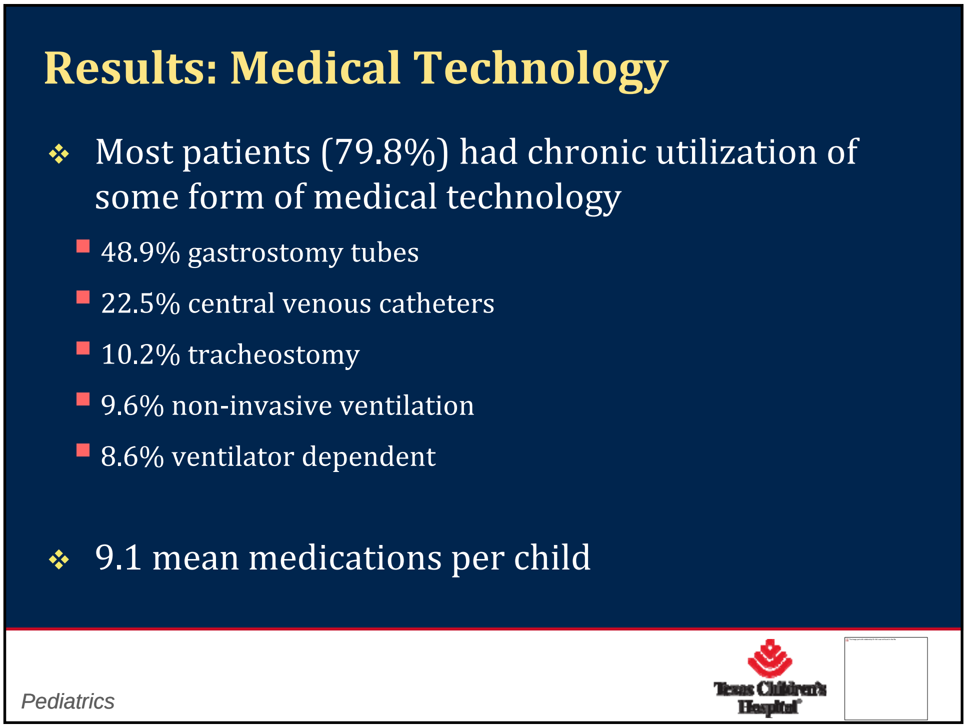

Results: Medical Technology

- Most patients (79.8%) had chronic utilization of some form of medical technology
  - 48.9% gastrostomy tubes
  - 22.5% central venous catheters
  - 10.2% tracheostomy
  - 9.6% non-invasive ventilation
  - 8.6% ventilator dependent
- 9.1 mean medications per child

Pediatrics

Follow Up: Mortality

- **20.7% of cohort died during 3 month follow-up….. Longitudinal unpublished data shows 60% still alive at 12 months**
- Among those who died, median time from enrollment to death was 23.5 days

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Myths surrounding palliative care

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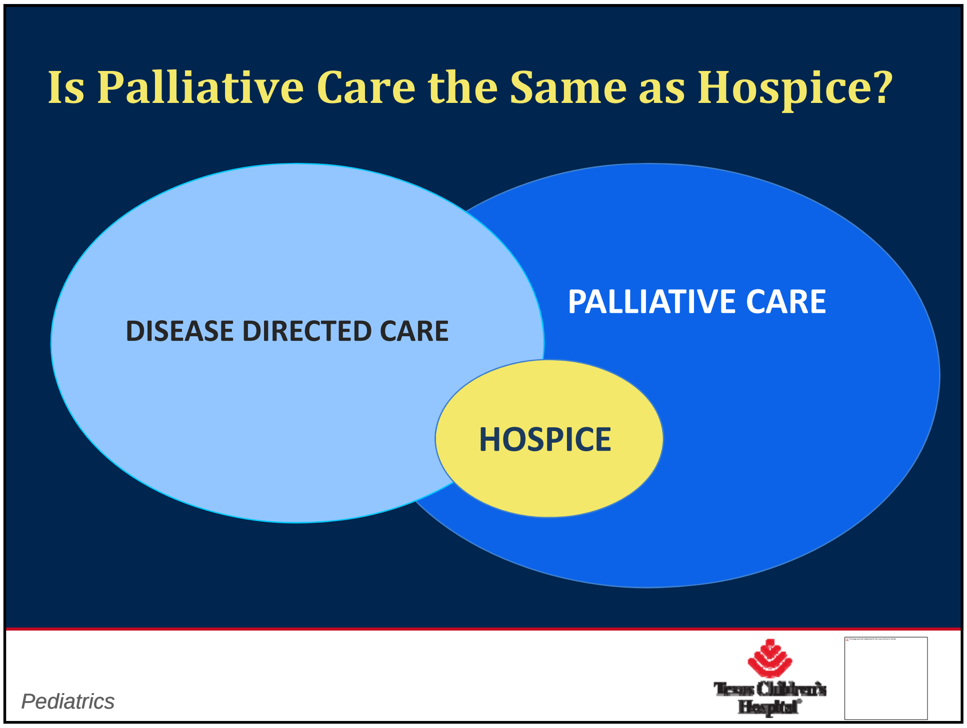

Is Palliative Care the Same as Hospice?

DISEASE DIRECTED CARE

PALLIATIVE CARE

HOSPICE

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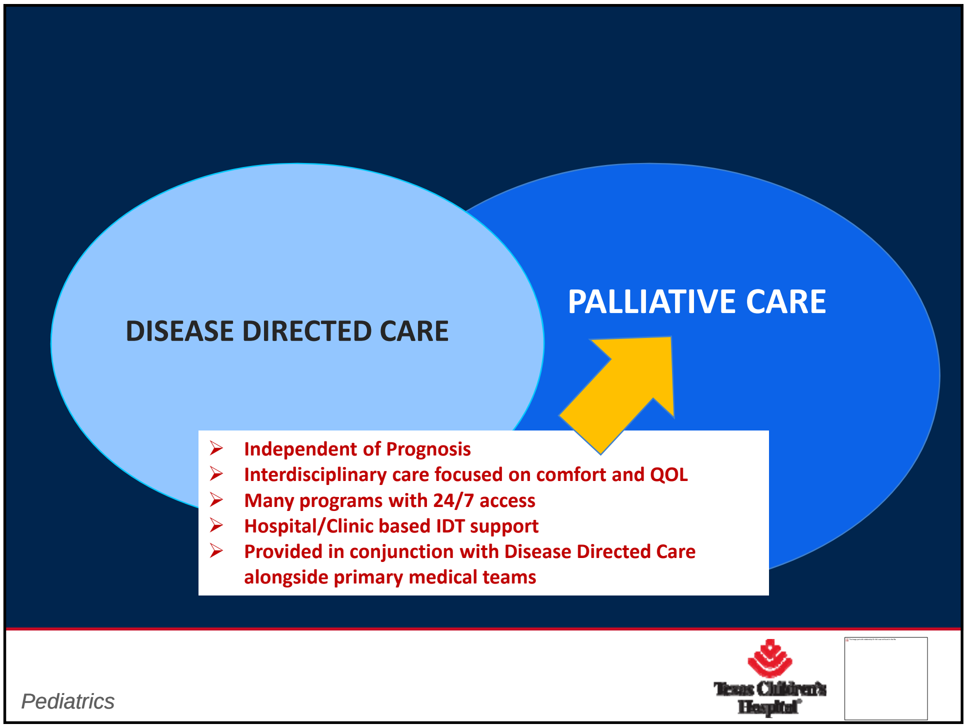

DISEASE DIRECTED CARE

PALLIATIVE CARE

- Independent of Prognosis
- Interdisciplinary care focused on comfort and QOL
- Many programs with 24/7 access
- Hospital/Clinic based IDT support
- Provided in conjunction with Disease Directed Care alongside primary medical teams

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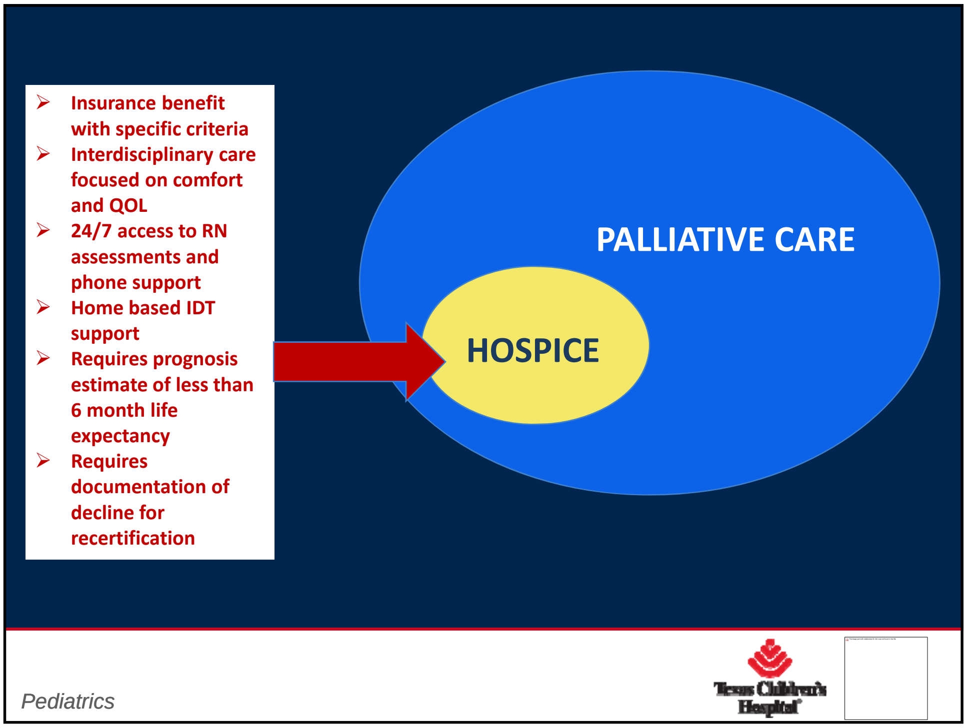
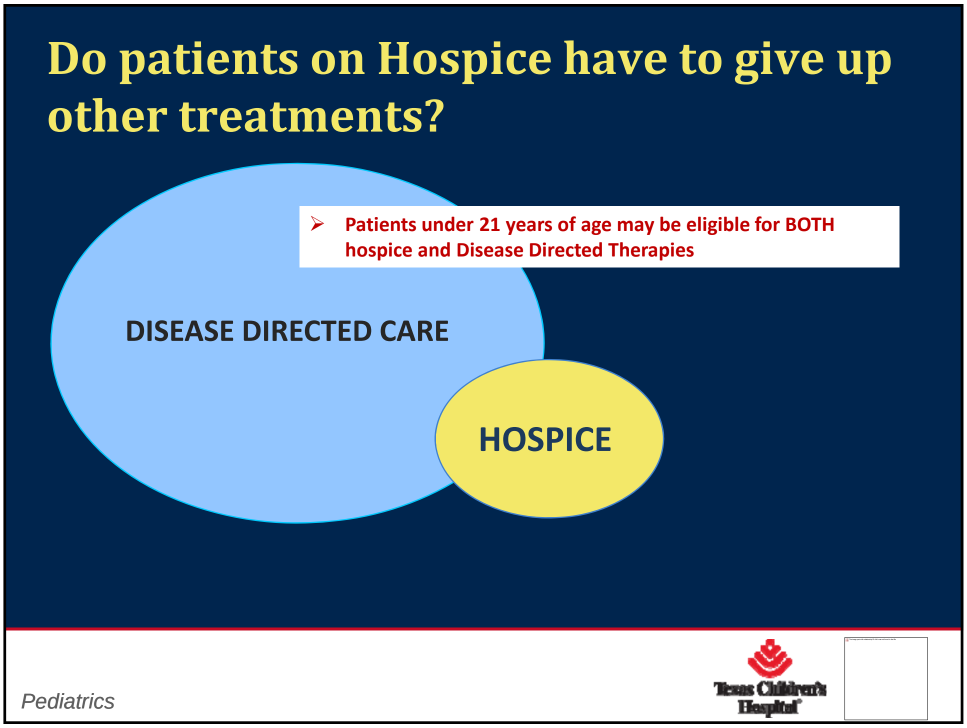


- Insurance benefit with specific criteria
- Interdisciplinary care focused on comfort and QOL
- 24/7 access to RN assessments and phone support
- Home based IDT support
- Requires prognosis estimate of less than 6 month life expectancy
- Requires documentation of decline for recertification

Do patients on Hospice have to give up other treatments?



- Patients under 21 years of age may be eligible for BOTH hospice and Disease Directed Therapies

Concurrent care

- Enacted on March 23, 2010, when the Patient Protection and Affordable Health Care Act was signed into law
- Provision in Section 2302, entitled "Concurrent Care for Children,"
- Requires that programs for children in state Medicaid or Children's Health Insurance Programs must allow patients to receive ***__hospice care__*** if eligible while still receiving potentially curative, disease directed treatment

Pediatrics

Implementation Challenges

- Physicians must certify that the child has a less than 6 month prognosis
- Eligible children are limited by existing reimbursement services under Medicaid or CHIP i.e. some states have CHIP programs without a hospice benefit
- No additional funding was provided
- No provision for privately insured or Medicare patients

Keim-Malpass, et al. J Pediatr Health Care. 2013

Pediatrics

Myths surrounding palliative care

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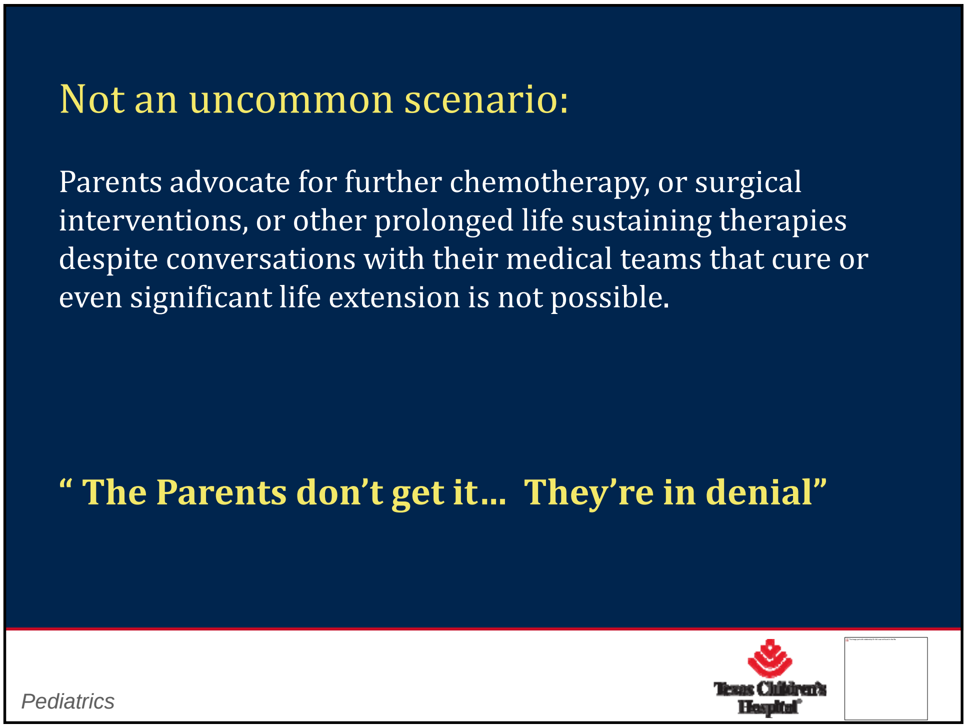

Not an uncommon scenario:

Parents advocate for further chemotherapy, or surgical interventions, or other prolonged life sustaining therapies despite conversations with their medical teams that cure or even significant life extension is not possible.

" The Parents don't get it… They're in denial"

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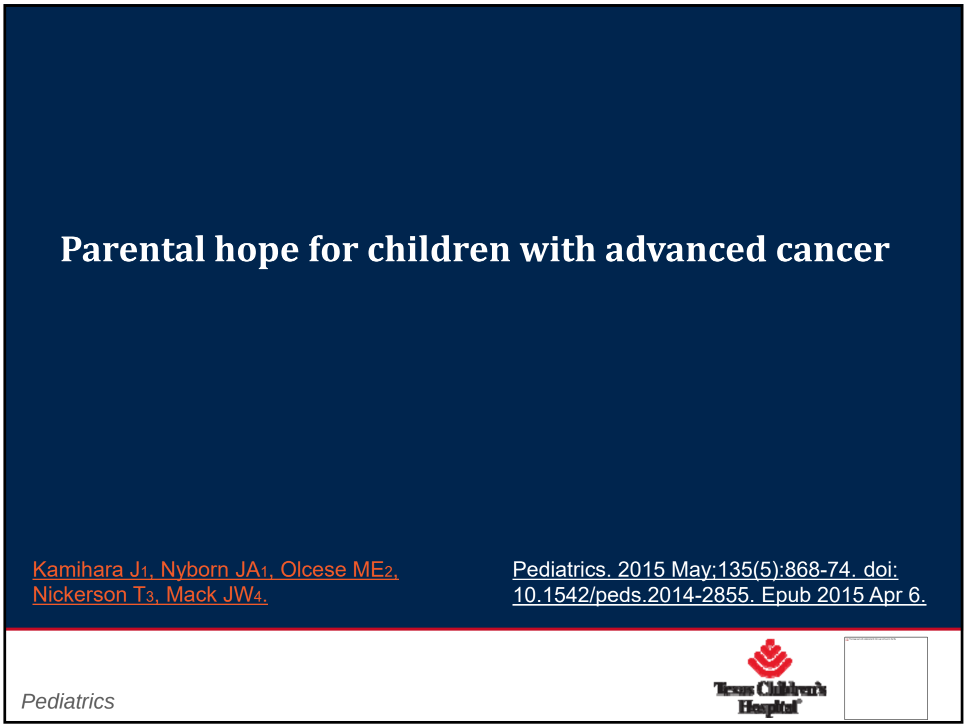

Parental hope for children with advanced cancer

Kamihara J[1], Nyborn JA[1], Olcese ME[2], Nickerson T[3], Mack JW[4].

Pediatrics. 2015 May;135(5):868-74. doi: 10.1542/peds.2014-2855. Epub 2015 Apr 6.

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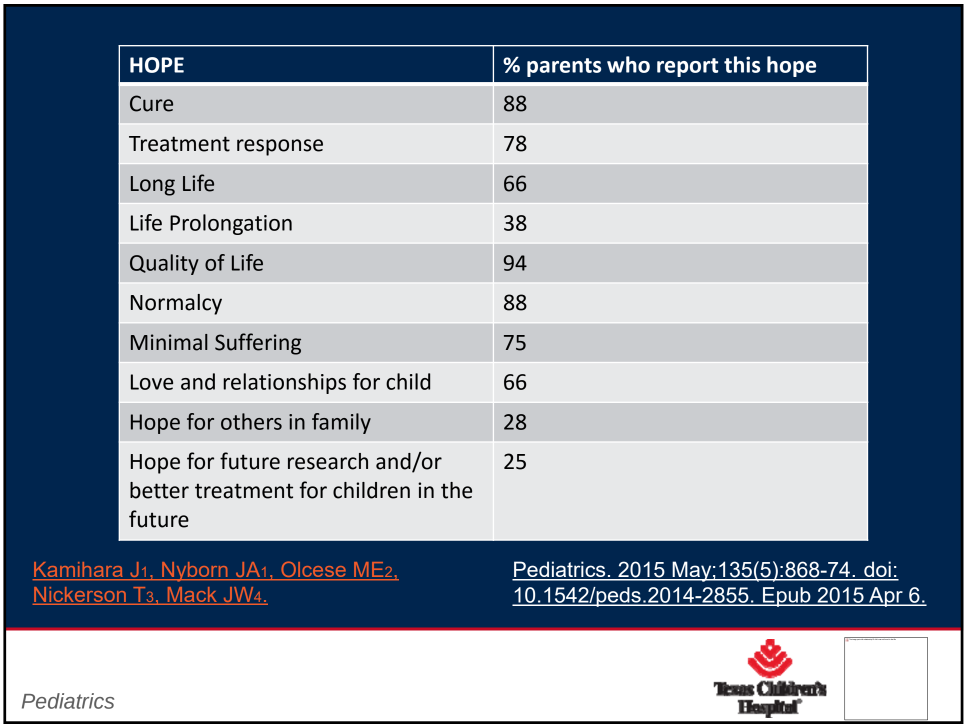

HOPE	% parents who report this hope
Cure	88
Treatment response	78
Long Life	66
Life Prolongation	38
Quality of Life	94
Normalcy	88
Minimal Suffering	75
Love and relationships for child	66
Hope for others in family	28
Hope for future research and/or better treatment for children in the future	25

Kamihara J[1], Nyborn JA[1], Olcese ME[2], Nickerson T[3], Mack JW[4].

Pediatrics. 2015 May;135(5):868-74. doi: 10.1542/peds.2014-2855. Epub 2015 Apr 6.

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Concurrent yet incongruent hopes and expectations

"..I hope he will be a miracle child…. I hope I can have good memories with him... I know what is going to happen...but I still have these hopes..."

"..It's not a curable situation….. I hope that it is going to be cured.... I hope my child makes it through this as whole as possible and has a normal life.... I hope for the least amount of pain and suffering...."

Kamihara J[1], Nyborn JA[1], Olcese ME[2], Nickerson T[3], Mack JW[4].

Pediatrics. 2015 May;135(5):868-74. doi: 10.1542/peds.2014-2855. Epub 2015 Apr 6.

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Why do we need PPC?

- ❖Children even in the most technologically advanced medical centers in the world continue to suffer from **pain and other symptoms** at the end of life

- ❖**Decisions** that families are faced with in an era of increasing medical technology are more and more difficult and require active physician support to navigate and communicate the medical complexities of care.

- ❖More children are **dying at home** – Most parents would prefer for their child to die at home

- ❖Families including **siblings** need continuous, long term compassionate, support

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Is suffering a given?

Serious Illness / Death

Suffering

Pain, Anxiety, Spiritual crisis, Financial, Family distress, hospitals, medications, community, fear

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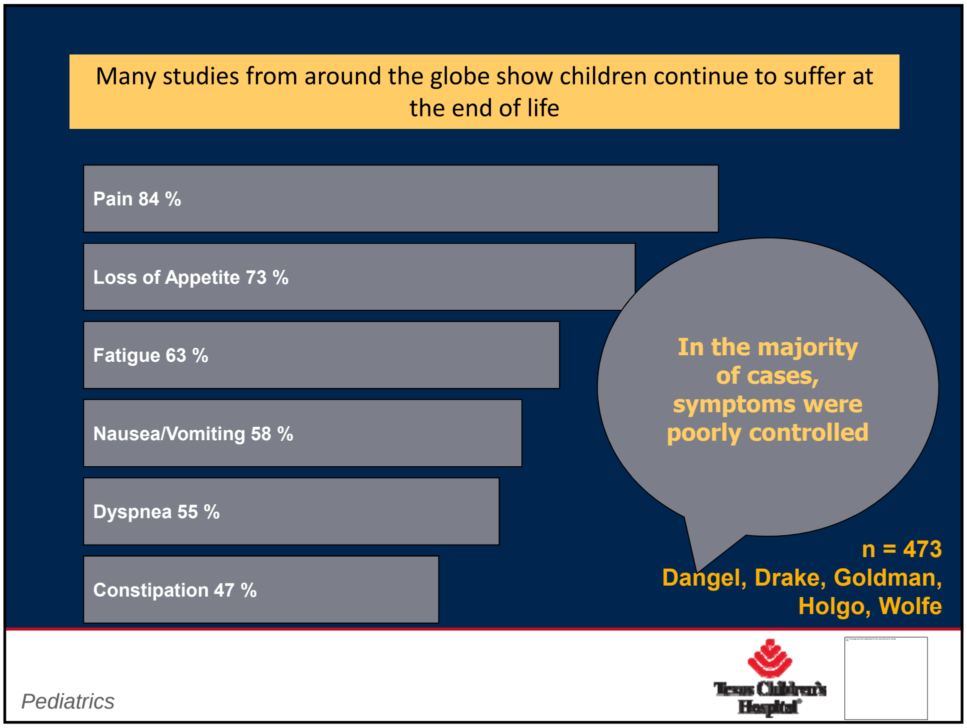

Many studies from around the globe show children continue to suffer at the end of life

Pain 84 %

Loss of Appetite 73 %

Fatigue 63 %

Nausea/Vomiting 58 %

Dyspnea 55 %

Constipation 47 %

In the majority of cases, symptoms were poorly controlled

n = 473
Dangel, Drake, Goldman, Holgo, Wolfe

Pediatrics

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

N ENGL J MED 363;8 NEJM.ORG AUGUST 19, 2010

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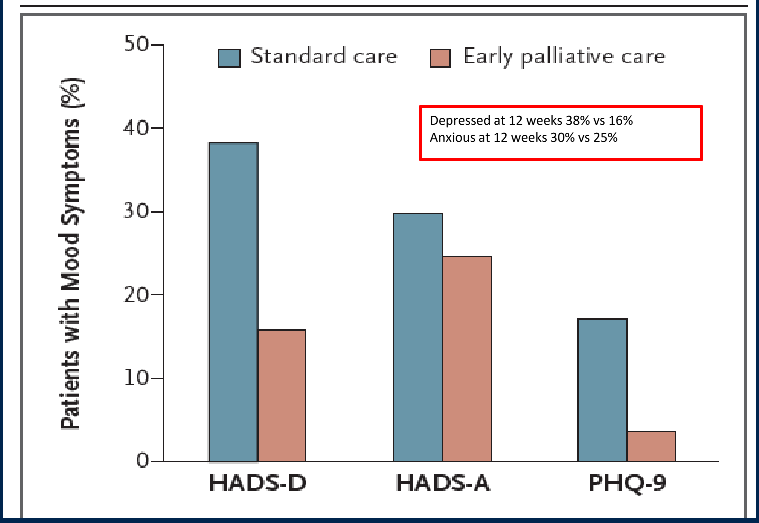
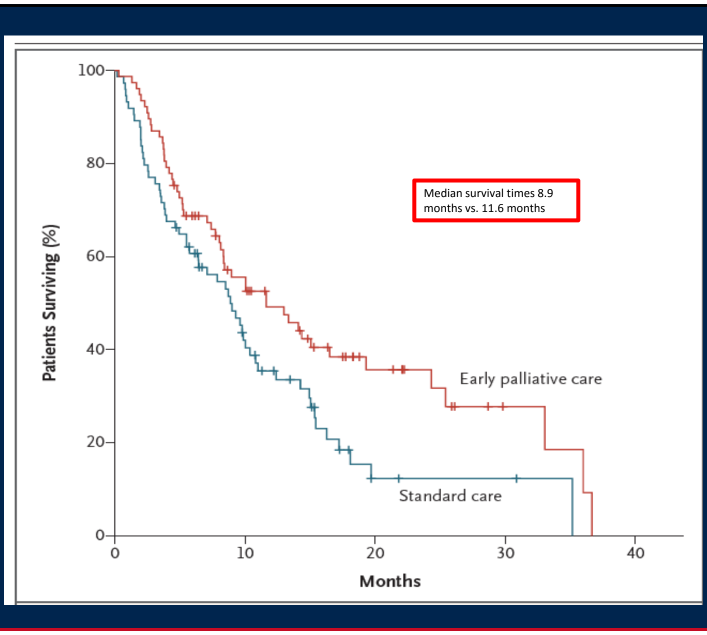
Study Overview

Patients with metastatic lung cancer randomly assigned to receive standard oncologic care or early palliative care, focused on symptom control and psychosocial support for patients and families, together with standard oncologic care.



Depressed at 12 weeks 38% vs 16%
Anxious at 12 weeks 30% vs 25%



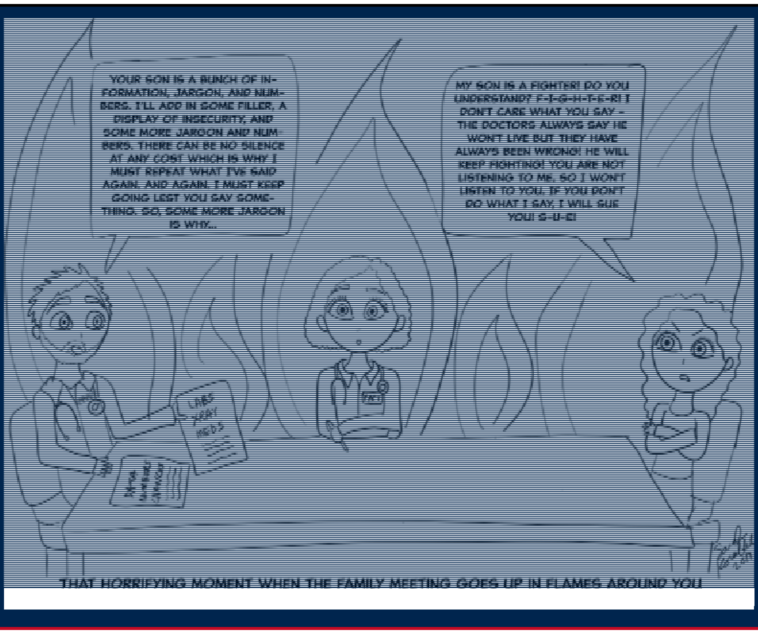
Median survival times 8.9 months vs. 11.6 months

Conclusions

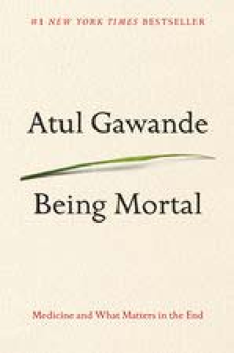
- Patients receiving early palliative care had lower rates of depression, a better quality of life, and better mood scores.
- They also received less aggressive care at the end of life, but surprisingly, had significantly longer survival than did patients receiving standard care alone.

The biggest communication problem is that we do not listen to understand.

We listen to reply



> “A family meeting is a procedure, and it requires no less skill than performing an operation.”



Excerpt From: Gawande, Atul. “Being Mortal.” Henry Holt and Company. iBooks.
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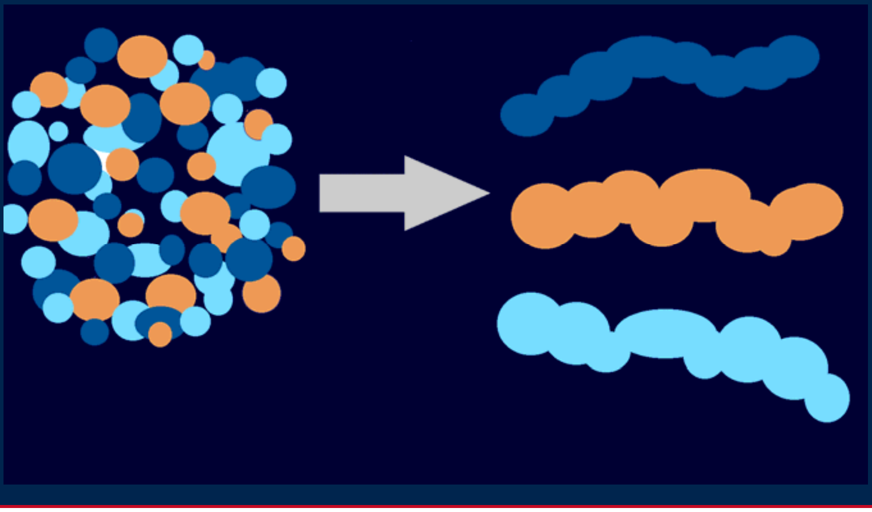
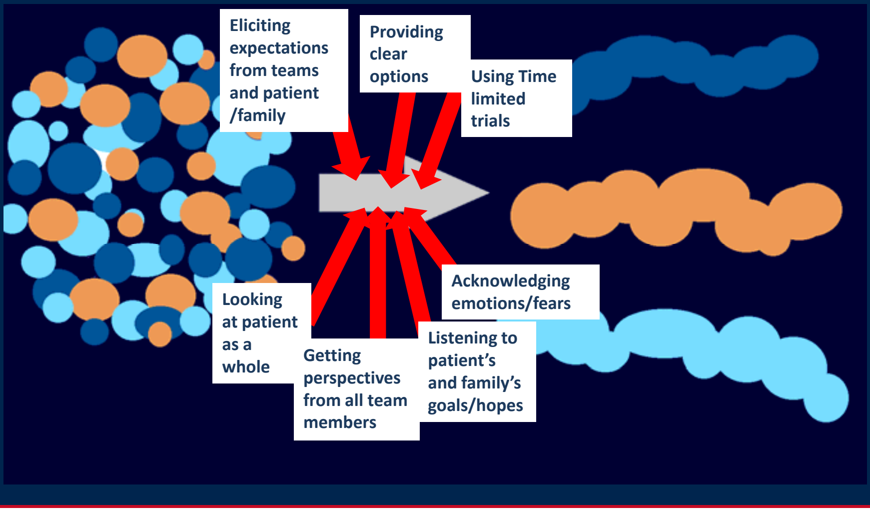
Finding a path forward



Finding a path forward



Eliciting expectations from teams and patient /family

Providing clear options

Using Time limited trials

Looking at patient as a whole

Getting perspectives from all team members

Listening to patient's and family's goals/hopes

Acknowledging emotions/fears

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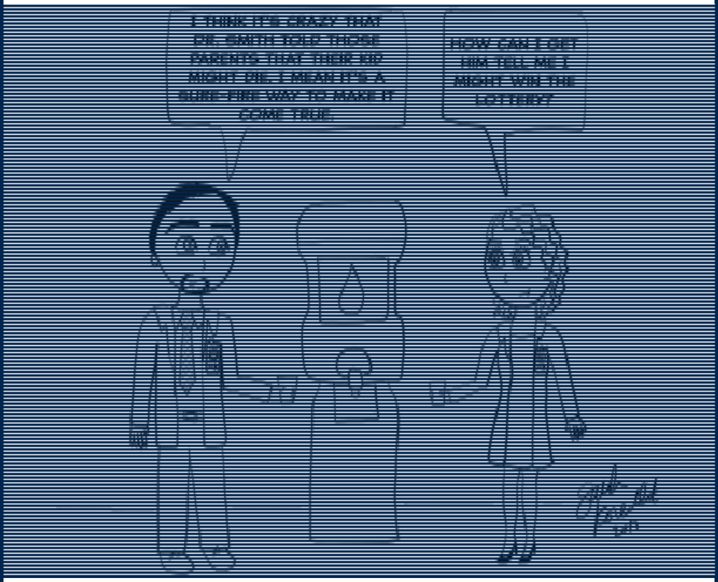

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Seven Reasons to Have Honest Prognostic Conversations

Mack and Joffe Pediatrics 2014

- Most parents want to have information about prognosis
- Prognosis communication builds a trusting relationship between the clinician, parent, and child
- Communication about prognosis respects and reinforces the parent’s role as a fiduciary and caregiver for the child in difficult times
- Honest conversations about prognosis enable patients and families to make thoughtful decisions about care and other important life plans
- Communication about prognosis is associated with greater hope and peace of mind
- Prognosis communication reduces uncertainty, which may be more distressing than the reality
- Honest conversation about prognosis opens up the opportunity for discussions about hopes, worries, and values, all of which help guide the care to come

---

A few key phrases go a long way

- Creates alignment
- Implicit acknowledgement that things won't go as desired
- "I wish we had chemotherapy that would cure the cancer"
- "We also wish for a miracle. If that does not happen, can we talk about how to best care for your child and family?"

Tell me more…….

- Reminds us to ask for patient/family thoughts, fears, hopes
- Allows for exploration of patient/family concerns, questions, emotions

I’m Worried……

- Gives an automatic warning shot to patient/parent
- Empathetic
- “Although we give you an exact time course for this disease, I’m worried that time may be short because….”
- “Although we have seen some children survive with these medical problems, I’m worried that in this case, it may not happen because….”

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Case Example

- Patient has a complicated medical history where prognosis is varied and can depend upon many factors
- Family is very optimistic
- Some clinical providers feel as if the family has not received all of the information

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Options

- Do not discuss prognosis as there is no clear survival in the literature and defer any conversations to the primary oncologist
- Review prognosis numbers from literature that you know with the parents
- Ask parent about what they understand and want to know regarding prognosis for their child

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Now what?

We don't know. There is no good literature or studies about prognosis for these types of medical problems. We will just have to wait and see.

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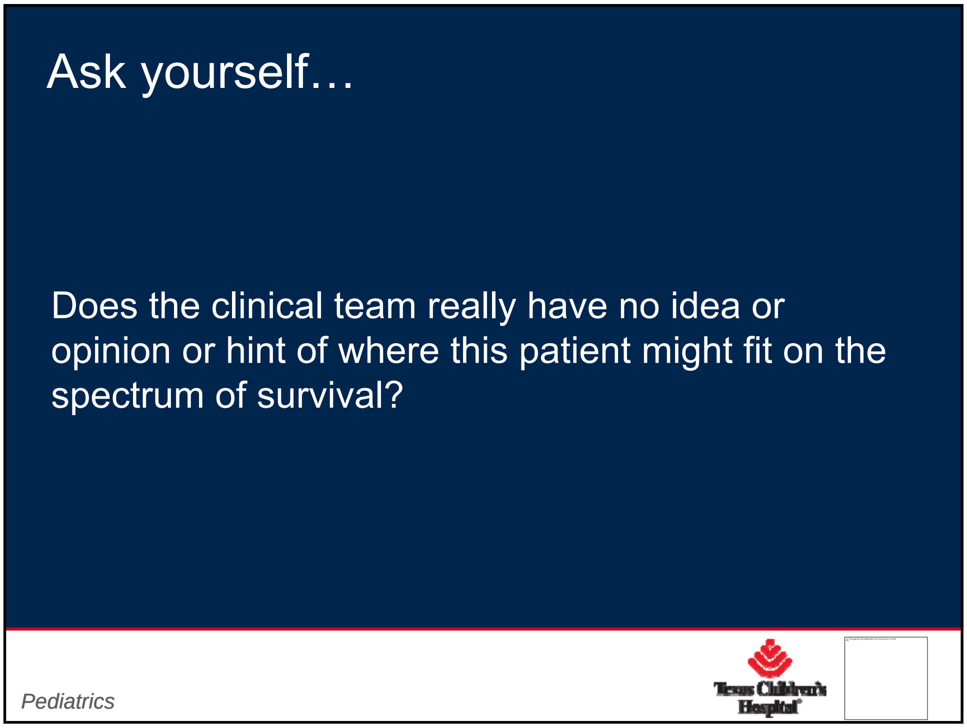

Ask yourself…

Does the clinical team really have no idea or opinion or hint of where this patient might fit on the spectrum of survival?

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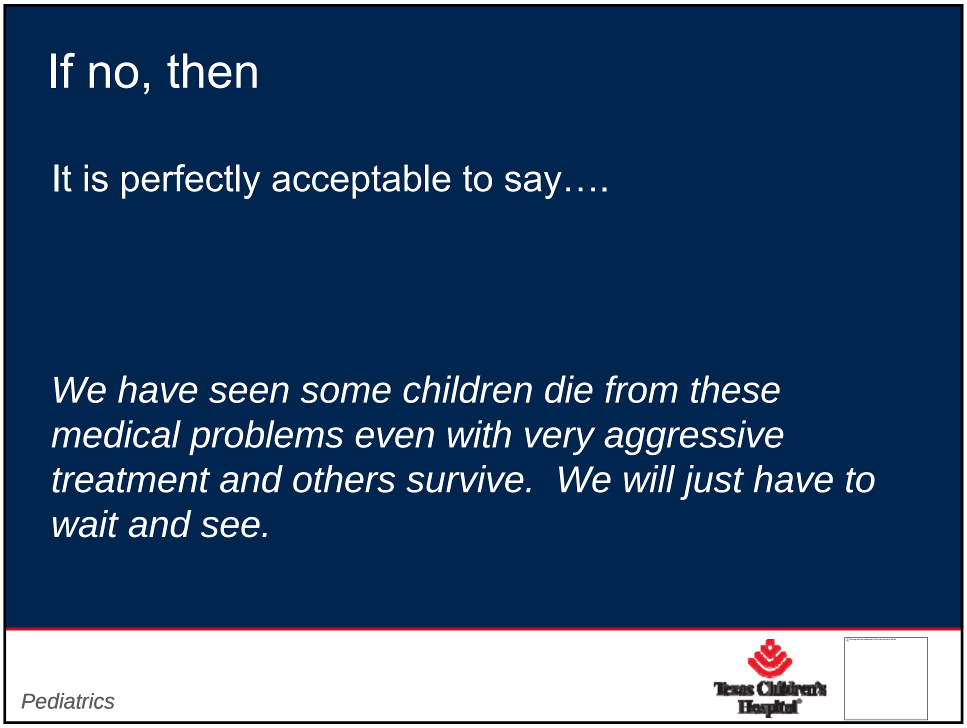

If no, then

It is perfectly acceptable to say….

We have seen some children die from these medical problems even with very aggressive treatment and others survive. We will just have to wait and see.

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BUT

Make sure you follow-up with caveats, like…

There may be times along the way where we might have a better idea of your child’s prognosis. For example, we look at how your child responds to certain treatments and whether your child has complications such as infections… other organ damage… etc.. We will let you know if we are worried and want you to tell us things that worry you.

If Yes, then

Although we have seen some children survive long term with these medical problems, **I’m worried** that your child may not because……

Myths surrounding palliative care

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- ❖ Palliative Care is psychosocial – it's not real medicine
- ❖ **There's no real data that Palliative Care is beneficial**

Improves Outcomes

- ❖Helps parents and children have a voice in identifying and realizing their care goals – essential to improved quality of life, experience and satisfaction
- ❖Enhances well-being, strength, and resilience – all required to have the reserve to undergo disease-directed treatment successfully
- ❖Makes it more likely that seriously ill children and their families have fun and meaning

Wolfe, J, Hammel, JF, Edwards, KE, et al. (2008). Easing of suffering in children with cancer at the end of life: Is care changing? *Journal of Clinical Oncology, 26*(10), 1717–1723.

Hays, RM, Valentine, J, Haynes, G, et al. (2006). The Seattle Pediatric Palliative Care Project: Effects on family satisfaction and health-related quality of life. *Journal of Palliative Medicine, 9*(3), 716–728.

Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. J Palliat Med.

Shown in Some Studies To Reduce Costs

California Home-Based PPC Pilot Findings:

- High satisfaction scores from caregivers – improved children's pain and other symptoms and parents' own experience and quality of life
- Health care cost savings of $3,331 PEPM

- Most savings were realized through a dramatic reduction in inpatient costs of $4897 PEPM
- Enrollees experienced a nearly 50% reduction in average number of inpatient days per month (dropped from 4.2 to 2.3)
- Average LOS per hospitalization dropped from average 16.7 days before enrollment to 6.5 days while in the program
- Overall savings totaled nearly $7 million. Pilot data spanned Jan 2010 to Dec 2012

Gans D, Hadler MW, Chen X, et al. Impact of a pediatric palliative care program on the caregiver experience. J Hosp Palliat Nurs 2015;17:559-565.

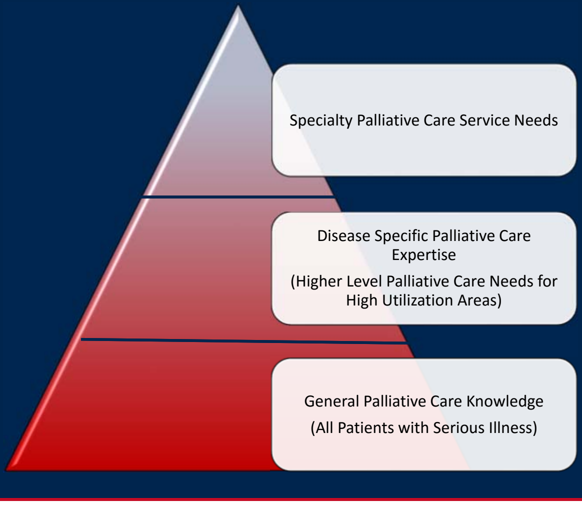
Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. *J Pain Symptom Manage.* 2016;52(3):329-335.

Pediatric Palliative Care and Inpatient Hospital Costs: A Longitudinal Cohort Study

- The 10% most costly inpatients treated at a children's hospital in 2010 were studied
- Technology dependence, older age, multiple chronic conditions, PICU admission, and death in 20 10 were independently associated with receipt of PPC.
- Among patients who died during the 2-year follow-up, PPC recipients had significantly lower inpatient costs.
- Among survivors, PPC recipients had greater inpatient costs.
- When controlling for patient complexity, differences in inpatient costs were not significant.

Maloney et al. Pediatrics 2015; DOI: 10.1542/peds.2014-3161

Palliative Care Needs



Specialty Palliative Care Service Needs

Disease Specific Palliative Care Expertise

(Higher Level Palliative Care Needs for High Utilization Areas)

General Palliative Care Knowledge

(All Patients with Serious Illness)

Cancer Action Network℠
American Cancer Society®

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

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AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

Center to Advance Palliative Care™
capc

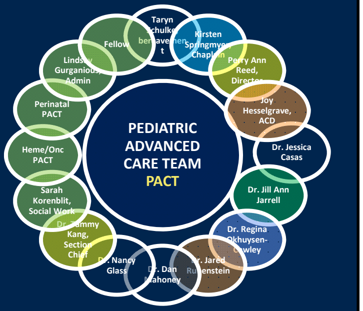
Thank You!

Jackson William Cook and Family

Sarah Korenblit , LCSW
Cartoonist-in-Residence and PACT Social Worker

Department of Pediatrics at TCH/Baylor Leadership
- Dr. Mark Kline
- Dr. Susan Blaney

Texas Children's Hospital Leadership
- Mark Wallace
- John Nickens
- Mary Jo Andre
- Jackie Ward
- Perry Ann Reed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Taryn Schulke, bereavement
Kirsten Springmyer, Chaplain
Perry Ann Reed, Director
Joy Hesselgrave, ACD
Dr. Jessica Casas
Dr. Jill Ann Jarrell
Dr. Regina Okhuysen-Cawley
Dr. Jared Rubenstein
Dr. Dan Mahoney
Dr. Nancy Glass
Dr. Tammy Kang, Section Chief
Sarah Korenblit, Social Work
Heme/Onc PACT
Perinatal PACT
Lindsay Gurganious, Admin
Fellow

Members of the Palliative Care Section and Palliative Care Community

The patients and families who inspire us every day

Texas Children's Hospital