



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



**Texas Children's
Hospital**[®]

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College of
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Pediatrics

Objectives

- ❖ List myths surrounding palliative care for children with serious illness, including common ethical issues that occur in the care of these patients
- ❖ Identify the truths of providing palliative care to children with serious illness including the differences between hospice care and palliative care; the importance of communication in navigating ethical issues that occur in the care of these patients
- ❖ Explain the differences between the traditional model of curative/palliative trajectory versus palliative as a continuum of care including Concurrent Care for Children and the overlap between Palliative Care and Medical Ethics





What is Pediatric Palliative Care?



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

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

- Communication with caregivers and patients is integral to delivering palliative care.
- Some ethical issues arise in the care of these patients
 - Fear of not being able to stop a therapy should not prevent beneficial therapies from being trialed
 - Clinicians must provide patients and families with adequate information about risks, discomfort, side effects and potential benefits
 - Clinicians should make a recommendation based on patient/family's values
 - Patients or caregivers cannot compel physicians to provide treatment they believe is highly unlikely to benefit the patient.

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 way to expedite the death of patients
- ❖ Palliative Care is just psychosocial – it’s not real medicine
- ❖ There’s no real data that Palliative Care is beneficial

Common Ethical issues in Palliative Care

- Medical Decisionmaking
- Information disclosure
- Conflict over goals of medical care (futility)
- Care at the end of life or margins of life

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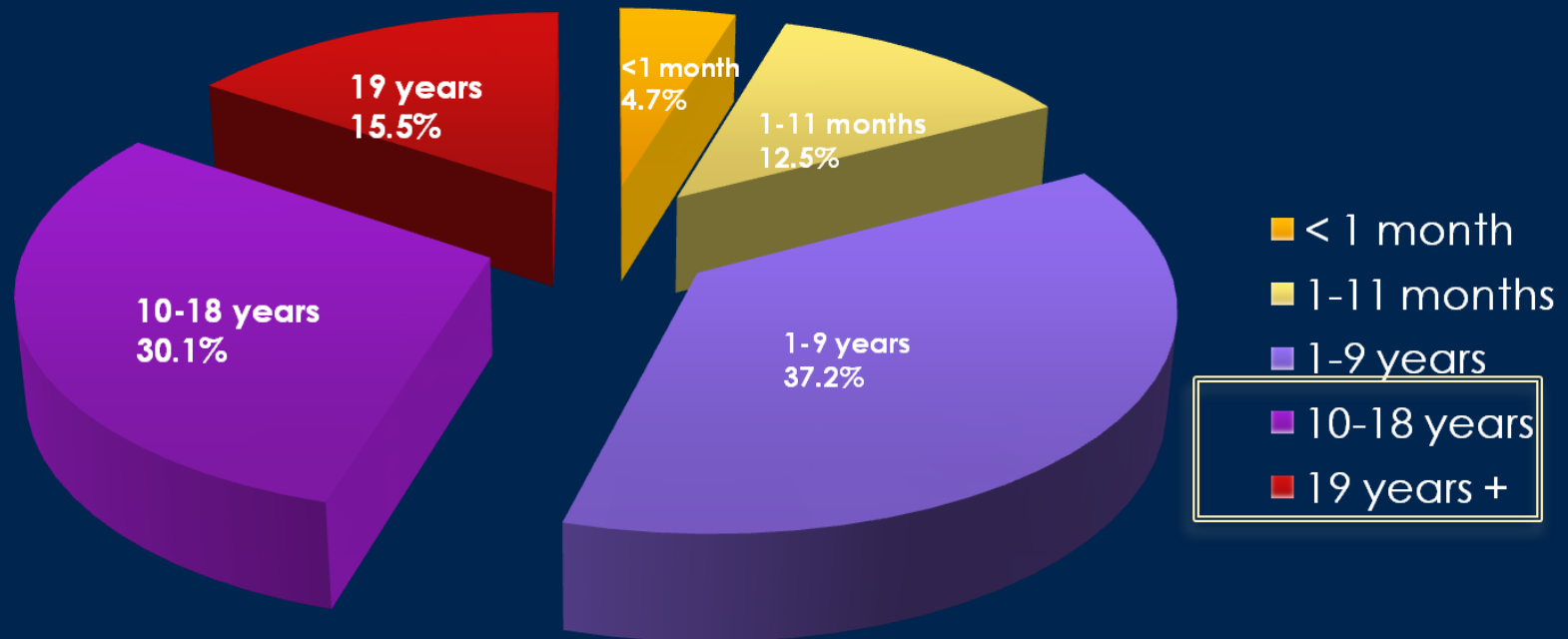
A Snapshot of the PPC patients in hospitals: Multicenter cohort study

- ❖ 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

Results: Demographics

Age of Study Group n=512



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

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**

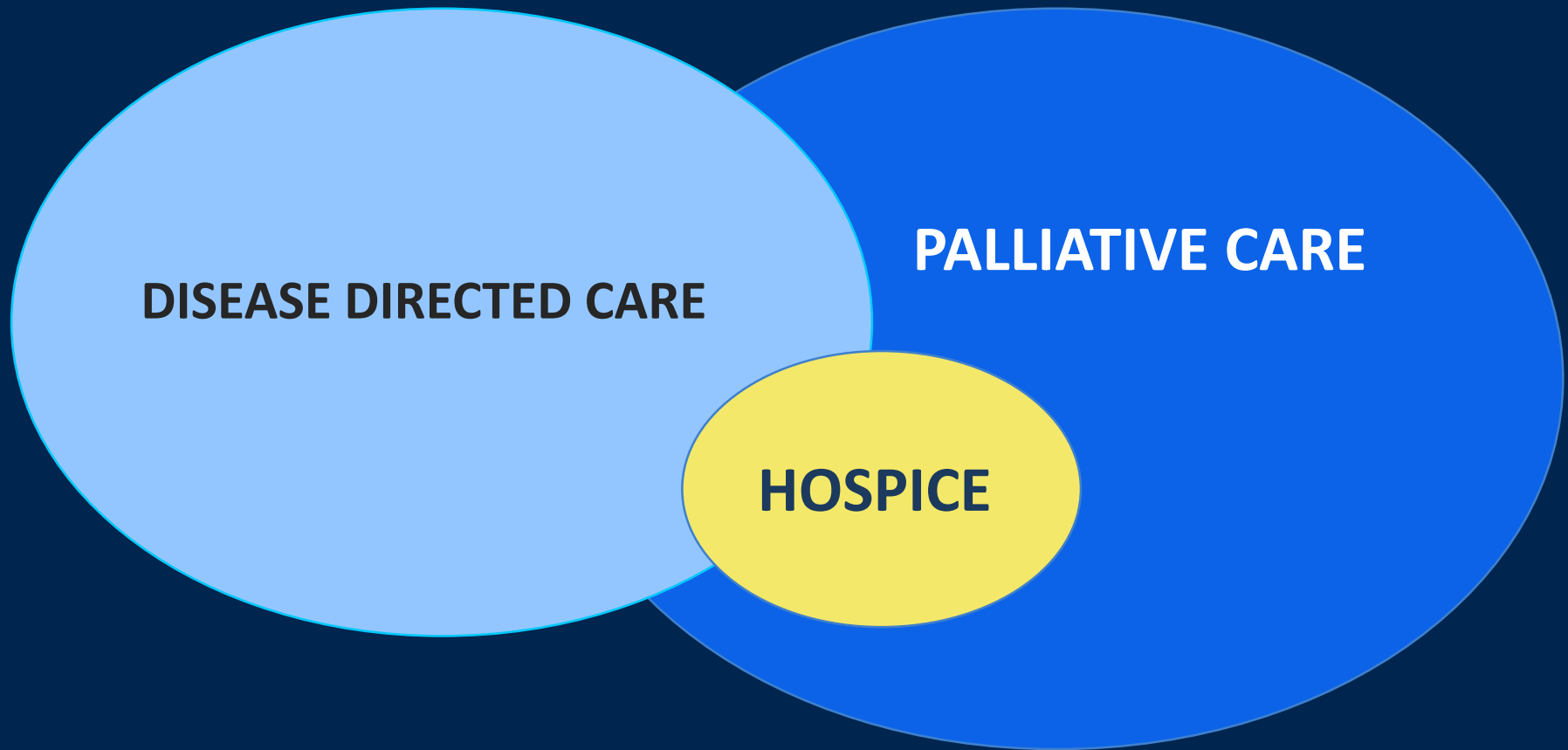
Benefits of Early Palliative Care Integration

- ❖ The American Society of Clinical Oncology (ASCO) issued a provisional clinical opinion on integrating palliative care into standard oncology care (March 10, 2012 *Journal of Clinical Oncology*)
- ❖ 7 randomized controlled trials, benefits of early specialty palliative care with oncologic care include:
 - ❖ Improved symptoms, QOL, and satisfaction
 - ❖ Reduced caregiver burden
 - ❖ More appropriate referral to and use of hospice
 - ❖ Decreased use of futile intensive care
 - ❖ Most also demonstrated cost lower than that of standard oncologic care alone

Myths surrounding palliative care

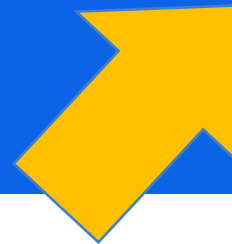
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Is Palliative Care the Same as Hospice?



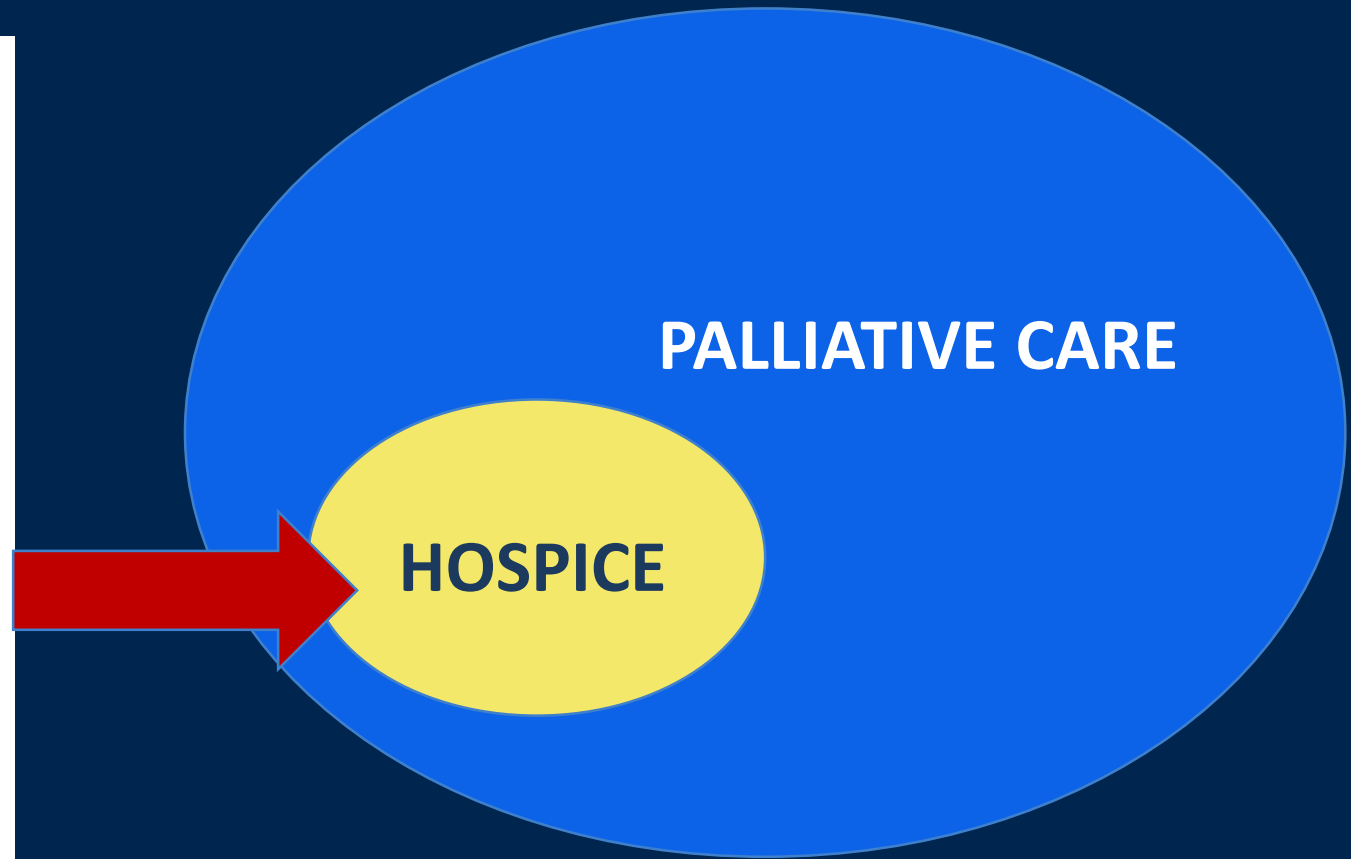
DISEASE DIRECTED CARE

PALLIATIVE CARE



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

- 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 eligible for BOTH hospice and Disease Directed Therapies

DISEASE DIRECTED CARE

HOSPICE

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

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Not an uncommon scenerio:

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”

Parental hope for children with advanced cancer

[Kamihara J₁, Nyborn JA₁, Olcese ME₂, Nickerson T₃, Mack JW₄.](#)

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

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 J₁, Nyborn JA₁, Olcese ME₂, Nickerson T₃, Mack JW₄.](#)

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

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 J₁, Nyborn JA₁, Olcese ME₂, Nickerson T₃, Mack JW₄.](#)

[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?

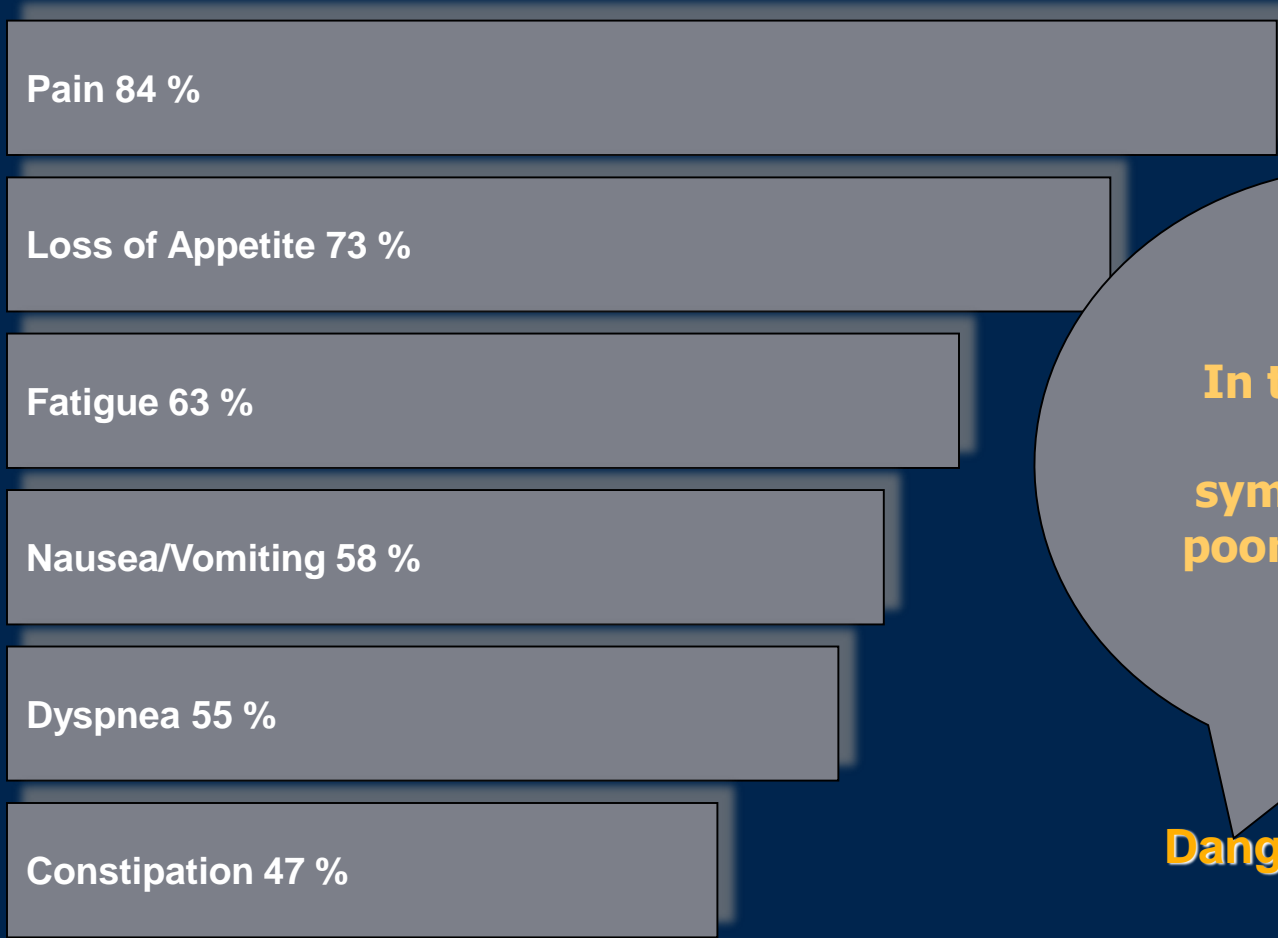
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Is suffering a given?



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

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



In the majority of cases, symptoms were poorly controlled

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

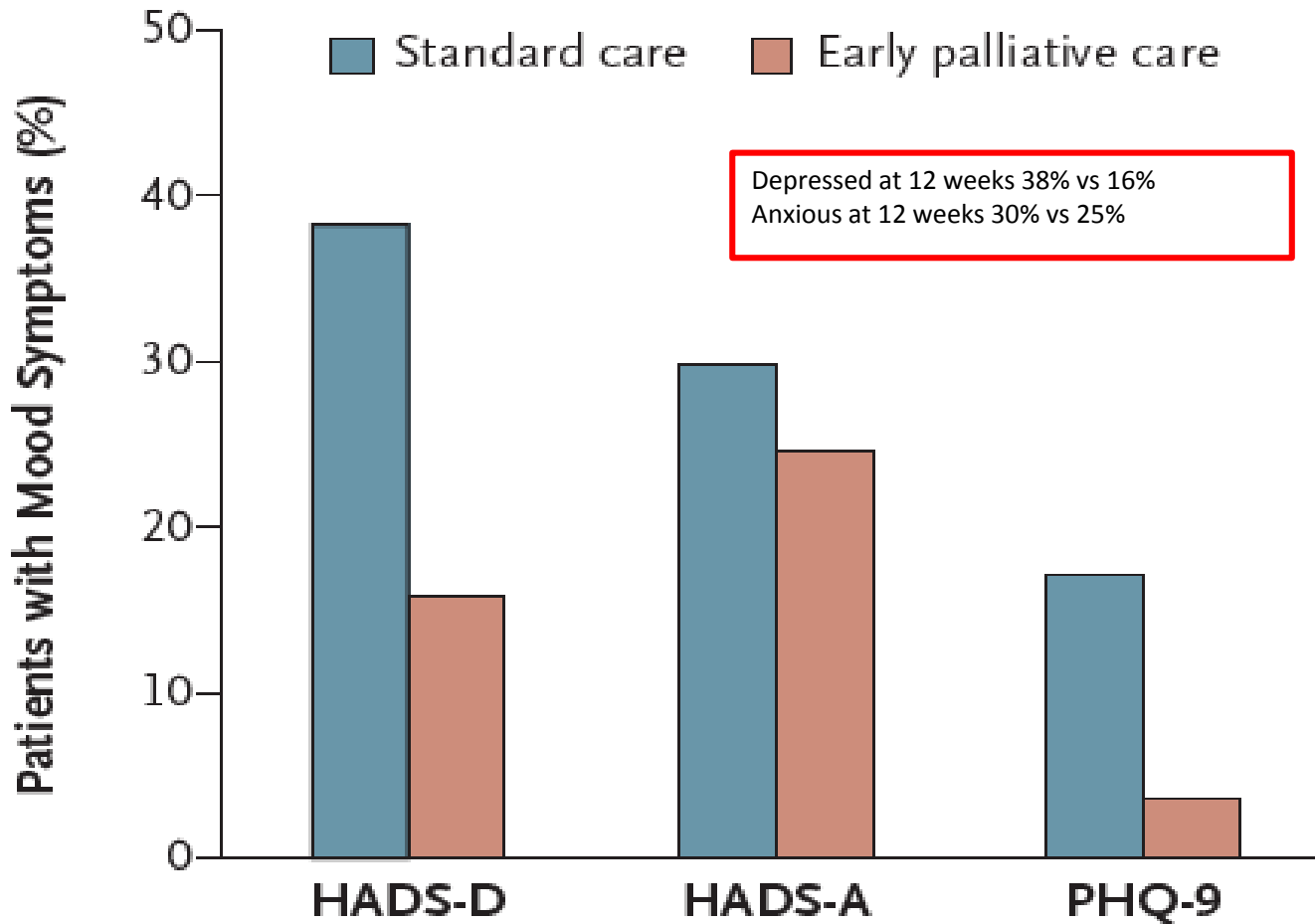
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

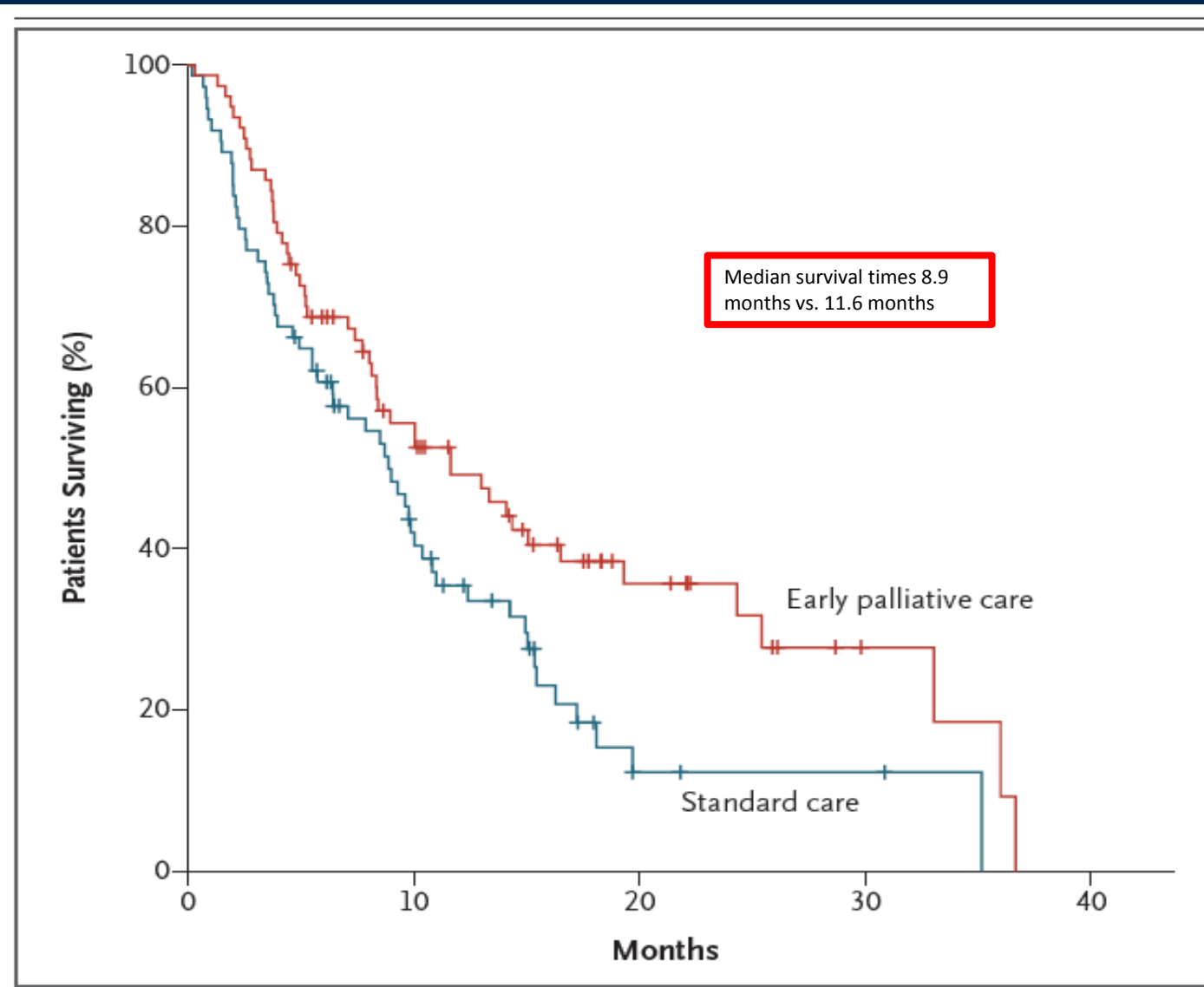
Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D.,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

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

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.





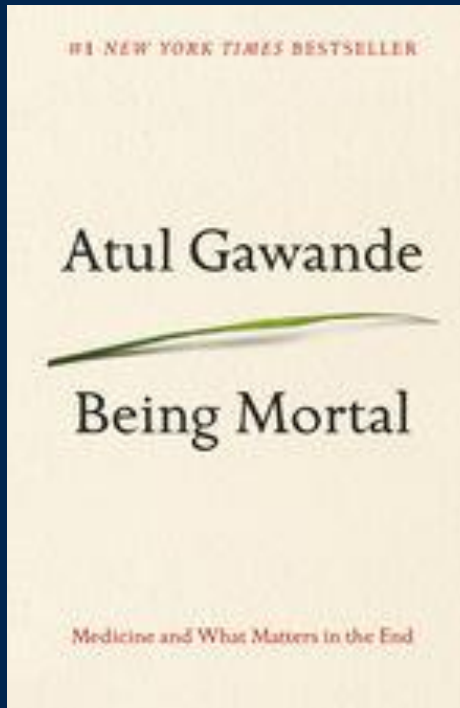
Conclusions

- ❖ 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

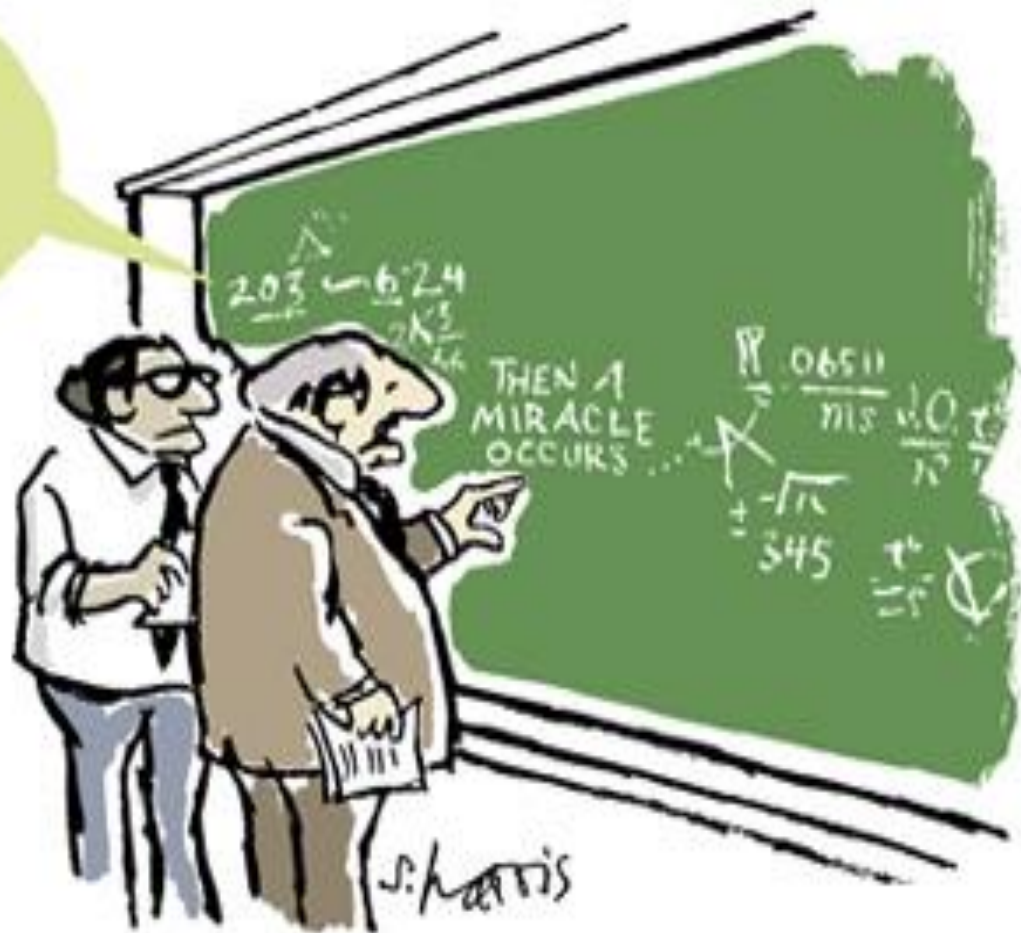
“A family meeting is a procedure, and it requires no less skill than performing an operation.”



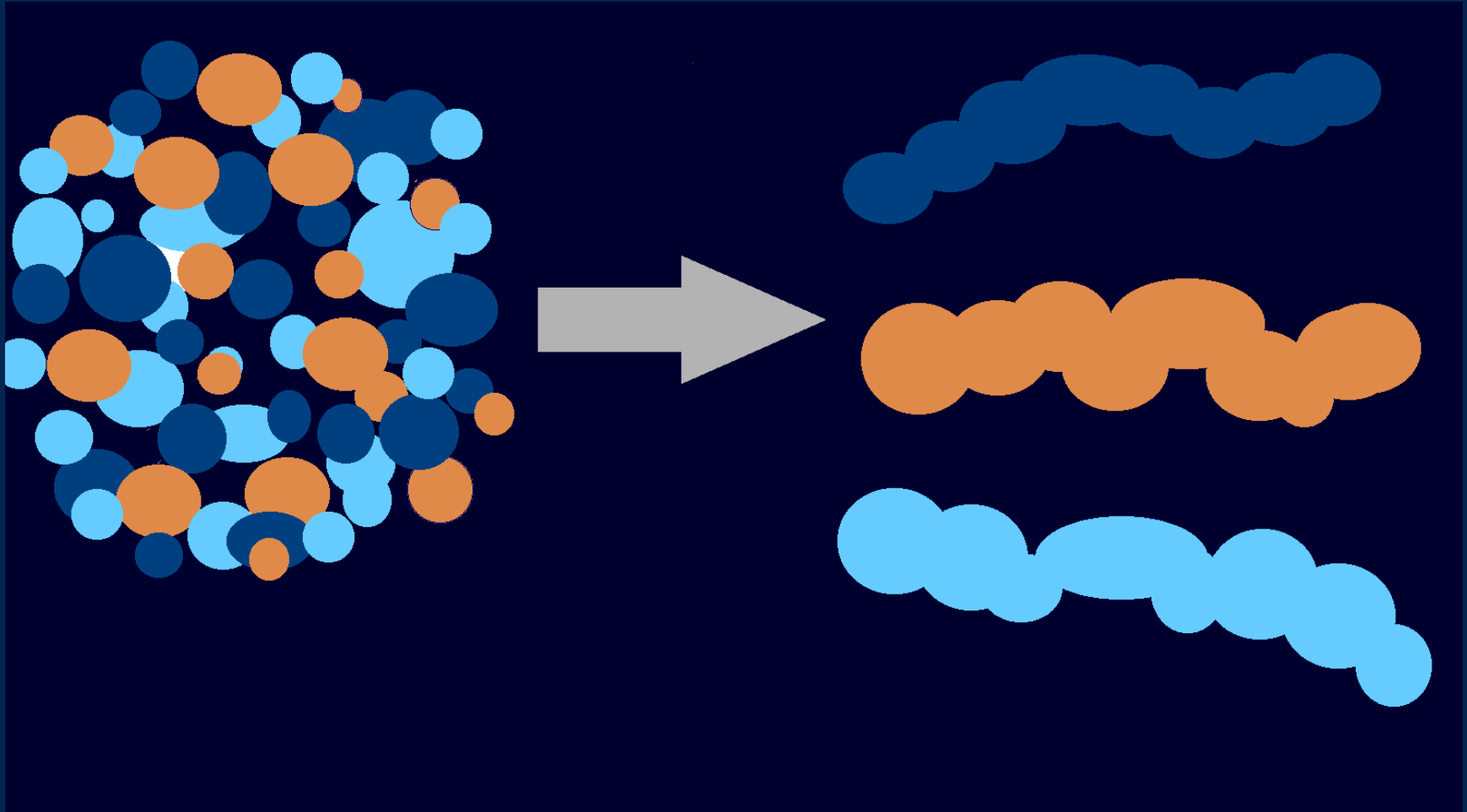
Excerpt From: Gawande, Atul. “Being Mortal.” Henry Holt and Company. iBooks.

This material may be protected by copyright.

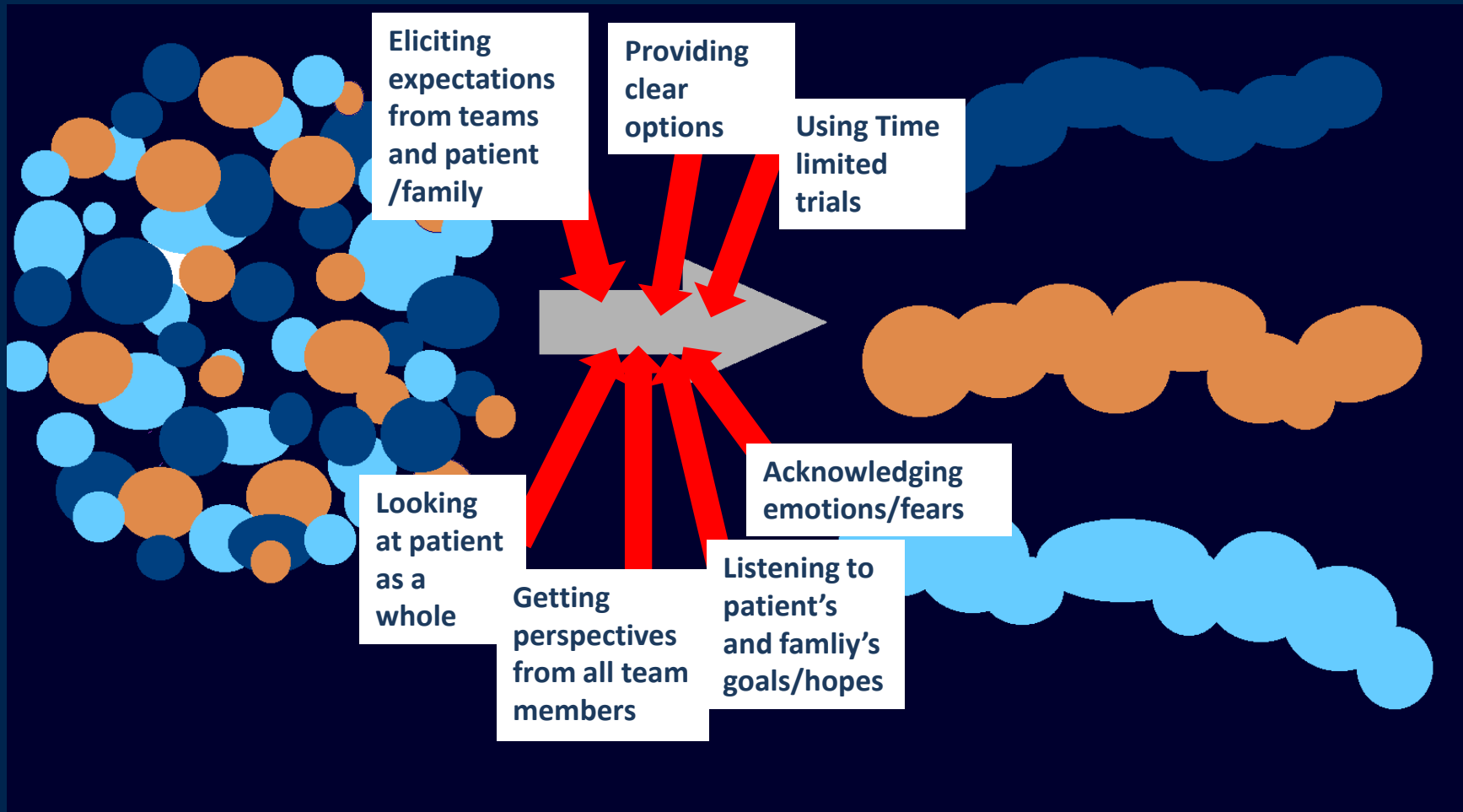
I THINK YOU SHOULD BE MORE SPECIFIC HERE IN STEP TWO



Finding a path forward



Finding a path forward



Original Investigation

July 26, 2016

Survival and Surgical Interventions for Children With Trisomy 13 and 18

Katherine E. Nelson, MD^{1,2,3}; Laura C. Rosella, PhD^{4,5}; Sanjay Mahant, MD^{2,3,6}; et al
Astrid Guttman, MDCM^{2,3,5}

[Author Affiliations Article Information](#)

[JAMA. 2016;316\(4\):420-428. doi:10.1001/jama.2016.9819](#)

From: **Survival and Surgical Interventions for Children With Trisomy 13 and 18**

JAMA. 2016;316(4):420-428. doi:10.1001/jama.2016.9819

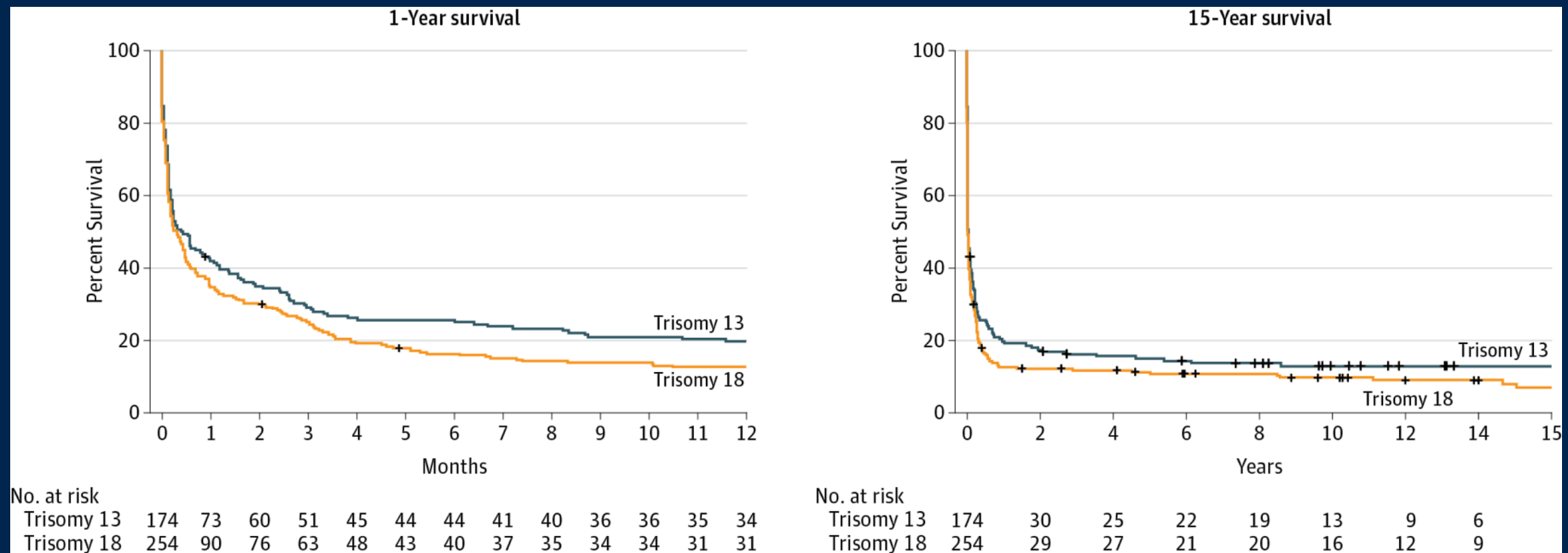


Figure Legend:

One-Year and 15-Year Survival of Children With Trisomy 13 and 18 and Number at Risk Black data markers indicate censored.

From: **Survival and Surgical Interventions for Children With Trisomy 13 and 18**

JAMA. 2016;316(4):420-428. doi:10.1001/jama.2016.9819

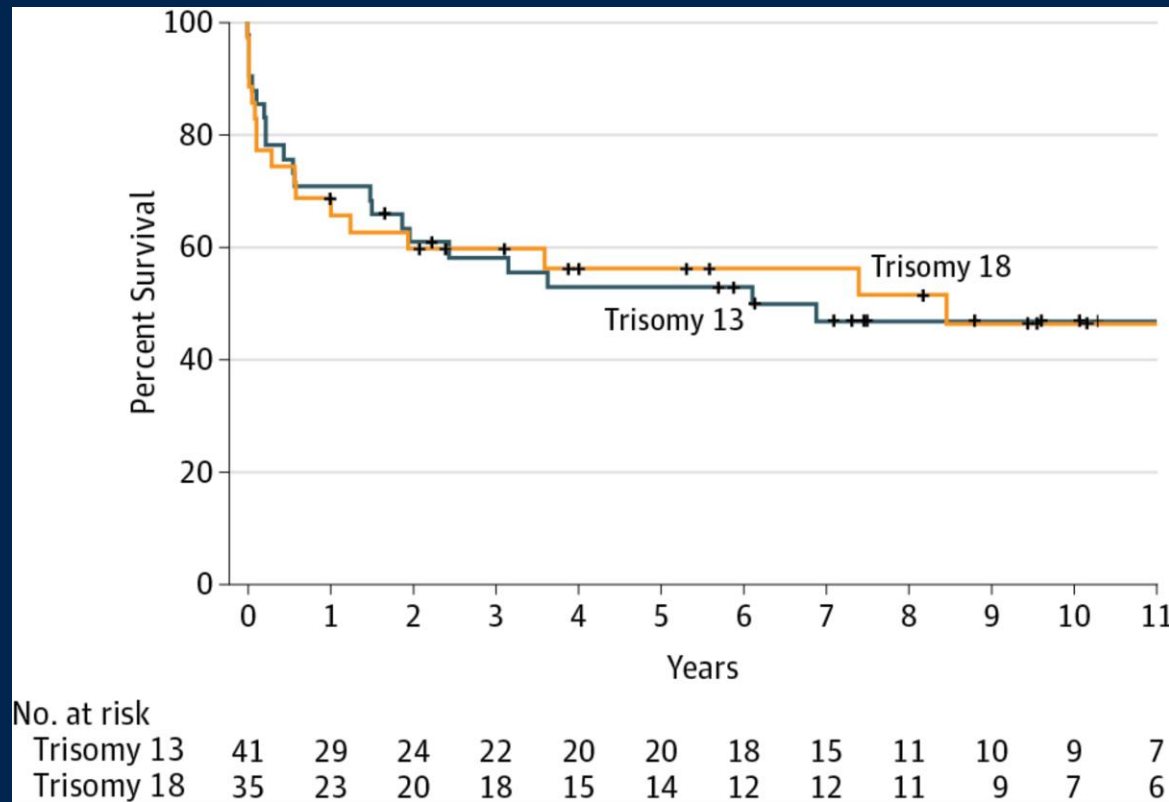
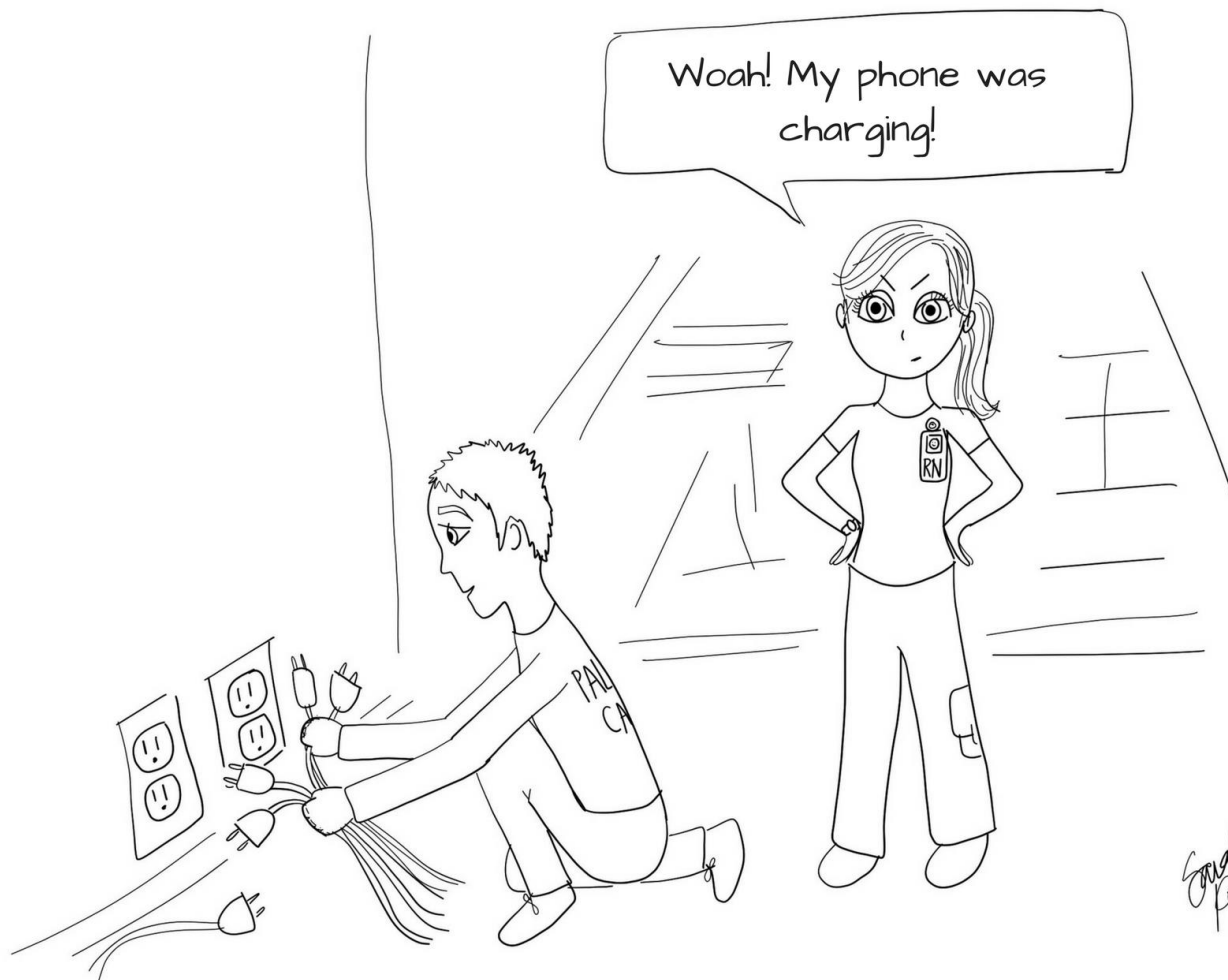


Figure Legend:

Survival After First Surgery and Number at Risk Among Children With Trisomy 13 and 18 Undergoing Surgeries Time 0 is the date of the surgical procedure. If the date of surgical procedure is unavailable, time 0 indicates the date of postsurgical hospital discharge. Black data markers indicate censored.

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A typical day on the Palliative Care Team, unplugging everything that can be unplugged.

Principle of Double Effect

- An act can embrace two effects – one intended to produce a positive result and one unintended negative effect
- The morality of the act is based on the intended effect and the act is ethically permissible only if:
 - The act is morally good or neutral
 - Only the good effect is intended
 - The good effect is not achieved by the bad effect
 - The good result outweighs the bad result

Ethics Discussion: Case 1

- 15 year old with recurrent leukemia now not eligible for potentially curative bone marrow transplant. Parents have requested care at home with hospice but have forbidden medical staff from informing the patient of his disease relapse or that hospice services will be used.

Ethics Discussion: Case 2

- 3 year old with progressive neurologic disorder now with neuro irritability, muscle spasm, and pain episodes. Medications including opiates for pain and benzodiazepines have been helpful per the parents but are sedating. The patient is DNR and now having escalating symptoms. The parents are concerned that increasing medications will cause her death.

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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 2010 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 at TCH



Services

Consultative Services

Comprehensive
Palliative Care
Services

End of Life
Services

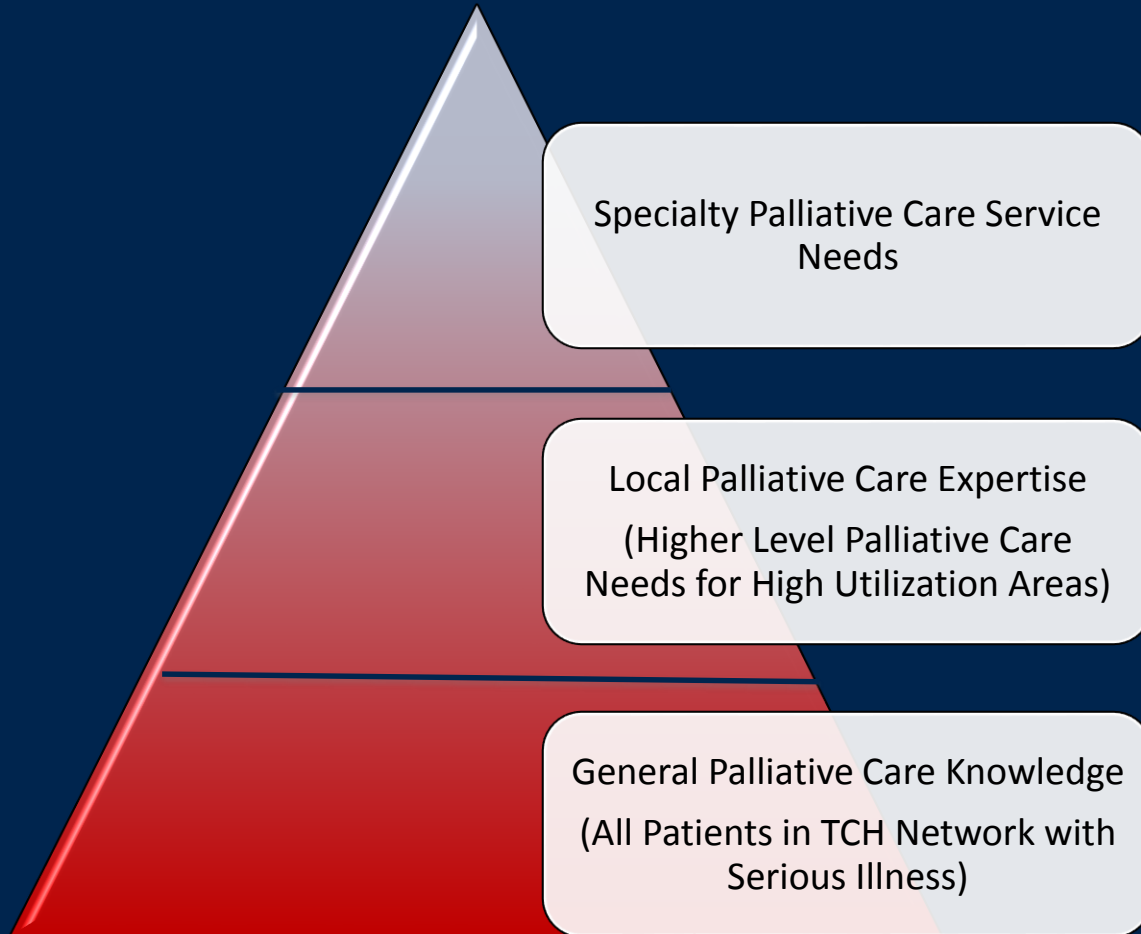
Bereavement
Services

Palliative Care Clinical Consult Service Began October 11, 2016

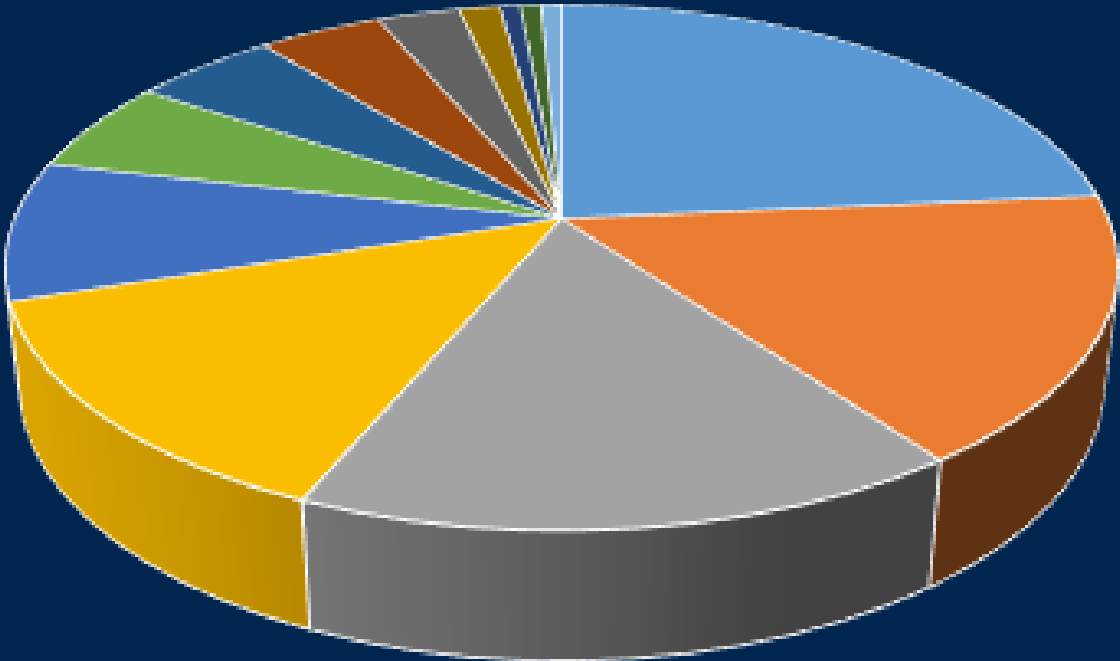
PACT office: 832-822-7228

PACT 24/7 Cell phone: 281-763-4622

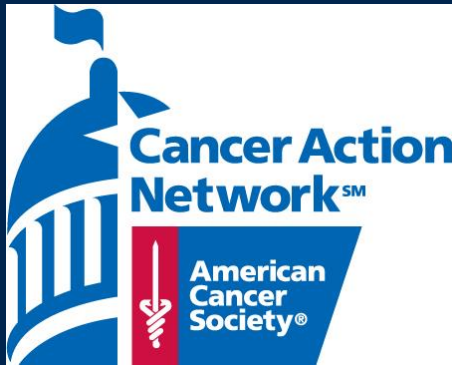
Palliative Care Needs



PACT Consults 10/11/2016 to date - 350



- PICU
- Cardiac ICU
- PCU
- NICU
- Heme/Onc
- Neurology
- Complex Care
- Pulmonary
- Cardiology
- Surgery
- GI
- ID
- Renal



Thank You!

Sarah Korenblit , LCSW

Our Cartoonist-in-Residence and PACT Social Worker

Department of Pediatrics Leadership

Dr. Mark Kline

Dr. Susan Blaney

Dr. Gordon Schutze

Texas Children's Hospital Leadership

Mark Wallace

John Nickens

Mary Jo Andre

Jackie Ward

*Members of the Palliative Care Section and Palliative Care Community at
TCH*

The patients and families who inspire us every day