

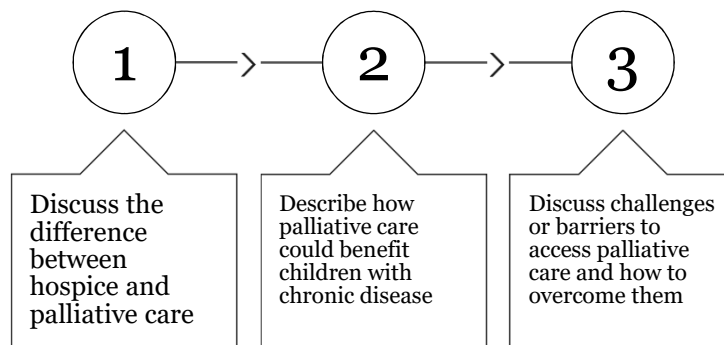
# Palliative Care in Pediatric Kidney Disease

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CURE 4 THE KIDS FOUNDATION CLINICS  
EPEC PEDIATRICS MODULE I



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## Objectives



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## What is Pediatric Palliative Care?

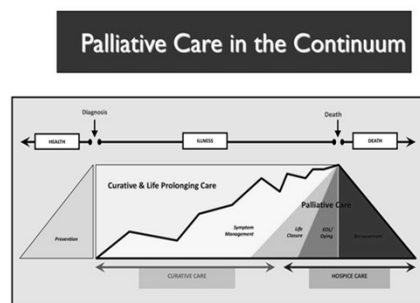


- Pediatric Palliative Care prevents, identifies and treats suffering in children with serious illnesses, their families, and the teams that care for them. It is appropriate at any stage of the illness, and can be provided together with disease-directed treatment.

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## Isn't that Hospice?

- Component of palliative care centered on end of life
- An insurance benefit associated with a terminal prognosis
  - Defined as having potential for death in 6 months or less
- Services and resources centered on end-of-life issues
  - In-home assessment for pain & symptom management
  - Ongoing psychosocial & decision-making support
  - Grief & bereavement support



MAY 2016

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What are the tasks involved . . .

Suffering requiring **communication**:

- Identifying problems and challenges
- Understanding illness
- Exploring hopes/Setting goals
- Advanced care planning
- Making decisions



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. . . What are the tasks involved . . .

Suffering requiring **care coordination**:

- Collaborating with other providers/specialists
- Facilitating logistics of medical and social needs
- Partnering with community programs
- Identifying community resources



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... What are the tasks involved

Suffering requiring **interventions**:

- Physical suffering
- Psychosocial suffering
- Spiritual suffering
- Bereavement
- Family support
- Team support
- Community support

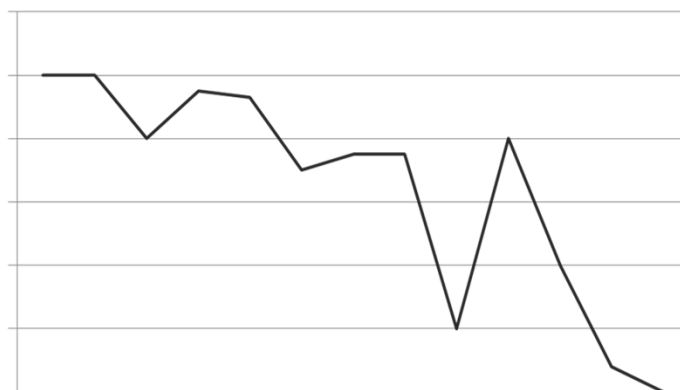


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A child's suffering:  
Sam



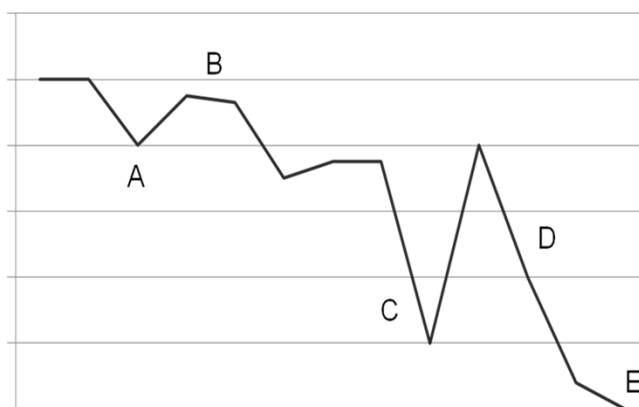
Healthy/Functional Status Over Time



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## Predictable opportunities to initiate PPC tasks

Healthy/Functional Status Over Time

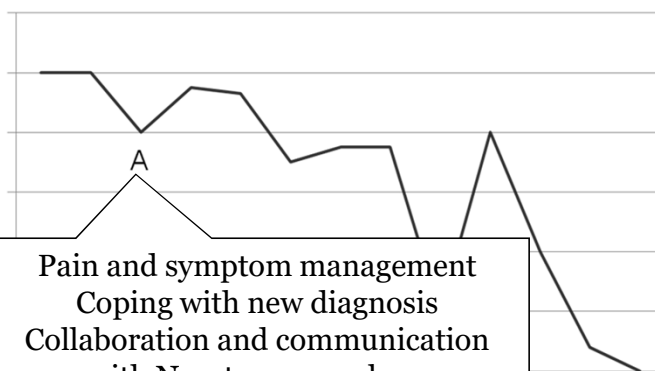


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## Acute decompensation and hearing bad news (Point A)

Healthy/Functional Status Over Time



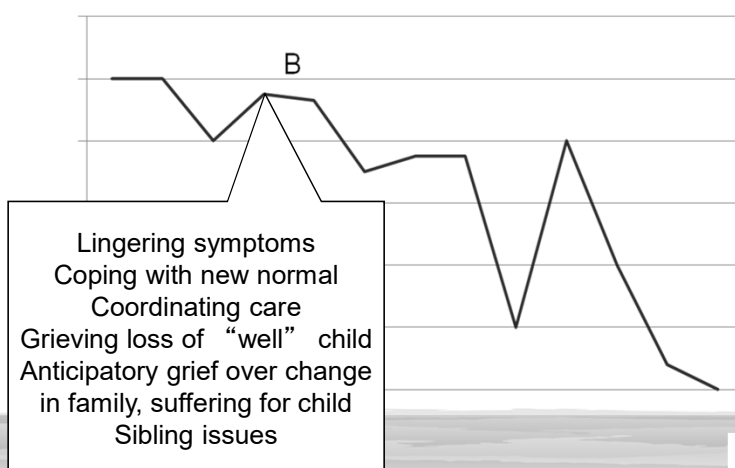
Pain and symptom management  
Coping with new diagnosis  
Collaboration and communication  
with New team members  
Sibling distress

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

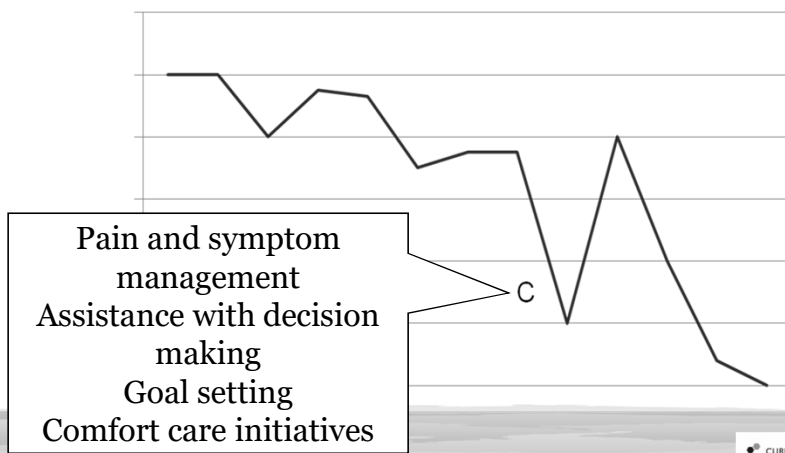
Healthy/Functional Status Over Time



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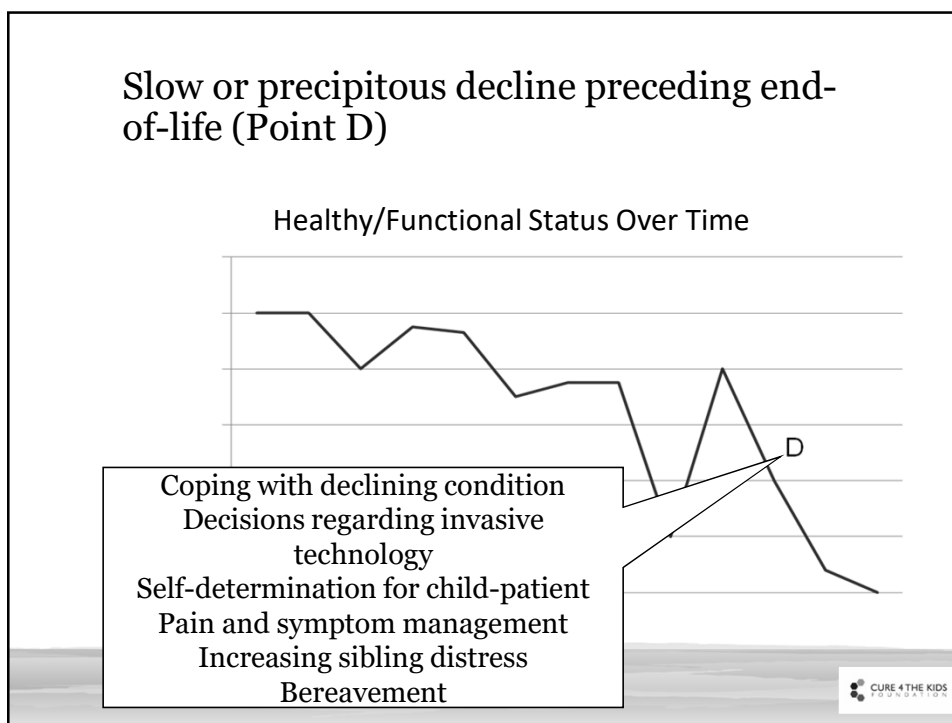
## Acute decompensations and unexpected recoveries (Point C)

Healthy/Functional Status Over Time



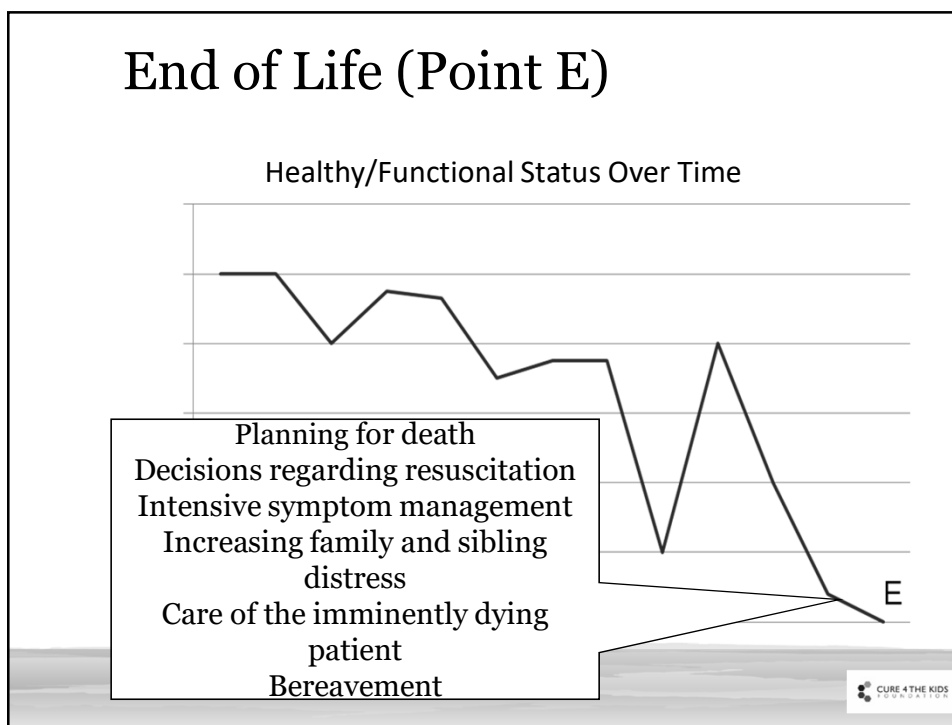
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## Slow or precipitous decline preceding end-of-life (Point D)

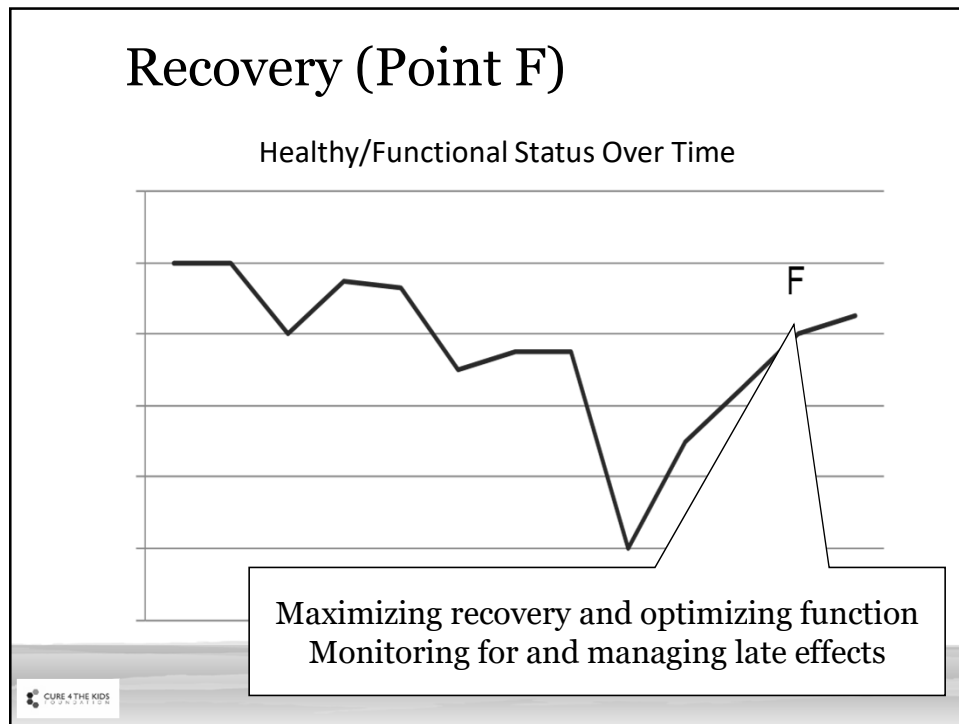


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## End of Life (Point E)



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## The family experience as context

- Stress and anxiety
- Multiple demands
- High degrees of uncertainty
- Balancing hopes for a good outcome with fears of a bad one: death
- Pressures last months to years and can erode resilience

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## Impact of pediatric palliative care

- Children with serious illnesses and their families benefit from PPC
- Earlier initiation of PPC improves symptom management & quality of life
- May lead to prolonged life



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## Epidemiology of life-threatening conditions . . .

Each year:

- 53,000+ children die in the US
- 500,000-1 million children suffer from complex, chronic conditions



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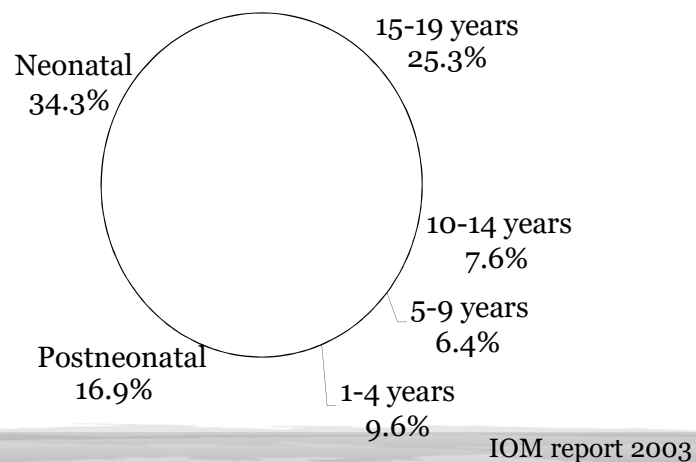
### ... Epidemiology of life-threatening conditions

- 10,000+ children diagnosed with cancer each year
  - Leading cause of disease-related death in children
- 40,000 children diagnosed with congenital heart disease
- 80,000+ infants are born severely premature

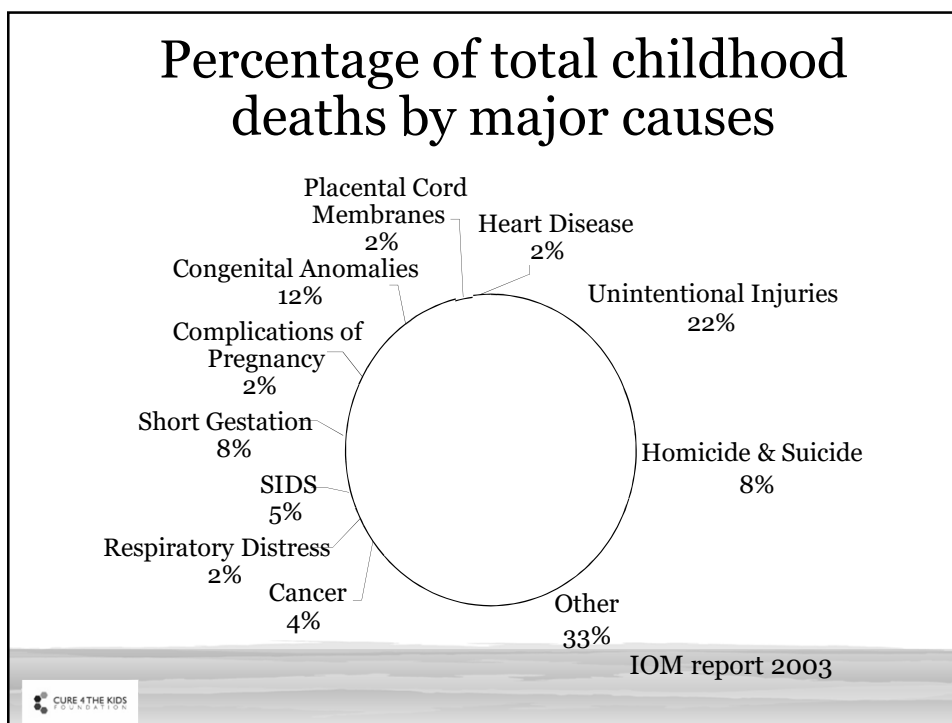


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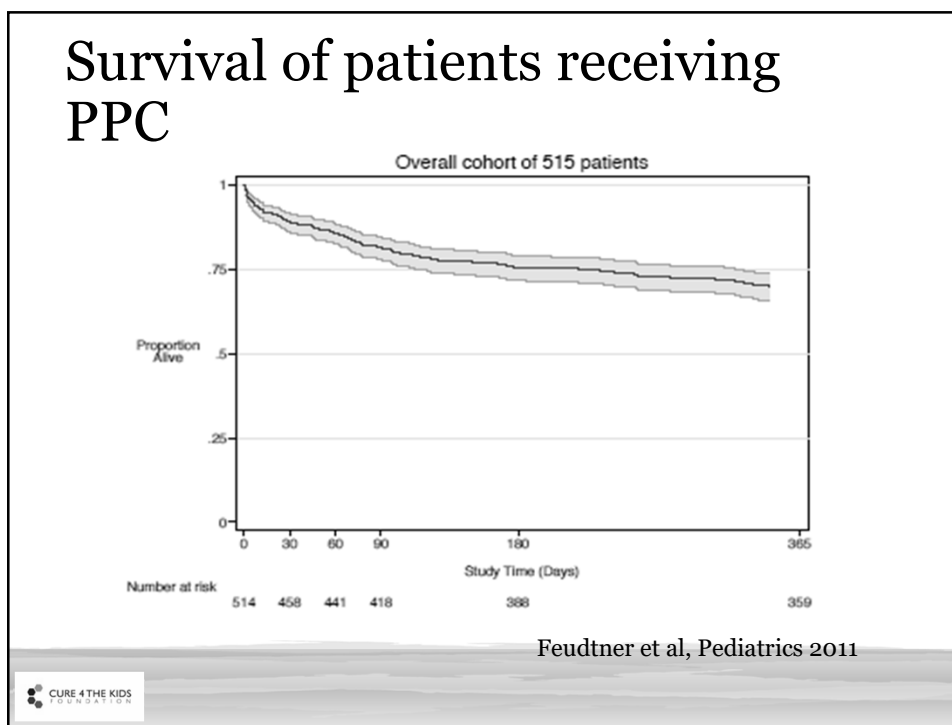
500,000 children live with complex chronic conditions and 55,000 children ages 0 to 19 die annually



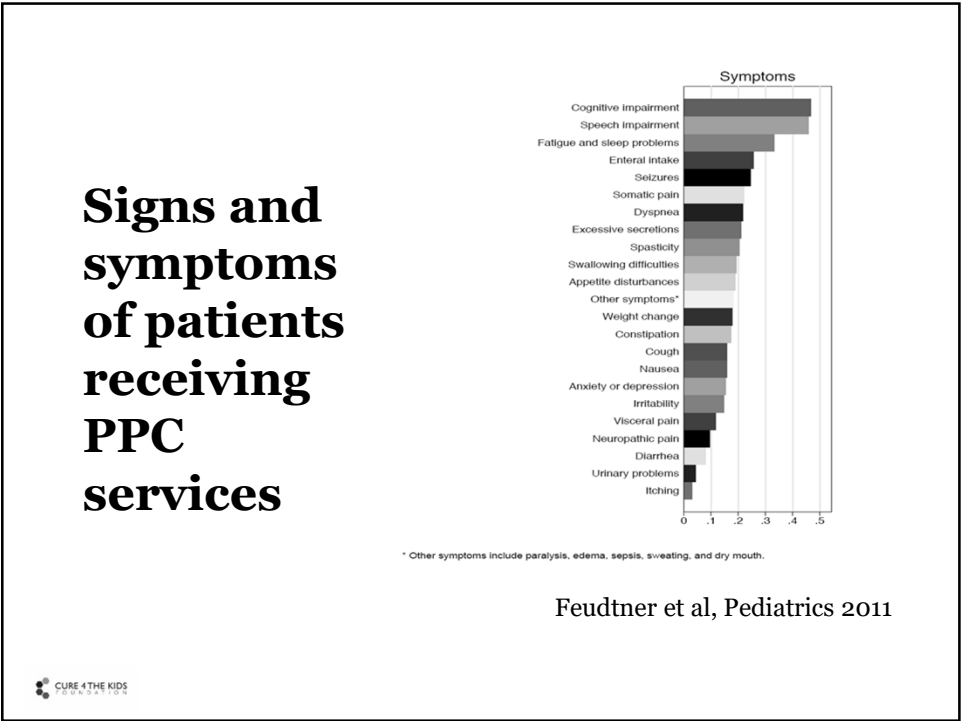
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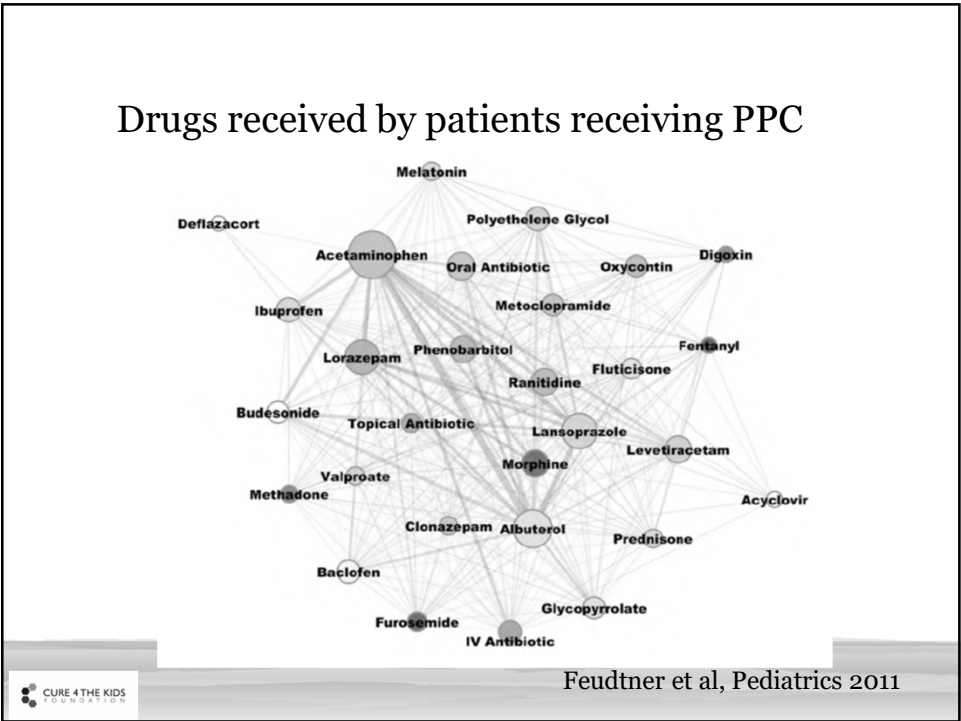
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## The demographics of a subspecialty service

...

### Most common diagnoses

- Genetic syndromes
- Congenital abnormalities
- Neuromuscular disease
- Cancer



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## ... The demographics of a subspecialty service

### Age distribution

- 5% less than 1 mo
- 13% 1-11 mos
- 37% 1-9 yrs
- 30% 10-18 yrs
- 16% 19+ yrs



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### Tasks of a subspecialty PPC service . . .

- Symptom management (58%)
- Cognitive impairment (47%)
- Seizures (25%)
- Dyspnea (22%)
- Pain (31%)
  - Somatic (22%)
  - Visceral (12%)
  - Neuropathic (10%)



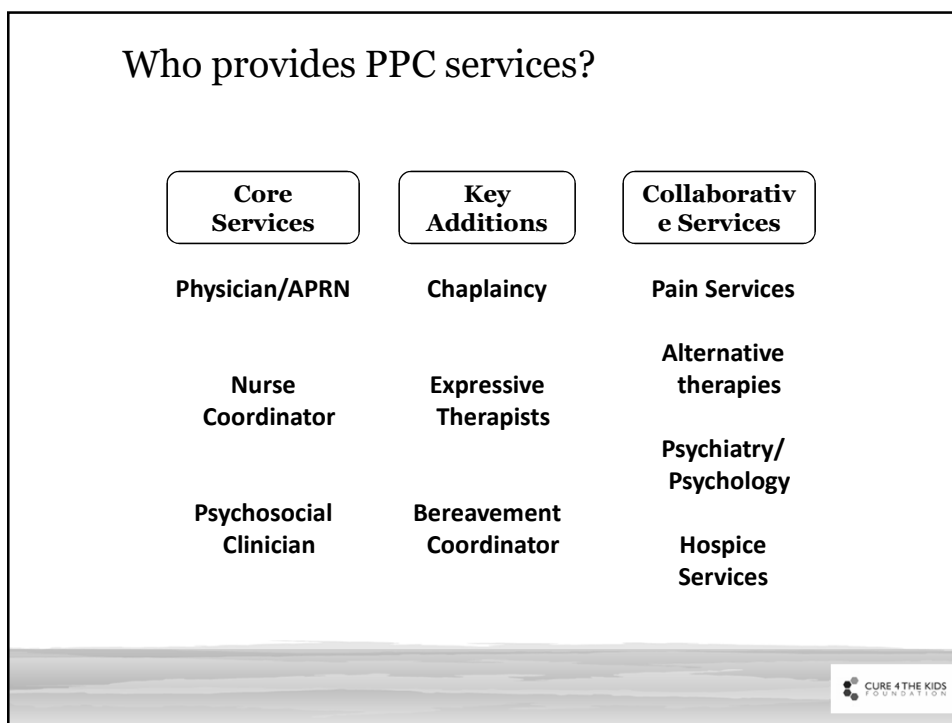
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### . . . Tasks of a subspecialty PPC service

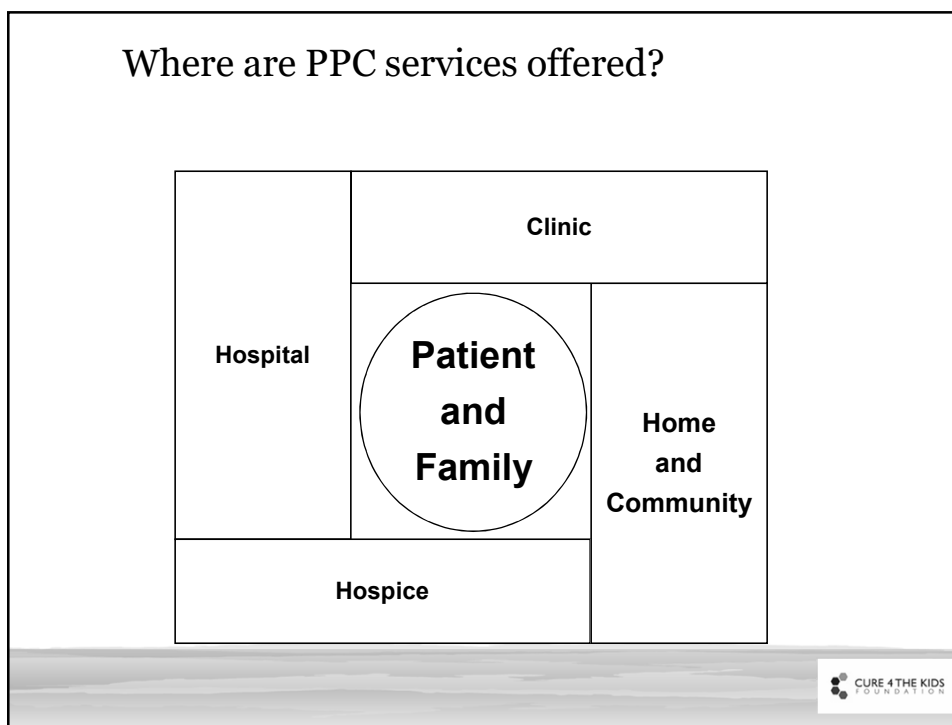
- Other tasks (42%)
- Communication (48%)
- Decision making (42%)
- Care coordination (35%)
- Transition to home (14%)
- Limiting interventions – DNR/DNAR (12%)
- Bereavement (11%)
- Recommendations at end-of-life (9%)



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## Myths in palliative care and hospice . . .

1. Palliative care = hospice = giving up hope
2. Child must be terminally ill or at the end of life
3. Child must have a DNR to have hospice care
4. Only for children with cancer
5. Must abandon all disease-directed treatment



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## . . . Myths in palliative care and hospice

6. Must abandon primary treatment team
7. Child must move to a different unit/location
8. Child will die sooner/lose hope if PC introduced
9. All families want end-of-life to be at home
10. Administering opioids causes respiratory depression and quickens death



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## Changing attitudes: Early integration of palliative care

...

- Care should be integrated at diagnosis
  - Provides focus of disease and suffering in all stages
  - Provides necessary supports to help families cope
  - Prevents perception of transition in care or abandonment



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## ... Changing attitudes: Early integration of palliative care

- Subspecialty care is integrated with primary team
  - Keeping PMD or primary specialist in control
- Disease modifying and palliative care strategies can work together and be synergistic
  - Better symptom and psychosocial management may improve tolerance of treatments and outcomes
  - Palliation and restorative strategies both aim to improve function



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## Introducing palliative care to families

- Introduce as close to diagnosis as possible
- “The part of care for kids with serious illness that focuses on:”
  - Helping patients and families manage the symptoms and stress of serious illness
  - Providing an extra layer of psychosocial support
  - Spending the time with patients and families necessary to help them understand disease and treatment



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## Integrating subspecialists early . . .

- Prevents disruptive transition to new care team at worst possible time
  - Decreases feelings of abandonment
- Minimizes fragmentation of care
- Provides umbrella of support throughout entire process
  - Additional support for primary team too (time, resources, self-care, prevention of compassion fatigue)



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### ... Integrating subspecialists early

- Allows patient and family self-determination about treatment options
- Empowers parents to be capable of maintaining dual goals of care concurrently
- Health care justice: access to emerging best practice



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### Integration strategies ...

- Prioritize symptom management & find a symptom to invite the PPC team to treat
- Consider PC as adjunct medical specialty that's part of package with service, not an optional service



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... Integration strategies ...

- Forget idea of prognosis entirely:
  - Resource management for complex needs of family and community
  - Preventive and anticipatory guidance for children with life-threatening conditions



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... Integration strategies ...

- Honest appraisal of “doing to” vs. “doing for”
- Think about list of applicable diagnoses
  - Acknowledge likelihood of cure
  - Acknowledge burdensome treatment course



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### ... Integration strategies

- Think about appropriate time points
  - Bad news/overwhelmed at diagnosis
  - Phase I enrollment
  - Relapse/recurrence
  - Serious complications
  - ICU admissions/transfers
  - Change in technology (new trach)
  - Listing for transplant



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### The language of PPC ...

- Interdisciplinary
- Life-threatening, not just life-limiting
- Children range in age from prenatal to young adult
- Family (biological, adoptive, foster, etc) core to decisions



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... The language of PPC

- Surrogate decision making
- Benefits/Burdens
- Goals of care
- AVOID: Withdrawal of support/care/treatment
- Transition to focus on quality and comfort



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# SUMMARY

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### Pearls . . .

- Refer to PPC early
- Focus on the relief of suffering
- Consider careful use of language



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### . . . Pearls

- Additional referral points
  - Complex, higher risks situations
  - Conflicts
  - Communication challenges
- PPC works with the primary care team to enhance care
- Define goals for care



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### Pitfalls . . .

- Confusing PPC with hospice or end of life care
- Asking families to choose PPC when they may not understand what it is
- Using language that suggests “giving up” or loss of hope
- Forcing PPC if they are not agreeing to aggressive therapy



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### . . . Pitfalls

- Waiting so long to refer that suffering increases
- Using terms like “withdrawing” or “withholding” care



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