Palliative Care in Pediatric Kidney Disease

ANGELA BERG DNP, APRN, CPNP
CURE 4 THE KIDS FOUNDATION CLINICS
EPEC PEDIATRICS MODULE I

Objectives

1. Discuss the difference between hospice and palliative care
2. Describe how palliative care could benefit children with chronic disease
3. Discuss challenges or barriers to access palliative care and how to overcome them
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.

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
What are the tasks involved . . .

Suffering requiring **communication:**
- Identifying problems and challenges
- Understanding illness
- Exploring hopes/Setting goals
- Advanced care planning
- Making decisions

. . . 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
What are the tasks involved

Suffering requiring **interventions:**

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

A child’s suffering: Sam

Healthy/Functional Status Over Time
Predictable opportunities to initiate PPC tasks

Healthy/Functional Status Over Time

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
Recovery and Accommodating to a New Life (Point B)

Lingering symptoms
Coping with new normal
Coordinating care
Grieving loss of “well” child
Anticipatory grief over change in family, suffering for child
Sibling issues

Acute decompensations and unexpected recoveries (Point C)

Pain and symptom management
Assistance with decision making
Goal setting
Comfort care initiatives
Slow or precipitous decline preceding end-of-life (Point D)

- Coping with declining condition
- Decisions regarding invasive technology
- Self-determination for child-patient
- Pain and symptom management
- Increasing sibling distress
- Bereavement

End of Life (Point E)

- Planning for death
- Decisions regarding resuscitation
- Intensive symptom management
- Increasing family and sibling distress
- Care of the imminently dying patient
- Bereavement
Recovery (Point F)

Healthy/Functional Status Over Time

Maximizing recovery and optimizing function
Monitoring for and managing late effects

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
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

Epidemiology of life-threatening conditions . . .

Each year:
• 53,000+ children die in the US
• 500,000-1 million children suffer from complex, chronic conditions
... 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

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

IOM report 2003
Percentage of total childhood deaths by major causes

- Unintentional Injuries: 22%
- Homicide & Suicide: 8%
- Other: 33%
- Cancer: 4%
- Respiratory Distress: 2%
- Short Gestation: 8%
- SIDS: 5%
- Complications of Pregnancy: 2%
- Congenital Anomalies: 12%
- Heart Disease: 2%
- Placental Cord Membranes: 2%

IOM report 2003

Survival of patients receiving PPC

Feudtner et al, Pediatrics 2011
Signs and symptoms of patients receiving PPC services

Feudtner et al, Pediatrics 2011

Drugs received by patients receiving PPC

Feudtner et al, Pediatrics 2011

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The demographics of a subspecialty service

Most common diagnoses
- Genetic syndromes
- Congenital abnormalities
- Neuromuscular disease
- Cancer

Age distribution
- 5% less than 1 mo
- 13% 1-11 mos
- 37% 1-9 yrs
- 30% 10-18 yrs
- 16% 19+ yrs
Tasks of a subspecialty PPC service . . .

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

. . . 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%)
Who provides PPC services?

Core Services
- Physician/APRN
- Nurse Coordinator
- Psychosocial Clinician

Key Additions
- Chaplaincy
- Expressive Therapists
- Bereavement Coordinator

Collaborative Services
- Pain Services
- Alternative therapies
- Psychiatry/ Psychology
- Hospice Services

Where are PPC services offered?

- Hospital
- Clinic
- Patient and Family
- Home and Community
- Hospice
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

. . . 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
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

... 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
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

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)
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

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
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

Integration strategies...

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

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
... 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

SUMMARY
Pearls . . .

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

. . . 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
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

. . . Pitfalls

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