Pediatric Palliative Care = Giving up Hope?
Addressing common myths & misconceptions when providing advanced medical care to children with serious illness

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Learning Objectives

- Review common obstacles for referral to Pediatric Palliative Care (PPC)
- Evaluate how PPC translates into providing hope in the face of serious illness
- Evaluate language during difficult conversations which might offer hope

Myths, Misconceptions, and Assumptions...

- You are taking care of a seriously ill child. You would not be surprised if she might die within the next few months. You are considering a palliative care consult...
- What are arguments might you hear from colleagues (or family) not to do that?

Assumption #1:

"If you can't add life to my son's days, then don't add days to my son's life"

Father of a toddler to Dr. Sunny Anand on PICU
More than 115 children die in the US every day...

- More than 1 child every 15 minutes...


Life-Limiting Conditions (LLC)

- ...are those for which there is no reasonable hope of cure and from which children will die before reaching adulthood.

- UK: Prevalence [32/10,000]
  - White: 27/10,000
  - Chinese: 32/10,000
  - Black: 41/10,000
  - South Asian: 48/10,000

- USA - Age 0-17: 74.3 million children (2014)
  - Prevalence [32/10,000]: > 237,000 with LLC
  - Mortality [1.5-1.9/10,000]: 10,800 - 13,700 die/year

- 15,000 die/year Age (0-24), who would benefit from PPC

- UK: 32/10,000 (high income country)
- South Africa 150/10,000 (upper middle income country)
- Zimbabwe 180/10,000 (low income country)
- No accurate figure globally: ICPCN estimates 15-20 million children worldwide (low estimate)
  - http://www.icpcn.org


- 99% of siblings present at time of death NOT regretting been there; 76% of siblings NOT being present, regretted it

- Siblings interviewed years after the death spoke of wishing they had received more information about their sibling’s death before the terminal period

- During high-school years may be vulnerable to a reconstruction of death-related concepts

- “What do you gotta do to get some attention in this family...?”

- Oncology: Siblings report heightened concerns about the impending death

- “Boeing 747”
- 10,800 -13,800 children 0-17 years die each year due to life-limiting conditions
- 26-33 “Boeing 747”
- one crash every 11-14 days

- “Please, please, please...”

- Sibling Care

How Many Children Would Benefit from PPC?

- USA: (conservatively estimated)
  - 237,000 children live with life-limiting conditions (LLC)
  - 570 “Boeing 747”
  - 10,800 -13,800 children 0-17 years die each year due to life-limiting conditions
  - 26-33 “Boeing 747”
  - one crash every 11-14 days

Boeing 747-400
416 passengers

USA Health Care System...

- “Please, please, please...”

- Sibling Care

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Assumption # 2:

Pediatric Palliative Care is usually for children with cancer...

Causes of Death in Children 0-19 years (USA, 2013)

1. Infant Mortality (<1 year) 23,440
   Fetal Deaths > 20 wks gestation 24,073
2. 1-19 Years 18,888

3. Life-limiting diseases >10,800
   Congenital malformations, chromosomal abnormalities 5,740
   Malignant Neoplasms 1,850
   Heart Disease 693
4. Accidents 7,645
5. Homicide 2,021
6. Suicide 2,143

Total 42,328

Causes of death in children due to life-limiting conditions

Cancer 31% [22%]
Congenital or genetic 16% [11%]
Neuromuscular / neurodegenerative 20% [17%]
Cardiovascular 12% [9%]
Metabolic 4% [3%]

Assumption # 3:

The “sudden death”...

The New York Times
When a Baby Dies

http://opinionator.blogs.nytimes.com/2015/12/16/when-a-baby-dies/
“Sudden” Death? Advanced Illness Marked by Slow Decline with Periodic Crises and “Sudden” Death

Outcomes Improved with PPC Involvement

- Parents of children with cancer report less distress from pain, dyspnea and anxiety at EOL Wolfe et al. (Oct. Dec. 2008)
- Children who received PPC/Oncology more likely to have fun (70% versus 45%) and to experience events that added meaning to life (89% versus 63%) Frank-Stemler et al. (Feb. 2010)

Assumption # 4:

- Parents have to choose between “Fighting For a Cure” or “To Give Up”
- PPC translates into “Giving Up Hope” and “Doing Nothing”

Continued treatment in face of serious illness

- In discussions of treatment options with families, Wolfe and Grier suggest “The very nature of miracles is that they are rare. However, we have seen miracles, and they have occurred both on and off treatment.” Pizzo, P.A., Poplack, D.G. (Eds) (2002) Principles and Practice of Pediatric Oncology (4th edn). Philadelphia, PA: Lippincott Williams & Wilkins.
- Motivated either by hope for a miracle, desire to extend life, or desire to palliate symptoms related to progressive disease

...in face of serious illness

Continued treatment in face of serious illness

- In other words, a child does not have to continue on disease-directed therapy in order to preserve hope, especially when the therapy significantly impacts child’s remaining quality of life
- Regardless, decisions regarding continued disease-directed therapy need to be carefully considered, weighing the potential for life extension and impact on quality of life.
- Even when the underlying condition can not be cured, sophisticated medical technology will be used to control symptoms and improve a child quality of life
- It is a very active and advanced approach to pain & symptom management and family support
Cheat-Sheet Hope Language 1/2

• Tell me about little Claire on a good day! Do you have any pictures?
• Considering what little Johnny is up against, what are you hoping for?
• I am hoping for a miracle, too. And I have seen miracles, but they are very rare and happen on treatment or off treatment...
• Just in case, the miracle or the cure is not going to happen (...if God/Allah has different plans for Sarah), what else are you hoping for?
• We want to make sure that Karen lives as long as possible, as well as possible!
• We are hoping for the best, but preparing for the worst.

Cheat-Sheet Hope Language 2/2

• So what I hear you saying, is the following...
• Did I get this right...?
• Then I would recommend the following...
• DNR/DNI (AND, limiting of painful interventions)
• I recommend to put in an order to protect your daughter from experiencing painful situations, such as chest compressions or intubation, in case the breathing or heart stops - are you fine with that?

Conclusions

Pediatric Palliative Care is...
• Provided by an interdisciplinary team who work with the patient's other physicians & health care providers: provides an extra layer of care
• Specialized medical care for children with serious illness
• Focused on relieving pain, distressing symptoms & stress of a serious illness
• Appropriate at any age and at any stage, together with curative treatment
• Goal is to improve quality of life for child/family

An early palliative care intervention (even from the point of diagnosis) is appropriate and beneficial treatments, increased quality of life and may in fact lead to prolonged (7) life.
• RCT, n=151; adult cancer patients receiving palliative care early in their illness lived longer (11.6 months vs. 8.9 months, P=0.02), with better quality of life, including decreased depression
• Results underscore the need for palliative care early in a serious illness
• This appear to refute the notion that palliative care means giving up. Patients received palliative care alongside their curative treatment.
• Although this is only one study, it is an exciting one & results are not surprising: PC clinicians regularly see these outcomes in practice - even in pediatric patients. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42.
Conclusions

• Hope and PPC include each other
• Pediatric Palliative Care:
  • Multi--> Inter--> Trans-disciplinary Team
• (1) “How can we help!”
• (2) Then listen...

Conclusions

• Not Providing PPC is now considered “bad”

Ethical Decision Making Process

• What can we do?
  • Possible interventions and approaches
• What should we do?
  • Goals of care: what are we hoping for this person?
• What would this person want?
  • Proxy, substituted judgment considerations
• Who gets to decide?
  • Authorized decision makers
• Who gets to weigh in?
  • Stakeholders

Examples...

Complex decision making can occur around

• DNR / AND Decisions
• Defining goals of care
• Considerations as to how to use technology
• Questions about withdrawing support
• Planning when uncertainty is a factor
• Conflicts and questions about what is best for the child

Goals of Care

• Establish broad goals and objectives
• Develop a mechanism for recording plans and changes in plans as they occur
• Identify who is involved in the goal planning group
• Refer to goals as changes occur
• Update goals as the situation evolves
Beauchamp and Childress: Helpful Guiding Principals

- Avoiding Harm
- Benefits and Burdens
- Doing to and Doing For
- Doing the Right Thing
- Substituted Judgment
- Weighing potential known harms with actual known harms

Example:
Medical Nutrition and / or Hydration

Goals may include any/all at different times
- Support growth and development, or sustain current functioning
- Prevent hunger
- Comfort
- Prevent other symptoms and discomfort, e.g.: third spacing, abdominal cramping, irritability

Laura

- Severe neurodegenerative disease diagnosed at birth: Opitz Type 1
- 3 months in NICU, family learning about diagnosis and prognosis
- Tracheated and vented in early days after birth for “short time” to “help mom adjust”
- Staff concerns regarding ethical appropriateness of these interventions given the diagnosis
- Family declined Hospice Care: “We need to give her a chance…”

Laura: continued

- Discharged home at 3 months of age with extensive nursing support: ICU level of care
- Family lived with this level of care and team of caregivers for 4 years
- Family’s experience with her condition, care and impact on their family grew
- Multiple ER admissions for variety of issues
- Multiple admissions to hospital: unfamiliar providers question family choices, offer therapies already tried, etc.
- Goals of care unclear: hospital staffed questions re: what they were being asked to do
- Weaned off ventilator at age 3 years, remained on trach collar
- Palliative care consult after mom questioned quality of life concerns: stimulated by Shons case in the media
- Palliative care assessment: multiple issues identified including marital tensions, changes in Laura’s breathing and ability to handle her feedings, concerns she may be unresponsive and only expressing discomfort, questions re: quality of Laura’s life

Laura: continued...

Palliative Care Interventions:
1. Defined goals of care: comfort and quality of life
2. Initiated marital counseling around disagreements in care planning
3. Defined “comfort care plan,” and steps for initiating symptom control strategies based upon behavioral cues
4. Education for in home nurses to ensure comfort with the plan, allow expression of concerns, and to reinforce goals of care

Laura: continued...

Palliative Care Interventions
1. Weekly nurse visits to assess comfort and changes, effectiveness of plan, status
2. Bi-weekly social work visits to provide family counseling, anticipatory guidance and coordination of care based upon family priorities
3. Weekly updates to PMD, MD HV’s occasionally
4. Intermittent meetings with in home staff to provide information, education, and reinforcement of family goals for care
5. Ethical issues discussions on going: benefits and burdens, tiring changes in plan to changes in child, creating forums for discussion and expressions of concern
Laura: continued…

- Signs and symptoms of feeding intolerance increased: “Feed to Comfort” plan initiated
- Weight loss distressing to in home nurses; no agitation or other signs of distress noted
- Family relieved to see her appear so comfortable
- Maternal conflicts decreased and parents were able to be mutually supportive
- Sibling moods improved, “testing” behaviors reduced
- Palliative Care team assisted in identifying subtle signs of discomfort, and prevention strategies to promote comfort and address discomfort

Laura: End of Life

- Died in the night, without apparent distress, presumed respiratory or cardiac arrest
- Parents expressed relief that her “suffering was over…”
- Bereavement follow up provided

Further Links

- Video: Kiran Stordalen and Horst Reichelbacher Pediatric Pain Palliative and Integrative Medicine Clinic Tour [https://www.youtube.com/12265488]
- “Children’s Comfort Promise: Doing everything possible to treat and prevent pain” Eliminating Needle Pain in children (Feb 2015) Staff video [https://vimeo.com/106286508]
- Short Movie Meet the Interdisciplinary Chronic Pain Clinic Team at Children’s Minnesota: LittleStars TV [https://www.youtube.com/watch?v=11838b6114]
- Video Tour of the Kiran Stordalen and Horst Reichelbacher Pediatric Pain, Palliative and Integrative Medicine Clinic at Children’s Hospitals and Clinics of Minnesota and an overview of the three programs that are offered as Children’s under this clinic: [https://www.youtube.com/12265488]
- Short Movie LittleStarsFilm: Kali’s Story - Beyond the NICU: This amazing pediatric palliative care short movie (7 min) features 8-year-old Kali’s journey at Children’s Hospitals and Clinics of Minnesota from NICU to today receiving care by the Pain & Palliative & Integrative Medicine program while inpatients, in the clinic, and at home (Jan 22, 2015): [https://www.childrensminnesota.org/clinical_services/pain_and_palliative_care_program]

Twitter: @NoNeedlessPain

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Further Training: CIPPC@ChildrensMN.org

9th Annual Pediatric Pain Master Class
- Minneapolis, MN | June 11-17, 2016 [http://www.cvent.com/d/kfq8qm]

Education in Palliative & End-of-life Care [EPEC]: Become an EPEC-Pediatrics Trainer
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