Pediatric Palliative Care in the 21st Century: Live as long and as well as possible

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Learning Objectives

- Review common obstacles for referral to Pediatric Palliative Care (PPC)
- Evaluate top myths in PPC
- Underscore importance of interdisciplinary team approach in PPC
Palliative Care

- Palliare (Latin) : to cloak
- Palliative care is about matching treatment to patient goals.
- 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

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 you might hear from colleagues (or family) not to do that?

Assumption # 1:

The death of a child is a rare event (especially in the USA...)

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

1. **Infant Mortality (<1 year)**
   - Infant Deaths > 20 wks gestation: 23,440
2. **1-19 Years**
   - Total: 18,888

<table>
<thead>
<tr>
<th>Category</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Life-limiting diseases</td>
<td>&gt;10,800</td>
</tr>
<tr>
<td>Congenital malformations, chromosomal abnormalities</td>
<td>5,740</td>
</tr>
<tr>
<td>Malignant Neoplasms</td>
<td>1,888</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>695</td>
</tr>
<tr>
<td>4. Accidents</td>
<td>7,645</td>
</tr>
<tr>
<td>5. Homicide</td>
<td>2,021</td>
</tr>
<tr>
<td>6. Suicide</td>
<td>2,143</td>
</tr>
</tbody>
</table>

**Total**: 42,328

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More than 115 children die in the US every day…

- More than 1 child every 15 minutes…

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**Boeing 747-400**

416 passengers
US Health Care System...

- 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

Assumption #2:

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

Causes of death in children due to life-limiting conditions
Access to PPC?

- Comprehensive palliative care is the expected standard of care for patients with advanced cancer, however access to, and availability of palliative care expertise for the majority of children with life-threatening conditions, is still lacking compared with adult services.

- In the U.S., the majority of infants, children, and teenagers with advanced illnesses who are near the end of life do not have access to interdisciplinary pediatric palliative care (PPC) services either in their community or at the nearest children's hospital.
Assumption # 3:

The “sudden death”...

“Sudden” Death? Advanced Illness Marked by Slow Decline with Periodic Crises and “Sudden” Death

Multiply relapsed cancer
Cystic Fibrosis
Advanced HIV
Refractory Seizure Disorder
Solid organ transplant recipient
Congenital heart disease

Joanne Wolfe, MD (Boston Children’s Hospital & Dana Farber Cancer Institute), with permission

Assumption # 4:

Specifically trained Pediatric Palliative Care specialist are not required...
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 (1) life.

- RCT, n=151: adult cancer patients receiving palliative care early in their illness lived longer (11.6 months vs. 8.3 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.

Outcomes Improved with PPC Involvement


- 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%) Friedrichsdorf SJ et al. J Palliat Med 2015


Assumption # 5:

- Parents have to choose between “Fighting For a Cure” or “To Give Up”

- PPC translates into “Giving Up Hope” and “Doing Nothing”

...in face of serious illness
Hope in face of serious illness


Continued treatment in face of serious illness


- Motivated either by hope for a miracle, desire to extend life, or desire to palliate symptoms related to progressive disease.

- 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.

- 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 the 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.
- “He is not dying because he is not eating...he is not eating, because he is dying...”

Cheat-Sheet Hope Language 2/2

- “Loving parents…” (“…equally loving parent realize that the child has come to the natural end of their life…)
- “I wish..., but at this stage it is not possible…”
- Responding to emotion “I can’t imagine what this might be like for you”
- “I am aware of the time…”
- 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?

Curative Care? Or Pediatric Palliative Care?

Well...the answer is yes!
Conclusions

Pediatric Palliative Care is...

- 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
- Provided by an interdisciplinary team who work with the patient’s other physicians & health care providers: provides an extra layer of care
- P.S.: Morphine & Midazolam do not shorten a child's life

Conclusions

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

Pediatric Palliative Care

“Hey Fluffy, in 2016 would it be okay not offering Pediatric Palliative Care for children with serious illness…?”

https://www.youtube.com/watch?v=DNFzJdmoHdc
"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

**Further Links**

- Video: Kiran Stordalen and Horst Rechelbacher Pediatric Pain, Palliative and Integrative Medicine Clinic Tour [https://vimeo.com/12263488](https://vimeo.com/12263488)
- Short Movie: Meet the Interdisciplinary Chronic Pain Clinic Team at Children’s Minnesota LinkSci a TV [https://www.youtube.com/watch?v=13Svq8FDeVI](https://www.youtube.com/watch?v=13Svq8FDeVI)
- Video Tour of the Kiran Stordalen and Horst Rechelbacher 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 at Children’s under this clinic: [https://vimeo.com/13357935](https://vimeo.com/13357935)
- 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 inpatient, in the clinic, and at home (Jan 22, 2015) [http://www.littlestars.tv/shorts-kalissaysstory](http://www.littlestars.tv/shorts-kalissaysstory)
Further Training

10th Annual Pediatric Pain Master Class
- Minneapolis, Minnesota, USA | June 17-23, 2017

Education in Palliative & End-of-Life Care (EPEC): Become an EPEC-Pediatrics Trainer
- Montréal, Québec, Canada | April 28-30, 2017 (Professional Development Workshop: 04/28/17)

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