Comprehensive Cancer Care for Children and Their Families

Institute of Medicine March 2015 Workshop Highlights

COCA-I 2015 Conference
Niagara Falls, Ontario, Canada
Disclosures

KOA Inc. provided support for this presentation.
1. Describe recent trends in childhood cancer care and the value of integrating pediatric palliative and psychosocial care to support the quality of life needs of children and families across the full life spectrum.

2. List the menu of options for action to improve quality of care and outcomes for pediatric cancer patients and their families that support survival with high quality of life.

3. Explain the value proposition for pediatric palliative care in the triple aim context of better health, better care, at lower cost.

4. Identify at least 3 available resources for helping improve palliative and psychosocial care understanding and integration with oncology services to improve care quality.

5. Describe at least 5 action steps that every healthcare institution and clinician can take to deliver optimal care for children with cancer and their families.
QOL consensus blueprints aplenty

Institute of Medicine Series 2000 to 2014

- Quality cancer care
- Palliative care
- Psychosocial care
- Survivorship care
- Pain care
- End of life

Stopping suffering across the continuum is our common denominator
Key Takeaway 1: We can conjoin as a “QOL workforce” and use our specialized skills to minimize suffering in all care settings.
March 2015 workshop

Who Participated?

• Multidisciplinary clinicians and researchers in pediatric oncology, palliative care, and psychosocial care

• Parents and childhood cancer survivors

• Food & Drug Administration

• National Cancer Institute

• Children’s Oncology Group

• Pharmaceutical companies

• Patient advocacy organizations

Objective

Develop menu of options to improve research and development, quality of care, and outcomes for children and families confronting pediatric cancer.
Person-centered & family-oriented care

Optimal Care = Improved Survival + Quality of Life

Survive AND Thrive
Workshop Agenda

- Pediatric research, drug development and treatment trends
- Integrating essential services to improve care quality
  - Pediatric palliative care
  - Psychosocial care
  - Communication skills
- Emerging care models to address health disparities
- Detecting and addressing pain and suffering for children and families
- Minimizing and treating long-term and late effects
- Improving care transitions
- Pediatric oncology data collection and registries
Pediatric oncology has been the exemplar of many key elements in quality health care:

- Interdisciplinary team-based care
- Connection of compassionate health professionals
- Translational research that brings basic discovery from the laboratory to the clinic and back
- Continuity over the life journey
- Combining compassion with care along the continuum
- Coordinated clinical trials network
Continuing challenges

Cancer remains **THE leading cause of disease death** in children

It is diagnosed in **10,380** US children under age 14 annually and we lose **1,250** children to cancer death every year

Even for “curable” cancers, treatment consequences present **substantial medical and psychosocial concerns that last lifetimes** – posting challenges for children, families, communities, and health systems

Children’s Oncology Group Long-Term Follow-Up Guidelines Version 4.0 (2013) available online at [survivorshipguidelines.org](http://survivorshipguidelines.org)
Implications of cure are not trivial

Long term complications of treatment

• Impairs growth and development
• Brain and vital organ function
• Fertility and reproduction
• Causes secondary cancers
• Interferes with QOL

Therapeutic exposures and adverse events. Bhatia presentation
Burdens increase over time

388,500 childhood cancer survivors are living in US now and 83.5% are at least 5 years post-diagnosis

- Nearly all experience chronic health condition by age 45 with 80% having life-threatening condition
- 35% have neurocognitive dysfunction (survivors age 20-49); many also have functional impairment and activity limitations

Key Takeaway 2: Caring for concerning conditions in adult survivors of childhood cancers will be a big part of everyone’s job

(Phillips 2015; Hudson 2013; Oeffinger 2006)
Poverty may mediate pediatric outcomes

• **1 in 5 US children live in poverty** based on household income and experiencing food insecurity

• **1 in 4 families lose > 40%** annual household income due to their child’s cancer treatment

**Food, energy and housing security**

Family poverty is linked to poorer treatment adherence and lower overall survival:

- Leukemia patients living in high-poverty area had lower survival rates and were more likely to experience early relapse

- Increased risk of graft-versus-host disease in children having BMT if they lived in homes with material hardship

**Potential intervention:** Screen for material hardship in clinic settings to increase family subsidies for food, housing and energy that improve child health outcomes.
Preventable suffering - Evan

There was not one day in those 4 years that Evan wasn’t either going through treatment or recovering from treatment. It was just absolutely brutal.”

- Gavin Lindberg, Evan’s Father

“We didn’t want one inch more discomfort for Evan if at home…”

“Children with cancer fight too hard every single day to be left with a fate like that.”

How can we not be set up for something so inevitable?
Every child should have the right to be cared for by doctors and nurses who have the *experience and expertise* to make these kids comfortable.

Gavin and Wendy Lindberg
Parents of Evan
INTEGRATING PEDIATRIC PALLIATIVE AND PSYCHOSOCIAL CARE
ENSURING CHILD & FAMILY WELL-BEING ALONG THE CONTINUUM
What is Palliative Care?
Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with *relief from the symptoms, pain, and stress of a serious illness*—whatever the diagnosis.

The goal is to *improve quality of life* for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists, who work together with a patient’s other doctors to provide an extra layer of support. It is *appropriate at any age and at any stage* in a serious illness, and *can be provided along with curative treatment*.

**Palliative care improves health care quality in significant ways:**

→ Relieves physical and emotional suffering
→ Strengthens patient-family-physician communication and decision making
→ Ensures well-coordinated care across health care settings
→ Makes it more likely that *children & families have fun and meaning*
Healing happens here

Key Message: Children’s oncology camps are important primary palliative care interventions that boost quality care and quality of life for children and families!
Who delivers it? Everyone

**Generalist palliative care**
Basic symptom management and communication to achieve goal concordant treatment and QOL

**Specialized team consultation**
For more complex cases – refractory symptoms, challenging care planning and communication

“It’s like when you’re filling in concrete... “The transplanters are the people who put the layer down, then [PedPC] are the people who go after and fill the holes, so the whole thing doesn’t start to crumble. But if it does start to crumble they’re the people who actually go with the hard hats and fix it.”

- Gwen Lorimer, PedPC patient, quoted in *The New Yorker*
Pediatric palliative care

- Helps parents and children have a voice in identifying and realizing their care goals
- Enhances well-being, strength, and resilience – all required to have the reserve to undergo cancer treatment successfully
Universal access to early PedPC

POLICY STATEMENT
Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations (October 2013) called for pediatric palliative care as an **essential aspect of providing optimal treatment** from diagnosis and continuing along course of care

**But...**

- **Only 58%** of COG member institutions have a pediatric palliative care service
- **Nearly one-third** of children’s hospitals still don’t have a palliative care program
- **Most** pediatric palliative care programs are understaffed

(Feudtner et al. Pediatrics 2013)
The Challenges of Palliative Care for Children

So much about treating seriously ill children is different from caring for adults

Barriers to implementing PedPC in practice:

- Ineffective **communication** about what it is and its benefits
- Lack of **resource alignment** with patient and family needs
- **Shortage of specialists** in the field combined with **insufficient generalist skills training**
- **Limited or no access** in settings where children with cancer receive care

**Action step:** Prioritize professional education and training in primary palliative care competencies

- Communication skills (prognosis, goals of care, transitions)
- Pain & symptom management
- Sensitivity to cultural and spiritual beliefs
- Grief and bereavement care
What’s in a name? Messaging matters.

**Palliative care...**
Focuses on relieving symptoms, pain and stress of serious illness.

Improves quality of life for both patient and family.

Provided by a team who works with a patient’s other doctors to provide an extra layer of support.

Appropriate at any age and any stage and can be provided along with curative treatment.

**Parents Want Palliative Care:**

- **86%** would be likely to consider PedPC for their child during cancer treatment
- **89%** think it's important that PedPC services are available in all hospitals caring for children

American Childhood Cancer Organization online survey (2014)

**Action step:** Use “palliative care” term consistently and the consumer-driven definition to explain it as an essential part of optimal cancer care
Why Palliative Care is a Solution

Improves quality of life

- Relieves pain, distress, uncertainty
- Addresses patient and family goals

- Improves communication and family satisfaction/well-being

- Coordinates medical and practical needs across settings

- Reduces resource utilization and costs by matching treatment to patient and family goals
PedPC a triple aim trifecta?

California’s Partners for Children Project

Positive results in achieving the IHI Triple Aim:

• 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 on paid claims; overall savings of $2,154 PEPM when including all estimated administrative costs of the pilot

• Most savings due to dramatic decrease in inpatient costs; overall savings totaled nearly $7 million

Bringing Ped Palliative Care Everywhere

**Where is it delivered?**
In every care setting. Inpatient and ambulatory clinic -- hospitals, cancer centers, community and home.

**When to deliver it?**
Early and often. As part of disease-directed treatment at diagnosis and continually across care continuum.

**Action step:** Expand hospital and community-based PedPC access through generalist and specialist skills training for physicians, nurses, social workers, child life specialists, and other professionals.
"It’s not just about the medicine"

Mattie

“We think of childhood cancer as a physical disease, but it is really much more than that...

Here are psychosocial issues just as complex and heartbreaking to manage...

such as when your child tells you he feels ugly and that no one wants to be his friend because he is so different,

or when he is in such excruciating pain that he is screaming uncontrollably,

or worse, when he is telling you he knows he is dying.”
Psychosocial challenges

• Anxiety over treatment or possibility of dying
• Stress of dealing with demanding treatments
• School and peer issues for children; work and finance demands for parents
• Strain on healthy siblings and family dynamics
• Info overload and pressure to make rapid treatment decisions
• Navigating new environment and new staff, often away from home community
• Painful and distressing procedures with disturbing side effects

A new pediatric psychosocial care standard will be publishing in Pediatric Blood & Cancer November 2015 special issue

Action step: Help endorse and promote implementation of the pediatric psychosocial standard in clinical practice
## Developmental differences

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Description</th>
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<tbody>
<tr>
<td>Very young</td>
<td>Fear of separation from parents&lt;br&gt;Having painful, frightening treatments&lt;br&gt;Behavior can change and regress</td>
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<tr>
<td>School age</td>
<td>School disruption is a huge strain&lt;br&gt;Loss of peer interaction and activities&lt;br&gt;Distress over procedures&lt;br&gt;Greater understanding of seriousness of cancer requires emotional and social support</td>
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<tr>
<td>Adolescents</td>
<td>Add strain on their quest for independence&lt;br&gt;Increased need for and use of social support&lt;br&gt;Focused on identity issues and image</td>
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<tr>
<td>Young Adults</td>
<td>Cancer may postpone, interrupt or alter romantic relationships and academic or vocational pursuits&lt;br&gt;Concerns about affects on careers, fertility, finances</td>
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“I know I am supposed to be happy, but I am not.

- How do I know there isn’t a cancer cell floating around?
- I still have pain and have to go to PT all the time.
- I can’t keep up with my friends and feel so out of the loop.
- I am way behind in school and I feel exhausted after a few periods.

Seriously, this sucks.”

**Key Message:** Camps provide important psychosocial support for kids and their families that helps their healing.
Good communication is a learned skill

Talking about what really matters to patients and families makes clinicians more effective in making recommendations. That helps parents in shared decision-making.

“Momcologist”

It also helps them be the kind of doctor, nurse, social worker, or other health professional that people want for themselves, their family and friends.
Person-centered communication

What matters to patients and families is as important as what is the matter with them.

Common communication pitfalls:
- Sticking to medical facts – “explainaholicism”
- Minimizing patient’s emotions
- Maintaining objective distance
- Hoping people have good coping skills

Focus on what is important to them.
- What are they hoping for?
- What are they most worried about?
- NOTE: Expect emotion

Takeaway tip: When you hear an emotion and feel compelled to respond with a fact, hit your pause button
Don’t do nothing. Just sit there.
Empathy fuels connection

Brené Brown on Empathy

- **Empathy is “feeling with people”** – it involves recognizing an emotion and communicating it
- Empathic opportunities = moments when people explicitly or implicitly express emotion
- Rarely can a “silver lining” response to painful emotion actually make something better (avoid “at least...”)

**Takeaway tip:**
Empathic responses bring connection and comfort

Empathy short: [https://www.youtube.com/watch?v=1Evwgu369Jw](https://www.youtube.com/watch?v=1Evwgu369Jw)
Honest communication. Always.

• Allows for development of shared knowledge between practitioners, child, and family

• Relieves distress and uncertainty so families don’t fear the worst

• Helps patients and families make informed decisions about their care based on their preferences and values so treatment aligns with their stated goals

MYTHBUSTING: Discussing prognosis DOES NOT take away hope

➤ Parents receiving more extensive info report feeling the most hopeful, even when prognosis is poor

➤ Parents who feel they have too little info actually are most likely to feel upset

➤ Prognostic disclosure is linked to greater peace of mind and trust in the physician

➤ Parents who know what is ahead feel more prepared to be there for their children

(Mack et al. 2006, 2007, 2009)
Consensus now: QOL communication is essential part of quality care

**Recommendation**: Provide patients and families with understandable information about cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and costs

**Recommendation**: Professional education programs for members of the cancer care team should provide comprehensive and **formal** training in communication
Guiding Principles: Person-centered and family-oriented communication

**Communicate honestly,** especially about treatment choices, QOL impact, and outcomes.

**Take the time** for honest communication.

**Convey hope** guided by honest communication about treatment choices and prognosis.

**Action step:** Pursue professional resources and training to enhance clinical communication skills
Hope

Hope is not an emotion: It’s a cognitive process.

- Hope happens when we can set goals, have the tenacity and perseverance to pursue those goals, and believe in our own abilities to act.
- Fears for the worst threaten hope when discussions do not take place.
- Hope is maintained even with truthful discussions that teach the patient and family that there is no chance of cure.

**Action Step:** Convey hope through honest communication about treatment choices, prognosis, and support for QOL.
“Once I found out we were dealing with EOL care, I did have hope.

Hope changes along the continuum.

When hope for a cure went out the window, then we hoped for a more sound, humane, and less painful death.

Empowerment and communication go hand in hand.”

- Victoria Sardi-Brown, Mattie’s Mother
Communication skills development

Effective communication:

• “Starts from the heart,” recognizing that crucial conversations are emotionally laden and require genuine listening to convey that you care about their concerns, goals and values

• Creates safe space that engenders trust by getting to the source of fears and discomfort, watching for physical, emotional and behavioral signals

• These are the places that trigger vulnerability and enhance opportunities for finding shared meaning and mutual purpose
Guidelines to influence expectations and perceptions of quality and value:

1. Identify emotional triggers
2. Respond Early to Intense Emotions
3. Enhance Customer’s Control
4. Hire the Right People and Prepare Them for the Role

Read the article at hbr.org/2015/10/when-the-customer-is-stressed
What does she need?

“I found survivorship to mean lying on the couch, not having the end of treatment anymore as my goal, and still struggling and feeling horrible and not knowing when it was going to end and how long I would have to wait...

In so many ways, I am still waiting”

Melinda Marchiano

COG Survivorship Care Guidelines info plus ongoing emotional support
QOL Communication Cues

“Always Ask” Tattoo: Pick a Few
1. Tell me about your child as a person
2. What is your understanding of your child’s situation now?
3. What is important to you?
4. What are you hoping for/what are your worries?
5. Where do you find your strength or comfort?
Working with empathy works!

Good communicators draw on a large repertoire of learned skills to collect essential person-centered data about their patient’s values, goals and concerns.

*These skills take practice to master.*

Good communication promotes patient trust plus professional resilience that prevents burnout.

**Takeaway Tip:** This book is a superb starter course to make you a better communicator in serious illness setting.
Scaffolds for learning

Access online tools at vitaltalk.org

EPEC®
Education in Palliative and End-of-life Care

Pediatrics Online Communication & Planning
Access at: epec.net/epec_pediatrics.php

Tip: Practice one new skill at a time and share with others (whom you trust) that you are working on improving your skills

Action step:
Equip clinicians AND empower patients/families at same time to change the culture of QOL communication.
Giving people the words to use

Common Practice transforms anxiety about dying into conversations about living...

Takeaway tip:
This game is an essential QOL conversation ice-breaker. It cultivates “consumer pull” to talk about prognosis, priorities, and goals.

mycommonpractice.com
Additional Resources

- Parent’s Guide to Enhancing QOL in Children with Cancer family handbook (acco.org)
- Courageous Parents Network online video library (courageousparentsnetwork.org)
- Get Palliative Care consumer information (getpalliativecare.org/whatis/pediatric/)
- Voicing My Choices (agingwithdignity.org/shop/product-details/voicing-my-choices)
- NIH/NINR Conversations Matter campaign (ninn.nih.gov/newsandinformation/conversationsmatter/pccm-about-7-2015#Vjkf66rRPM)
“Because of what we have gone through, there is enormous determination among all of us that we will make this matter – that the cancer knowledge and delivery of care can and should improve, including palliative care.”

Dr. Jennifer Cullen, mother of Alexandra
Legislative advocacy

Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act:

1. Maximizes QOL
2. Moves research forward
3. Helps improve access to treatments

S1883/HR3381 has 9 Senate and 92 House bipartisan cosponsors.
To take action visit:
http://www.stbaldricks.org/blog/post/speak-up-for-kids-cancer-tell-congress-to-support-the-star-act?gclid=CJja47vo9cgCFdURHwedZ04C9A

Palliative Care and Hospice Education and Training Act (PCHETA)
HR3119 information at patientqualityoflife.org
Summary of key workshop messages

1. **Listen to the child and family about symptoms and toxicities** -- provide a means for them to report symptoms, including psychosocial distress, and have those symptoms effectively addressed

2. Provide psychosocial care during and after treatment for children and their families

3. Document, monitor, and where possible, prevent long-term effects of childhood cancer treatment

4. Consider and ameliorate health disparities

5. Standardize pediatric palliative care and psychosocial care to ensure every child and caregiver receives this high-quality care -- no matter their ethnicity or where they are located

6. Support and pursue research and development promoting cure and quality of life so all children have opportunity to both survive and thrive
10 next steps menu

**Educate. Energize. Engage.**

- Avoid conflating palliative care with EOL care or hospice
- Talk about palliative care and psychosocial support as essential elements of optimal cancer care and QOL for every audience
- Tell your colleagues about available resources to help enhance communication skills and QOL services integration
- Understand that honest communication is a priority in your job
- Avoid “explainaholicism” and practice empathy
- Tattoo “Always Ask” on your arm
- Commit to change and get some training – play My Gift of Grace!
- Be a voice in your community for promoting QOL child/family needs by taking advocacy action
- Persuade your professional organization and colleagues to embrace the new psychosocial standard
- Talk about camps as an important aspect of supporting QOL for families
Together we can boost quality of life and help make healing happen

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