Easing Suffering and Enhancing Wellbeing in Children with Cancer and their Families

Joanne Wolfe, MD, MPH
Division Chief, Pediatric Palliative Care
Department of Psychosocial Oncology and Palliative Care
Dana-Farber Cancer Institute
Director, Pediatric Palliative Care
Boston Children’s Hospital
Disclosure

There are no relevant financial relationships to disclose
Objectives

1. Describe a framework of family suffering and potential interventions to enhance wellbeing
2. Review impact of primary palliative care interventions on family suffering and wellbeing
3. Review impact of subspecialty palliative care interventions on family suffering and wellbeing
1. A Framework to Ease Suffering and Enhance Wellbeing
WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Integrating Palliative Care

Hope for cure, life extension, a miracle...

Individualized blending of care directed at underlying illness and physical, emotional, social and spiritual needs of child and family with continuous reevaluation and adjustment

End-of-life care

Bereavement Care

Hope for comfort, meaning...
Primary vs Subspecialty PPC

• Primary
  – Team provides interdisciplinary support and integrates a palliative care approach

• Subspecialty
  **Clinical:** more complex care
  **Education:** enhance knowledge, skills, behaviors and attitudes
  **Innovation and research:** advancing the field
  **Advocacy:** system wide changes

Quill and Abernethy Generalist plus Specialist Palliative – Creating a More Sustainable Model Care NEJM, 2013
Suffering

Suffering is a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It lasts until the threat is gone or integrity is restored.

The meanings and the fear are personal and individual, so that even if two patients have the same symptoms, their suffering would be different.
A Framework for Easing Suffering

"Visible" threats
Life-threatening illness
Physical Symptoms

"Invisible" threats
Disruptions from "normal life"
Emotional symptoms
Existential concerns
Socio-demographic concerns

Targeted Interventions
(e.g. Symptom treatment trials)

Global Interventions
(e.g. Screening, resilience training, palliative care consultation)

Family Integrity
Parents
Siblings
Patient

"NEW" Family Integrity
Parents
Siblings
Patient
Social Suffering: Household Material Hardship in Families of Children with Cancer

Family Psychological Distress:  
Parent’s Psychological Distress in Pediatric Advanced Cancer

### Parent Perceptions of Child's Illness Associated with Increasing Psychological Distress, Multivariate Analysis¹

<table>
<thead>
<tr>
<th>Perception</th>
<th>Increased Parental Distress Scores²</th>
<th>Average Increased K6 Score $\beta$ (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prognostic understanding aligned with concrete goals of care</td>
<td>−4.0 (−2.1 to −5.8)</td>
<td></td>
</tr>
<tr>
<td>Overall child suffering &quot;a lot&quot; or &quot;a great deal&quot;</td>
<td>3.0 (0.7 to 5.3)</td>
<td></td>
</tr>
<tr>
<td>&quot;Great&quot; financial hardship due to child's illness</td>
<td>3.1 (1.0 to 5.2)</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviation: K6, Kessler-6 Psychological Distress Scale

¹ n = 70

² Multivariate linear regression model showing average change in K6 score, independent of other listed factors.

Rosenberg et al. Psychological distress in parents of children with advanced cancer. JAMA Peds 2013
Long-term psychosocial outcomes in bereaved siblings of children with cancer

Rosenberg et al. Long-Term Psychosocial Outcomes Among Bereaved Siblings of Children with Cancer JPSM 2014
Spiritual Suffering: Most parents of children receiving PPC feel that Religion, Spirituality, or Life Philosophy is important in helping them deal with tough times.

The data suggest that easing suffering and enhancing wellbeing requires **Interdisciplinary Team work**.
2. Does primary PPC integration improve child and family wellbeing?
What is the most common response you get when you ask a child, “How as school?” “How are you feeling?”
I'M

DEPRESSED

LONELY

CRYING

SCARED

DYING

LOST

HURTING

EMPTY

ANXIOUS

TRYING

BROKEN

LYING

FINE.
**PediQUEST Study**

**Amplifying the Child’s Voice**

**Pediatric Quality of Life and Evaluation of Symptoms Technology:** Computer-based data collection system that collects child (or parent) reported symptoms and QoL and is able to generate printed feedback reports and email alerts.
The PediQUEST Study
Hypothesis

Increasing awareness of providers and parents about child’s symptoms and quality of life will decrease the child’s experience of suffering

(A primary palliative care intervention study)
The PediQUEST Study

Baseline measurement Individual
Randomization (block randomization by site)

Control

Enrollment

Intervention

PedsQL, MSAS and FPS-R
At least once a month
At most once a week
X 3 Months (w/re-enrollment)

Satisfaction assessed at 4th and 8th PQ survey
Feedback Reports
Family Satisfaction

Reports help me understand better how my child is feeling

Reports help me talk to the doctor

I worry about confidentiality of reports

I would like to keep using reports

Reports are easy to understand

4th PQ administration

8th PQ administration
Feedback Reports
Provider Satisfaction

✓ Provided new information about *psychosocial issues* (61%)
✓ *Reports* contributed at least sometimes to *consulting a specialist* (29% to 56% depending on specialty)
✓ Useful when *speaking to patients* (50%)
✓ Did *not* significantly *increase consult time* (84%)
✓ PediQUEST reports considered *somewhat to very helpful* (64%)
Results of the PediQUEST RCT

Wolfe et al, Improving the Care of Children With Advanced Cancer by Using an Electronic Patient-Reported Feedback Intervention: Results From the PediQUEST Randomized Controlled Trial. JCO 2014
The PediQUEST Study: Reasons for Participation

The PediQUEST Study

Conclusion

*Feedback* alone has *some effect on child suffering* but can be strengthened
Question

Why was feedback alone insufficient to significantly improve symptom distress and quality of life outcomes?
Possible Explanations

• PediQUEST feedback had a limited effect in activating clinicians and families to attend to symptom distress, perhaps related to barriers in
  – Attitudes and expectations
  – Knowledge and skills
  – Practical considerations

Normalization of symptoms
3. Does subspecialty palliative care integration improve family outcomes?
**Integrating palliative care for patients with metastatic non-small-cell lung cancer**

Early Pall Care | Standard Care | Diff
---|---|---
Change in Quality of Life (TOI) | +2.3 | -2.3 | P=0.04
Depression (PHQ-9) | 4% | 17% | P=0.04
Survival | 11.6 mos | 8.9 mos | P=0.02

**Utilization Trends**

<table>
<thead>
<tr>
<th></th>
<th>Early Pall Care</th>
<th>Standard Care</th>
<th>Diff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median inpatient days</td>
<td>5.0d</td>
<td>7.0d</td>
<td>2.0d</td>
</tr>
<tr>
<td>Hospice admission &lt;3 days prior to death</td>
<td>3.0%</td>
<td>14.7%</td>
<td>11.7%</td>
</tr>
</tbody>
</table>

Temel et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer NEJM 2010

**Early** versus late PC also found improve survival and QOL outcomes among adults with advanced cancer in a multicentered study

Bakitas et al Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III RCT. JCO 2015
Integrating palliative care for children with cancer

Prevalence and degree of suffering from common symptoms in the last month of life in baseline and follow-up cohorts. The graph shows proportion of children who, according to parental report, had a specific symptom in the last month of life and who had “a great deal” or “a lot” of suffering as a result. P values represent univariate comparisons.

Prevalence of children dying in the Intensive Care Unit and/or an outside hospital by time period of death.

Emerging data suggest that integrating PPC improves outcomes

- 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%)

- Families who received PPC/Oncology report improved communication
  Kassam A, Skiadaresis J, Alexander S et al. Differences in End-of-Life Communication for Children with Advanced Cancer who were Referred to a Palliative Care Team. Ped Blood Cancer In Press

- Children receiving PPC experience shorter hospitalizations and fewer emergency department visits

- Among children undergoing SCT, PPC consultation is associated with less intervention-focused care and greater opportunity for EOL communication and ACP

- PC is associated with less intensive treatment at the end-of-life in AYA patients who died in the hospital
Enhanced Intervention: PediQUEST Response (Respond to Pediatric Oncology Symptom Experience)

Hypothesis: compared to an enhanced feedback system alone, combining feedback with early intensive follow-up by a Palliative Care Response Team will more effectively reduce child symptom distress and improve child and family quality of life.

Rationale: embedding a palliative care team within oncology will:

- Active the child, parents and providers
- Increase adherence with the intervention
- Provide more targeted and timely telephone and/or face-to-face response to a child’s distress experience.
Profound Gratitude to my PPC Research Team

Veronica Dussel, MD MPH
(Research partner extraordinaire!)
Center for Research and Implementation in Palliative Care at the Institute for Clinical Effectiveness and Health Policy, University of Buenos Aires, Argentina

Liliana Orellana, PhD
(Primary Statistician)
Deakin University, Australia

Co-Investigators:
Christy Ullrich, MD MPH (DF/BCH)
Chris Feudtner, MD PhD MPH (CHOP)
Jason Freedman (CHOP)
Abby Rosenberg, MD MS (Seattle Children’s)
Ross Hayes (Seattle Children’s)
Justin Baker, MD (St Jude)
Erica Kaye, MD MS (St Jude)
Stefan Friedrichsdorf (Children’s Health Care)
Mary Cooley, PhD (DFCI)
Marie Bakitas, PhD (UAB)
Cynthia Gerdhardt, PhD (Children’s National)

Buenos Aires Research Team:
Staff Researchers:
Luciano Uzal, anthropology
Maria Laura Requena, sociology
Research Fellow:
Gisella Santos, pediatrician
External collaborators:
Celeste Jerez, anthropology
Victoria Riso, Physical Therapy MPH Candidate

Research Support Team:
Madeline Biladeau, BS
Rachel Holder, BA
Jeet Das, BA
Hasan Al-Sayegh MBChB
Karen Carroll (CHOP)
Karina Schmidt (Seattle Children’s)

IS Support Team:
Dmitry Botvinnik (DFCI)
Madhuri Deodhar (Atrium Technology, India)

Thank you!