Trends in Pediatric Palliative Care Research

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Conceptual models
  - Palliative Care
  - Suffering

Retrospective/Cross Sectional research findings to date
  - Relational aspects of care
  - Disease-directed therapy
  - Symptom suffering
  - Contextual factors

Prospective Intervention Study: Preliminary results
  - PediQUEST

Next Steps
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…
Survival of patients receiving PPC

Feudtner et al, Pediatrics 2011
Diagnoses in patients receiving PPC

Feudtner et al, Pediatrics 2011
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.

Eric Cassel, MD
“Visible” threats
Life-threatening illness
Type, site, stage
Disease-directed treatment
Duration of illness
Symptoms
Pain, fatigue, anorexia, insomnia
Symptom Treatment SE
Emotional Factors
Anxiety, fear, depression

“Invisible” threats
Disruptions from “normal life”
Clinic visits, admissions, home care
Change in family roles
Loss of school and friends
Loss of play time
Emotional factors
Anxiety, fear, depression
Being a burden
Need to meet others’ expectations (win the battle)
Existential concerns
The meaning of being ill

Socio-demographic factors

Global Interventions
(e.g. communication, interdisciplinary work, PediQUEST)

Targeted Interventions
(e.g. symptom treatment trials)
Disease-directed therapy
Understanding Parents’ Approaches to Care and Treatment of Children with Cancer when Standard Therapy has Failed

- Ethnographic study of 34 (17 US, 17 UK) children with cancer whose disease recurred with less than 30% chance of cure, followed until death or close of study.
  - No major differences between US and UK families.
  - A majority of parents accepted continued cancer-directed therapy when offered, and/or sought additional options on their own, when not offered.
  - Parents do not see cancer-directed therapy and symptom-directed care as mutually exclusive, alternative approaches.

Bluebond-Langner et al JCO 2007
Parents’ Views of Cancer-Directed Therapy for Children With No Realistic Chance for Cure

Parents who reported that their children experienced suffering resulting from cancer-directed therapy were less likely to recommend standard chemotherapy to other families (OR 0.46; P=.02)

Mack et al, JCO 2008
Relational Aspects of Care
Parent and Physician Perspectives on Quality of Care at the End of Life in Children With Cancer

Higher ratings of care associated with…

Parent perspective
− Giving clear information
− Communication is sensitive and caring
− Communicating with child
− Preparation for death

Physician perspective
− Less pain
− Shorter hospitalization at the end of life

Mack et al, JCO 2005
End-of-Life Care Preferences of Pediatric Patients

• 20 patients aged 10-20 years, and matched parents and physicians, participated in a qualitative interview within 7 days of making an EOL decision related to:
  – Participation in phase I trial – 4 enrolled, 3 declined (N=7)
  – Resuscitation status (N=5)
  – Initiation of terminal care (N=8)
• Top factor that influenced the 20 Patients’ EOL Decision
  Thinking about my relationships with others (95%)
  “If I can help someone else, that’s wonderful, I think.” 14 yo
  “If I don’t take it, my family would support me, but they don’t want me to quit…” 19 yo

Hinds et al, JCO 2005
Symptom Suffering
Early Studies

Wolfe et al. NEJM 2000.

Wolfe et al JCO 2008
Symptoms and Suffering from Fatigue at End of Life

Pain
- High suffering
- Side effects from treatment
Dyspnea
- High suffering
- Side effects from treatment
Anorexia
- High suffering
- Unsuccessful treatment
Nausea/Vomiting
Diarrhea

Psychological Symptoms
- Anxiety
- Sadness
- Fear

Ullrich et al. JPSM, 2010
Pain and distress in Children with HIV/AIDS

- Pain and distress in the last 48 hours was documented in 55% of children with HIV/AIDS (n=165) who died in the general wards (Henley Devel World Bioeth 2002)

- 20% prevalence of pain in 985 HIV-positive children (Gaughan et al Pediatrics 2002)
  - Lower CD4 T-lymphocyte percentage, female gender, and an HIV/AIDS-related diagnosis were highly associated with an increased risk of reported pain.
  - Children reporting pain were over 5 times more likely to die than those not reporting pain (hazard ratio 5.07; 95% confidence interval 3.23–7.95)
Distress in cognitively impaired, non-communicating children

- Study to detail the everyday occurrence of pain in non-communicating children with cognitive impairment
- 34 parents completed daily pain diaries for two weeks, each day for 5 defined periods rating whether their child had been in pain and its duration and severity.
- Results
  - 74% of children experienced pain on at least one day
  - 68% with moderate or severe pain on at least one day
  - 12% with mod-severe pain lasting greater than 30 minutes on 5 or more days
  - NO CHILD WAS RECEIVING PAIN MEDICATION

Stallard et al Arch Dis Child 2001
Signs and symptoms of patients receiving PPC services

* Other symptoms include paralysis, edema, sepsis, sweating, and dry mouth.

Feudtner et al, Pediatrics 2011
Drugs received by patients receiving PPC

Feudtner et al, Pediatrics 2011
Technology in patients receiving PPC

Feudtner et al, Pediatrics 2011
Bereaved Parents' Perspectives about Hastening Death in Children with Cancer

Figure 2. Proportion of parents who considered hastening their child’s death across increasing levels of child’s suffering from pain (n=138; Cochran-Armitage trend test, P=.02). HD indicates hastened death.

Dussel et al, Arch Ped & Adol Med 2010
Contextual Factors
## Impact of Planning Location of Death on Patterns of Care

<table>
<thead>
<tr>
<th>Increased</th>
<th>Decreased</th>
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<tr>
<td>Deaths in home setting</td>
<td>Admissions to hospital in last month</td>
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<td>Deaths in ICU</td>
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<tr>
<td></td>
<td>Intubation in last 24 hours</td>
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<td>Attempted CPR</td>
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Looking Beyond Where Children Die: Impact on Parent Experience

Dussel et al, JPSM 2008
Financial Impact of Losing a Child to Cancer

Dussel et al, JCO 2011
PediQUEST Study

Pediatric Quality of Life and Evaluation of Symptoms Technology: Computer-based data collection system that collects patient (or parent) reported symptoms and QoL and has the ability of generating printed feedback reports and email alerts.
The PediQUEST Study

Study Goals

1. To assess the **feasibility** of performing a randomized controlled supportive care study in a population of children with advanced cancer (Feasibility Study)

2. Explore **determinants** of child’s suffering and parent-physician discordance (Descriptive Study)

3. Preliminarily **assess if** routine feedback of symptom and QoL data to providers and families has any **effect** on child’s symptoms and QOL (Evaluation Study)
Among children with advanced cancer, providing families and doctors up-to-date information about the child’s quality of life and symptoms eases suffering.
PediQUEST Methods

*Design*: Pilot of an RCT

*Setting*: 3 US large pediatric cancer centers

*Subjects*: Children ≥ 2 years old with ≥ 2 weeks of progressive, recurrent, or non-responsive cancer or no cancer-directed therapy + 1 parent English speaking and paper and pencil and/or computer literate

*Follow-up*: 3-month enrollment renewable until end of study or death
Collaborators

Mentees
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PediQUEST collaborators
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Thank you!