Improving Family Outcomes with a Communication Intervention in the Pediatric ICU

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Palliative and End-of-life Care

- **Palliative care**: care focused on improving communication about goals of care and maximizing comfort and quality of life
- **End-of-life care**: care for those who are actively dying
### Palliative Care Consults

**Six Center Consortium**

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>Total n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic/Congenital</td>
<td>210</td>
<td>40.8</td>
</tr>
<tr>
<td>Neuromuscular</td>
<td>201</td>
<td>39.2</td>
</tr>
<tr>
<td>All Cancers</td>
<td>102</td>
<td>19.8</td>
</tr>
<tr>
<td>Hematologic</td>
<td>36</td>
<td>7</td>
</tr>
<tr>
<td>Solid Tumor</td>
<td>36</td>
<td>7</td>
</tr>
<tr>
<td>Brain Tumor</td>
<td>29</td>
<td>5.6</td>
</tr>
<tr>
<td>Respiratory</td>
<td>66</td>
<td>12.8</td>
</tr>
<tr>
<td>Other</td>
<td>55</td>
<td>10.7</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>51</td>
<td>9.9</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>43</td>
<td>8.3</td>
</tr>
<tr>
<td>Metabolic</td>
<td>37</td>
<td>7.2</td>
</tr>
<tr>
<td>Renal</td>
<td>14</td>
<td>2.7</td>
</tr>
<tr>
<td>Immunology</td>
<td>12</td>
<td>2.6</td>
</tr>
</tbody>
</table>

FIGURE 4
Survival function in the cohort of 515 patients who received pediatric palliative care consultation services and among patients with the 3 most prevalent conditions.
Priorities in Palliative Care Research

National Institutes of Health

Agency for Healthcare Research and Quality

- Pain and Symptom Management
- Communication
- Health Services
Importance of Communication in the ICU

- <5% of patients can participate in ICU decisions about withholding treatments
  - Communication is primarily with family
- Families rate communication skill as more important than clinical skill
  - More complaints and compliments
- Families under immense burdens
  - High level of anxiety and depression

Prendergast, AJRCCM, 1997; Prochard, Crit Care Med, 2001
Palliative care communication intervention: a study in the PICU

Evaluate the effects of a standardized communication intervention in the pediatric ICU on:

• Reducing family symptoms of acute & long-term stress disorders
• Family perceptions of clinician communication and conflict
• ICU length of stay and resource utilization
Rationale for Study

- Hospitalized children most likely to die in an ICU setting (Carter et al., 2004)
- 21% of parents met criteria for PTSD diagnosis 4 months after child’s ICU discharge (Baluffi et al, 2004)
- Parents frequently report conflict with clinicians in ICU admissions longer than 8 days (Studdert et al, 2003)
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Study Aims/Outcomes

Process evaluation to characterize:
• Pediatric ICU experience
• Barriers and facilitators to implementation of the intervention

Data collection:
• Ethnographic observations of ICU at baseline
  • In-depth description of what constitutes “usual care”
• Audio record a sub-sample care conferences (n=30)
• Debriefing interviews after 3 month interviews
  • 30 families (15 each of intervention & usual care)
  • 15 clinicians
Intervention

• Focus on communication, establishing goals of care, supporting families with decision making, end-of-life care transitions, grief & bereavement
Outcomes & Measures

• **Primary: Stress Outcomes**
  – Long-term stress @ 3 months (PCL-Checklist)

• **Covariates**
  – Demographics
  – Acute stress at discharge (Acute Stress Disorder Scale)
  – Depression (PHQ-9)
  – Anxiety (GAD-7)
  – Family functioning (Family Relationship Index)
  – Social Support (MSPSS)

• **Secondary**
  – Communication & Conflict (CQOC)
  – ICU length of stay, resource use
Consort Diagram = Enrollment Process (July 2010 – April 2014)

4656 children in ICU

489 children eligible (11%)

220 enrolled (45%)

105 Intervention (n=176)

1 FM = 64%
2 FM = 32%
3 FM = 4%

Data Collection
• Baseline: 100%
• Discharge: 88%
• 3 months: 89%
• Lost: 7%

115 Control (n=204)

1 FM = 63%
2 FM = 31%
3 FM = 6%

Data Collection
• Baseline: 100%
• Discharge: 92%
• 3 months: 87%
• Lost: 7%

4167 children ineligible (89%)

269 not enrolled (55%)

Reasons:
• 70% discharged < day 8
• 9% discharge plan
• 8% PACT patient/already enrolled
• 2% language other than English/Spanish
• <1% other

Reasons:
• 10% not approached
• 16% declined
• 13% could not be reached
• 12% child discharged/died
• 2% custody issues
• 1% other

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• Lost: 7%

93% Retention
Response Burden

• Questionnaire response burden is low
  • Baseline QA (94 items): Mean score=1/10 (range 0-6)
  • Discharge QA (29 items): Mean score=0.6/10 (range 0-4)
Future Directions

- Multicenter prospective inception cohort study

- 400 patients and their parents initiating care with interdisciplinary hospital-based pediatric palliative care teams at Boston Children’s, Children’s of Philadelphia, U. of Minnesota, Seattle Children’s

- Symptoms, Prescribed Treatments, and Restriction of Intevention Orders (ROI)
  - Aim 1: Patients’ Baseline: Assess distressing signs and symptoms that patients have at time of cohort entry, based on patient or parent report, including ranking of distress and impact.
  - Aim 2: Parents’ Baseline: Assess distressing signs and symptoms reported by parents about themselves at time of cohort entry, including ranking of distress and impact on their lives.
  - Aim 3: Patient and Parent Follow-Up: Via patient and parent interviews, assess and analyze changes in patient and parent distressing signs and symptoms at 3 and 6-months after cohort entry.
Future Directions cont.

• **Multicenter prospective inception cohort study**

  • **Trajectories of Symptoms, Changes in Treatments and ROI Status, and Utilization Patterns**
    • Aim 4: Using the longitudinal 6-month data, analyze the relationship between patients’ symptom trajectories and palliative care interventions
    • Aim 5: Follow hospital care for the 24-months to *evaluate the relationship between distress and hospitalization patterns*, and the *impact of palliative care on hospitalization patterns*.

  • **Patient Pain or Irritability, Disturbed Sleep of Patients and Parents, and Parental Chronic Stress**
    • Aim 6: In a cohort subpopulation (n=50), collect baseline information regarding patient and parent sleep, parent hair cortisol levels (chronic stress), parent performance on psychomotor vigilance testing (potential impact of sleep deprivation), and measure patient and parent sleep via actigraphy in the home environment.
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