Pediatric Palliative Care: A 5-Year Retrospective Chart Review Study

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T32NR011972 & F31NR014762
Disclosures & Objectives

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The authors declare no conflict of interest

Learner Objectives:
The learner will be able to:

• Identify children whom would benefit from palliative care describe the sample based on gender, age, and diagnosis.

• Describe the length survival based on disease condition; the hazard ratios for death based on age, and gender; and the pattern of pain management before and after referral to palliative care.

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T32NR011972 Interdisciplinary Training for Nurse Scientists in Cancer Survivorship Research
F31NR014762 Reiki as in Innovation for Symptom Management with Children in Palliative Care
Purpose

• Describe a large cohort of pediatric patients receiving palliative care
• Examine the relationships between patient disease type, age, gender, and race
• Compute survival curves and hazard ratios
• Compare pain scores before and after referral to palliative care.
What is palliative care for children?

The active total care of the child’s body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Who benefits from palliative care?

Any child with a life-limiting or life threatening illness

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Vindpuss, “Sunshine girl” March 15, 2015 via Flickr, Creative Commons Attribution.
Methods

• All children who were referred to palliative care between the ages of 2 and 16 during the study period (1/1/2009 through 12/31/2013)

• Data were collected from the electronic medical record through hand collection and electronic search

• Data were proofed, de-identified, and checked for outliers

• Variables gender, race, and age were put into categorical variables for analysis
Analysis

- Kaplan-Meier estimation survival curves
- Cox regression modeling to build predictive models of survival
  - Based on: gender, age, race, disease categories
- Daily mean pain scores were calculated
  - Children were included in the analysis if they had pain scores 3 days pre-referral and 5 days post-referral to palliative care
Results, $N = 256$

<table>
<thead>
<tr>
<th></th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (Male)</td>
<td>137 (53.5)</td>
</tr>
<tr>
<td>White</td>
<td>224 (87.5)</td>
</tr>
<tr>
<td>Black</td>
<td>26 (10.2)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (2.3)</td>
</tr>
<tr>
<td>Alive at the end of study period</td>
<td>158 (61.7)</td>
</tr>
</tbody>
</table>
# Referring Diagnoses

<table>
<thead>
<tr>
<th>Referring Diagnosis</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>107 (41.8)</td>
</tr>
<tr>
<td>Congenital/Genetic</td>
<td>97 (37.9)</td>
</tr>
<tr>
<td>Transplant</td>
<td>23 (9.0)</td>
</tr>
<tr>
<td>Trauma</td>
<td>14 (5.5)</td>
</tr>
<tr>
<td>Other</td>
<td>14 (5.5)</td>
</tr>
</tbody>
</table>
## Results, $N = 256$

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at referral</td>
<td>9.5 (4.5) years</td>
<td>3.45 years</td>
<td>2.0 to 16.9 years</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>6.3 (5.7) years</td>
<td>6.8 years</td>
<td>birth to 16.9 years</td>
</tr>
<tr>
<td>Time from diagnosis to</td>
<td>5.2 (5.4) years</td>
<td>2.8 years</td>
<td>0 to 16.9 years</td>
</tr>
<tr>
<td>referral</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time from referral to</td>
<td>6.8 (7.7) months</td>
<td>3.8 months</td>
<td>4 days to 3.7 years</td>
</tr>
<tr>
<td>death</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Survival Curves

Gender

Race

Cumulative Survival (%)

Cumulative Survival (%)

Months on palliative care

Months on palliative care

Gender

Race Categories

White

Black

Other

Gender

Female

Male

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Survival Curves

Age

Cumulative Survival (%)

Referring Diagnosis

Cumulative Survival (%)

Age Category
- Preschool
- Early Elementary
- Late Elementary
- Adolescent

Referring Diagnosis Category
- Cancer
- Congenital Genetic
- Transplant
- Trauma
- Other

Months on palliative care

0 8.2 16.4 24.6 32.9 41.1
Pain Scores

- Pain scores were examined for 48 children
- Pain scores were significantly different after referral to palliative care when compared to pain scores before referral to palliative care
- \( t(47) = 1.816 \ p < .05 \), one-tailed test
Limitations

- Retrospective chart review
- 23 children lost to follow up
- Date of death was often difficult to find
- Date of referring diagnosis was also difficult to find
Conclusions

• Describing this large (N=256) cohort provides important information on the complexity of disease processes for children referred to palliative care and types of illnesses referred

• Pain decreased after referral to palliative care
Next Steps

• Dissertation: Acceptability and Feasibility of Reiki for Symptom Management in Children Receiving Palliative Care

• Continued research with children receiving palliative care using complementary therapies including Reiki, massage, hypnosis, and others
Questions?

Thomas Rydberg, “Skateboarding is the coolest” June 22, 2012 via Flickr, Creative Commons Attribution.