A Learning Collaborative to Improve Home-Based Care for Children with Serious Illness

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Learning Objectives

• Discuss common barriers to providing high quality care for children in hospices serving mainly adults

• Describe the approach used by the CHLA Hospice and Palliative Care Learning Collaborative to address barriers and expand access to hospice (home based care) for children

• Identify at least three strategies to improve the ability of adult hospices to provide high quality care for children
Past Limitations to Pediatric Hospice Use

• Difficulty stopping disease directed treatment for children
• Difficulty saying when “6 months” prognosis
• In 2010, only 12.5% of eligible children with Medi-Cal received hospice care (Lindley, 2016)
Policies Removed Barriers

- California: Partners for Children program
- Federal: 2010 ACA, Section 2302, Concurrent Hospice Care
Barriers to home-based care

- Barriers to referral
- Barriers to receiving high quality care
CHLA Hospice and Palliative Care Learning Collaborative Goal:
Expand Children’s Access to Home Hospice and Palliative Care Across Southern California

• Partner with home hospice and palliative care agencies
• Increase the comfort, knowledge and resilience of professionals caring for this high need population
• Improve communication and coordination between CHLA and home agency staff
Collaborative Design:
Why a Learning Collaborative?

• All teach, All learn
• Focus on practice and implementation
• Generous financial support for the effort provided by the Tower Cancer Research Foundation
Collaborative Overview

1. Recruitment and Agenda Development
2. Session I: June 24, 2016
3.Between Sessions:
   – Focus on agency efforts
   – Support from CHLA
   – Develop agenda Session II
4. Session II: November 4, 2016
Agency Recruitment

• Initially identified 10 hospice or home care agencies serving mainly adults
• Goal: 5 agencies
• Recruited: 6 agencies
Participating Agencies

- Libertana Home Health (LA, Ventura)
- Companion Hospice Agencies
  - Orange
  - Riverside/San Bernardino
  - Simi Valley (LA, Ventura)
  - Pasadena
  - West LA
  - Downey
- Trinity Kids Care (LA, Orange)
- Universal Home Care (LA)
- Vitas Healthcare (LA, Orange, San Diego, Inland Empire)
- Hoffman Hospice (Kern)
Session attendance

• Total of 50 people at each session (June and November)
  • June:
  ‒ 36 from outside agencies
  ‒ 14 from CHLA (including palliative care team)
  • November:
  ‒ 26 from outside agencies
  ‒ 24 from CHLA (including palliative care team)
Designing sessions

• Used conference registration process to solicit ideas for session topics that would be most useful to participants

• All agencies were interested or very interested in every topic
<table>
<thead>
<tr>
<th>Topic</th>
<th>Very interested</th>
<th>Interested</th>
<th>Not interested</th>
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<tbody>
<tr>
<td>Pain assessment and management for pediatric patients</td>
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<td>Differentiating substance abuse disorder from pain disorders for pediatric patients</td>
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<td>Assessment and management of nausea and vomiting for pediatric patients</td>
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<td>Assessment and management of terminal delirium for pediatric patients</td>
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<td>Assessment and management of terminal dyspnea for pediatric patients</td>
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<td>Assessment and management of constipation for pediatric patients</td>
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<td>Giving bad news to children and their families</td>
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<td>Leading a family goal setting meeting including: discussing prognosis, treatment withdrawal/limitation for pediatric patients</td>
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<td>Understanding concurrent hospice care for children</td>
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<td>Determining decision-making capacity of pediatric patients</td>
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<td>Advance directives or advance care plans for pediatric patients</td>
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<td>Use of intravenous hydration and/or non-oral feedings in end-of-life care for children</td>
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<td>Spirituality in end-of-life care for children</td>
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<td>Talking with children about death and dying</td>
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<td>Bereavement support for families (parents, siblings, etc.) after the death of a child</td>
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<tr>
<td>Other</td>
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Based on The Palliative Care Network of Wisconsin (PCNOW) survey, mypcnow.org
Description of participants

June
Participants from outside agencies:
• Medical: 11
• Psychosocial: 9
• Administrative: 8
• Case managers/care coordinators: 4

November
Participants from outside agencies:
• Medical: 9
• Psychosocial: 6
• Administrative: 3
• Case managers/care coordinators: 3

Sixteen participants attended both the June and November sessions.
Session 1: June

**AM**
- Goals of Care: How we walk the walk and talk the talk
- Breakout sessions:
  - I. Comfort for Kids: Addressing pain, dyspnea and GI symptoms
  - II. When a Child is Dying: Loss, meaning and hope

**PM**
- Care at Home: Updates in hospice and palliative care policy
- Case Discussions: Transitioning from hospital to home (and back again)
- Team Meetings
In between sessions

• Agenda development LS 2:
  – more specific details about medications
  – helping parents cope with actively dying child
  – networking

• Individual Agency Activities
  – Calls/visits
  – Projects/focus areas
Session 2: November

- Agency presentations
- Reducing Suffering at End of Life
- Lunch/Networking

- Breakout sessions:
  - I. Physical Comfort for Kids: Medications
  - II. Working with Siblings
- Art and Music Therapies for Children with Serious Illness
Evaluation: Change in Comfort Level

Rating scale:
1 = Not comfortable performing without further instruction
2 = Comfortable performing with close supervision
3 = Comfortable performing with minimal supervision
4 = Comfortable performing independently

Mean score on non-medical items for all attendees
- June: 2.90
- November: 3.09

Mean score on all items for all medical staff only
- June: 2.91
- November: 2.95

Mean score on medical items only for medical staff only
- June: 3.02
- November: 2.90
QUESTIONS 1 - 7

“Comfortable performing independently”

- Family Conference
  - June: 43%
  - November: 50%
- Bad News
  - June: 29%
  - November: 50%
- DNR orders
  - June: 37%
  - November: 52%
- Home Hospice
  - June: 37%
  - November: 47%
- Approach
  - June: 30%
  - November: 45%
- Withdrawal
  - June: 24%
  - November: 50%
- Pain Assessment
  - June: 41%
  - November: 50%
QUESTIONS 15 - 20

“Comfortable performing independently”

- Decision-Making: 24% (June), 32% (November)
- Advance Care: 35% (June), 48% (November)
- POLST: 38% (June), 43% (November)
- Bereavement: 29% (June), 32% (November)
- Explaining Concurrent: 33% (June), 41% (November)
- Enrolling Concurrent: 30% (June), 35% (November)
QUESTIONS 8-14
MEDICAL TEAM ONLY

“Comfortable performing independently”

- Oral Opioid: June 63%, November 52%
- Parental Opioid: June 47%, November 41%
- Adjuvant Analgesics: June 57%, November 40%
- Terminal Delirium: June 22%, November 13%
- Terminal Dyspnea: June 35%, November 31%
- Nausea/Vomiting: June 39%, November 40%
- Constipation: June 52%, November 38%
Evaluation of Sessions

How well did sessions meet the Collaborative objectives?

• Enhance communication/coordination
  – June: 72% said “extremely well”
  – November: 57% said “extremely well”

• Increase comfort/knowledge in caring for pediatric patients
  – June: 63% said “extremely well”
  – November: 68% said “extremely well”
Evaluation of Sessions

% Strongly agree: I can apply this presentation to my work

- Goals of care session (June): 78%
- Care at home session (June): 74%
- Case discussions session (June): 72%
- Medical breakout (June): 68%
- Psychosocial breakout (June): 67%
- Concurrent care session (Nov): 81%
- Art/music therapy session (Nov): 57%
- Medical breakout (Nov): 79%
- Psychosocial breakout (Nov): 81%
Evaluation of conference: Count of Qualitative comments

June
Most valuable part of conference
• Collaboration: 3
• Discussion: 9
• Networking: 6
• Information: 1

November
Most valuable part of conference
• Collaboration: 1
• Discussion: 6
• Networking: 2
• Information: 17

Suggestions for improvement (from both conferences)
• Thanks/well done: 10
• More networking: 3
• More info/resources: 8
• More collaboration: 7
Other Comments

Before sessions:
• “This looks like it would be such an asset to our small community of palliative and hospice workers! Thank you so much for the effort. I would love to join this collaboration.”
• “I just want to take a moment to thank you for offering and inviting us. It means a great deal to myself and my staff …”
• “My team is very excited and would like to attend [your conference]. I have six companies in California; how many people can I bring?”

After first session:
• “The conference was wonderful! My staff are so excited. . . . The format was wonderful, and it was actually great to speak with the Trinity Kids folks. . . . I have always felt and hoped that all the hospices would be about exchanging ideas and resources. Leave it to kids to show the adults the way.”
Examples of tools/strategies to expand home-care capacity for children with serious illness
Summary: Lessons learned

- Valued of networking and chance to learn and reflect
- Format of sessions well received
- Comfort level with children overall improved
- Agencies wanted more information about CHLA team’s role.
- Challenging finding time for one-one discussions