Improving Quality in the Provision of Pediatric Palliative & End-of-Life Care

COALITION FOR COMPASSIONATE CARE OF CALIFORNIA
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Susan Shields MSN, APRN, CPNP, ACHPN

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Disclosure

The presenter for this presentation has disclosed no conflict of interest related to this topic.
By the conclusion of this session the learner will be able to:

• Identify 3 barriers to the provision of pediatric palliative care at the bedside.
• Describe quality improvement measures for the provision of palliative care.
• Describe methods to improve knowledge of palliative care and nurse comfort in the provision of palliative care.
• Analyze the impact of a pediatric palliative care champions program on the provision of pediatric palliative care at the bedside
• Investigate methods to develop palliative care expertise at the bedside in order to ensure that palliative care is integrated within the organizational culture of their institution.
What is Palliative Care?

• At its core, palliative care is a beautiful, total-care concept with a team consisting of doctors, nurses, chaplains, social workers, therapists and others depending on the patient’s needs. The goal is to relieve suffering and give support wherever needed to improve quality of life.
• According to **Mattie Stepanek**, a child who died from a life-limiting neuromuscular illness, pediatric **palliative care** "no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently". Oct 30, 2017
Which Children are Candidates for Palliative Care?

• Any child with a complex medical condition AND the following criteria may qualify for help from the Palliative Care Team:
• The condition causes significant pain or other symptoms
• The condition causes emotional, social, spiritual or physical distress
• The condition causes fragmentation of medical care and communication
• The condition disrupts the ability to perform age appropriate life activities
• The condition results in frequent ER department visits, hospitalizations, or prolonged length of hospital stay
• The condition requires assistance with complex decision-making and determination of medical goals of care.
BACKGROUND

Johns Hopkins All Children’s Hospital

Licensed beds 259
Percentage ICU Beds 57%
Inpatient admissions 6,600
Total surgeries 8,500
Emergency Center visits 48,100
Outpatient Visits 400,000
EARLY PROGRAM DEVELOPMENT

- Limited resources
- Grant funded
  - 1 FT APRN
  - 1 FT Child Life Specialist/Grief Counselor
  - 1 PT Physician
  - No Patients
  - Limited understanding of Palliative Care Hospital wide
Program Growth – 2 Years

• Education, conferences, meetings, consults
• Average Daily Census increased to 20-25
• Need for additional staff

• How do we monitor quality of PC, continue culture of PC, continue to provide the same level of care with limited resources?
Bridging the Gap - Palliative Care Champions

• Maximizing staff resources by providing more concentrated training to create experts at the bedside
• Promote comprehensive quality care for PC patients across the hospital system
• Enhance the collaboration that occurs between unit staff and the PC team
• Develop a formal program to train and provide ongoing support and education to the unit champions
Defining the Need

- Limited resources
- Lack of knowledge
- Need to evaluate nurses comfort level with palliative care
- How to educate nursing staff

Desire for palliative care to be integrated at the bedside
Staff Comfort & Confidence

- Intro PC to Patients/Families: 61%
- Care for dying child & family: 65%
- Non-Pharmalogical Therapies: 91%
- Symptom Management: 50%
- Ongoing Communication: 65%
- Facilitation of Grief Process: 57%
- Resource Identification for: 57%

Pre-workshop
Strategy

Phase I
- Staff education

Phase II
- Palliative Care Champions Program
Phase I – Staff Education through ELNEC-PPC

- Introduction to palliative care (pediatric)
- Communication
- Neonatal/Perinatal
- Ethical/Legal
- Cultural/Spiritual
- Symptom/pain management
- Care at time of death
- Loss/grief/bereavement
- Models of excellence
- Healthcare provider self-care
Phase II – Palliative Care Champions Program

Identify Champions
- Director approval
- 2 years in RN role
- Desire to serve in role

Initial Education
- End-of-Life Nursing Education Consortium – Pediatric Palliative Care
- Orientation Workshop (4hr)
- Shadow Palliative Care Team (4hr)

Ongoing Education
- Quarterly Educational Sessions (2hr)

Maintenance Requirements
- Attend at least 75% of quarterly sessions each year
- Obtain CHPPN certification within 2 years
- Demonstrate continued involvement by fulfilling role duties
Initial Education: Welcome to the Role Workshop

- 4 hour continuing education session
- Focus on role of the Champion
- Review hospital policies pertaining to end of life and PC
- Discuss End of Life care and expectations in various units

- Education – Focus on Communication
- Role playing
- Use of words – terminology
- Tools for palliative care
Ongoing Education: Quarterly Education Sessions

- Symptom management
- Palliative Care consults
- Transition to end of life care
- Ethics of End of Life management
- Resilience/Self Care/Mindfulness
- Organ Donation
- Palliative Care and End of Life care in the ICU
- Loss/Grief and Bereavement
- Quality of Life – Music therapy, memory making, Make-A-Wish organizations
- Advance Directives
- Palliative Sedation
Phase II – Palliative Care Champions Program

**Patient & Family**
- Access to more comprehensive care
- Facilitation of a comfortable death in any area of the hospital

**Staff**
- Empowered to provide palliative care
- Decreased stress by empowering staff to support one another

**Champions**
- Comfort & confidence in providing end-of-life & palliative care
- Increased ability to identify appropriate patients for consult
- Enhanced ability to mentor other staff in provision of palliative care

**Palliative Care Team**
- Increased support in reaching more patients
- Better access to appropriate patients for consults

- **Benefits**

  - **Access to more comprehensive care**
  - **Facilitation of a comfortable death in any area of the hospital**
  - **Empowered to provide palliative care**
  - **Decreased stress by empowering staff to support one another**
  - **Comfort & confidence in providing end-of-life & palliative care**
  - **Increased ability to identify appropriate patients for consult**
  - **Enhanced ability to mentor other staff in provision of palliative care**
  - **Increased support in reaching more patients**
  - **Better access to appropriate patients for consults**
Outcomes – Staff Education through ELNEC-PPC

- 7 workshops
- 296 people trained
Outcomes – Staff Education through ELNEC-PPC

Quotes from Participant Evaluations:

- I feel better prepared for caring for a child & their family during the dying process. In addition, this has reignited in me a passion I have for end of life care, and I am excited to see where it takes me from here.

- Hard to explain in words, but has helped to remind me of the reasons I chose to work with this patient population and a renewed commitment to do it well and mentor others.

- Palliative care comprises a large part of what we do. It’s nice to gain some tools to help us navigate through such difficult issues
Outcomes – Staff Education through ELNEC-PPC

Changes in Staff Comfort & Confidence

- Intro PC to Patients/Families
- Care for dying child & family
- Non-Pharmaceutical Therapies
- Symptom Management
- Ongoing Communication with Patients/Families
- Facilitation of Grief Process
- Resource Identification for Patients/Families

Pre-workshop
1 month post-workshop
6 month post-workshop
Outcomes – Palliative Care Champions Program

**Palliative Care Champions**
- Satisfaction with program and education/training
- Comfort & confidence in provision of palliative care
- Time spent in role

**Staff**
- Perception of support

**Patient & Family**
- Number of consults
- Time from admit to consult
- % of physicians that consult

**Palliative Care Team**
- Decreased moral distress
| Champions Trained | • 73 trained (Current 49)  
|                  | • Inpatient areas, EC, procedural area, Nursing Supervision, Dialysis, Pain Team |
| Champions Educating | • CEU offerings  
|                   | • Increasing staff awareness  
|                   | • Developing criteria for automatic referrals |
| Champions Mentoring | • Encouraging staff to attend ELNEC-PCC  
|                    | • Mentoring staff on all aspects of providing palliative care |
| Champions Getting Certified | • 22% have obtained CHPPN |
OUTCOMES OF CHAMPION INTEGRATION

- Trigger referral criteria – PICU
- Trigger referral criteria – EC
- Ongoing development of trigger criteria for NICU, CVICU
- Champions now in outpatient settings, other disciplines
- Badging for champions for easy recognition
- Champions providing ongoing unit-based education
- Champions recognizing and advocating for specific diagnosis referral criteria
- Expertise used for end of life
Implications for Practice

Engaging frontline staff
Maximizing resources
Impacting organizational culture
Susan W. Shields, MSN, APRN, CPNP, ACHPN  
Palliative Care Program  
Johns Hopkins All Children’s Hospital  
501 6th Ave South, St. Petersburg, FL 33701  
(727) 767-7655  
sshield2@jhmi.edu

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